# CARING FOR DIABETES IN CHILDREN AND ADOLESCENTS

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Third edition

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# Foreword

I am pleased to be asked to introduce the 3rd edition of this popular manual for families facing the challenge of taking care of diabetes in their child. It is a step by step outline of what diabetes is and the practical details needed for everyday care. Previous editions of this manual since 1998 have successfully empowered families with the practical knowledge on how to take charge of their child's diabetes. The popularity of these manuals has been such that they have been translated into several languages. The manuals have reflected best practice and have been used by diabetes centres around Australia and New Zealand as the main source of advice for parents with a child with diabetes. They have given families detailed advice in an easy readable way so that even unexpected challenges such as sick days can be safely managed at home.

Whilst this current manual is an essential resource for families new to diabetes, it is also highly recommended as an update for those already experienced in diabetes. Exciting new research is continually improving diabetes management and new and more effective ways of controlling diabetes are constantly being introduced. Because most diabetes management occurs at home, parents also need to be updated of any advances in controlling their child's diabetes. This edition contains detailed information on many new advances including new ways of monitoring diabetes control and new insulin delivery systems, iesuch as continuous glucose monitoring systems integrated with insulin pump therapy.

The manual is truly comprehensive and provides guidance on the wide spectrum of issues impacting on diabetes. The advice offered has taken into account the recommendations in the latest national (NHMRC) and international (ISPAD) evidence-based guidelines. It covers diabetes in all of the ages and stages between infancy and adolescence and addresses the latest recommendations for targets to aim for in diabetes control. Issues such as hypoglycaemia treatment and prevention, diet, carbohydrate counting and insulin adjustment for carbohydrate quantity, schools, camps, preventing diabetes complications, screening for associated conditions like thyroid problems and coeliac disease, and, the impact of psychological factors, are all comprehensively covered. Whilst much of the manual is devoted to type 1 diabetes, an expanded section on type 2 diabetes in adolescents is included.

The editors, Associate Professors Geoff Ambler and Fergus Cameron, and the many contributors, are to be congratulated on producing this updated and comprehensive guidance for parents in caring for diabetes in their children or adolescents. It will instil confidence in the minds of parents and provide them with the confidence and information needed to be important members of the team caring for their child's welfare.

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# Introduction

Caring for diabetes in children and adolescents is a challenging task for families and their health professionals. Education and knowledge are essential elements in being able to look after your child's diabetes from day to day and in special situations. This resource aims to provide this information for you. It will help you revise and build on your knowledge from your diabetes education and also serve as a ready reference when new situations arise.

While teaching will differ slightly between different diabetes centres, the content has been contributed to and edited by health professionals from major children's diabetes centres in Australia: therefore it reflects a common approach and practice.

This resource also takes into account the current guidelines from the National Health and Medical Research Council (NHMRC) and the International Society of Paediatric and Adolescent Diabetes (ISPAD) and assists with their practical application.

This third edition includes significant revisions and updates, particularly on insulin therapy and insulin pump therapy. Parents, grandparents, friends and other carers, as well as young people with diabetes, will find this book useful. We hope it helps you.

**Please note**: The information in this resource has been carefully checked and is believed to be accurate at the time of production. If you are unsure of whether any particular information is appropriate or applicable to your child, you should check with your diabetes team first.

Brand names or trade names are used for clarity in places throughout the book. It is recognised that these are the registered property of the respective companies.

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# Chapter 1 Diabetes – the basics

This resource will help you and your family learn about diabetes and will be useful to look up when you need to check information at home. It has been written by health professionals who have extensive experience in caring for children and adolescents with diabetes. This first page gives some key points about diabetes; these points are covered in detail later.

# What is diabetes?

Type 1 diabetes is the common form of diabetes in children and occurs when the pancreas is unable to make enough insulin. Insulin is a hormone which allows the body to use glucose in the blood as energy. The glucose in the blood comes mainly from the food we eat and from stores in the liver and muscle. When a person has diabetes, the blood glucose level rises because of the lack of insulin and they become unwell with the symptoms of diabetes which may include excessive thirst, excessive urination, weight loss and dehydration. Type 1 diabetes always requires insulin treatment.

**Type 2 diabetes** is a different form of diabetes that is less common in children and teenagers but common in adults. The pancreas can still produce insulin but the body is resistant to the insulin working. It is often associated with being overweight and is discussed in detail in chapter 13 – 'Type 2 diabetes'. Type 2 diabetes may not need insulin treatment.

# Why does diabetes occur?

Some people carry genes that make them more likely to get diabetes. Type 1 diabetes develops in these people only when something triggers the immune system to start damaging the pancreas. These triggers are believed to be factors in the environment, but are still not well understood. There are also genetic risk factors for type 2 diabetes, but the major risk factors are being overweight, inadequate exercise and unhealthy eating patterns.

# **Treatment of diabetes**

The care of children and adolescents with diabetes requires a team of specialised health professionals who educate your child and family in diabetes management and help you and your family look after the diabetes.



# Chapter 1

# Chapter 2 The pancreas, insulin and diabetes

# **Key Points**

- In type 1 diabetes the pancreas can't make enough insulin, causing the blood glucose to be too high
- Diabetes in children is usually type 1 diabetes and needs treatment with insulin by injection or insulin pump
- Frequent passing of urine, thirst, drinking a lot, weight loss and tiredness are the common symptoms of diabetes
- We don't fully understand what causes diabetes, but genes and things in the environment are likely factors

### Insulin and the pancreas

Insulin is a hormone produced by special cells (called beta cells) in the pancreas. Hormones are chemical messengers that circulate in the blood, sending messages to other parts of the body. The pancreas is located deep in the upper part of the abdomen, behind the stomach (see the illustration). The pancreas has two main functions:

- 1. Digestion of food the pancreas produces enzymes that are released into the bowel after a meal to help digestion of food. Diabetes does not affect this part of the pancreas.
- 2. Production of hormones there are groups of cells in the pancreas called islets of Langerhans that produce a variety of hormones insulin and glucagon are two important ones. These hormones help to regulate energy in the body. In diabetes, the main problem is that the cells that make insulin (the beta cells) are damaged and therefore blood glucose levels become elevated. The glucagon producing cells also become damaged which adds to the loss of glucose regulation later, even when insulin is being replaced. This is because glucagon's function is to help increase blood glucose levels if they become too low.

### Insulin, food and energy

After we eat, the food is digested in the stomach and the upper part of the bowel. The nutrients from the digested food are taken into the bloodstream. The carbohydrates (sugars and starches) in our food are broken down into glucose which enters the bloodstream. This glucose is used immediately for energy or can be stored in the liver or muscle as a substance called glycogen. Glucose can be released from glycogen when needed and glucose output from the liver and muscle contributes to blood glucose levels, as well as food that has been eaten recently.



Position of the pancreas in the body

We need insulin to help the body use glucose from the bloodstream for energy. Glucose is the major energy source for the cells of the body, but normally glucose can only pass from the bloodstream into cells if insulin is present. If there is no insulin, blood glucose levels will be high but none of the glucose can be used for energy since it cannot enter the cells. Insulin has been described as being like *"a key that unlocks the door of cells"* and lets glucose in to be used for energy.



How insulin helps the body use glucose from the bloodstream for energy

Ketones are other substances that the body can sometimes use for energy if it cannot use glucose. In people without diabetes, ketones start to be produced from fat as an alternative energy source when supplies of glucose are becoming low, such as during fasting or illness. This can sometimes be the case in people with diabetes but usually in diabetes, production of ketones means there is a lack of insulin and the glucose that is present in the blood is unable to be used for energy. You will learn more about ketones in chapter 10 'Sick days'.

# Chapter 2

### What is diabetes?

Diabetes mellitus (often just called diabetes) occurs when the body cannot produce enough insulin, or when the insulin that the body makes does not work properly. The name comes from the ancient Greek word '*diabetes*' meaning siphon or running through (referring to the passing of large amounts of urine) and '*mellitus*' meaning honey-like (referring to the sweetness of the urine due to excess sugar as identified by ancient physicians).

There are two main types of diabetes and some other less common forms:

**Type 1 diabetes mellitus** is the type that is almost always found in children and adolescents and occurs because the pancreas loses the ability to make insulin. People with type 1 diabetes need insulin treatment to stay alive. In the past, type 1 diabetes was sometimes called insulin-dependent diabetes mellitus (IDDM). Most of this resource is about type 1 diabetes, but there is also a section on type 2 diabetes.

**Type 2 diabetes mellitus** usually affects older people but is increasingly being seen in younger people. It is often associated with being overweight. These people make some insulin but the insulin does not work well. Type 2 diabetes can often be controlled by changes to diet and weight control but may need tablets or insulin injections. Type 2 diabetes is covered in more detail in chapter 13 'Type 2 diabetes'.

**Other types of diabetes** occur much less commonly and are usually associated with other conditions that damage the pancreas (usually called secondary diabetes). There are also some rarer genetic forms of diabetes. When diabetes is diagnosed, tests will usually be done to clarify the type of diabetes present, especially if there are any features that are not typical of type 1 diabetes.

### What causes type 1 diabetes?

The cause of diabetes is complex and not fully understood. We do know that diabetes occurs because of a combination of a person's genes and some things in the environment. If a person who has inherited the tendency to develop diabetes comes in contact with a trigger in the environment, then diabetes may develop. The triggers are poorly understood, but may be common things in our environment which are harmless to most people; for example, common viruses or things that we eat. The trigger may be different for different people.

If diabetes is triggered, the body's immune system which normally protects us from infections, begins to attack the beta cells of the pancreas. The immune system seems to have been tricked into thinking that the beta cells are foreign to the body and starts to destroy them, causing a decrease in insulin production. It can take from a few weeks to a few years for all of the beta cells to be destroyed. Type 1 diabetes is an example of an *autoimmune* condition.

The pancreas has many beta cells to spare, so symptoms of diabetes do not occur until more than 90 per cent of the cells have been destroyed. This means it is difficult to tell if someone is developing diabetes (i.e., it is difficult to tell they are in the prediabetes phase) until the symptoms of diabetes occur. Special blood tests can detect people in the prediabetes phase and are being used for research and diabetes prevention trials. At this stage there is no treatment proven to stop diabetes developing.

#### It is important to remember the following points:

- Diabetes cannot be caught from another person. It is not contagious.
- Type 1 diabetes is not caused by eating too much sugar or any other foods.
- There is nothing you could have done to prevent your child from getting diabetes. It was something that was going to happen anyway.
- Your child cannot grow out of type 1 diabetes. It does not change to type 2 diabetes as they get older.

### What are the symptoms and signs of diabetes?

When diabetes develops, glucose levels rise above normal, often as much as five to ten times normal. Excess glucose spills over into the urine, drawing water with it and causing excessive passing of urine and dehydration. Thirst increases as the body tries to compensate and the young person may drink large amounts of fluid.

Weight loss is common over weeks to months since the body cannot use glucose for energy and instead starts to break down fat and muscle. Excessive tiredness and mood changes are common because the child is feeling unwell. Breakdown of fat causes chemicals called ketones to accumulate in the blood and this can cause abdominal (tummy) pains, nausea and vomiting.

#### The common symptoms and signs of diabetes are:

- frequent passing of urine
- increased thirst and drinking
- weight loss
- tiredness
- mood changes

#### Other possible symptoms include:

- oral or vaginal thrush or skin infections (these organisms thrive in a high glucose environment)
- abdominal (tummy) pains
- decreased school performance because of feeling unwell
- excessive hunger





#### **Ketoacidosis**

Where the diabetes comes on quickly, or is found late, the child can become very ill. Glucose and ketone levels become very high in the blood and there is severe dehydration and loss of salts from the body. This is called diabetic ketoacidosis and is life-threatening and requires urgent hospital treatment.

The onset of diabetes can be especially rapid in babies and young infants, and symptoms and signs may be less easily noticed than in older children.

#### How is diabetes diagnosed?

In most cases the diagnosis of diabetes is simple. If symptoms suggest diabetes, your doctor will perform a blood test and a urine test (looking for glucose levels and ketones). Normally the urine contains no glucose; glucose only spills over into the urine when the blood glucose is high, so glucose in the urine is highly suggestive of diabetes. A high blood glucose level is used to confirm the diagnosis. In most cases no other tests are necessary, but occasionally in doubtful cases a diabetes specialist may recommend other tests, including a more detailed blood test called a glucose tolerance test (GTT).

If you have a relative or friend with symptoms that sound like diabetes, advise them to see a doctor without delay and to ask specifically to be tested for diabetes. Early diagnosis can prevent severe illness with diabetic ketoacidosis.

#### Can the pancreas recover?

Many treatments have been tried to stop the damage to beta cells in the pancreas, but at present there is no safe or effective way to do this. This is an active area of research. When insulin treatment is started, the pancreas is able to rest and recover to some degree, but not enough to produce all the insulin the body needs. For a time, the child's own pancreas may continue to produce up to half or more of the insulin needed by the body and this period is called the *'remission phase' or 'honeymoon period'*. This can be a period where children require quite small doses of insulin. Unfortunately the damaging processes in the pancreas are irreversible and continue. Over a period of time, from a few weeks to many months, the pancreas becomes unable to produce any insulin and all of the body's need for it must be met by injection.

#### How common is diabetes?

Each year in our population about 15 to 25 children per 100 000 develop type 1 diabetes (for children aged less than 15 years). Diabetes can come on at any age in children, but around 10 to 12 years is most common and it is also quite common around 4 to 6 years. It is estimated that there are around 7000 children and adolescents in Australia with type 1 diabetes under 15 years of age. On average, at a high school there will be one student per 500 with diabetes and in primary schools about one student per 1200.

Our population has an intermediate incidence of type 1 diabetes compared to other countries around the world. Incidence is low in Asian populations (a quarter to one half of our incidence) and highest in Finland (approximately double our incidence). The differences probably relate to genetic factors. The incidence of type 1 diabetes is gradually rising around the world and the reasons for this are not clear.

### What are the risks for other family members?

While inheritance of genes contributes to the risk of diabetes, the risk for other family members developing diabetes is still generally low. The long-term risk of a brother or sister developing diabetes (assuming no type 1 diabetes in any other close family members) is about 3-6 per cent. In an identical twin the risk is much higher, at least 35-50 per cent. If there is more than one person with type 1 diabetes in the immediate family, risks for other children will be higher.

For parents with diabetes, if the mother has diabetes the risk for a child is 1-3 per cent, but if the father has diabetes the risk is 4-8 per cent. If both parents have type 1 diabetes the risk for a child is 10-25 per cent. Remember that diabetes is not contagious – the risk relates to genetic factors.

If there are other autoimmune conditions in close family members (for example, autoimmune thyroid disease or coeliac disease), diabetes risk may be greater than the figures quoted above.



### Associated video resource for this chapter

#### **Diabetes Type 1 and Insulin Production**

Etsuko Uno and Drew Berry, Walter and Eliza Hall Institute of Medical Research, 2009

This animation illustrates how insulin is normally produced in the body and how its production is affected in type 1 diabetes

Insulin Production and Type I Diabetes

### **Common questions and answers**



#### Why does insulin have to be given by injection or pump? Why can't it be given in tablets?

Current insulin preparations cannot be given by mouth because the insulin is destroyed by the acid in the stomach. Researchers are working to develop insulin-like medications that can be taken by mouth. The tablets that some older people with type 2 diabetes take are not insulin tablets and do not work in children with diabetes. Other ways of giving insulin are actively being researched.



#### Should we have our other children tested for risk of diabetes?

Many people worry about the increase in risk of other children in the family getting diabetes. Blood testing is available to look for diabetes antibodies and higher risk genes and this is an active area of research. One problem at present is that if a high risk of diabetes is found in another child, there are no proven treatments to prevent it. There are continuing studies on possible preventions. Your doctor and other diabetes team members will be able to give you the latest information on diabetes screening and prevention trials.



#### Why is the cause of diabetes still not fully worked out?

We know that diabetes is caused by a combination of genetic factors and factors in the environment. Both of these are very complex. The genetic risk seems to relate to a complex combination of many genes, rather than just a few. Some of the factors in the environment that may trigger diabetes have been suggested, but how these may trigger diabetes is still not fully understood.



#### Can I decrease the risk of diabetes in my other children?

No factors have been clearly proven to alter diabetes risk, although some studies are in progress. Discuss the latest information with your diabetes specialist.



#### Will my child be able to come off insulin later in life?

No. Type 1 diabetes requires life-long insulin therapy. Not until a cure is found will it be possible for people with type 1 diabetes to stop insulin treatment.

# Chapter 3 What to expect at the time of diagnosis

# **Key Points**

- The diabetes team includes your child and family, a diabetes doctor, diabetes educator, diabetes dietitian and social worker or psychologist
- Your child will start feeling well again soon after starting insulin
- Learning about diabetes and starting to come to terms with the diagnosis are your most important tasks during the first few weeks

### The diabetes team

Diabetes is a condition which is best cared for by a team. The team members interact closely, but all have their special areas. Your child and family are an important part of the team that help look after the diabetes. At the hospital and clinic, you will meet the health professionals who make up the rest of the diabetes team:

- A diabetes doctor, who is a specialist in the medical care of diabetes in children and adolescents. In hospital, young doctors in training (called residents, registrars and fellows) work with the diabetes specialist.
- A diabetes educator (or nurse educator), whose main role is to teach your child and family all about diabetes and how to care for it now and in the future.
- A diabetes dietitian, who focuses on food and nutrition.
- A diabetes social worker or psychologist, who helps families cope with the diagnosis of diabetes and the impact it has on their lives. Where there are other psychological stresses for which people need help, other professionals assist the team, such as a psychologist or psychiatrist.
- The hospital ward and outpatient nursing staff, who care for your child at the hospital and help with teaching.

All of these health professionals provide education, counselling and advice at the time of diagnosis and in the subsequent months and years. The team help you start to come to terms with the shock of the diagnosis and help you learn how to cope. The aim of diabetes education is to give your child and family the knowledge and skills to be self-reliant in the care of diabetes.

Diabetes requires frequent adjustment of treatment for different situations and with growth and development. The diabetes team continue to help you with this at follow-up visits and by telephone if there are concerns between visits. As children mature, they gradually gain more knowledge and take on more responsibility for their diabetes. They are helped by education at clinic visits, educational updates for families and activities such as diabetes camps.

Remember that your child and family are an important part of the diabetes team.

Chapter 3 The aim of the whole team is to help keep the diabetes well controlled so that it can be kept in the background of your lives. We want to keep your child well-adjusted, happy, healthy and safe. We also like to work in close cooperation with your family doctor (GP) and other people who may be involved in your child's care such as the local paediatrician or other local health professionals – these people are also often part of the primary diabetes team.

### What happens at diagnosis

#### When your child is first diagnosed with diabetes, the most important things are:

- to start insulin treatment under medical supervision so that blood glucose levels can be lowered safely and appropriately
- to give your child and family support while you are coming to terms with what has happened
- to give your child and family time to learn about the management of diabetes, with the close support of the diabetes team.

There are different approaches to the first week, depending on the preference of your diabetes centre or hospital and your child's particular circumstances. In some cases, children will be admitted to hospital initially, while others will have all of their care as outpatients. In general, the aim is to have the child in hospital for the shortest time possible. Regardless of the local approach, management principles will be similar and a good outcome will be expected. Your diabetes team will guide you and explain what they feel is the best approach for your child and family.



#### **Outpatient stabilisation**

Some children are not admitted to the hospital at all. This is called outpatient stabilisation or a diabetes day care program. Evidence indicates that stabilisation of diabetes can be safely achieved without admission to hospital with no disadvantages and with potential benefits for some. Diabetes centres that do this have set up outpatient programs and staff and have criteria for when outpatient stabilisation is suitable.

Where outpatient stabilisation is possible, your child may only spend a few hours or one night in hospital. During this time your child will be assessed, you will learn some very basic things about diabetes care and insulin treatment will be started. Arrangements will be made for you to come back to the diabetes centre each day for several days for a program of education and stabilisation and then for more sessions over the next few weeks. Nursing staff will assist with the first few insulin injections until you have acquired those skills. During the first few days, families will spend a number of hours (up to 8 hours or so) at the diabetes centre but then will be able to go home with their child at night. This has the advantages of avoiding overnight stays in hospital and minimising disruption to the family. At all times, families can phone the hospital if any concerns arise.

#### **Hospital admission**

Some hospitals prefer a program where the child is admitted to hospital for a short time and then completes later education as an outpatient.

Children with newly diagnosed diabetes will always be admitted to hospital if:

- they are quite sick initially with diabetic ketoacidosis or other illness
- the family lives too far away to travel to the hospital each day
- the child is very young (usually less than two years old)
- there are difficulties with language or the family has other special needs
- there are other reasons that the diabetes team feel need a stay in hospital

The aim is always to keep the hospital admission to the minimum time possible and continue further education and stabilisation out of hospital. With children, it is best for a parent to stay at the hospital if possible during this time.



### Other things that happen in the first week

Children with diabetes will generally be feeling well within a few days of starting insulin treatment. A diagnosis of diabetes is understandably a major shock to the child and the family and it takes some time to come to terms with this. It is important to reassure your child that she or he will become well and remain well. Often in the first 24 to 48 hours everyone in the family is feeling shocked and totally exhausted, so trying to get some rest is important.

Whether or not your child is admitted to hospital, the first week will be busy with education sessions and learning activities. The diabetes team will try to arrange specific times for educational sessions to allow families to fit this into their schedules. Parents should try to be available as much as possible to concentrate on education and be with their child as much as they can during this difficult time. Arranging some time off work may be necessary and a letter can be provided to your employer to help with this. Sessions can sometimes be fitted in around work or are possible on weekends in some centres.

Also during the first few days, families are advised about the equipment they will need at home for diabetes management and arrangements are made for these to be obtained. Some families may qualify for special allowances or a health care card and arrangements are made to apply for these.

At first, the diagnosis of diabetes and all the things you need to know about diabetes may seem overwhelming. By the end of the first week, families will be starting to feel more confident to care for the diabetes. There will always be ongoing support and guidance from the diabetes team.



### Common questions and answers



I believe in the past that all children with newly diagnosed diabetes stayed in hospital for for up to a week or more. Why is this no longer so?

There is now quite a bit of evidence that the same outcome can be achieved with a shorter stay in hospital or without staying in hospital at all. Different hospitals and diabetes centres have different approaches, some preferring a stay in hospital and others preferring all outpatient management. We can't say that one approach is better than the other; both will have a good outcome. Your diabetes team will advise what the local preference is and what they think is best for your child.



#### I was worried when the hospital said my child did not need to be admitted and we went home after the first insulin injection, to return the next morning. What if something happens at home?

The diabetes team carefully selects which children are suited for outpatient stabilisation. Families are briefed in the basic skills and given clear and simple advice. If they are at all worried they have direct telephone access to the diabetes team.



# Can we see our family doctor for follow-up of our child's diabetes?

Your family doctor is very important in your child's overall health care; however you must also have regular visits to your diabetes team. International recommendations and best practice are that children with diabetes should be seen at least 3 or 4 times each year by a team with specialised knowledge and experience in children's diabetes. The diabetes team keeps in touch with your family doctor so that he or she is fully informed about the diabetes. Your family doctor's role in the diabetes management is to develop a care plan (so you have access to all the services your child needs), manage vaccinations, minor illnesses, travel needs etc. As well as your regular visits to your diabetes team, you should see your family doctor regularly about the diabetes care plan. If you don't see your family doctor regularly it is difficult for them to help you when you need them.

# **Chapter 4 Coping with Diabetes**

# **Key Points**

- There will be many different feelings to cope with about diabetes
- Diabetes can be stressful for the whole family, but things should settle down over time
- The social worker or psychologist is a member of the diabetes team who can help with these issues
- The diabetes team will help ensure that you are accessing any support services or financial assistance that you may qualify for

# **Coping with the diagnosis – first feelings**

The period just after you find out your child has diabetes is likely to be a very unsettled time for the whole family. At this difficult time your usual ways of coping with things are disturbed and you are likely to feel vulnerable and confused. You may have a whole range of feelings. These include:

- **Shock:** You may have a feeling of unreality. You feel you are operating on 'automatic' and that the news hasn't hit you yet.
- **Denial:** The news feels so overwhelming that you simply can't believe it. You think that there has been a mistake; for example, the test results have been mixed up. Children can also be in denial and can express this by trying to avoid injections or finger pricks.
- **Anger:** You wish there was someone to blame. You may find yourself being angry with the doctor, nurses, your partner or other family members. You may ask 'why me, why my child?' People sometimes question their faith or feel that life has dealt them an unfair blow.
- **Sadness or depression:** There is always loss involved. It is the loss of the fully healthy child. With any loss, mourning occurs and can continue on and off for some time. Your mood can range from feeling sad to feeling quite depressed.
- **Fear:** You may be flooded by fears for your child. You worry about your child's survival, the impact of diabetes on his or her life and future goals and ambitions. Much of the fear is that of the unknown. As you learn about diabetes and put your new skills into practice, some of these fears begin to fade.
- **Guilt:** As a parent you want to protect your child from hurt and harm. You may find yourself thinking about the last few weeks and wondering if you could have done something differently. There is nothing you could have done to prevent your child from getting diabetes. Sometimes brothers and sisters may have feelings of guilt also and it is important to address these.

Children can feel guilty too. Sometimes they feel like diabetes is a punishment for something they have done wrong. We know from child developmental milestones that children are egocentric; therefore they think that the world revolves around them. If something bad happens they tend to blame themselves. Constant reassurance that they are not to blame can help and talking to their social worker or psychologist can also help them to explore these thoughts. If there is diabetes in the family you may worry about having passed it on to your child. Talk to your doctor so that you understand the role of family factors and clear up any worries.



#### How to cope

Keep in mind that this difficult time will pass and you will regain your feeling of balance. The feelings of shock and confusion will subside. What helps most is talking through your feelings with family, friends and members of the team treating your child. A social worker (or psychologist) on the diabetes team is specially trained to help you understand your reactions and make sense of your family's experience. You don't have to feel that you are not coping to need their help. Asking for help is one way of coping.

You need to recognise that you are in a vulnerable state and so be mindful of your own needs. This can mean putting aside some time just for you. If you are feeling overwhelmed by the amount of information you have to take in, talk to the people teaching you. They will understand that you may need to go slowly because of how you feel. Don't be afraid to ask about something again if you don't understand the first time.

#### **Children's feelings**

Your child may experience any or all of the feelings already described. Like you, they need someone to talk to. You are the best person to help them through this difficult time because you know them so well.

Don't be alarmed if your child starts acting like a much younger child. For example, a four-year-old may ask for a bottle or a toddler may go back to crawling instead of walking. This 'regression' is a normal reaction to stress and sickness and is only temporary. Your child needs a lot of support and attention.

Older children may need encouragement to share their feelings. You can help by acknowledging your own feelings: 'I've felt pretty mad (or sad) at times about you getting diabetes, I wonder how you feel?'. This sort of statement gives the child permission to express feelings that they might be struggling with themselves.

Chapter 4 It is important that a young person's identity does not become defined by diabetes. It can be tempting to ask your child what their blood glucose levels are as soon as they walk through the door after school. Children do not want to identify themselves as a 'diabetic' with nothing else to offer or share. Try asking about other things first, like how their day went, to assist building your relationship and communication. Adolescents especially have been known to say that the only thing they talk and argue about with their parents is the diabetes.

It is important to find ways of communicating about the diabetes without having diabetes being dominant. One method is "to actively help" with the diabetes cares, rather than just ask if something has been done. This helps in a number of ways; you know what is happening with the diabetes (and don't have to ask), it gives moral support and prevents problems such as errors with insulin doses.

#### **Family relationships**

A crisis puts stress on family and close relationships. You may find yourself being irritable and flaring up easily. Remember that you are all under stress and these reactions are part of the situation.

Sometimes partners or other family members feel 'out of step' with their reactions to the diagnosis. One is very tearful and wants to talk about things. The other becomes practical and wants to 'get on with it' and not dwell on the sadness or other feelings. These are different ways of coping with the same situation. Accepting each other's differences can help people to still support each other.

#### **Brothers and sisters**

Brothers and sisters of the child with diabetes also need to have their feelings understood. They need to know what is going on and be given a simple explanation of diabetes. Some may fear that they too will get diabetes or some other illness. Some may feel guilty that they did not get the diabetes or wonder if recent fights or conflict caused their brother or sister to become ill. They may feel that their needs are being neglected because of the attention that diabetes demands. They need support and reassurance also.



# Coping after the diagnosis

After the period around the diagnosis, there are many issues that will arise and new hurdles to face. Children may feel different from their friends and feel their life is ruled by diabetes and routines. They may be reluctant to let people know they have diabetes or be embarrassed to test blood glucose or eat when needed. They may become more dependent on their parents at a time when they would otherwise be becoming more independent. Your child may also worry about the extra demands their diabetes places on the family and may worry about the possibility of long-term complications.

Parents' concerns often include fear of low blood glucose levels and grappling with day-to-day management issues and blood glucose levels. They may worry about long-term complications and that they are not doing a good enough job with the diabetes. Parents also worry about how much responsibility they should let their child have for the diabetes and when to start handing over more responsibility in the teenage years. There may be a tendency to be over-protective. Sometimes it is frustrating that others do not understand the amount of work involved in looking after someone with diabetes and having to re-explain the condition to the child's new teachers, friends and others.

Each family will face a different set of challenges, although many of the issues will be similar. Families usually find their own ways of dealing with these. It is good for you to try to develop an approach where diabetes management is regarded as important, but can mostly be put in the background while you get on with life.

The responsibility for day-to-day diabetes care ideally needs to be shared with a partner or another close person. To share the practical tasks is to share the emotional burden. 'Time out' for mothers and fathers (especially those of infants and toddlers) is essential. The support of family and friends is very valuable and you need to try to encourage this. This means giving basic education about diabetes management to a range of people. If more detailed education is needed for other family members or friends, your diabetes team can help arrange this. It is important not to feel that you are carrying the weight of the world yourself. For adolescents, remember that they carry a significant responsibility and it is important that you find ways of helping with this responsibility without making them feel that you are trying to run their lives or control them.



Most diabetes centres arrange for discussion about all of these issues through the social worker or psychologist with the team. This is especially important at the time of diagnosis, but also later. Sometimes situations can arise where aspects of diabetes are too much for your child or family to cope with at the time. This is especially where the social worker or psychologist from the diabetes team can help. You should not feel reluctant to ask for help in these situations, as the diabetes team fully understand the difficulties that can occur. The assistance of a social worker or psychologist can also be accessed through your family doctor if needed, as part of their involvement in your care plan.

Mixing with other children and families can also often be very helpful – you learn how others face the similar challenges and ways they have found to deal with them. Local Diabetes organisations or your diabetes health professionals can put you in touch with other families, or you may meet them at education days, parent support groups and other functions. Diabetes camps can be a way for your child to meet others their own age with diabetes and to begin to become more independent and self-reliant in a carefully supervised environment.

After the initial learning phase, it is important to maintain the momentum with all aspects of the diabetes routines. The "novelty" of the new routines wears off quickly and often young people hit a difficult patch some weeks to months after the diagnosis

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as they come to the realisation that diabetes is a long-term condition with continuing daily demands. Parents and caregivers need to be on the lookout for faltering routines, such as insulin omission, less blood glucose monitoring or false recording. They need to give close support to children and teenagers of all ages and be prepared to take over control of diabetes routines again if needed for a time. The short and long-term complications of poorly controlled diabetes can be severe and life-threatening, so there is no place for complacency. Your diabetes team will discuss such issues with you and help you formulate your approach if you are facing such problems.

### **Financial assistance**

Because of the extra care and costs associated with a child with diabetes, there are avenues for extra financial assistance. Eligibility changes from time to time and may vary in different states. Your diabetes team will advise which allowances it may be possible to apply for. In Australia, latest details can also be obtained from Centrelink, and local diabetes organisations.

#### Health Care Card and Carer's Allowance



You will need to apply for a Health Care Card from Centrelink. This can be continued to young adulthood if the young person is still studying or not yet financially independent. The Health Care Card allows prescription items to be purchased at much lower prices and concessions for other medical services.

Some families may also qualify for a fortnightly payment called a Carer's Allowance. This is considered by Centrelink on an individual basis and is more likely to be approved for those who are under 10 years or with additional health problems or disabilities. Your diabetes team will advise about the latest details which can change from time to time.

#### National Diabetic Services Scheme (NDSS)

This government-sponsored national scheme subsidises the cost of diabetes supplies, such as test strips, lancets, insulin pump supplies etc. Syringes and needles are available free of charge.

A registration form is required which must be signed by your child's diabetes team and forwarded to the NDSS. Supplies can then be bought at cheaper rates through Diabetes Australia, any NDSS approved pharmacy or some hospitals. Not all pharmacies are in the NDSS scheme – Diabetes Australia can provide a list.

#### Others

Other financial subsidies exist for pension card holders and others with special circumstances. The diabetes team social worker will be able to tell you about all of these. If you have any special questions or concerns about subsidies, benefits or financial matters, the diabetes team social worker or local diabetes organisations can help.

### **Common questions and answers**



#### We were surprised when we were asked to see the social worker at the hospital because we didn't think we had those types of problems. Why was this?

Diabetes has a major impact on the child and the family and it is important to talk with someone about this. The social worker in the diabetes team meets with all families and their children to help them explore the social impacts on the family system and find ways to deal with these.



# My wife and I have not had a night out with just the two of us since our daughter developed diabetes. What should we do?

It is important to have some support from close family and friends where possible. Often a relative or close friend will be happy to have some diabetes education so they can look after your daughter sometimes. Resources such as this will help, and education sessions can be arranged through your diabetes educator if needed. Some time-out from diabetes is important for parents.



#### Since our two-year-old developed diabetes, we have been worried about the effect on the behaviour of our five-year-old. What can we do?

The two-year-old will need a lot of attention, but it is also important to find time to do things as a family, and special time for one or both parents to have with your other children. Brothers and sisters can sometimes worry a lot about things such as the possibility that their brother or sister may die, they themselves may get diabetes or that they caused the diabetes. Reassurance is needed, and the social worker or psychologist can help with these common concerns.



# My 10 year old is very capable and independent. When can I let her do all her diabetes cares by herself?

Even once children and teenagers are capable in many aspects of diabetes self-care, evidence shows that it is very important for parents or caregivers to remain closely and actively involved in supervising and assisting with the daily care. While the level of assistance will be different than for younger children, your continued involvement shows your support and guidance and allows you to know that the diabetes is being appropriately managed. Try to be actively involved rather than being seen to "check-up on" or "nag" about routines. The consequences of poor diabetes control are so serious that this role is an important responsibility of parents.

# **Chapter 5 Insulin Treatment**

# **Key Points**

#### Key points for diabetes management are:

- Insulin therapy: Is required to replace the insulin that the body cannot make. Insulin has to be given by injection or insulin pump into the fat layer under the skin (subcutaneous). It cannot be given by tablets, since digestion destroys the insulin. Other ways of giving insulin could be possible in the future
- A food plan: A healthy food plan and a regular intake of carbohydrates are required to balance with the insulin that is given by injection or insulin pump
- Exercise: Exercise and being active are part of a healthy lifestyle. It is important to understand how exercise affects diabetes
- Monitoring: Regular and frequent blood glucose monitoring is essential and ketone monitoring when needed
- Education and knowledge: There is a lot to learn about diabetes to maintain good control. This learning is an ongoing process
- Regular follow-up with the diabetes team

# **Managing diabetes**

The management of diabetes is a balance between factors which lower blood glucose (mainly insulin and exercise) and those which raise blood glucose (mainly food and stress hormones). This is illustrated in the following diagram. Managing diabetes is all about understanding these factors and learning to make adjustments for them. Details of all of these aspects are given in later sections.



Factors that must be balanced in diabetes management

### **Different types of insulin**

A variety of insulin types are available and these can be used in different patterns of injections. Insulin can also be delivered by an insulin pump (see chapter 18). Available insulins differ in their profile of action – that is, how quickly they start to act, when the maximum effect is and how long the effect lasts. The profile of action is determined by how quickly the insulin breaks down into single molecules and is absorbed from under the skin and also binding with carrier proteins. Your diabetes team will discuss with you what they feel is best for your child at the time of diagnosis. Later on it may be necessary to change insulin types or the pattern of injections or use an insulin pump, as different things suit different children at different ages and stages of development.

Before the 1980s, all insulin was extracted from the pancreases of pigs (porcine insulin) and beef cattle (bovine insulin). In the 1980s it became possible to make human insulin synthetically in the laboratory and human insulins are the preferred treatment in most children and adolescents. These are identical to natural insulin and are highly pure. Beef insulins are occasionally used in some patients with special circumstances.

Recently a number of chemically modified insulins have become available called insulin analogues. These have been designed to have better properties which improve the diabetes management in many people. We are likely to see more specially tailored insulin types become available over the next few years. The availability of different insulins gives your doctor a wider choice of insulins to match your child's needs at any particular time.

#### Insulin is given in one of two ways:

- Injections: most children have an injection routine that uses a combination of rapid or short acting insulin and long acting insulin. Injections are usually given 2, 3 or 4 times per day. The table on page 23 summarises the different types of insulin in common use. Some books use the term 'intermediate acting' insulin. Here we include these insulins in our long acting insulin category as this is the terminology in common use.
- Insulin pumps: only rapid acting insulin is used in pumps (i.e., no long acting insulin). An insulin pump delivers insulin continuously in small amounts (basal insulin) with bursts of insulin (called boluses) activated by the user to cover meals and correct high glucose levels.

#### Insulin types used in Australia

The table later in this section lists types of insulin available in Australia and gives a guide to their characteristics. All insulins are synthetic human insulins or human insulin analogues, except where "beef" is shown. The timing characteristics of the insulins shown are a guide only – there is much variation between different children, at different doses and different ages and you may find they work differently in your child. Your diabetes team will decide which insulins are best for your child and discuss this with you.

#### Rapid and short acting insulins

These are insulins that are absorbed quickly into the body after the injection and are used as part of the insulin plan for most children and adolescents. Rapid acting insulins are also used in insulin pumps which deliver insulin continuously.

# Chapter 5
The rapid acting insulins in this category (Humalog, NovoRapid, Apidra) have been designed to be absorbed more quickly than the original short acting or regular human insulins (Actrapid, Humulin R). Rapid acting insulins have the convenience of being able to be given immediately before a meal. They may cause less hypoglycaemia in some people because of their shorter duration of action. On the other hand, rapid acting insulins do not suit all people well as they may be too sensitive to the rapid onset of action or the insulin action may not last long enough.

#### Long acting insulins

These have a slower onset and a longer duration of action and are also known as basal insulins. Most people on insulin injections have these once or twice a day as part of their insulin plan. These insulins have characteristics that slow their rate of absorption and action. The most recent additions to the range of long acting insulins have been the insulin analogues glargine (Lantus) and insulin detemir (Levemir). These newer analogues offer significant advantages and are now in widespread use, although have not completely replaced long acting human insulins. People receiving their insulin through an insulin pump do not use any long acting insulin, but need to have some available at home in case of pump malfunction (see Chapter 18).

#### **Beef insulins**

Beef insulins are now rarely used. They tend to have a slower onset of action and a less obvious peak than human insulins. Occasionally beef insulins may be recommended if your doctor feels it would help an unstable pattern for which other adjustments have not worked. They are likely to be less available over time.

#### **Pre-mixed insulins**

Pre-mixed combinations of rapid or short acting and long acting insulins are available but are not used frequently in children and adolescents. This is mainly because the ratios of the two types of insulin often need to be changed in children and this cannot be done when they are pre-mixed. There are some situations where they can suit young people or are the best compromise and your diabetes team will discuss this with you if needed. An increasing range of pre-mixed insulins may become available as new chemically altered insulins are developed.

#### Different patterns of insulin dosage

Ideally, the insulin doses given would mimic the levels produced by a normally functioning pancreas. That is, a small background level of insulin (basal insulin) with pulses of insulin action at times of meals or snacks, as shown in the figure.



Insulin Type	Preparations and manufacturer	Onset of action	Peak of action	Duration of action
Rapid acting insulin analogues	NovoRapid (insulin aspart, Novo Nordisk)	15-30 minutes	1-2 hours	3-5 hours
	Humalog (insulin lispro, Eli Lilly) Apidra (insulin glulisine			
	Sanofi-Aventis)			
Short acting insulins	Actrapid (regular human insulin, Novo Nordisk)	30-60 minutes	2-4 hours	5-8 hours
	Humulin R (regular human insulin, Eli Lilly)			
	Hypurin Neutral (regular beef insulin, Aspen)			
Long acting insulins	Protaphane (human isophane insulin, Novo Nordisk)	2-3 hours	4-12 hours	8-24 hours
	Humulin NPH (human isophane insulin, Eli Lilly)			
	Hypurin Isophane (beef isophane insulin, Aspen)			
Long acting insulin analogues	Levemir (insulin detemir, Novo Nordisk)	1-2 hours	No pronounced peak	20-24 hours
	Lantus (insulin glargine, Sanofi Aventis)	2-4 hours	Relatively peakless	20-24 hours
Mixed insulins	Rapid / long acting mix NovoMix30 (Novo Nordisk) Humalog Mix25 (Eli Lilly) Humalog Mix50 (Eli Lilly)	30 minutes	4-12 hours	8-24 hours
	Short / long acting mix Mixtard 30/70 (Novo Nordisk) Mixtard 50/50 (Novo Nordisk) Humulin 30/70 (Eli Lilly)			

With injections, we aim to approximate the body's requirements by using a combination of rapid or short and longer acting insulins. Usually injections are given two, three or four times per day. The closest way at present to simulate the pancreas' normal secretion pattern is to use a continuous insulin pump (see section 18).

The following describes some commonly used patterns of insulin injections. Recent trends in management have seen more children and adolescents receiving 3 or 4 insulin injections per day or using insulin pumps. Your diabetes team will advise on the most appropriate insulin plan to start with and for subsequent treatment. The initial plan could change later, depending on how well it works, your child's age and other variables.

#### Four times daily injections - basal-bolus or multiple daily injections (MDI)

In this routine, people have:

- Before breakfast: rapid or short acting insulin (meal bolus)
- Before lunch: rapid or short acting insulin (meal bolus)
- Before main evening meal: rapid or short acting insulin (meal bolus)
- Once or twice daily (before breakfast and/or bedtime): long acting insulin (basal insulin)

This routine is often referred to as a basal-bolus injection plan or multiple daily injections (MDI). Commonly about 40 to 45% of the insulin is given as long acting insulin and the rest is divided up in the rapid or short acting doses. This offers very good flexibility for insulin adjustment and when part of a comprehensive diabetes management plan has been shown to have advantages for diabetes control. It is the commonest starting insulin plan for older children, adolescents and adults. It is also commonly used in younger children, although they will need assistance with injections, particularly at school.

There are different ways of applying and adjusting this insulin pattern which can be summarized as:

#### 1. Conventional MDI with consistent carbohydrate intake

In this pattern, a person has a fairly consistent carbohydrate intake on a day to day basis and tends to keep the pre-meal insulin doses fairly constant from day to day.

#### 2. Flexible carbohydrate and insulin adjustment

In this method, pre-meal insulin doses are adjusted from day to day based on variations in carbohydrate intake and activity patterns. There is no exact formula for how this is done. It is based on a person's experience and judgement of how food and activity affect their BGLs and involves making small increases or decreases from their usual doses according to the circumstances of the day.

#### 3. Insulin to carbohydrate ratio

This is a further extension of flexible day to day adjustment in which the pre-meal insulin dose is calculated according to the amount of carbohydrate that will be eaten using a formula.

All of these methods can be applied well and which one is used is often a matter of the recommendations of your diabetes team and your personal preference. These methods are further discussed in chapters 6 and 12.



Figure showing a basal-bolus or MDI injection pattern

#### Two or Three times daily injections

In some children and adolescents, a two or three times per day injection plan may be recommended. This may depend on factors such as age, ability to give injections (e.g., at school) and motivation. These simpler injection plans can work well for certain periods, but ultimately the aim for most children and adolescents is to move to a multiple daily injection plan (see above) or insulin pump as they become older. This can usually occur by the age of 9 or 10 years and is generally achievable by the time children reach high school.

A variety of 2 and 3 times per day injection plans can be used. Different plans will suit different children and your diabetes team will advise what they think is best at any time in consultation with you and your child. These injection plans usually involve long acting insulin being given either before breakfast or before bed, or sometimes both, and rapid or short acting insulin being given before breakfast and at afternoon tea or dinner. Your diabetes team will explain the details.



Figure showing an example of a 3 times per day injection pattern with injections at breakfast, afternoon tea and bed

#### Other patterns of insulin dosage via injection

Many other patterns of insulin dosage may be used, depending on individual needs. Those described above are in most common use. It is common in the honeymoon or remission phase (in the first months after diagnosis) that less rapid or short acting insulin is needed, sometimes none at all for a time. As times goes on however, this will again be needed.

#### Insulin pump therapy

Insulin therapy in type 1 diabetes is increasingly being given by insulin pump therapy. With an insulin pump, a small computerised insulin pump delivers insulin continuously via a small plastic cannula that is inserted under the skin and changed every 3 days. The user or a carer activates the pump to give insulin to cover meals or to correct the blood glucose level. Insulin pumps use rapid acting insulin only. Patients using an insulin pump do not have to give insulin injections, except in special circumstances. Pump users still need to regularly monitor blood glucose levels.



Insulin pumps are an option for most children and adolescents with type 1 diabetes. Your diabetes team will discuss suitability and timing of pump therapy for your child. After the diagnosis of diabetes, it is common for children to be on injection therapy for a time and then progress later to insulin pump therapy if that is agreed to be appropriate. However, insulin pump therapy can be started at any time. Insulin pumps are covered in detail in chapter 18.

# What is the right pattern and dose of insulin for my child?

The doses, type and timing of insulin injections or whether an insulin pump is used are individually decided for each child. The appropriate doses of insulin are those which keep the blood glucose levels and the overall diabetes control in the desirable range. This varies greatly between individuals depending on body size, duration of diabetes, types of insulin being used, puberty, food intake and exercise.

#### Here is a general guide to total daily insulin needs in children and adolescents:

- In the honeymoon or remission phase: 0.2 to 0.5 unit of insulin for every kg of body weight per day.
- Children beyond the honeymoon phase: 0.7 to 1.2 unit of insulin for every kg of body weight per day.
- Adolescents: May require much larger doses, up to 1.5 units or more of insulin for every kg of body weight per day.

For example, Kristine is a 10 year old girl who weighs 36kg. Her usual insulin doses are approximately 6 units of Apidra before each main meal and 14 units of Lantus pre-bed. The total insulin per day is approximately 32 units which is 0.9 units/kg/ day, within normal expectations.

## **Devices for insulin injections**

Insulin has to be given by injection or pump infusion into the fatty layer under the skin (subcutaneous layer). Insulin can be given by:

- Injection with an insulin pen, or
- Injection with an insulin syringe, or
- Continuous infusion using an insulin pump (see chapter 18)

#### **Insulin pens**

Insulin pens are devices that are pre-filled with insulin or are loaded with pre-filled cartridges. Current pens hold 300 units of insulin which allows for multiple doses of insulin to be given before the cartridge or pen needs changing. At injection time, the dose of insulin is dialled up on the pen and administered. Pens cannot mix different types of insulin together, so if more than one type of insulin is needed at the same time of day, more than one pen injection is needed. Alternatively, some insulin types can be mixed together in syringes (see below). One type of pen can be adjusted in half unit steps which is often useful for toddlers and young children.

All major insulin manufacturers have pen devices available for their insulins. Needle lengths of 12.7 mm, 8 mm, 6mm, 5 mm and 4mm are available for pens. Generally 8 mm needles are most suitable for children and young people; 4, 5 or 6 mm needles are too short for some people to get the dose of insulin beneath the skin layers properly, but may be recommended for some very lean people



#### **Insulin syringes**

Insulin pens are generally preferred and most convenient for giving injections; however syringes will deliver insulin perfectly well and can be used if preferred or if pens are not available. They are available in various sizes (25, 30 50 and 100 units) depending on the dose required and are available with two different length needles (12.7 mm and 8 mm).



Your edu your chil for accur infants. Insulin sy vials mus serious d

Your educator will advise if syringes are appropriate and which syringe is best for your child. In general, the smallest syringe that will hold the required dose is best for accuracy and 8 mm needles are generally more suitable for small children and infants.

Insulin syringes are disposable and made for single use only. Syringes, pens or insulin vials must never be shared with another person because of the risk of spreading serious diseases such as hepatitis or HIV.

#### Automatic injection devices

Automatic injection devices are available for some types of pens and for syringes. These may be useful for children who have a particular fear of needles or in helping children to give their own injections.

For syringes, these are devices into which the syringe can be loaded, the needle is hidden from view and when a button is pressed the needle is automatically inserted into the skin. Some models also press the plunger to inject the insulin. Your diabetes team can discuss with you if these may be helpful for your child.

#### **Needless devices (jet injectors):**

Jet injectors are devices which have no needles and force insulin under the skin with air pressure. The injection is not painless and they are generally not recommended because the insulin absorption is unpredictable, they are expensive and can cause more injection site problems. They are rarely used nowadays and are mentioned here for completeness.

## How to give an insulin injection

#### Checking the insulin before injecting

#### The vial, cartridge or insulin pen should be checked for:

- The expiry date.
- The date you opened or started the insulin cartridge or bottle (write this on insulin bottles when you open them), since any opened insulin vial or cartridge should only be used for a maximum of 4 weeks, then discarded .
- The name are you giving the correct amount of the right insulin? Different insulin types have colour coded cartridges, but if your insulin pens look similar, mark them clearly so you can easily tell them apart
- The appearance: different insulins may have a different appearance in the vial or pen.

#### **Clear insulins:**

Many insulins have a clear appearance (like water) whether they are long, short or rapid acting. If your insulins should be clear, do not use any vial or pen that is cloudy, discoloured or otherwise altered from the usual appearance.

#### **Cloudy insulins:**

Some particular long acting and mixed insulins have a cloudy appearance in the vial (e.g., Protaphane, Humulin R, Mixtard). These types of insulin need to be mixed well before use (see below). Do not use a vial or pen if the insulin is flaky, clumped, discoloured or cannot be mixed properly.

#### Giving an injection with a pen

This will become an easy and routine procedure after a while, but the steps are listed here to help with learning. You will be taught how to load and use your particular brand of pen by the diabetes team.

- 1. Wash hands.
- 2. Check that you have the correct insulin pen (have your pens clearly marked) and that there is enough insulin remaining in the cartridge for the current injection. It is preferable to use a new needle for each injection.
- 3. If giving a cloudy long-acting or mixed insulin, be sure to mix the insulin well by inverting the pen 10 to 20 times. The cartridge contains a glass ball which mixes the insulin. Do not shake the pen as this will damage the insulin. Clear insulins do not need to be mixed.
- 4. Prime the pen (get rid of any air bubbles). Dial up a 2 to 4 unit dose and, holding the pen vertically, inject into the air to expel air bubbles (air shot) and to prime the pen. The pen is primed if drops of insulin without bubbles are coming from the needle. If not, keep repeating this procedure until a bubble-free stream of insulin is achieved with the air shot.
- 5. Dial up the required dose.
- 6. Select the injection site.
- 7. Steady the skin by taking a small pinch of skin with the index finger and thumb at the chosen site. The pinch needs to be at least to the depth of the needle. This is especially important in lean people, otherwise the injection may go too deep into the muscle layer and hurt more and the insulin will act differently. People who are not lean may not need to do a pinch, especially if using short needles (4, 5 or 6mm), but only use a no-pinch technique if advised by your diabetes team.
- 8. Insert the needle straight into the pinched-up skin (i.e., at 90 degrees) to its full depth and push the pen button slowly all the way down to push in the insulin. In very lean individuals, injecting at a 45 degree angle to the skin may be necessary to avoid the injection going too deep.
- 9. Leave the needle in for 5-10 seconds, then gradually let go of the skin and pull out the needle.
- 10. Remove the needle from the pen after injection and dispose of in an approved sharps container.



Pinching the skin to give an insulin injection. A small pinch with the finger and thumb is enough.

#### How to draw up a mixed dose of insulin from penfill cartridges

· E (1) 3.	1. Wash hands.
and the second second	2. Check that you have the correct <i>insulin</i> types. You will be drawing up the <b>rapid or</b> <b>short-acting insulin first</b>
(GA)	<ul><li>3. If your long-acting insulin is "cloudy" insulin, mix by tipping the cartridge up and down ten to 20 times.</li><li><i>Do not shake the cartridge</i> as this damages the insulin. Clear insulin does not need to be mixed.</li></ul>
Colored and a second	<ul> <li>4. Open a new syringe. Make sure there is <i>no air</i> in the syringe by first pushing the plunger right down. Insert the needle into the cartridge of <b>rapid or short-acting insulin</b>.</li> <li>Pull back the plunger of the syringe to draw up the dose of insulin required plus an extra 2 units which allows you room to get rid of any air bubbles. The rubber stopper in the cartridge will gradually move down as you draw out the insulin and equalise the pressure.</li> </ul>
to	5. Remove the syringe from the bottle, hold it vertically and push the plunger gently to get rid of any air bubbles and any extra insulin to obtain the correct dose. It may help to tap the side of the syringe to remove all air bubbles.
C Solo	<ul> <li>6. Insert the needle into the cartridge of longacting insulin and turn it upside down. Pull back the plunger to obtain the correct dose. If you draw back too much, you will have to discard the whole syringe and start again. Do not push any insulin into the cartridge.</li> <li>7. Now you are ready to inject the insulin</li> </ul>

If you still need to draw up insulin from *vials (bottles)* the procedure is similar, except air has to be injected into the bottles before starting to avoid problems with suction and airlocks in the bottles.

#### Mixing insulins in a syringe

If more than one insulin type is being given at the same time, sometimes these can be mixed together in one syringe and given as one injection. Not all insulins can be mixed since the action characteristics may be altered; your diabetes team will advise with your particular insulins. Manufacturers advise that the basal insulin analogues Lantus and Levemir should not be mixed with any other insulin.

It is important not to cross-contaminate the insulin vials when doing this. It is particularly important not to accidentally get long acting insulin into your rapid or short acting insulin vial, since this will diminish the rapid or short acting insulin effect. If you always do it the same way then there is less chance of a mistake. The recommendation is that the rapid or short acting insulin is always drawn up first into the syringe.

Insulin can be drawn up from pen cartridges (3 ml) or 10 ml bottles (also called vials). Obviously pen cartridges are designed to be used in pens, but insulin can also be drawn up easily and conveniently from them using syringes. In general, we now recommend using penfill cartridges when using syringes because the drawing-up technique is simpler.

#### Giving an injection with a syringe

#### To give an injection with a syringe:

- 1. Draw up insulin as described in the diagram on page 30.
- 2. Take a small pinch of skin with the index finger and thumb. The pinch needs to be at least to the depth of the needle. This is especially important in lean people, otherwise the injection may go too deep into the muscle layer and hurt more and the insulin will act differently.
- 3. Insert the needle straight into the pinched up skin (i.e., at 90 degrees) to its full length and push the plunger slowly all the way down to push in the insulin. In very lean individuals, injecting at a 45 degree angle to the skin may be necessary to avoid the injection going too deep.
- 4. Leave the needle in for about 5-10 seconds, then gradually let go of the skin and pull out the needle.
- 5. Dispose of the syringe in an approved sharps container.

## **Injection sites**

The injection sites recommended are away from large blood vessels or nerves to avoid excessive bleeding or nerve damage. These areas include the abdomen (tummy) and waistline, the front and outsides of the thighs and the upper outer part of the buttocks. Some people also use the arms but this is a less commonly recommended site.

The abdomen (tummy) is the preferred site of injection because insulin is absorbed more quickly and uniformly from the abdomen. Also the abdomen is less affected by exercise than other sites. Many children have all of their injections in the abdomen, and by moving around all the available areas on the abdomen, problems of lumps (lipohypertrophy) can be avoided. Some people on multiple injections have injections in the abdomen, except for the pre-bed long acting dose which they have in the thigh to get a slower overnight absorption. If using different sites, it is preferable to use the same site at the same time of day (e.g., morning injection in tummy, evening injection in buttocks). In general, insulin absoprtion is quickest from the abdomen, followed by the arms, buttocks and thighs. The rate of insulin absorption can be speeded up by exercising muscles – thigh and arm muscles are most affected by this, so you should be careful about injections at these sites before exercise.

Injections in the arms are generally not recommended, especially in small children who have only a thin layer of fatty tissue beneath the skin here. It is easy for the insulin injection to go too deep and end up in the muscle and be absorbed too fast. However, some diabetes centres may recommend that arms be used at certain times – discuss with your educator.



Recommended site for insulin injections

Once you have decided with your diabetes team on the best place for injections for your child, it can be a good idea to use a poster and reward chart to guide this at home, especially for young children. One example is if injections are given regularly in the abdomen (tummy), draw a picture of a child with different sections of the tummy marked with the days of the week. This can help you remember to rotate the sites each day. Too little rotation of injection sites is one of the main problems seen with insulin injections.

Injections are given into the fatty layer under the skin, but they should not go deeper into the muscle layer as this tends to speed up the absorption of the insulin. Standard technique is to take a small pinch of skin and give the injection at a 90 degree angle to the skin (i.e., straight in). 8mm needles are recommended for most children and adolescents, especially those who are lean. If the longer 12.7mm needles are used (or in very lean individuals even with short needles), injection at a 45 degree angle may be needed to avoid the insulin going too deep and into muscle.

People who are not lean may not need to do a pinch, especially if using short needles (4, 5, or 6mm), but only use a no-pinch technique if advised by your diabetes team.

## Disposal of syringes and pen needles

Used syringes and pen needles should be placed in an approved sharps container which needs to be kept out of reach of children. These can be obtained from wherever you get your diabetes supplies (chemist, Diabetes Australia or hospital). When full, these sharps containers need to be properly disposed of. Unfortunately, uniform arrangements for sharps disposal do not exist across Australia. Check first with your local council about their sharps disposal arrangements. If satisfactory arrangements do not exist then your chemist or hospital will usually be able to dispose of them for you. Do not place syringes or pen needles in anything other than an approved sharps container.



Needles, syringes, pens, insulin cartridges and insulin bottles should never be shared with others because of the possible risk of contamination and spread of infection.

### Insulin storage

Bottles and cartridges (penfills) of insulin not currently being used are stored in the refrigerator between 2 and 8 degrees C until their date of expiry. They usually have a long storage life under these conditions. If they freeze accidentally they must be thrown away.

The insulin bottle or cartridge that has been opened for current use is generally kept at room temperature, since injections are more comfortable if the insulin is not cold (except hot climates, see below). Opened insulin bottles or pens can be stored in a cool dark place out of the fridge for 4 weeks. Insulin should be discarded after this time since it may not be as effective. In hot climates however, it is advisable to keep all insulin refrigerated including that in current use; allowing 15 to 20 minutes for it to come up toward room temperature may make the injection more comfortable.

Insulin that gets over-heated (e.g., left in a hot car) will lose its effectiveness and should be discarded. Vigorous shaking damages insulin and should be avoided. If you think that your insulin is not working well, perhaps related to storage conditions, discard it and use a new cartridge.

Remember to always have at least one spare bottle of each type of insulin on hand in case of accidental breakage.

# How long to wait between the insulin injection and eating

Most insulin injections are given before a meal or snack. For rapid acting insulins (Humalog, Novorapid, Apidra), the child should eat within 15 minutes of the injection or pump bolus, otherwise hypoglycaemia is likely. For children on these insulins it is important that the meal is ready and available before the insulin is given.

With short acting insulins (Actrapid, Humulin R), waiting 20-30 minutes is generally recommended after the injection to allow the insulin to start being absorbed. When short acting insulin is given at afternoon-tea time or at lunch time at school, waiting is often not practical so we generally recommend no waiting period for injections at these times.

If the blood glucose level has been trending low just before the injection, waiting is also not recommended. If the blood glucose level has been high, then waiting at least 20-30 minutes or longer (if this is practical) can help the blood glucose levels. Bear in mind that these guidelines are not rigid but should be followed if they fit into the daily routine.

# Common injection problems and how to avoid them

#### Leaking of insulin after the injection

#### If this occurs regularly, try:

- Holding the skin with a more gentle pinch
- injecting more slowly and slowly counting longer before pulling out the needle

#### Slight bleeding and a small bruise

This will occur sometimes because the needle goes through a small blood vessel. It is nothing to worry about and does not stop the insulin from working properly. Avoid injecting into any obvious skin blood vessels (which look like fine blue lines beneath the skin).

#### **Painful injections**

Insulin injections should cause minimal discomfort with modern fine needles. Make sure that a new needle or syringe is being used each time, because needles start to blunt after 1 injection. Injections can be more painful if cold insulin is being injected. If your insulin has been in the refrigerator, try to remember to take it out of the fridge 15-20 minutes before you want to inject.

If the injection is not being given deeply enough, the insulin may split the deeper layers of the skin, causing pain. If the insulin is being given too deeply, it may go into the muscle layer which can also cause pain.

Some children who are used to only having injections in one area will complain that injections are more painful when they move sites. Often this is a psychological phenomenon and may be avoided by getting children used to using various sites and areas from the start.

#### Fatty lumps around the site of injection (lipohypertrophy)

This is a common problem when insulin is repeatedly given into the same sites, either by injection or pump. These lumps don't look good, and more importantly, insulin absorption from these sites is likely to be variable and incomplete. These lumps can be prevented by moving the location of the injection within the same site daily (e.g., moving to a completely different part of the tummy each day) and varying pump sites as widely as possible. If present, these lumpy areas usually go away after several weeks of avoiding giving insulin in that area.



#### Hot temperature and insulin absorption

The absorption of insulin in some people may be quicker in very hot weather, especially the rapid or short-acting insulin. Some children need less insulin on hot days. Monitoring the blood glucose levels helps you work this out for your child. Insulin absorption and action may also be more rapid if you take a hot bath or shower just after taking insulin, so be careful of this.

#### Mistakes with insulin doses

It is important to be concentrating and unhurried at insulin injection or bolus times, but occasionally a mistake will occur with an insulin dose. Provided the mistake is recognised, appropriate adjustments are usually easily made. If you are not sure how to compensate, or it is a major mistake, contact your educator, diabetes doctor or hospital for advice without delay.

Errors in insulin doses can be dealt with by thinking about which type of insulin has been given in too large or too small a dose and how long the insulin will act.

- If the mistake has been to give too much insulin, test the blood glucose more frequently and give extra carbohydrate.
- If the mistake has been to give too little insulin, test the blood glucose more frequently and compensate with extra small doses of rapid or short acting insulin.

A common example of a mistake with a person on injections is giving the morning dose of insulin in the evening. This sometimes means that a much larger dose than needed has been given in the evening and hypoglycemia is a risk. Deal with this by feeding extra carbohydrate and testing the blood glucose every 2 hours during the evening and overnight. Set your alarm to make sure you wake up to check the blood glucose level. As a guide, it is necessary to eat nearly the same amount of carbohydrate overnight as during a usual daytime.

## **Common questions and answers**



#### Why are different children on different insulin types?

Insulin treatment has to be tailored for the individual child. Different insulin types suit different children, and this may depend on the age, how long they have had diabetes, their eating and activity pattern and other factors. Sometimes your child may need to change insulin types. Your diabetes team will work out what suits your child best at any time.



## My child's insulin doses keep having to be put up. Does this mean his diabetes is getting worse?

No. Doses have to increase as children grow and this is normal. They also increase when the honeymoon period is over, and increase quite a lot during the teenage years.



## How does the diabetes team decide how many injections per day my child needs?

This is an individual decision for your child and may change with age and duration of diabetes. There is increasing use of multiple daily injection plans or insulin pumps, since these are recognized to have advantages for long-term diabetes control, reduction of complications and lifestyle flexibility. Your diabetes team will discuss these issues with you and your child.



#### Are insulin pens better than syringes?

Both pens and syringes give a dose of insulin just as well, but pens tend to be quicker and more convenient. Younger children on mixed injections may use syringes, as it decreases the number of injections required per day.



## My child has fatty lumps at the injection sites — is this a problem?

Yes. This is called lipohypertrophy, and is caused by giving too many injections in the one place or putting pump sets in the same area repeatedly. It does not look good and also causes unreliable absorption of insulin. It goes away if these sites are rested. It is prevented by changing the point of injection or pump set as often as possible.



#### Should I move to a completely different injection site every day?

Insulin is absorbed differently from different areas of the body. The abdomen (tummy) is the best injection site and many use this for all injections, but some children prefer to use other areas. It is best to give the injection at the same time of the day into the same area (e.g., morning injection always into tummy, but moving around that area).



#### My 13-year-old daughter wants to give her injection through her clothes when she goes out so as not to be embarrassed by lifting up her clothing. Will this cause problems?

Although this is not the best practice and cannot be generally recommended, it is better to have the injection through the clothes than to avoid it because of embarrassment. A number of studies have shown no harm from injecting insulin through clean clothing.



I have heard that some people use different types of short acting insulin at different times of day (e.g., short acting insulin (Actrapid or Humulin R) at breakfast and rapid acting insulin (NovoRapid or Humalog or Apidra) at dinner. Also I have heard of people who have long acting, short acting and rapid acting insulin all together at the same time. Please explain?

As a wider range of insulins have become available, diabetes specialists have tried to customise insulin types and patterns to better suit an individual's requirements and gain improved control. Thus, variations from traditional insulin patterns are increasingly used. This requires detailed knowledge of insulin characteristics and should only be done on the recommendation of your diabetes team. As more new insulins become available, more variations in insulin patterns are likely to be seen.

## Chapter 6 Food and healthy eating

## **Key Points**

#### Key points for diabetes management are:

- Children with diabetes need a normal, healthy food plan as is appropriate for the whole family
- Learn about healthy eating and encourage them to eat a wide variety of foods
- Controlling blood glucose levels is a balance between the carbohydrate foods that we eat, insulin doses and activity
- Understanding the effect of the amount and type of carbohydrate on BGLs is important in achieving good diabetes control
- Different carbohydrate foods affect blood glucose levels differently

   the glycaemic index describes this. Try to include some low
  glycaemic index food in each meal and snack
- Limit the amount of food containing sugar, but some sugar in food is a normal part of a balanced diet
- Limit the intake of fats, particularly saturated fats
- Reading food labels helps you work out what to eat
- Healthy eating and an active lifestyle will help maintain a healthy weight

### Introduction

The food plan (or nutritional plan) for diabetes is really just a healthy way of eating and it is good for the whole family.

This section is all about food and diabetes. Your dietitian will go through all of this information with you to ensure you develop a good understanding of the food plan for diabetes. The healthy eating plan that is promoted for diabetes is basically the same that is promoted for all children. Throughout this section you will learn how easy it is to choose and eat good food. The rewards for following a healthy eating plan will be that your child will feel fit and healthy and will grow and develop normally.

### The Australian dietary guidelines for children

The Australian dietary guidelines for children (from the National Health and Medical Research Council) are great for all people to follow, including children and adolescents with diabetes. They can be summarised as follows:

- Enjoy a wide variety of nutritious foods
- Eat plenty of vegetables, legumes and fruit

- Eat plenty of cereals (including breads, rice, pasta and noodles), preferably wholegrain
- Include lean meat, fish, poultry and/or alternatives
- Include milks, yoghurts, cheese and/or alternatives
  - Reduced fat milks are not suitable for children under 2 years, but reduced fat varieties should be encouraged for older children and adolescents
- Choose water as a drink
  - Alcohol is not recommended for children and adolescents
- Limit saturated fat and moderate total fat intake; low fat diets are not suitable for infants
- Consume only moderate amounts of sugars and foods containing added sugars
- Choose foods low in salt
- Children and adolescents need sufficient nutritious foods to grow and develop normally. Growth should be checked regularly
- Physical activity is important for all children and adolescents
- Encourage and support breastfeeding
- Prepare and store food safely

## **Components of food**

Food comes in a variety of shapes, sizes and colours and has many different tastes and textures. Most foods are made up of a combination of nutrients. A basic understanding of the different nutrients that are contained in the food we enjoy eating is important.

#### The main nutrients in food are:

- **Carbohydrates:** Carbohydrates are the most important source of energy for the body. Out of all the nutrients, only carbohydrates directly affect blood glucose levels. The amount and type of carbohydrate eaten are both very important. Examples of carbohydrate-containing foods are bread, pasta and milk.
- **Proteins:** Proteins are important building blocks in the body and are essential for normal growth and repair of body tissues. Examples of protein-containing foods are meat, fish and eggs.
- **Fats:** Fats and oils are also essential for growth and development and are an important source of energy. A certain amount is essential for good health but too much or the wrong type becomes unhealthy.

#### Other nutrients and components of food include:

- **Vitamins and minerals:** These are important for the normal functioning of many body processes. The best way to have a balanced vitamin and mineral intake is through a healthy variety of foods, especially fruit and vegetables.
- **Fibre:** An adequate intake of fibre is important for bowel health and is believed to have a number of long-term health benefits.
- Water: Water is the most common component of the body. Drinking plenty of fluids is important for general health. Your child should drink more if it is hot and if they are more active or have high blood glucose levels. Water is the healthiest fluid of all to drink.

## Chapter 6

## The healthy living pyramid

The healthy living pyramid provides a basic guide to healthy eating for all people. It emphasises the type of foods that we should eat most, those that we should eat moderately and those that should only be eaten in smaller amounts. It also emphasizes the importance of physical activity. This advice applies to all children and adolescents, whether or not they have diabetes.



## Carbohydrate

Carbohydrate or 'carbs' are energy foods. During digestion, carbohydrates are broken down into glucose and are absorbed into the blood. Blood glucose is the fuel for our body just as petrol is the fuel for a car. Blood glucose levels go up and down throughout the day. They rise after eating carbohydrate and fall as we use the glucose in our blood for energy.

In people without diabetes, blood glucose levels are closely controlled by insulin produced by the pancreas in response to the food they eat. In people with diabetes the amount and type of carbohydrate eaten is balanced with the amount of insulin given. It is important to eat regular meals throughout the day and know how much carbohydrate they contain to keep the blood glucose levels in balance.

The insulin plan for your child will usually be selected based on your child's usual eating patterns and the amount of carbohydrate eaten. Most children (including infants and toddlers) will require three main meals and three snacks per day.

Teenagers or adults may have more flexible eating patterns. It is important to discuss the insulin and food plans with your dietitian to ensure that they work well together.

#### Carbohydrate: when, how much and what type?

Understanding these questions is an important part of the diabetes food plan.

#### The main points are:

- 1. **Spread of carbohydrate:** The intake of carbohydrate foods should be spread across the day. For most children this will be divided into three meals (breakfast, lunch and dinner) and two or three smaller snacks (morning tea afternoon tea and sometimes supper) at fairly regular times each day. This is appropriate for all children, whether they have diabetes or not.
- **2. Amount of carbohydrate:** Regulation of the amount of carbohydrate eaten is important for good results with any insulin plan. Using a simple system to count carbohydrates such as exchanges or serves can be a useful guide. Different insulin plans will have different flexibility with meal times and carbohydrate quantity and your dietitian will discuss this individually.
- **3. Type of carbohydrate:** Think about the type of carbohydrate. Different carbohydrates have different effects on blood glucose levels. This concept is called the *'glycaemic index'* of food. It is important to include low glycaemic foods as these may assist with blood glucose control.

#### When to eat

A normal eating pattern is to spread carbohydrate intake across the day in regular meals and this is important for diabetes management. The aim is to have the insulin action (from injections or pump) matching the carbohydrate intake to keep the blood glucose levels within target as much as possible. Depending on the insulin plan, going too long without carbohydrate during the day may result in the blood glucose level dropping too low.

Overnight when your child sleeps and is not eating, the blood glucose level is maintained because of the carbohydrate eaten before bed, less activity, less insulin acting overnight and ongoing glucose output from the liver. Some children require a snack before bed (supper) to help maintain the blood glucose level overnight – include some low GI food such as milk. However, newer insulin plans and insulin pumps mean that supper may be optional for some children – check this with your diabetes team.



Your dietitian will usually advise that your child have three main meals each day (breakfast, lunch and dinner) and two or three snacks (morning tea, afternoon tea and sometimes supper). Some insulin plans and insulin pumps allow some flexibility in the timing of meals and snacks and your diabetes team will discuss this with you.

Some teenagers and young adults, especially those on rapid-acting insulins or insulin pumps, may require little or no between-meal snacks. Your diabetes team will advise about individual circumstances.

#### How much to eat

The aim is to eat an amount of carbohydrate that suits healthy nutritional demands, as for any child. In general, children's metabolism is best suited to having a fairly similar intake of carbohydrate each day, which is spread across the day in a similar way.

The current recommendations are that all children and adolescents with type 1 diabetes should count or quantify carbohydrates and this is especially important for those using adjustable insulin plans (insulin pumps or multiple daily injections). There will always be some variation in carbohydrate intake from day to day, depending on appetite, activity levels and other factors. As long as the variation is not large, blood glucose levels should remain satisfactory.

Two systems are in common use to help guide the amount of carbohydrate to be eaten at each meal.

#### 1. Counting carbohydrate in exchanges or grams

Counting carbohydrate exchanges is a simple system to help estimate the amount of carbohydrate in different foods, with the aim of helping matching insulin doses to carbohydrate intake.

One exchange of a carbohydrate food is the amount that contains approximately 15 grams of carbohydrate.

Remember that an exchange of carbohydrate does not refer to the total weight of the food, but the amount of that food that contains 15 g of carbohydrate.

For example, the following common foods all contain about one exchange

- (15 grams) of carbohydrate:
- one slice of bread
- one medium banana
- 250 ml of milk
- one medium potato
- one large orange
- 1/3 cup cooked rice
- 1/3 cup cooked pasta



Your dietitian will suggest an approximate number of carbohydrate exchanges for each of your child's meals or snacks and you can then choose from a variety of carbohydrate containing foods to make this up. For example, a teenager may have 3 to 4 exchanges of carbs for breakfast whereas a toddler may have 1 or 2. In flexible insulin plans and insulin pumps, there is more flexibility and the insulin dose is directly based on the amount of carbohydrate that the person chooses to eat.

Your dietitian will introduce you to resources that give information about about how much carbohydrate is in various foods and how much of that food is one exchange (15 grams) of carbohydrate. On packaged foods, the nutrition information panel is the best way to get information on carbohydrate quantity. The carbohydrate content of the food is shown in grams and this allows you to work out the approximate number of exchanges.

#### 2. The serves system

This is another type of system that can be used to ensure appropriate carbohydrate distribution over the day for patients on insulin injection plans, although is not suitable for those using insulin pumps. It is not based on a specific quantity of carbohydrate but rather an individual's preferred serving size. Therefore a serve of a particular food is likely to be different for different children and at different ages. This does not matter, as long as you remain consistent. However, in practical terms, one serve is often fairly close to one exchange of carbohydrate.

The number of serves of carbohydrate that your child eats at each meal or snack should be based on their usual intake, activity level and appetite and may vary a little from day to day. Your dietitian will suggest an approximate number of serves for each of your child's meals and snacks (e.g., three to four serves for breakfast) and you can then choose from a variety of carbohydrate-containing foods to make this up. When choosing the foods, you would also think about the type of carbohydrate and choose at least one low GI food at every meal and snack.

A typical serving size may correspond to a slice of bread, a glass of milk or juice, one piece of fruit or simply the amount that fits into the palm of the child's hand (usually 10-20 grams of carbohydrate). The key is to be consistent with serving sizes of particular foods from day to day.

Serves and exchanges are often similar, but not always the same. It is best to get used to one system or another and then follow that. The system that you follow may depend on the local preference in your diabetes centre, who will provide you with further information. Remember that both systems can work well.

### **Carbohydrate counting is important for diabetes management** Carbohydrate for meals and snacks should be counted in:

grams, or

exchanges (one exchange equals approximately 15 grams of carbohydrate),

or serves.

#### Using carbohydrate counting in the diabetes management plan

The above sections have talked about the importance of carbohydrate counting and how this helps to match insulin doses to the amount of carbohydrate that is eaten. This is also discussed in chapter 12 on Insulin adjustment.

Carbohydrate counting can be used in a number of different ways in meal planning. Your diabetes team will teach you one of these methods, depending on your child's age, insulin plan, eating pattern and other needs. This may change over time. Don't worry if other people you know are using a different plan.

#### 1. Consistent carbohydrate intake

In this method, the aim is to have a food plan in which there are consistent amounts of carbohydrate intake for the meals and snacks each day. For example, a child may always like about 3 exchanges of carbohydrate for breakfast, 2 exchanges for morning tea etc. The type of foods can be varied by understanding carbohydrate exchanges. The insulin pattern is designed to match this consistent intake of carbohydrate from day to day.

This method suits people who find they have a fairly consistent intake of carbohydrate from day to day.

#### 2. Flexible carbohydrate and insulin adjustment

In this method, the person with diabetes has an understanding of their usual carbohydrate intake, which they count using exchanges, and their usual insulin doses and activity. They also recognise how their blood glucose levels respond to variation in carbohydrate intake, activity patterns and insulin doses. They learn to adjust insulin doses, especially pre-meal doses, if needed to account for this variation in carbohydrate intake and other factors with the aim of achieving blood glucose targets.

For example, a child who usually has 7 units of NovoRapid to cover their usual breakfast will increase that dose by 1 or 2 units if they are hungry and eat a bit extra.

#### 3. Insulin to carbohydrate ratio

This is another level of carbohydrate counting. In this method, the person has a formula for how much insulin is needed to cover 1 exchange of carbohydrate (15 grams of carbohydrate) and they calculate the dose according to how much they are going to eat at a meal. They can also make a correction for high or low blood glucose and activity.

For example, a teenager might have 2 units of rapid insulin per exchange (15 g) of carbohydrate before each meal. Therefore if he eats 3 exchanges he will have 6 units; if he eats 4 exchanges he will have 8 units.

All these methods rely on counting of carbohydrates which you and your child will become more skilled at. However, children and families require regular updates to remain skilled at carb counting. Your diabetes team will advise which form of applying carbohydrate counting is recommended and your preferences will be discussed. Diabetes can be managed appropriately with any of these methods, depending on the individual circumstances.

#### Type of carbohydrate and the glycaemic index (GI)

Different carbohydrates have different effects on blood glucose levels because of differences in rates of digestion and absorption. This concept is called the glycaemic index or GI. Foods with a high GI are quickly digested and absorbed and cause a rapid and large rise in blood glucose levels. Foods with a low GI are more slowly digested and absorbed and produce a more gradual rise and fall in blood glucose levels, which is preferable for children with diabetes. We usually consume a mixture of low, medium and high glycaemic index foods at meal times. It is important to know about glycaemic index and try to include at least one low glycaemic index food in each main meal for your child. This will help achieve more stable blood glucose levels.

#### Try to include at least one low GI food in each main meal for your child. When the GI is low, the blood glucose rise is slower and lower.

The glycaemic index is all about understanding the effect of different carbohydrates on blood glucose levels. There are a number of factors that influence how carbohydrates are digested, including fibre content, cooking and processing, amount of fat and protein presence of sugar, type of sugar and type of starch.

Carbohydrate containing foods can be classified as low, intermediate or high GI according to the known effects on blood glucose levels. Foods are given a ranking from 0 to 100. A ranking  $\leq$  55 is a low GI food, 55 to 70 is medium GI and > 70 is a high GI food. Some packaged foods now include a symbol indicating if they are low GI, but this is not required labelling.

As can be seen in the graph below, the blood glucose rise after eating white bread is much quicker and higher than when pasta is eaten. White bread is a high glycaemic index food (GI greater than 70) and pasta is a low glycaemic index food (GI less than 55). Information like this is available for many foods.



Comparison of blood glucose levels after eating white bread or pasta

#### Low GI foods (GI less than 55)

Good choice low GI carbohydrates include pasta, milk, yoghurt, rolled oats, baked beans, wholegrain breads, fruit loaf, noodles and spaghetti, sweet potato, apples, pears, peaches, oranges and grapes. Adding lemon juice or vinegar to a meal (as a salad dressing) can also help lower the glycaemic index of that meal.

It has also been recognised that low GI foods have an important carry-over effect. The benefits of a low GI breakfast will carry over and benefit the blood glucose levels at the next meal. A simple change such as switching to low GI bread and having a low GI breakfast cereal has been observed to significantly improve blood glucose control throughout the day.

#### Intermediate GI foods (GI 55 to 70)

These include basmati rice, crumpets, bananas, wholemeal crispbread, wheat cereal biscuits, oatmeal, Shredded Wheatmeal biscuits, pineapple and rockmelon.

#### High GI foods (GI more than 70)

High GI carbohydrates include puffed wheat, white bread, wholemeal bread, baked potato, mashed potato, calrose rice, waffles, jelly beans, watermelon, cornflakes, chocolate rice cereal, water crackers and soft drinks and Lucozade. High GI foods can be included as part of a balanced diet, but it is important to combine them with lower GI foods when possible.



Many parents have already noticed that some types of carbohydrate containing foods seem to last longer or always produce a more desirable blood sugar level compared to other foods which seem to be used up before the next meal or snack. This is the difference between a low GI and a high GI food.

The GI should never be used in isolation when making food choices for your child with diabetes. The dietary guidelines for children should always be considered when introducing new foods into your child's diet. It is also important to think about where the foods fit in the healthy food pyramid as well as their GI value. Low GI foods in the eat least section still need to be limited. High GI foods in the 'eat most' section can be included regularly but ideally combined with low GI choices. Remember that it is usual to eat a varied diet that includes low, intermediate and high GI foods. If you want to learn more about the GI ask your dietitian for more information.



Sugar (or sucrose) is a type of carbohydrate. Sugar can be included as part of a normal healthy diet as long as it is eaten in moderation, especially if included as part of a meal. Foods containing sugar often do not raise blood glucose levels as high as some common starchy foods. Using the glycaemic index, sugar itself has a GI of 65 which is intermediate and many sugar-containing foods such as milkshakes and yoghurts have low GI values. Foods that contain added sugar are often higher in carbohydrate and fats so it is important to read the nutrition information on the packet so that you can decide if it is a suitable food and estimate how much to eat. This will be covered later in this section.

## **Artificial sweeteners**

A number of different artificial sweeteners are available and widely used in products such as diet soft drinks and cordials and other 'diet' or 'low joule' products. These include aspartame (Nutrasweet and Equal), saccharin, sucralose (Splenda), stevia, isomalt and cyclamates.

Artificial sweeteners have been widely used and are generally believed to be safe if taken in moderation.

Products such as diet soft drinks and cordials are suitable for people who have diabetes, since non-diet drinks do result in major elevations of blood glucose levels. However, remember that water is the healthiest drink for everyone and diet drinks are best reserved as an occasional item.

Sugar can be included in small quantities as part of a well balanced, low GI diet, making the use of artificial sweeteners mostly unnecessary. Where sweetening is required in a mixed food or recipe (containing carbohydrate, protein and fat), sugar can often be used. This is because in mixed food, the absorption of the sugar is slowed down by other ingredients.

Products containing the sweeteners isomalt, sorbitol, mannitol, xylitol and maltitol can have a laxative effect if too much is eaten.

## **Special diabetic products**

The labelling of food can be confusing. Some foods are labelled as 'suitable for people with diabetes' or 'no added sugar, but they may not be recommended by your dietitian.

#### Reasonable choices would be food products labelled as:

- diet or low joule cordials and soft drinks
- diet or low joule jelly
- no-oil salad dressings.

Diabetic confectionary, ice-cream and biscuits are an unnecessary part of the diet and are not encouraged. These 'special diabetic foods' are often expensive, offer no benefit over the real thing and may contain compounds such as sorbitol which may have a laxative effect.

#### Try to avoid:

- diabetic cakes
- carbohydrate-modified ice-cream

- diabetic chocolate and lollies
- diet biscuits
- carbohydrate-modified jams and diet jams.

## **Proteins**

Proteins are important building blocks of the body. Proteins play an important role in growth and repair of body tissue and can also be used as a secondary source of energy by the body.

Protein foods include meat, chicken, fish, cheese, eggs, nuts, legumes and seeds. Some protein foods also contain carbohydrate and fat; for example, milk and yoghurt.

Protein foods can be quite high in fat so it is important to eat foods from this group in moderation as the healthy food pyramid suggests. Choose lower fat options such as lean meats and low fat dairy foods.



### Fats

Fats are an important part of our diet and a certain intake is required for healthy growth and development. There are different types of fat in foods and we now know that polyunsaturated fats (vegetable oils), monounsaturated fats (canola and olive oils) and omega-3 fats (fish oils) are much more healthy than saturated fats. It is also important to remember that all fats are high in energy, and if too much fat is eaten, excess weight gain may occur.

It is important to establish good eating habits from an early age. We know that there is an increased risk of elevated cholesterol and vascular disease in diabetes. Reducing saturated fat in the diet is recommended, not only for people with diabetes but for the general population to reduce the risk of vascular disease. A high intake of saturated fat is strongly associated with high cholesterol and increased risk of heart disease.



#### How can we eat less saturated fat?

The best way to reduce saturated fat in our diet is to reduce the intake of fat from meat and dairy foods and from fats used for frying and baking. Many children's snack foods are high in saturated fat.

Substituting 'healthier' fats such as monounsaturates and polyunsaturates will help to control blood cholesterol levels and reduce the risk of heart disease.

#### Suggestions:

- Try selecting reduced or low fat dairy products in place of traditional full fat products. Reduced fat milk is suitable for children over 2 years of age.
- Replace saturated spreads like butter, with monounsaturated and polyunsaturated spreads and oils.
- Try to select low fat options when buying takeaway and select those that are cooked with oil low in saturated fat.
- Avoid deep frying. Oven baking or grilling is preferred.
- Trim visible fat from meat. Buy lean cuts of meat and lean mince.
- Try to limit takeaways to once or twice a week.
- Watch out for snack foods which are high in saturated fats (e.g., chips, some biscuits and savoury biscuits and dip).
- Ask your dietitian about suitable snack foods or read the snack section in this section.
- Try canola, olive or sunola oils which are high in monounsaturates, but these may also need to be limited if your child is overweight.
- Avocados and nuts are high in monounsaturates but still need to be limited to reasonable quantities or excess weight gain may occur.

## Fibre: make sure your child has enough

Fibre refers to material in food which is generally not absorbed, but is very important in keeping the bowel and digestive processes in balance. It also helps keep our bodies healthy by helping to prevent some diseases, keeping our bowels regular and making us feel full. Fibre is only found in plant foods such as wholegrain and wholemeal breads and cereals, brown rice, wholemeal pasta, fresh fruit and vegetables, legumes and pulses (e.g., baked beans and lentils), nuts, bran and dried fruits. Soluble fibre is linked to reducing cholesterol and other forms of fibre (e.g., resistant starch) are linked with disease prevention.

How much fibre your child needs each day will depend on their age. It is recommended that young children (aged 1-8yrs) need 14-18 g/day. Older children should aim for 20-28 g dietary fibre per day. To achieve this, choose high fibre breakfast cereals, wholegrain bread and a good intake of fruit and vegetables. For packaged foods, a high fibre choice contains 3 g fibre or more per serve.



## **Fluids**

Having enough fluid intake is part of a balanced healthy eating plan for all people. The best fluid to drink is water. Fresh fruit and some other foods contribute to daily fluid intake. Fluids such as milk and juice contain carbohydrate and need to be counted in your child's carbohydrate intake. Fruit juices should be limited to no more than one glass per day and consumed in combination with a mixed meal. Diet soft drinks and diet cordials can be included in moderation and will not affect blood glucose levels.

Plenty of fluids are especially important in hot weather and when exercising. During sick days (see chapter 10), fluid intake is very important, especially if the blood glucose levels are high (water or other carbohydrate-free fluids). When not feeling well, carbohydrate-containing fluids are easier to tolerate than normal foods.

## 'Free' foods

Free foods are foods that contain minimal amounts of carbohydrate and fats and do not affect blood glucose levels when eaten in moderation.



Note: Eating too much of some free foods can affect blood glucose

The following free foods list includes some vegetables, some fruits, beverages, condiments, spices, flavourings, spreads and sweeteners.

Foods containing protein and fat are not free foods because they are often high in calories. Meat, chicken, eggs, cheese and fish are protein foods that don't contain carbohydrate. These foods contain some fat and are recommended to be eaten in moderation, not as a free food. Also, some free foods (e.g., soy sauce, Vegemite) are very high in salt, so large amounts are discouraged.

If your child is asking for free foods regularly, it is likely that their current meal plan needs increasing to satisfy their appetite and meet their growth requirements – your dietitian can assist with this. Eating very large amounts of some free foods can affect blood glucose.

#### Free foods list

- Vegetables: All vegetables are free except potato, sweet potato, corn, taro, yam and cassava.
- Fruits: Small amounts of strawberries, lemon and passionfruit.
- Beverages: Broth, tea, coffee, herb tea, low joule or diet cordial and low joule or diet soft drinks. Limit diet drinks to two glasses per day in general. Coffee and tea are not recommended for young children.
- Flavourings: Cocoa, coffee, diet toppings, vanilla and other essences.
- Spreads, dressings and seasonings: Vegemite, Promite, Marmite, fruit spreads or jams (small amount) and fish paste, salad dressings and mayonnaise.
- Seasonings such as herbs and spices, garlic, parsley, mint, mustard, tomato sauce, tomato puree, vinegar, Worcestershire sauce, stock cubes, soy sauce, pepper and lemon juice.

## **Reading food labels**

Learning to read food nutrition labels will be of great help in making food choices. Different products will suit different people, depending on the amount of food they eat, body weight, blood glucose control, blood cholesterol and the amount and type of exercise.



The two main things to consider when looking at a food label are:

- the total amount of carbohydrate (which includes sugar), and
- the amount and type of fat

There are food labelling standards for Australia and New Zealand that all food labels need to comply with. Compulsory information includes energy (kilojoules), protein, total fat, saturated fat, total carbohydrates, sugars and sodium. Total carbohydrate is shown and, beneath this, the amount of the total carbohydrate that is made up of sugars. Total fat is shown and, below this, the amount of that fat that is saturated fat. Remember that foods lower in saturated fats are generally healthier.

Some food packages will display GI information, but this is not compulsory for food labels. Not all foods have been tested for GI value.

#### Information to look for

Look at the following information in the nutrition panel:

- **Serving size:** Compare this with the amount your child will be eating or drinking. Is your serve size the same as that stated on the package? The serving size is the average serving size of the product but your child may eat more or less than this amount.
- **Fat:** Try to avoid foods high in saturated fat. For snack foods, choose lower fat products -aim for less than 5 g fat per serve or less than 10 g fat per 100 g.
- **Carbohydrate total:** The total carbohydrate includes all sugars and starches, both natural and added. Remember that approximately 15 grams of total carbohydrate equals one exchange of carbohydrate.
- **Sugars:** This tells you how much of the total carbohydrate is sugar. This will include added sugar as well as naturally occurring sugar such as lactose (milk sugar) and fructose (fruit sugar).
- **Ingredients:** When the ingredients are listed on a product they are listed in order of greatest to least quantity by weight. The ingredient which is used most is listed first and that used least is listed last. If sugar or a type of fat is listed first, this may not be a good everyday food choice. Look for added fats and sugars!

## Examples of labels

Here are examples of nutrition labels from two products and a guide to the information they contain.

Nutrition information – Low fat fruit yoghurt 150g tub					
Serving size: 150 g, Servings per tub: 1					
	Average quantity per 150 g serving	Average quantity per 100 g			
Energy	589 kJ (140 Cal)	393 kJ (94 Cal)			
Protein	6.9 g	4.6 g			
Fat: total saturated	2.0 g 1.2 g	1.3 g 0.8 g			
Carbohydrate: total sugars	22.5 g 21.4 g	15.0 g 14.3 g			
Sodium	102 mg	68 mg			
Calcium	226 mg	151 mg			
	Ingredients: Skim milk, milk, sugar, milk solids, fruit (6%), water, live acidophilus and bifidus cultures, halal gelatine, thickener, flavours, acidity regulators.				

Nutrition information – Barbecue Shapes – snack biscuits					
Serving size: 25 g, Servings per package: 8					
	Quantity per serving	Quantity per 100g			
Energy	546 kJ	2184 kJ			
Protein	2.6 g	10.2 g			
Fat: total saturated	6.3 g 2.9 g	25.2 g 11.7 g			
Carbohydrate: total sugars	15.8 g 0.4 g	63.3 g 1.4 g			
Sodium	188 mg	752 mg			
	Ingredients: Wheat flour, vegetable oil, tomato powder, salt, emulsifier, yeast, sugar, parsley, garlic, glucose, Worcestershire sauce, onion powder, raising agents, flavours (natural, nature identical), spices, vegetable extract, flavour enhancer (E260).				

### Questions to ask yourself when reading food labels

This example uses the two food labels above.

#### I. How much yoghurt is my child going to drink or eat?

Your child will eat 150 g if he or she eats the whole tub. Note that the nutrition information is given for this serving size and also per 100 g of yoghurt.

#### 2. What is the total carbohydrate in this tub of yoghurt?

There is 22.5 g in the whole tub (150 g), or approximately 1.5 exchanges of carbohydrate.

#### 3. What about the sugars in the yoghurt?

Sugar is listed as an ingredient and makes up most of the carbohydrate in this product. This is not a problem, since it is mixed with protein and fat in this product which will slow its effect on blood glucose levels. Yoghurt is generally a low GI product (see below).

#### 4. What is the main ingredient in the yoghurt?

Skim milk, since it is listed first in the ingredient list.

#### 5. Is the yoghurt high in fat?

No, it is low in fat and saturated fat. The total fat content is only 1.3 g per 100 g.

#### 6. Does the yoghurt have a low, medium or high glycaemic index (GI)?

This is not shown on the nutrition label. Brief lists of foods and their GIs are given earlier in this section. In general, dairy products have a low GI. Your dietitian can give you more information about GI.

## 7. Are the 'barbecue shapes' an appropriate carbohydrate food for everyday eating?

The shapes do contain carbohydrate. However, they also contain 25.2 g of fat per 100 g (i.e., they are 25.2 % fat). Foods with more than 10 g per 100 g should only be eaten occasionally and in moderation. About half of the fat in the 'shapes' is a saturated fat which should be kept to a minimum in the diet. The shapes are also high in sodium (salt). Thus the shapes should be regarded as an occasional food to be eaten in moderation and not an everyday food.

#### 8. How many of the Barbeque Shapes make up one 15g exchange?

You cannot tell this from this nutrition label. Some nutrition labels might tell you how many biscuits make up one serving, but not in this case. You could estimate by knowing that the pack is made up of 8 x 25 g servings, each serving containing 15.8 g of carbohydrate or about 1 exchange. Alternatively, weighing reveals that there are approximately 13 biscuits per 25 g of the product or per exchange of carbohydrate. Weighing and measuring is not always necessary, but can be a good idea when you are using unfamiliar foods or serving sizes.

## Ingredients in disguise

Fats and sugar are sometimes called by other names in ingredient lists. Use the following lists to see how many different fats and sugars are contained in your food choices.

Fat is also known as:	Sugar is also known as:
<ul> <li>vegetable oil/fat</li> <li>animal fat/oil</li> <li>shortening</li> <li>copha</li> <li>lard</li> <li>tallow</li> <li>chocolate</li> <li>palm oil</li> <li>coconut oil</li> <li>milk solids</li> </ul>	<ul> <li>sucrose</li> <li>glucose</li> <li>dextrose</li> <li>malt</li> <li>maltose</li> <li>glucose syrup</li> <li>corn syrup</li> <li>molasses</li> <li>golden syrup</li> <li>fruit syrup</li> <li>fruit juice concentrate</li> <li>honey</li> </ul>

## Nutrition claims on food labels

Food packaging and advertising use a number of terms to make claims about the product. Some of these are explained here: they may not always mean what you think. If in doubt, read the nutrition panel which helps you work it out for yourself.

- Lite or light: May refer to colour (e.g., light olive oil), salt content (e.g., lite chips) or to fat content. This can be confusing, so check the nutrition panel.
- **No added sugar:** May still contain fruit sugar (fructose) or milk sugar (lactose). Check the nutrition panel for the carbohydrate content.
- **Cholesterol free or low cholesterol:** Cholesterol free does not mean fat free. Cholesterol is only found in products of animal origin. Avocados, for example, are cholesterol free but not fat free.
- Low joule: The food or drink has been artificially sweetened, but may still contain carbohydrate. Check the nutrition panel.
- **Diet:** Products that have a lower energy content (kilojoules or kJ) than other similar foods (e.g., diet yoghurt).
- **Carbohydrate modified:** A sugar alternative such as sorbitol is used. Check the nutrition panel for carbohydrate and fat content. These foods still contribute energy to the diet and are not necessarily suitable alternatives.
- Low fat: The food contains less than 3 g of fat per 100 g.
- **Reduced fat:** The fat content has been reduced but the food may still be high in fat (e.g., reduced fat cheese). These may still be fine to eat, but consider how much and how often you eat them.
- **No added salt or reduced salt:** There has been no salt or less salt (sodium) added to the food.
- **High fibre:** The food must contain at least 3 g of fibre per average serve.
- All natural: A very non-specific claim. Read the nutrition label.
- **Toasted or oven baked:** Check the fat content of these foods. It may still be quite high.
## Advice for specific age groups

As children grow and develop, the initial meal plan will require adjustment. The management of diabetes varies greatly at different ages and stages of development.

#### Infants and toddlers (under five years)

Breastfeeding is encouraged for infants with diabetes. Breast milk or human milk substitute formula remains a major nutrient source until one year of age. Solids may be introduced at four to six months.

Fussy eating, food fads and food refusal are common in toddlers and when these occur in a child who has diabetes this can cause great anxiety for parents. It is not unusual for a toddler to eat erratically and be unpredictable, but usually with persistence and a consistent approach, more regular eating patterns can be are established.

Young children often wish to eat more frequently than older children, but a diabetes meal pattern of 3 main meals and 3 snacks each day works well for this. Whereas a "grazing" style intake was previously recommended for toddlers with diabetes, it is now recognised that this makes matching insulin to food intake more difficult and also makes blood glucose interpretation more difficult because the child has usually just eaten. 3 meals and 3 snacks for toddlers and young children works well and helps establish good eating patterns.

The meal environment is important in establishing good eating habits in children. TV, computers and other distractions should be turned off and everyone should sit at the table for at least 15 minutes, even if not choosing to eat. If a young child asks for food between meals/snacks, offer water or try distraction techniques, e.g., reading a book, playing a game. If a young child will not eat at the meal they should still stay at the table and hopefully will start to eat. If not, they can be offered something after the meal, although that still needs to be a reasonable food choice.

As healthy eating habits for life are being established by the whole family, a variety of food colours, tastes and textures should be promoted. To guard against parents becoming slaves in the kitchen, toddlers should be given a simple choice between one food or another rather than asking 'what would you like to eat?'.

#### School-age children

Children's energy needs are constantly increasing with rapid growth and activity. Energy intake nearly doubles from 6 to 12 years of age. Regular review of meal plans is therefore essential. Eating patterns tend to be more regular at this age and most children adapt well to having three main meals and two or three snacks during the day. School-age children are encouraged to carry 'hypo food' and be aware of the need for extra carbohydrate for exercise. School-age children need to be guided about choices from the school canteen and fast foods. Also, avoid swapping of food at lunchtime which is common, since swaps may have different carbohydrate quantities or be less suitable choices.

#### **Adolescents**

Adolescence is a natural period of establishing independence and of rebellion; diabetic management is one more thing to rebel about. Growth is rapid, lifestyle is more irregular and there is often more snacking, eating out and fast foods. The issue of alcohol use may also arise. The desire for independence can cause resentment of restrictions, particularly if food is the focus.

Adolescents on multiple insulin injections or insulin pumps enjoy the flexibility of being able to adjust daily routines to match their lifestyle. Accurate counting of carbohydrate is important in order to take advantage of this flexibility. It is important that healthy food choices and regular meals are still reinforced. Undesirable practices such as skipping insulin, over-restricting food intake to reduce weight or episodes of binge eating are often seen in this age group.

## **Children's parties**

We all love eating out, parties and celebrations. They are important for children's social development and diabetes is no reason to miss out. For these occasional times, the meal plan can be relaxed without affecting overall diabetes control.

- The number one rule is **HAVE FUN!** Parties are special for all children.
- Before the party, chat to your child about what foods may be there and what they may choose.
- Encourage savoury food choices (e.g., chips, popcorn, party pies and sausage rolls). Allow some high sugar foods such as birthday cake or ice-creams.
- Provide the host with simple instructions about 'hypo 'management and reassure them that high sugar foods occasionally will do no harm.
- It is easy to have diet soft drinks and diet cordials at parties for everyone to enjoy.

If blood glucose levels are high after the party, don't be tempted to restrict intake at dinner, as this may result in a low blood glucose level later in the night. Offer healthy carbohydrate food choices at the evening meal, test the blood glucose level before bed and give extra snacks if needed.

Sometimes children eat less food at parties because they don't think they can eat party food or they are too busy playing. If this is the case and there have been lots of active games, it is important that your child has a good supper before going to bed to avoid overnight hypos. They may need to eat extra supper if they ate little at the party.



If you are holding the party you can easily control the food provided. Remember to plan lots of active games. Children don't expect all high sugar foods and anything that is a novelty is fun enough. Try a theme or dress-up party with foods to match (e.g., American baseball and hot dogs, Mexican tacos or a Hawaiian pool party).

## Healthy takeaways

Takeway food can be a part of a healthy eating plan for your child, particularly if you select foods lower in fat and sugar such as the following:

- **Sandwich bar:** Rolls, bagels, foccacia, pita bread, sandwiches and so on, filled with lean meat, chicken, fish, egg, baked beans or cheese and salad.
- **Pasta or pizza parlour:** Pasta with tomato-based sauces; lasagne; thin-based pizza; vegetarian pizza topped with tomato, onion, capsicum, pineapple, mushrooms and a light sprinkling of cheese.
- **Salad bar:** Fresh salads such as coleslaw, potato, tabouleh, pasta, bean and rice; low fat yoghurt; fruit smoothies; fruit salad; pita bread, rolls and sandwiches; milkshakes.
- Chinese: Steamed rice or noodles, stir-fried dishes, steamed dim sims.
- Lebanese: Kebabs with meat or chicken and salad, felafel rolls.
- Hot food or takeaway shop: Hamburger plain with salad, steak sandwich, grilled fish, BBQ or charcoal chicken, chicken burger, baked potato, chunky potato wedges, mashed potato and gravy, soup with a roll, toasted sandwiches.



## **Adapting recipes**

You will still be able to use your favourite recipes for meals and snacks. Some modification may be necessary to reduce the fat or sugar content. Discuss this with your dietitian if unsure.

#### Suggestions in cooking

- Halve the sugar in your usual cake recipes (e.g., if the recipe usually has one cup sugar, change it to half a cup). Sugar is still necessary for taste and texture and it doesn't cause a big rise in blood glucose levels if included as part of a balanced diet.
- Try to use polyunsaturated or monounsaturated margarine, canola or olive oil in cooking in place of butter, lard or dripping.
- Try to use low fat ingredients where possible (e.g., low fat cheese and milk).
- Try to incorporate some low GI foods in your ingredients whenever practical (e.g., oatbran, dried apricots, muesli, yoghurt, fruits).

## **Snack ideas**

It is important to have some variety in the foods that your child eats. Some children get into a habit of very limited choices which they then tire of.

#### Here are some ideas

- Fresh fruit salad try it with yoghurt or low fat ice-cream.
- Bread, muffins, raisin bread, crumpets or bagels.
- Baked beans or spaghetti on toast, jaffles.
- Currant buns, scones or fruit scones, pancakes or pikelets.
- Microwaved popcorn or on the stove with a tiny amount of oil.
- Pretzels or rice crackers plain or flavoured.
- Bagels or pitta crisps.
- Dip and crackers or raw vegies mix low fat yoghurt, creamed cottage cheese or ricotta with french onion packet soup mix or peanut butter.
- Fruit smoothie mix low fat milk, low fat yoghurt and fruit.
- Hot chocolate drink low fat milk and cocoa mix or a couple of teaspoons of Milo in milk.
- Crackers: water crackers or other light cracker biscuits.
- Low fat yoghurts put a container in the freezer for about an hour to make a delicious frozen snack
- Low fat ice-cream.
- Light flavoured milk or milk with flavouring
- Fruit snack packs.

Ask your dietitian for more snack ideas.

## **Diabetes and coeliac disease**

People with type 1 diabetes have an increased risk of developing coeliac disease. Coeliac disease affects approximately 5 per cent of children with diabetes.

Coeliac disease is a condition where the lining of the small intestine (or small bowel) is damaged due to a sensitivity to the protein gluten, found in the grains wheat, rye, oats, barley and triticale. The damaged lining of the intestine makes it very difficult for the body to absorb nutrients from food and can result in weight loss, poor growth, lack of energy, diarrhoea and a swollen belly. However, in children with diabetes, there may be no obvious symptoms of coeliac disease. Children who have diabetes and undiagnosed coeliac disease may be more susceptible to hypoglycaemia due to unreliable absorption of food.

A blood test can be done to screen for coeliac disease (anti-gliadin antibody, anti-endomysial antibody or anti-tissue transglutaminase antibody). If this screening blood test is positive, a small bowel biopsy will usually be recommended, as this is the only way to confirm the diagnosis.

Treatment involves avoiding all foods which contain gluten. The diet relies on potato, corn and rice products, fruit, dairy and other gluten-free food items to meet carbohydrate requirements. Commencing a gluten-free diet will allow the lining of the small intestine to recover, improving absorption and promoting normal growth and development. Where a child has coeliac disease, special resources are available to help. Families can join the Coeliac Society and obtain more of information and support.

## **Common questions and answers**



## How accurate do I need to be with the amount of carbohydrate foods?

Modern insulin plans (injection or pump) work best when there is accurate matching of carbohydrate intake to insulin doses. Thus, it is worth working on this and doing the best you can. Sometimes it is not easy, e.g., unfamiliar foods or restaurant meals, but at home you can more easily estimate accurately by using scales and reading food labels as needed.



## What should I do if my child's blood glucose level is high at meal or snack time?

The approach varies according to the circumstances and whether the child is treated with injections or a pump.

Injections: The meal or snack should be given as usual, but if they are not very hungry then eating a little less is fine. Not giving food when a child is hungry just because the blood glucose is high is not recommended and may be interpreted as punishment. If insulin is due at the time, giving extra rapid or short-acting insulin is a good idea. If an insulin dose is not due, you should also consider giving an extra injection of rapid or short-acting insulin so that the BGL does not stay high. If the blood glucose remains high or there are ketones in the urine, refer to the section on sick days. If this is happening regularly, then it is more appropriate to review overall insulin doses.

Pump: a correction can easily be given with the pump, either with a meal or snack, or in-between. The pump wizard or calculator guides this.



## What happens if my child eats too much carbohydrate at a meal or snack?

This will happen sometimes as appetite varies. If it is significantly more than the usual, blood glucose levels may be elevated, but usually only for a few hours. If your child is more active and eating more, then it usually balances out well, since extra carbohydrate is needed when more active.

If your child is on a pump, the extra carbohydrate can be bolused for after the meal or a correction dose given later if needed.

If on injections and insulin is not due but your child is very hungry and eats a lot, then give an extra rapid or short-acting insulin injection so the BGL does not go high.



#### What if my child does not want to eat?

Your child may be feeling unwell or just not hungry. On many insulin patterns, e.g., pump or multiple daily injections, the meal can often be delayed until the child feels ready to eat provided that the BGL level is fine. Work at establishing consistent eating patterns as discussed earlier in this chapter and avoid feeding young children too often, since this may reduce appetite at routine meal and snack times.

Sometimes it is reasonable to offer substitutions of food, but this should not be for "junk foods" and be careful of setting up a pattern where you become a slave in the kitchen, trying to cater for all whims. Offer a limited number of healthy choices e.g., Would you like yoghurt or banana instead?



## Just after diagnosis my child was very hungry and eating a lot, but is now less hungry. Why is this?

At first, the body has to make up for the weight loss before the diabetes was treated. After that the appetite usually decreases back to normal. Your diabetes team will advise and also guide you with any insulin adjustments that may be needed at the time.



## Will my child become overweight as a teenager or adult because they have diabetes?

No, but this is possible if the balance between food intake, insulin and exercise is not right. Genes are also a factor, so if there is a tendency to being overweight in the family, there is increased risk. Sensible, healthy eating, particularly keeping the diet reasonably low in fat, and adequate exercise are the keys to avoiding gaining too much weight. If you are concerned about your child's weight, speak to your diabetes doctor and dietitian who can help to get the balance right.



#### Is it OK to have artificial sweeteners?

Sweeteners such as sorbitol in diabetic sweets should be kept to small quantities only, since diarrhoea and tummy cramps may occur. Artificial sweeteners are widely used in diet drinks and cordials and if taken in moderation are safe and acceptable. Some sweeteners (e.g., Splenda, stevia) can be used in baking, but using ordinary sugar is a reasonable alternative since in a mixed food type the effects on blood glucose levels are likely to be small. Extensive use of artificial sweeteners is not necessary because sugar can be used in moderation as part of a healthy, balanced diet without upsetting diabetes control.

## **Chapter 7 Monitoring diabetes control**

## **Key Points**

- Diabetes monitoring can be divided into:
  - Monitoring of blood glucose levels throughout the day
  - Monitoring of blood or urine ketones when the blood glucose is high, or the child is unwell – see section 10
  - Monitoring of long-term control the Haemoglobin A1c test See section 16
- Test the blood glucose level (BGL) preferably four to six times per day, or more often if needed
  - Vary the times of tests sometimes to know what is happening at different times
  - Test at night periodically
- Target ranges for blood glucose levels are generally:
  - Before meals 4 to 7 mmol/l
  - After meals 5 to 10 mmol/l
  - at bed time 6 to 10 mmol/l
  - at 3am 5 to 8 mmol/l
  - your diabetes team may give you individualized targets which are slightly different to these
- Keep a record of BGLs, either a record book or electronically
- Check the blood or urine for ketones if:
  - Your child is unwell, especially if the BGL is > 15 mmol/l
  - ✤ Your child is well:
    - If using injections and the BGL remains persistently above 15 mmol/l over a few hours of checking
    - If using an insulin pump and BGL > 15 mmol/l, always check for ketones (refer to chapter 18)

## **Blood glucose monitoring**

Blood glucose measurements are important to:

- monitor daily blood glucose control and allow insulin adjustment
- detect high or low blood glucose levels so that treatment can be given if needed
- monitor and treat diabetes during illnesses and exercise.

#### **Blood glucose meters**

An accurate blood glucose meter is essential for management of diabetes.

A variety of blood glucose meters are available from different manufacturers. These currently all rely on a drop of blood from a fingerprick being placed on or drawn into a special strip from which the machine reads the blood glucose level.

There are two main types of meter available:

- Bio-electric meters: The glucose in the blood generates an electrical current on the strip. This current is converted by the machine to a blood glucose level.
- Reflectance meters: The glucose in the blood changes the colour of the test strip. The machine reads the colour of the strip by reflecting a light beam from it and converts this into a blood glucose reading.

Your diabetes educator will guide you as to the most suitable blood glucose meter for your child – different meters may suit different children and families. When choosing a meter you may consider different features such as size, test time, size of drop of blood required, price and other features such as memory and ability to transfer readings to computer programs.



#### Special points about blood glucose meters:

- All available machines will give satisfactory readings if used properly. All can be prone to errors if not used or maintained correctly.
- Most meters need to be calibrated to the batch of strips you are using. The instructions for the meter will tell you how to do this.
- Some meters have control solutions or check strips available, which you can use to check the accuracy of the readings according to the manufacturer's recommendations. However, these are not always readily available and have an additional cost. If you are concerned about the performance of your meter, contact the manufacturer for advice and service or ask your diabetes team.
- Meters should be cleaned regularly according to the manufacturer's instructions to avoid particles of blood obscuring the measurement processes.
- Most meters can give falsely low readings if too small a drop of blood is used. Your educator and the meter instructions will guide you as to the size of the drop required.

## Chapter 7

- Meters all have a limited life span and may become more troublesome or unreliable after three to four years of use. Within this time it is recommended that you upgrade your meter or check its accuracy more frequently.
  - Machines have a temperature range within which they are meant to operate and can be less accurate when used outside this range.
  - No meter is as accurate as a laboratory blood test but they are accurate enough to guide diabetes management. Accuracy is within 10 to 15 per cent when used correctly. It is best not to use more than one brand of meter at any time since there will be minor variation between different meters.
  - A number of meters can store readings which can be accessed from the memory
    or downloaded via a computer link. Your diabetes centre has the facilities to
    download readings to a computer or it is available for home use. Meter memories
    and downloads are not a substitute for keeping a more complete diabetes diary or
    electronic log book this is still important as it allows recording of insulin doses
    and notes to be made about any other issues affecting the diabetes on a daily basis.
    Such information is important to allow informed adjustments.
  - Meters are mechanical devices and can break down or be damaged. It is a good idea to have a spare meter as a back-up. An alternative back-up is to also have some visual test strips at home. These are strips onto which a drop of blood is placed and then wiped off after a measured time period. The approximate blood glucose can then be read by comparing the colour of the strip with a colour chart on the side of the package. Several brands of these are available from your chemist or supplier.



#### **Obtaining the blood sample – lancet devices (finger prickers)**

A number of lancet devices (also called finger pricking or finger stick devices) are available and your educator can advise which is best for your child. The part that pricks the finger is called a lancet. Very fine lancets cause less pain and damage to the fingers and are recommended for use in children. Some devices allow the depth of penetration of the lancet to be varied which can reduce discomfort in some children. Some devices also allow a blood sample to be collected from sites other than the finger – areas that can be used include the side of the hand, forearm and thigh. This is called *alternate site* testing and may be preferred by some. One precaution is that alternate site testing may not be as accurate as pricking the finger at times of hypoglycaemia or when the BGL may be changing rapidly. In any such situations, obtaining the sample from a finger is best.

### When should we test?

The amount of blood glucose testing needed varies from person to person and from time to time, however more monitoring of BGLs is generally associated with better control, since there is more information available on which to base insulin adjustments. Very young children often need more testing and children of all ages need to test more if the diabetes control is unstable.

### **Recommended testing**

- Four to six times per day to give a picture of what blood glucose levels are like over the 24-hour period but sometimes more often. It is unwise to do less than 4 BGLs per day and more are often needed. These BGLs are required to maintain the BGL in a safe range and to identify problems early.
- Times to test are:
  - Before breakfast (often called the fasting or waking BGL) and before all other main meals.
  - Before bed. A blood glucose level between 6 and 10 mmol/l is desirable at bed time. If the blood glucose level is less than 6 mmol/l, an additional snack is needed for most people.
  - One or more other tests varied at other times of the day (e.g., before morning tea or afternoon tea, during the night).
  - Test at night regularly. 11pm and 3am are useful times to test. This is not practical every night, but up to once per week is recommended. This is especially important if morning blood glucose levels have been low, long-acting insulin doses have been changed, your child has had a very active day or has low readings during the evening. The blood glucose level should be 6 mmol/l or higher in the late evening and above 5 mmol/l at 3 am. If you find abnormal night readings, you must make adjustments and keep testing until BGLs become satisfactory. Contact your diabetes team if unsure.
- Before during and after sport or vigorous exercise.
- More often during sick days or if high blood glucose levels are suspected.
- If low blood glucose (a hypo) is suspected.
- After a hypo to confirm that the blood glucose is back in the desired range.
- After meals (post-prandial testing): Many people are in a pattern of testing BGLs before main meals. However, we now realise that it is also important to sometimes check BGLs after meals to make sure that the pre-meal dose of insulin was adequate. If you are not checking after meals, there is the possibility of large glucose rises which will contribute to less satisfactory overall control and to a risk of complications. Test sometimes 2 hours after breakfast (before morning tea), 2 hours after lunch (before afternoon tea) or 2 hours after dinner (before supper). The target is to have a BGL in the range 5-10 mmol/l at these times.

### Performing a test and recording

- 1. Calibration and set-up of the meter will vary according to the manufacturer's instructions, which should always be followed. Make sure strips are not past their use-by date. It is important that the date and time are set correctly in the meter since this is important for you and your diabetes team when assessing BGLs. Be careful to check and reset the time and date if needed after battery changes.
- 2. Wash and dry hands or the other area to be pricked. This is important to avoid infection and so that food or drink residue does not give a falsely high reading. This is a common reason for an unexpected high reading.
- 3. Ensure that a new lancet is being used. The points of lancets dull very quickly, causing more discomfort and damage to the fingers. Preferably change the lancet for every BGL test or at least once per day.
- 4. Prick the finger on the sides of the finger tip (see illustration). Avoid pricking the tops or the pads of the fingers as repeated pricking in these locations can cause loss of fine touch sensation. Spread the finger pricks around different fingers so thickened areas do not develop. Some children prefer not to use certain fingers (e.g., the second or index finger). If you are using a device where pricks can be done other than on the fingers (alternate site testing), full details will come with the device.



Where to prick fingers for testing

- 5. Squeeze an adequate drop of blood onto the strip. If the strip you have sucks up the blood, make sure that you hold it against the blood droplet for enough time to draw a good sample. Remember, meters can give errors if too little blood is placed on the strip.
- 6. When the test result is available, record this in your blood glucose record along with any relevant notes (see the example below). Even though most meters have memories for a number of blood glucose readings, it is important to keep a record book or electronic record to allow patterns of readings to be examined and make other notes about insulin doses, food, activity, illness and so on which may be affecting readings. The record book (either manual or an electronic version) is a very important resource for you, your doctor and educator to assess progress and help make adjustments.

Pump users should enter blood glucose levels into their pump, to use in the bolus calculation and to store an electronic record (see chapter 18). Some meters used with pumps automatically store the BGL in the electronic pump record.

### Sample page from a blood glucose record book

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### What are the target blood glucose levels?

The blood glucose level of a person without diabetes is quite tightly controlled within a range of approximately 3.5 to 8 mmol/l. In people with diabetes, blood glucose levels are likely to be more variable and it is not possible to always keep the blood glucose within this range.

Target blood glucose ranges are recommended to keep blood glucose levels as near as possible to the normal range, without the risk of too many low readings (hypoglycaemia). Each child should have their targets individually determined with the goal of achieving a value as close to normal as possible. The ranges vary a little for different ages.

At bed time the recommended target range is set a little higher to reduce the chance of hypoglycaemia at night. The blood glucose level should be checked regularly in the late evening or overnight (2 to 3 am). Levels above 6 mmol/l in the late evening and above 5 mmol/l at 2-3 am are desirable.

#### **Recommended target ranges:**

- Target ranges for blood glucose levels are generally
  - Before meals: 4 to 7 mmol/l
  - After meals: 5 to 10 mmol/l
  - at bed time: 6 to 10 mmol/l
    - at 3am: 5 to 8 mmol/l
- your diabetes team may give you individualized targets which are slightly different to these depending on local practices or your individual circumstances

## **Realistic expectations and problems with blood**

### glucose levels

While we would like to have all blood glucose levels within the target range, this is rarely possible. Blood glucose levels may vary for many reasons, including variation in food, activity, insulin absorption and mood. Some of these are predictable and some totally unpredictable.

Aim to have as many readings as possible within the target range, but accept that this is often not possible. Realistically, most people achieve only 60 to 80 per cent of readings within the target range. Unless the out-of-range readings are very high, this pattern is still compatible with good overall control. Of course, when more than a few readings are out of the target range, it is important to explore why. Too many readings or constant readings outside the target range mean insulin doses need reviewing and perhaps other aspects such as food and exercise. If most readings are within the target range then the overall control is likely to be good.

There are also certain times when some people find control more variable or difficult, such as during school holidays, when travelling or in the winter months when activity may be less. All you can do is try to adjust factors within your control and consult your diabetes team if things are too difficult or not settling with time.

It is important not to use judgmental words like 'bad' to describe your child's blood glucose levels. Usually a high or low level is beyond their control and it is important that they do not feel they are being judged by their levels (e.g., you are bad if you have a bad blood glucose level). For levels outside the target range it is better to talk simply about high or low blood glucose levels.

It is important that parents maintain a degree of supervision over blood glucose testing and recording that is appropriate for the child's age. Understandably, children can tire of blood glucose testing and recording. Unless supervised, this can become too infrequent, be done carelessly, be poorly recorded or not done at all. There can be the temptation for children to 'fudge' results by writing in a reading without testing or by writing in readings that will better please their parents or diabetes team. This often occurs in otherwise responsible children and indicates the difficulties that diabetes can pose. A sympathetic approach with firm guidance and a spirit of teamwork will often prevent or overcome such problems. Reviewing the meter memory and meter downloads are useful to check on the accuracy of recording.

## Unstable blood glucose levels

When blood glucose levels are unstable, there are a number of things to think about and check:

- Do extra blood glucose monitoring to get a better idea of the day's readings and allow patterns to be seen.
- Is the blood glucose technique correct and has the meter been checked for accuracy? Check the technique and check the meter with control solutions. If there is any doubt about the meter, contact the manufacturer for advice.
- Make sure your child is washing and drying their hands well before the test, or using a mini-wipe. Wet hands will cause dilution of the blood sample and a falsely low reading.
- Are all the insulin doses being given? Some older children and teenagers may forget injections or pump boluses and need reminders and supervision.
- If your child is on an insulin pump therapy and levels are suddenly high, check to see that the pump is operating and check the line and cannula.
- Is the insulin being given into lumpy sites? Check the sites and move away from lumpy areas. This is an extremely common problem. Insulin absorption can vary by up to 25 per cent from day to day, even in healthy injection sites. This variability is made worse if injection sites are lumpy.
- If cloudy insulin is being used, is it being mixed properly before injection or injected appropriately? Improperly mixed insulin suspensions and injections that are too deep or shallow will cause a lot of day-to-day variation.
- Is the insulin out of date or has it been affected by extremes of temperature? This is especially common in summer and when away on holidays.
- Is the carbohydrate intake variable or uncontrolled? This is also a very common issue.
- Are appropriate adjustments of food and insulin being made to cope with sports and exercise?
- Are emotional factors upsetting your child? This can contribute to stress, poor adherence with diabetes routines and unstable blood glucose levels. Ask your diabetes team for advice.
- Is your child unwell with an infection or other illness? Consult your doctor if this may be the problem.
- Sometimes the reason for unstable blood glucose levels is not clear and it is a matter of waiting for a pattern to emerge. Contact your educator or doctor if you are concerned.

## Haemoglobin A1c

Haemoglobin A1c measurement is a blood test which should be performed about every three months to look at overall long-term diabetes control. It is discussed more in chapter 16.

## **Ketone testing**

Testing for ketones is necessary if the blood glucose is persistently elevated above 15 mmol/l or during periods of illness.

Always check for ketones in the following circumstances:

- If your child is unwell and the BGL is > 15 mmol/l
- If your child is well:
  - If using injections and the BGL remains persistently above 15 mmol/l over a few hours of checking. If your child is well and has one BGL above 15, it is not necessary to check for ketones right away. Recheck the BGL in about 2 hours and check for ketones then if the BGL remains above 15 mmol/l. Regardless of whether it is necessary to check ketones, you may still decide to give a correction dose of insulin if the BGL is high (see chapters 9 and 10)
  - If using an insulin pump and BGL > 15 mmol/l, always check for ketones without delay (refer to chapter 18)

Traditionally ketones have been tested in urine; however some meters are available that can test ketones in blood. Blood testing for ketones can give an earlier warning of ketones and is likely to be more accurate. Nevertheless, urine ketone testing is quite adequate in most situations.

When ketones are present with a high blood glucose, this means more insulin is needed. This is discussed in detail in chapter 10. Urine test strips also detect glucose which appears in the urine if blood glucose levels are high, but the main point of urine testing is to detect ketones.

## Continuous glucose monitoring systems (CGMS)

Continuous glucose monitoring systems have started to become available. At the time of publication, only one system is available in Australia – the Medtronic CGMS. Other systems are also likely to be available in Australia soon. These glucose sensors can give a glucose reading continuously every 5 minutes for up to 6 days via a probe placed under the skin. The probe communicates wirelessly with an insulin pump or other receiving device which displays and stores the BGL readings.

Sensors have trend indicators and alarms to indicate to the user if the glucose is above or below the set level or if there is a rapid change in glucose levels occurring. It is important to realise that the current generation of continuous sensors measure "tissue" glucose rather than "blood" glucose". In most situations there is good correlation between tissue and blood glucose levels, however in times of rapidly changing blood glucose levels there may be significant lag in the sensor response and the correlation between tissue and blood becomes less accurate. CGMS sensors also start to lose accuracy at lower blood glucose levels, so this needs to be borne in mind when setting low glucose level alerts. The trends and patterns of the readings are the most important thing.



A CGMS device wirelessly connected to a receiver

CGMS gives much more information about blood glucose patterns. Some finger prick BGLs are still needed, but usually only 2 or 3 per day. The main barrier to greater use of CGMS is currently the cost. More details about CGMS can be found in chapter 18.



An exampling of BGL profiles over 4 days from a CGMS device

The ultimate goal in continuous glucose sensing is for a "closed-loop" between a glucose sensor and an insulin delivery system. In a closed-loop system insulin would be delivered in response to current glucose levels in much the same way as a healthy pancreas. Such systems are under development.

## Non-invasive blood glucose monitoring

Many other interesting technologies for blood glucose measurement are under research and development; however, this is a technologically difficult area and there is usually a long time between the idea and the reality.

Non-invasive glucose monitoring has long been a goal, i.e., a method of measuring the BGL without having to prick the finger or place a probe under the skin. Currently there are no such devices available for use, but this is an active area of research. Your diabetes team will keep you informed of new developments and their progress.

## **Common questions and answers**



#### How accurate are blood glucose meters?

Blood glucose meters are not as accurate as laboratory blood glucose measurements, but if the test is done correctly, the degree of accuracy is perfectly fine and within 10 to 15 per cent. Many meters will give inaccurate results (read low) if not enough blood is applied. Using the same meter consistently will decrease any variation that occurs between different meters.



### My child will only test twice daily, at breakfast and dinner. Is this OK?

No. The minimum number of BGLs that are required for safety and to guide insulin adjustment is 4 per day and at least one overnight BGL a week. Children can tire of BGL testing and it is very important that you encourage and support your child to do their tests.



#### My son will not keep a diabetes record book as he says the readings are all in the memory of his blood glucose meter. Is this a problem?

Currently, there is no electronic meter record which is an adequate replacement for the diabetes record book. Because meter memories are rarely reviewed people do not recognise when things are going wrong. When a book is used, many readings are easily seen and give immediate feedback on how the diabetes is going. It is important that you support your child/adolescent whenever they are doing their BGLs at home. Help them by writing the result in the book for them. This also allows you a chance to review the results in a non- threatening way. You should review your child's/adolescent's BGLs at least once a week. If preferred, computer based versions of log books can be used.

For pump users, the pump system can serve as a complete record, provided that all BGLs are entered into or transferred into the system.



## I worry that I cannot get all of the blood glucose readings in the target range. What am I doing wrong?

Probably nothing. It is impossible to get all readings in the target range in diabetes. There will always be a number of readings above, and occasionally some below. If most of the readings are in or near the target range you are doing well. If many readings are outside the target range, insulin doses need to be reconsidered. Your doctor will arrange a haemoglobin A1c test every three months which gives a check on overall diabetes control.



## Does it matter if my child does not wash his hands before a blood glucose reading?

Yes, this could be a problem as food or drink particles on the fingers may give a falsely high reading and infection is more likely. If soap and water are not available, wet wipes are a good alternative. Make sure the hands are dried properly before testing.



### My child has favourite finger prick sites. Does this matter?

Yes. Favourite spots will often get thickened scar tissue and tend to hurt less, but the finger prick sites will heal more slowly and infection may be an increased risk. The finger prick sites should be spread around different fingers and always remember to use the sides of the fingertip. Some people do prefer not to use certain fingers and this is fine as long as they are being spread around a reasonable amount.



#### My child has difficulty getting enough blood from finger pricks. Any suggestions?

Make sure the fingers are warm and that the prick is done in the correct position where blood can be squeezed toward the end of the finger. If blood is being squeezed toward the end of the finger you should see it getting redder, not paler. It may help to keep the finger below the level of the heart when doing a test. Some lancet devices (finger prickers) have an adjustable setting – try adjusting this to a greater depth.



### What do we do if our blood glucose meter breaks down?

Call the manufacturer or your educator, and a replacement should be able to be quickly arranged. It is a good idea to have a spare meter available as a back-up. Alternatively, most pharmacies sell meters or you can get some visual test strips. With visual test strips, a finger prick is done as usual and blood is placed on the strip. The blood is wiped off the strip after the specified time, and the colour of the strip is compared with the chart on the bottle to give an approximate reading. Several brands of visual test strips are available.



## Should we be using CGMS? Our son is not keen on the idea and it seems expensive?

CGMS is an emerging technology and is likely to be increasingly used. Systems will improve further and it will be used more if it becomes cheaper. Good diabetes management can still occur with sufficient finger prick BGL monitoring, so if you are not keen to pursue CGMS, concentrate on getting a good amount of testing by fingerprick and looking for patterns. However, CGMS can assist with additional glucose profiling and is especially popular amongst some pump users. It is also an option to use CGMS for occasional periods for extra information, rather than continuously. Ask your diabetes team for the latest information.

## Chapter 8 Hypoglycaemia (low blood glucose levels)

## **Key Points**

- Hypoglycaemia (a hypo) occurs when the blood glucose level is less than 4 mmol/l, or where there are symptoms of a hypo at a level close to this
- Main causes of hypos are exercise, missed or delayed meals, not eating enough carbohydrate, or having too much insulin
- To treat a mild or moderate hypo give approximately 10 to 20 grams of fast-acting carbohydrate (sugary food) such as is contained in:
  - glucose tablets or glucose gel 10-20 grams (not tablets in children under 5 years)
  - Lucozade 60-120 ml
  - ordinary soft drink or cordial 125-250 ml
  - fruit juice 125-250 ml
  - sugar or honey (two to four teaspoons)
  - jelly beans 3 to 6 large or 6 to 12 small jelly beans (not in children under 5 years)
- The amount of glucose needed to treat a hypo depends on a child's size, insulin plan, recent insulin doses and recent exercise. Bigger, older children and adults require the larger amount and sometimes more
- Usually, follow up the fast-acting carbohydrate with an exchange or serve of slow-acting carbohydrate such as bread, milk, biscuits, apple, banana, but not all will need these (often not needed for those on pumps)
- In a severe hypo, the child may be extremely drowsy or disorientated or become unconscious or have a fit.
- To treat a severe hypo:
  - Do not give anything by mouth
  - Lie the child on their side
  - Give an injection of glucagon. 1 ml if over five years, 0.5 ml if under five
- Call an ambulance if the situation does not improve quickly or you need help
- Mini-Dose Glucagon is a special strategy to treat or prevent further hypoglycaemia when a child is mildly unwell and blood glucose levels are trending low, but not severely low – see chapter 10, Sick days

Hypoglycaemia (commonly called a hypo) occurs when the blood glucose level is too low. There is some debate in medical circles about an exact "cut-off" value that defines hypoglycaemia, however for practical purposes most would agree with a level of less than 4 mmol/l. Hypos can be graded according to whether they are mild, moderate or severe. Mild hypos are common and nearly all children experience these at times. Fortunately, severe hypos are rare, but you need to know how to deal with them just in case.



## Symptoms of hypos

A hypo is a blood glucose level of 4 mmol/l or less, or if your child has one or more of the following symptoms at a level near 4 mmol/l:

- paleness
- shakiness
- headache
- sweating
- feeling hungry
- dizziness

- heart pounding
- irritability, change in mood
- lack of concentration
- confusion, vagueness
- crying
- weakness
- blurred vision

Your child may show other symptoms, but these are the most common.

In severe hypos the blood glucose is very low. The child becomes very drowsy, extremely disorientated, aggressive, unconscious or may have a fit or convulsion (see below).

Infants and young children are usually not able to indicate that they feel unwell and may show few signs. Parents or carers may only recognise subtle signs such as paleness or irritability – if in doubt check the blood glucose level.

#### Hypo symptoms occur for two reasons:

- 1. The body produces chemical messengers (hormones) to attempt to raise the blood glucose level. Adrenaline is the main one and causes most of the symptoms.
- 2. The brain is not getting enough glucose to keep working normally. Unfortunately there is no foolproof way of recognising a hypo, so when in doubt checking the blood glucose level will tell you what is happening.

Not everyone feels the same when their blood glucose level is low and the symptoms and signs may not always be the same. However, most people with diabetes learn to recognise the feelings they have when their blood glucose is too low. Occasionally, some people have difficulty knowing because they don't feel different at all. Chapter

With diabetes, the blood glucose could drop low at any time, but a hypo is often related to an **imbalance between insulin, food and exercise**. To understand this, it is helpful to recall how each of these affects the blood glucose:

- insulin lowers blood glucose
- carbohydrate in food raises blood glucose
- exercise usually lowers the blood glucose

#### The main causes of hypos are:

- exercise, without decreasing the insulin or without eating extra carbohydrate
- missed or delayed meals, or eating too little carbohydrate at meals
- a recent dose of insulin was too much for the body's needs
- alcohol intake (see the section on adolescents in chapter 15).

The most common times for hypos are just before the next meal or snack is due or after sport. However, hypos can also occur unexpectedly and for no obvious reason. Hypos are usually mild and the treatment is simple but sometimes they can be severe.

## What to do for a mild or moderate hypo

#### Step 1

Give some fast-acting carbohydrate to raise the blood glucose level quickly. This should be something that can be eaten or drunk quickly and easily and contain glucose or sucrose. Your local diabetes team may advise a preference, but any of these will work.

Older children and teenagers will need more than small children, hence a range is given. 10 g is likely to be adequate for a small child, but a large teenager will need 20 g or more.

Examples include:

- 10 to 20 g of glucose tablets or glucose gel (take care with the amount as these may come in different sizes and strengths; tablets are not suitable for children under 5 years of age)
- 60 to 120 ml Lucozade (Lucozade contains 18 g glucose per 100ml)
- 125 to 250 ml (approximately half to one cup) orange or fruit juice
- 125 to 250 ml (approximately half to one cup) ordinary soft drink (i.e., not a diet drink)
- Sugar or honey 2 to 4 teaspoons
- Jelly beans 3 to 6 large, or 6 to 12 small (note, this is approximate since a variety of sizes are sold). Jelly beans, other sweets or glucose tablets are not advised in children under 5 years due to choking risk.

### Step 2

This is usually followed by one exchange or serve of slow-acting carbohydrate to help maintain the blood glucose level, or if a meal is due soon, have that earlier. Some people find through experience that they may not need the extra long-acting carbohydrate (or need a lesser amount) – this is common in insulin pump users, depending on the cause of the hypo.

### Examples of slow-acting carbohydrate include:

- one slice of bread
- one exchange or serve of plain biscuits
- one apple or one banana
- 250 ml (1 cup) milk.



#### Important points about hypos:

- Thinking about why the hypo occurred is important in deciding how much treatment to give more glucose / carbohydrate treatment is likely to be needed if an insulin dose or bolus has just been given or if vigorous exercise has been occurring
- Foods to treat hypos should always be carried by the family or child or be readily available (e.g., with the teacher at school, in the car or in a handbag).
- When a young person is having a hypo, they should remain supervised until recovered and should not be left alone at any time. The hypo treatment should be with the child or brought to the child; the child should not be sent away to get the hypo treatment.
- The person should wear an identification bracelet or necklace indicating that they have diabetes or at least carry some form of identification (e.g., wallet card, indicating diabetes).



- Babies and toddlers may require less carbohydrate to treat a hypo your diabetes team will discuss this with you. Teenagers and adults need more carbohydrate than young children to treat a hypo.
- Infants and young children are best given fluids to treat hypos initially. Jelly beans, lollies or glucose tablets may be a choking risk.
- If a hypo occurs when a meal or snack is due within half an hour, give some fast-acting carbohydrate followed straight away by the meal or snack, instead of giving the extra slow-acting carbohydrate.
- After a hypo your child will usually be feeling better within 5 to 10 minutes; however, it may take a little longer to see a measurable rise in blood glucose levels (10-20 minutes). Aim to raise the BGL to above 5.5 mmol/l. Ideally the blood glucose should be checked again 15 to 20 minutes after a hypo, but often families find this unnecessary as the child is fine and wants to resume normal activities. Always keep a close eye on your child after a hypo. If the child is not improving after 5 to 10 minutes, recheck the blood glucose level and repeat the hypo treatment if necessary.
- Avoid the tendency to over-treat mild hypos, as this causes large blood glucose peaks (sometimes called rebound highs) that will affect overall control. A hypo can provoke a strong urge to continue to eat in some people, so be mindful of this.

## What to do for a severe hypo

### The symptoms of a severe hypo are:

- extremely drowsy or disorientated
- unconscious, or
- having a fit or convulsion.
- 1. In a moderate to severe hypo a judgment needs to be made about whether or not to try treating with sweet foods or drink. The child needs to be conscious enough to be able to swallow. If the child is too drowsy or disorientated to understand what you are saying or does not respond to simple instructions then nothing should be given by mouth give a full dose glucagon injection.

Do not try to give anything by mouth if the child is unconscious or fitting - glucagon is needed.

- 2. Call for help of anyone around.
- 3. Place the child in the coma/unconscious position, making sure they can breathe. See the illustration below – do not place a pillow under the child's head. If the child is having a fit or convulsion do the same thing. Do not attempt to place anything in the mouth. Lie the child on their side and stop them from hurting themselves.



Correct position to place an unconscious child

4. Give an injection of glucagon if you have one. Glucagon is a hormone that raises the blood glucose level by making the liver release its store of glucose. All families should keep glucagon at home and carry it when they travel.

If two adults are available one should stay with the child while the other gets the glucagon. Don't be afraid to give the glucagon – it can't do any harm, it can only do good in the case of a severe hypo.

- 5. Call an ambulance if the situation does not improve quickly or you need help. The emergency number throughout Australia is 000 or 112 from some mobile phones. The ambulance officers will decide if your child needs to go to hospital or is recovering satisfactorily.
- 6. Always contact your diabetes team for advice after a severe hypo. It is important to think about why the severe hypo occurred and how to prevent further episodes.

### Giving a glucagon injection with the GlucaGen hypokit (Novo Nordisk)

The GlucaGen Hypokit contains a synthetic form of glucagon and comes in a kit with everything that you need. Remember to check the expiry date of your glucagon periodically and obtain a new supply just before the old one expires. While keeping or using expired glucagon is not recommended, if you find that the glucagon is past its expiry date and a severe hypo occurs, you should still give the glucagon as it is likely to work and will cause no harm.

A glucagon injection is given as follows:

- 1. Remove the orange cap from the bottle.
- 2. Remove the grey needle guard.
- 3. Inject all the sterile water from the syringe into the bottle containing the powder (the glucagon). Leave the syringe in the bottle.
- 4. Swirl (don't shake) the bottle with the syringe in it until the glucagon has dissolved (leave your finger on the plunger to stop it coming back).
- 5. Draw up all the glucagon (1 ml) if over five years of age, or half the glucagon (0.5 ml) if under five years of age.
- 6. Inject into the front of the thigh or buttock (upper, outer part of buttock) just as you would an insulin injection. You will see that the needle is longer than an insulin needle so that the glucagon goes in deeper to the muscle layer where it works best.
- 7. Do a blood glucose level.



A GlucaGen Hypokit

### Recovery from a severe hypo

- The child will usually wake in about five to ten minutes. If a fit has occurred it is usually short and does not cause permanent damage.
- When the child is awake, give sips of ordinary soft drink or other sweet drink and later follow this with some slow-acting carbohydrate, as in step 2 for a mild-moderate hypo. Try to avoid over-feeding and be guided by BGL levels.
- A severe hypo or the Glucagon treatment can make your child vomit. They may also have a headache. Continue to give sips of sweet drink.
- Monitor the blood glucose level frequently (every 15-30 minutes) and when possible give your child some slow-acting carbohydrate food.
- Your diabetes doctor or educator or on-call service should be contacted.
- Do not omit the usual insulin injection after the hypo but seek medical advice as to the dose of insulin to give.
- Blood glucose levels are often high soon after a severe hypo. This should not be treated with extra insulin.
- The ambulance should be called if things do not improve quickly or you just want some help – state that your child is a diabetic and has had a severe hypo and is fitting or unconscious. The ambulance officers will help as needed, but if the child is recovering well, a trip to hospital is not always necessary.
- Remember to replace your glucagon as soon as possible

## Mini-dose glucagon treatment

Mini-dose glucagon is a special way of using low-doses of glucagon by subcutaneous injection when there is a continuing tendency to low glucose levels, but not severe hypoglycaemia. This is in a situation where your child is unwell, but not seriously unwell and not persistently vomiting. This is covered in detail in chapter 10 – Sick days. It can often help you get through a difficult period of lowish BGLs and may help avoid a trip to hospital.

For severe hypogleemia (drowsy, coma or seizures), it is very important however, that full doses of glucagon are given as outlined above and not mini-dose glucagon.

## How often do hypos happen?

Many hypos are preventable; however, mild hypos are common. A person with good diabetes control can be expected to have a few mild hypos each week. Severe hypos are much less common and many children with diabetes never have a severe one. When a hypo occurs, it is always wise to consider what may have caused it. This is usually delayed or missed food or increased activity or exercise without taking more food or less insulin. Some hypos happen for no apparent reason.

If any of the following are happening, it is likely that insulin adjustment is needed and if in doubt you should contact your child's diabetes educator or doctor:

- More than three or four hypos per week, especially if no reason evident
- Hypos are tending to occur at the same time of the day
- Any severe hypo
- Night hypos, especially if no reason evident

## Night hypoglycaemia

It is important to remember the possibility of hypos at night. They are more likely to occur after a lot of exercise during the day or if the child has eaten poorly or is unwell. Sometimes children wake with hypos at night, but often they can sleep through and the hypo remains undetected. Recurring night hypos can be dangerous and contribute to memory and concentration problems. Fits or convulsions at night are a risk. The following will help to prevent or minimise night hypos:

- Regularly checking the blood glucose level at the child's bed time or in the late evening aiming for a level of 6 to 10 mmol/l. If less than 6 mmol/l, some extra slow-acting carbohydrate should be given, for example 5-20 g. The amount needs to be judged according to the circumstances of the day and past experience, e.g., give more if has had a very active or low BGL day, less if the BGL is close to 6 mmol/l, more for larger children etc.
- If BGL is less than 4 mmol/l before bed, treat as a hypo with fast-acting then slow-acting carbohydrate. If low during the evening, it is wise to re-check the BGL at 2-3 am.
- Some need to have a higher target BGL before bed your diabetes team will advise if this is needed.
- Occasionally (e.g., three or four times per month) checking the blood glucose level when the child is asleep in the late evening (around 11 pm) and/or at 3 am. At 11 pm the blood glucose should generally be above 6 mmol/l and at 2-3 am above 5 mmol/l.
- Pre-bed, late evening or overnight blood tests should especially be considered if the child has exercised a lot that day or evening, has eaten poorly or is unwell.
- Some find it necessary to reduce evening insulin doses after sport or exercise to prevent delayed night time hypos (see chapter 11) or if using a pump, to use a lower temporary basal rate overnight.
- Alcohol intake increases the risk of night hypoglycaemia

Some children in the honeymoon phase (soon after diagnosis) may have lower BGLs overnight (e.g., 3.5 to 4 mmol/l) which is not hypoglycaemia because their pancreas is still producing some insulin. Your diabetes team will discuss this with you.



## Hypoglycaemia unawareness

This means that hypoglycaemia is occurring (as measured by BGL or observed by others), but the person with diabetes is not aware of it.

Toddlers and young children frequently do not sense hypos well or cannot tell you about them and detecting hypos relies on those caring for them. Children will gradually learn to recognise and express their hypo symptoms. After a hypo, encourage them to tell you how they felt to help them learn.

In older children and adolescents, hypoglycaemia unawareness can develop if they have a period where they are having too many hypos or frequent overnight hypoglycaemia. This arises because the body's defence mechanisms against hypos (such as adrenaline) reset their level at which symptoms will be produced. This can be a dangerous situation because severe hypos may come on suddenly without the usual warning. If hypos are occurring without symptoms, you should contact your doctor or educator for advice. Fortunately this is a fairly uncommon problem and can usually be fixed by adjustment of insulin doses. Avoiding lots of hypos or long hypos minimises the risk of hypo unawareness arising. It is usually necessary to run the blood glucose levels a little higher for a period to restore normal hypoglycaemia awareness.

## **Common questions and answers**



## My four-year-old doesn't have many hypos, but when he does he doesn't seem to recognise them. What should I do?

Young children are often not good at recognising hypos, and even if they do feel funny, may have trouble knowing what this is or expressing it. With time they usually learn what it feels like and are able to tell you. When a hypo occurs, after treating it spend a few moments asking how the child felt and whether they felt any symptoms. This can help the learning process.



#### My seven-year-old daughter seems to be having hypos at school every morning and asking the teacher for jelly beans. The teacher says she looks OK, but treats it as a hypo because she is worried. What should I do?

It may be hypoglycaemia, but some children can go through a stage of saying they are low to get lollies. The only way to sort out what is happening is to test the blood glucose at these times, and where possible always test before treating a hypo. It may also be wise to change the hypo treatment you have available at the school (e.g., juice boxes are a good alternative).



### How many hypos is too many?

Most children have occasional mild hypos, often up to four per week. Usually there is a logical explanation such as extra activity or eating less. If more than this number is occurring, if there is no explanation for frequent hypos or there are any severe hypos, some adjustment to the diabetes management may be needed. Contact your educator or doctor if unsure.



### I have heard that glucagon can make children vomit. Should I try not to use it if possible?

In a severe hypo where the child is unconscious or fitting or too drowsy or uncooperative to take anything by mouth, you must give glucagon in the full recommended dose. It can do no harm and will raise the blood glucose. It is true that afterwards there can be some nausea and vomiting but that can be easily dealt with.



## My daughter gets a bad headache after hypos. What should we do?

This is not uncommon, and the best thing to do is rest. If necessary, a dose of paracetamol will help.



### My 15-year-old son is very particular about his diabetes control and always has excellent blood glucose levels. In the past three weeks he has had three major hypos which came on without warning. Luckily we were there to treat him. What is happening?

This is hypoglycaemia unawareness, and can happen if the blood glucose levels are generally running too low. The body does not produce a hypo response until the blood glucose becomes very low, and then it is too late for the person to respond. The problem can be corrected by adjusting the insulin so that the blood glucose levels are in a more normal range and he may need to run his BGLs a little higher for a while. If this is happening you need to contact your educator or doctor as soon as possible.



## We worry about our daughter having a hypo at night, and possibly having a fit. How can we avoid this?

The risk of night hypos can be minimised by checking the blood glucose before bed, and if the level is less than 6 mmol/l, having some extra supper. It is wise to periodically check some blood glucose levels at night, either in the late evening or middle of the night. It is especially a good idea to test in the late evening or overnight if your child has exercised a lot that day, eaten less or is not well. Reducing the evening dose of insulin after vigorous sport or exercise will also help reduce the risk of night hypos. For some insulin plans, having some supper is important to reduce the risk of night hypos. The availability of CGMS (continuous glucose monitoring systems) also allows night BGLs to be monitored and can be used regularly or occasionally to check the overnight BGL profile.



### How can we tell if our child is having a hypo at night?

Children sometimes wake up if they are having a hypo and they may have a bad dream. If your child has had a restless night or wakes up feeling unwell you should be suspicious of hypos and think about overnight testing. Some night testing is recommended for all people with diabetes.

Chapter

## Chapter 9 Hyperglycaemia (high blood glucose levels)

## **Key Points**

When blood glucose is above 15 mmol/l:

- try to identify possible reasons
- If your child is unwell or if the blood glucose remains above 15 mmol/l, test the urine or blood for ketones
- If blood glucose remains high and there are ketones present, extra insulin is needed
- Drink extra (sugar-free) fluids
- Pump users must always respond to high BGLs without delay

**Hyperglycaemia** or a high blood glucose is when the blood glucose is higher than the desirable range. Target blood glucose ranges were discussed earlier, but are included here as a reminder.

**Recommended target ranges:** 

- Target ranges for blood glucose levels are generally
  - Before meals 4 to 7 mmol/l
  - After meals 5 to 10 mmol/l
  - at bed time 6 to 10 mmol/l
  - at 3am 5 to 8 mmol/1

Nearly all people with diabetes have some blood glucose readings above the target range. Often this will be just a short-term rise (a few hours) and then the blood glucose levels fall to the desirable range.

## Why blood glucose levels may be high

There are a number of reasons why the blood glucose readings may be high. These include:

- Eating extra carbohydrate foods.
- Less exercise than usual.
- Sometimes temporarily during or just after vigorous exercise (stress effect).
- Measuring the blood glucose too soon after a meal usually wait two hours after eating.
- The insulin dose may be too low or may have been forgotten.
- Emotion, such as excitement or stress.
- Infection or other illness.

#### Caring for diabetes in children and adolescents

- Glucose on the fingers will give a falsely high reading; if this is suspected, wash the hands and re-check the blood glucose level.
- Insulin pump users may be a problem with the infusion set or function of the pump



## What to do about high blood glucose levels

## (above 15 mmol/l)

A high blood glucose is a cause for concern. If the BGL is over 15 mmol/l then you should try to find a cause (from the list above). If the BGL has been elevated for more than 2 hours or there are symptoms such as thirst, increased urination, excessive tiredness or feeling unwell then ketones should be assessed.

Usually an injection of short acting insulin (or correction bolus for pump users) should be given to return the BGL to the normal range. The only times that extra insulin should not be given is if the high BGL is due to a stress response during or immediately after exercise (the BGL will usually come down by itself) or if it was due to sugar on the fingers.

If BGL remains persistently elevated (above 15 mmol/l) for a number of hours and is not corrected, the following are likely to occur:

- symptoms such as increased thirst, increased urination and excessive tiredness
- ketones are likely to develop
- the child could become sick with ketoacidosis (see section 10 'Sick days ').

General responses to high BGLs are similar, but there are some differences according to whether treatment is with injections or an insulin pump. This is outlined below and see more detail on Pumps in Chapter 18.

#### Do the following with any high blood glucose levels:

#### If receiving insulin via injections:

- Repeat the blood glucose level in about 2 hours. You may have given an extra injection or bolus or may be expecting a spontaneous fall in either case a repeat BGL is a good idea.
- If your child is unwell (e.g., fever, vomiting, listless etc) or if repeat blood glucose level is still above 15 mmol/l, then test for ketones.

- If the blood glucose is above 15 mmol/l and there are ketones present, extra insulin is needed (see chapter 10 'Sick days ').
- Even if ketones are not present, consider giving an extra dose of rapid or shortacting insulin to correct the BGL – again, follow the guidelines in chapter 10.
- Drink plenty of fluids when the blood glucose is high; drink water or diet (sugar-free) drinks. This helps to lower the blood glucose and prevent dehydration.
- Try to identify possible causes (e.g., illness, missed insulin dose others as above).
- Look to see if there is a pattern of the blood glucose rising at the same time each day in this case an increase in the appropriate insulin dose should be considered.
- Avoid strenuous exercise if the BGL is high, especially if ketones are present. If the body is lacking in insulin, exercise will not bring the BGL down (see more information in chapter 10 'Sick days' and chapter 11 'Exercise and sport')
- It is important to check the blood glucose levels after an extra insulin dose to make sure it is satisfactory. Be careful with giving extra doses of short-acting insulin before exercise (the exercise may bring the glucose level down), in the evening, at bedtime or overnight. At these times it is essential that the BGL is checked 2 to 3 hours later.

#### If receiving insulin via a pump:

- High blood glucose levels always need to be addressed without delay in pump users, since there is no pool of long-acting insulin in the body to help protect against ketosis and ketoacidosis
- Full details are given in chapter 18 on Pumps, but outlined here
- If BGL is above 15 mmol/l, do the following:
  - Immediately check for a problem with the infusion set or pump delivery
  - Check the blood for ketones (urine ketones if blood strips are not available)
  - If ketones are negative (less than 0.6 mmol/l in blood or negative or trace in urine), a correction bolus can be given with the pump. If there is any doubt about the infusion set, this should be changed.
  - If ketones are positive (more than 0.6 mmol/l in blood or small, moderate or large in urine), a correction dose of insulin should be given with a pen or syringe. Do not rely on the pump at this point regain control with injections and then sort out any pump or delivery set problems later
  - Think about causes as outlined above, e.g., missed boluses
  - Drink extra fluids (water or sugar-free) and avoid strenuous exercise until the BGL is settling

## **Common questions and answers**



My three-year-old receives insulin via injections and sometimes has blood glucose levels around 16 to 18. Should I give him extra insulin at these times?

Usually, yes. High BGLs are usually caused by insufficient insulin for the food that has been eaten. This is corrected by an appropriate extra dose of insulin or "correction bolus". If he is well, check the BGL 1-2 hours later. If BGL remains above 15 mmol/l, or he is unwell in any way, check for ketones. If the blood glucose stays up or there are ketones present or he is unwell – refer to the guidelines in chapter 10 'Sick Days'. Check with your doctor or educator if unsure.



### When we check our daughter's blood glucose level before supper and bed it is often high, but this is only about one hour after her dinner. What should we do?

The blood glucose will often be elevated just after a meal. Leave the test until at least two hours after a meal where possible, even if this means testing after she has gone to bed. This is a better guide to whether the insulin needs adjusting.



#### My son's BGLs are often high despite increasing the insulin dose, and my educator suggested that he may not be giving his insulin. I am not happy about this suggestion because my son is a good boy and he knows that he needs his insulin.

Insulin omission is very common, not only with children and teenagers but adults as well. Many children and adolescents will omit insulin repeatedly if they are not helped or supervised with their injections or pump boluses. The reason children and adolescents miss some insulin is due to an inability to prioritise and plan because they have not yet reached this stage of brain development. This inability to do injections or boluses without assistance is not the child/adolescent being "bad"; it is expected if they don't receive enough help and supervision. Also, giving insulin everyday is hard work and to do it in the long term, the person needs support from their family and friends.

We recommend that you support your child or adolescent on a daily basis with their injections or pump boluses. When at home, the pre-meal BGL and the meal content should be discussed together and the record book filled in. There can be discussion of the appropriate dose of insulin and the need for any adjustments and the dose can be checked and administered. Cross-checking doses will reduce errors and ensures that they are done accurately. Children and adolescents should not go away into another room unsupervised to test BGL or deliver insulin. At school, it is also best when possible to have someone assisting with supervision of BGL monitoring, recording and insulin administration.



# My 12 year old daughter is on an insulin pump. If the BGL is a little high before bed (for example 16 mmol/l), can we just wait to see if it settles overnight?

No, this situation needs attention now. Insulin pump users do not have any pool of long-acting insulin in their system, so are prone to more rapid development of ketones or ketoacidosis if there is interruption to insulin delivery. Check the infusion set and pump for delivery issues, check the blood (or urine) for ketones and sort out the situation as outlined here and in the Pump chapter before going to bed. An additional BGL check during the night is also likely to be needed.

## Chapter 10 Sick Days

## **Key Points**

- Illness may cause high blood glucose levels or low blood glucose levels:
  - Infections with fever often cause high BGLs
  - Gastroenteritis (vomiting and diarrhoea) illnesses often cause low blood glucose levels
- If high blood glucose levels are not treated, ketones will develop and your child could become very sick with diabetic ketoacidosis
- Treat the underlying illness. See your doctor if concerned
- Measure blood glucose more often, every two hours at first
- Drink more fluids:
  - Sugar-free fluids if the blood glucose level is above 8 mmol/l
  - Fluids containing carbohydrate if the blood glucose level is below 8 mmol/l.
- Check for ketones regularly when sick, especially if the blood glucose level is above 15 mmol/l
- Do not omit or stop insulin. If blood glucose levels are low, less insulin may be needed – check with your doctor or educator about what dose to give if unsure.
- If the blood glucose level is above 15 mmol/l and ketones are present, extra rapid or short-acting insulin is needed – this section tells you how to work out the extra dose. Sometimes extra insulin will be needed if the BGL is 8-15 mmol/l.
- Insulin pump users need special precautions see more detail in Chapter 18
- Call for advice or go to the hospital if:
  - ✤ you are unsure what to do
  - vomiting persists
  - unable to keep blood glucose level above 4 mmol/l
  - unable to get blood glucose level below 15 mmol/l with extra insulin doses, or unable to clear ketones
  - child is becoming more unwell
  - you are worried or exhausted or don't know what to do next
  - your child is very young
- For illnesses with persisting low blood glucose levels:
  - give extra glucose containing fluids
  - reduced insulin will be needed
  - mini-dose glucagon may also be needed

## Sick days - introduction

Children and adolescents with well controlled diabetes are not at greater risk of getting sick with infections or other illnesses. However, when children with diabetes do get sick, much greater care and attention is required. If the guidelines in this section are followed, most sick days can be dealt with at home.

#### Sick days can cause:

#### 1. High blood glucose levels:

These are more common during illness, particularly in viral illnesses with fever (e.g., influenza or a bad cold) or in bacterial illnesses (e.g., tonsillitis or ear infections). The blood glucose levels rise as 'stress' hormones are released to help the body cope with illness; however, these stress hormones work against insulin and the normal insulin given does not work as well (called insulin resistance). Blood glucose levels will often still be high even if the child's appetite is poor because of continuing release of glucose from the liver.

#### 2. Low blood glucose levels

This is likely to occur in stomach and bowel illnesses (gastroenteritis) with nausea, vomiting and especially diarrhoea but without other general symptoms such as fever. The blood glucose levels are low because the child's appetite is often decreased and the food and drink that is taken is not being well absorbed.

### If, during illness, high blood glucose levels are not treated:

- Ketones will develop in the blood (and be found in the blood or urine on testing).
- The body is likely to become dehydrated (high blood glucose levels drag fluid out of the body into the urine).
- Severe illness with ketoacidosis may occur see below.

Knowing how to manage sick days should prevent any major problems like this developing.

#### The goals of sick day care are to:

- prevent dehydration
- prevent ketoacidosis (high levels of sugar and ketones in the blood)
- prevent hypoglycaemia (low blood glucose levels).

## What are ketones?

Ketones are chemicals in the blood which come from the breakdown of fat. The body makes ketones as an alternative energy source to glucose in some situations. When there are ketones in the blood they will also be found in the urine and thus a urine test can also be used to identify ketones.

Ketones in diabetes indicate that there is too little insulin in the body.

Two situations can occur:

#### 1. Glucose levels are high:

This is the commonest situation. Even though the blood glucose level is high, the body cannot use glucose for energy because of the lack of insulin. Thus, fat is broken down to form ketones as an alternative energy supply. This can happen during illness or when insulin doses are too low or have been missed. When the blood glucose is high, ketones in the blood or urine are a warning sign that the body needs more insulin (see below). If ketones continue to build up, the child can become very sick with ketoacidosis.

# Chapter
Here the body is lacking insulin and glucose. This can happen in stomach and bowel illnesses with vomiting and diarrhoea. In this situation more glucose intake is needed, so insulin doses can continue to be given to turn off ketone production. If this extra glucose cannot be taken by food or drink, a stay in hospital may be needed. In illnesses with low blood glucose levels, insulin doses should not be stopped or omitted, but may need to be lowered (see below).

### What is ketoacidosis?

Ketoacidosis is a serious illness that occurs when the blood glucose and ketones in the blood are very high and the person becomes very dehydrated, often with nausea, vomiting, abdominal pain, laboured breathing and unusual smelling breath (similar to nail polish remover or acetone). The blood becomes too acid because of a build-up of ketones and there is great loss of body salts and fluid. Ketoacidosis occurs when high blood glucose levels and a lack of insulin are present for many hours due to illness or missing insulin. Ketoacidosis requires urgent hospitalisation and treatment. Untreated ketoacidosis can cause severe illness or death.

### How to test for ketones

#### Testing for ketones in the blood

Meters are available that allow for measurement of ketones as well as glucose in the blood. Measuring ketones in the blood has the advantage over urine testing in that it gives an earlier and more accurate picture of the ketones in the body. This is because it takes some time for ketones to be converted to the form that is measured in urine and for these to be passed into the urine.

Measuring the blood ketones is a similar procedure to measuring blood glucose, except a different strip is inserted into the machine. The machine will report the amount of ketones (beta-hydroxybutyrate) in the blood as a number. Guidelines will come with the machine to guide you as to the action required, depending on the level. The following is a general guide:

Blood ketone reading (mmol/l): (beta—hydroxybutyrate)	Less than 0.6	Negative or trace only
	0.6 to 1.5	Small to moderate ketones
	Above 1.5	Moderate to large ketones (the higher the number, the more ketones)

Refer to the information below for how to respond if there are small, moderate or large ketones in the blood or urine, depending on the BGL level. Extra insulin is likely to be needed.

#### Testing for ketones in the urine

#### This is done using urine test strips, as follows:

1. Check the expiry date of the ketone test strips. Some brands of strips also measure the amount of glucose in the urine, which will be high if the blood glucose has

been high. Out-of-date strips or strips that have not been stored well-sealed may not work properly. If the strip does not read negative before you use it, it is spoiled and should not be used.

- 2. Let some urine run over the test strip, by passing urine directly onto the strip or collecting a small amount of urine in a container and dipping the strip.
- 3. After the time specified on the test strip bottle, compare the colour of the strip with the chart on the side of the bottle. Timing is important to get the correct reading.
- 4. The urine ketone reading will be either

Negative - no colour change

Trace – just a slight colour change (slightly pink)

Small (+, 1 mmol/l or 10 mg/dl also shown on bottle)

Moderate (++, 5 mmol/l or 50 mg/dl also shown on bottle), or

Large (+++, 15 mmol/l or 150 mg/dl also shown on bottle) - strong purple colour

Always be concerned when ketones are present – the more ketones there are, the more cause there is for concern.



Checking the colour of a ketone strip against the chart on the bottle

### When to test for ketones

#### Always check for ketones in the following circumstances:

- If your child is unwell and the BGL is > 15 mmol/l
- If your child is well:
  - If using injections and the BGL remains persistently above 15 mmol/l over a few hours of checking. If your child is well and has one BGL above 15 mmol/l, it is not necessary to check for ketones right away. Recheck the BGL in about 2 hours and check for ketones then if the BGL remains above 15 mmol/l
  - If using an insulin pump and BGL > 15 mmol/l, always check for ketones without delay (refer to chapter 18)

#### When to re-test:

• Follow the table on page 98. In general, if ketones are present on the initial test and BGL remains above 15 mmol/l, re-test for ketones in about 2 hours. Testing for ketones more often than this is usually not helpful.



### **Guidelines for sick days**

- 1. Take care of the underlying illness: Children often get minor illnesses, but with any significant illness your doctor should be consulted for advice.
- 2. Relieve symptoms: Paracetamol or ibuprofen can be used to treat fever, headaches or other discomfort. Your doctor may also advise other medications for specific illnesses. Many medications for children are available in sugar-free formulations (e.g., paracetamol, most antibiotics); however, even if they contain sugar the amount is not sufficient to cause problems and the medication should be given as prescribed.
- 3. Measure the blood glucose more frequently every two hours initially, but every hour if the blood glucose is low.
- 4. Check for ketones during any illness, especially if the blood glucose level is more than 15 mmol/l. If any ketones are present, continue to check each two hours or so for ketones until negative.
- 5. Drink more fluids:

If the blood glucose level is more than 8 mmol/l, drink water or sugar-free drinks. If the blood glucose is less than 8 mmol/l, drink liquids containing carbohydrate (e.g., fruit juice, normal soft drinks, icy poles, normal sweet jelly).

Give your child small drinks frequently, rather than large drinks occasionally. Often there will be no appetite for food – don't worry about this, but make sure to keep up plenty of fluids to avoid dehydration.

As a guide try to get your child to drink half to one cup of fluid over each hour.

- 6. Do not omit or stop the usual doses of insulin: If blood glucose levels are low, you may need to seek advice about whether to lower the usual doses. Sometimes in this situation insulin doses may need to be reduced by 30 per cent or more.
- 7. Give extra insulin: If the blood glucose level is above 15 mmol/l and ketones are present, extra rapid or short-acting insulin is needed . Sometimes extra insulin will be needed if the BGL is 8-15 mmol/l and there are persistent ketones see the table in this chapter. Continue to check the blood glucose about every two hours until the blood glucose falls and check for ketones every two hours or so until negative.
- 8. Avoid strenuous exercise when unwell, especially if ketones are present.
- 9. When teenagers or young adults who predominantly look after their own diabetes are unwell, parents should resume care and supervision, as the teenager may be too unwell to make appropriate decisions. Extra support and care from all around is helpful.

If there is any uncertainty about what to do during a sick day, call your diabetes doctor, educator or hospital for advice. You should certainly do this if:

- vomiting is frequent or persistent (more than two or three vomits may mean hospital admission is needed, especially in young children)
- blood glucose levels cannot be kept above 4 mmol/l
- blood glucose levels cannot be kept down below 15 mmol/l after two extra doses of insulin or unable to clear ketones
- your child is becoming more unwell or develops other symptoms (e.g., abdominal pain, drowsy, confused, deep or heavy breathing)
- you are very worried or exhausted or do not know what to do next
- your child is very young.

### Giving extra insulin during sick days

- Extra insulin is needed if the blood glucose level is greater than 15 mmol/l and there are any ketones present in urine or blood tests. Don't wait until the next insulin dose is due give an extra dose right away. Sometimes extra insulin will be needed at a glucose level between 8–15 mmol/l during illness if there are persistent ketones. The table later in this chapter guides you about this.
- Use rapid or short-acting insulin only for extra doses. Do not use long-acting insulin for these extra sick day doses.
- Give an extra 5 per cent, 10 per cent or 20 per cent of the total daily dose of insulin according to the table below. Use the smaller dose in the range first or if you think your child is very sensitive to the rapid or short-acting insulin.
- Add up all insulin doses for a usual day and divide by ten to get the 10 per cent figure, from which the others are easily calculated.
- Continue to check for ketones every 2 hours or so.
- If the blood glucose level is still not below 15 mmol/l after two to four hours, repeat the extra insulin dose (unless the blood glucose level is clearly falling quite quickly).
- If the blood glucose level remains above 15 mmol/l after two extra doses of insulin, contact your diabetes doctor, educator or hospital.
- Insulin pump users will use correction doses through the pump if there are no ketones or with a pen injection if ketones are present specific details are given in chapter 18.



#### Guide to extra insulin doses and monitoring for sick days:

	Ketones: none or minimal Blood ketones less than 0.6 mmol/1 Urine: negative or trace	Ketones: small to moderate Blood ketones 0.6 to 1.5 mmol/l Urine: + to ++	Ketones: moderate Blood ketones more than 1.5 mmol/l Urine: ++ to +++
BGL more than 15 mmol/l	Give a 5% extra insulin dose. Check blood glucose and ketones again in about two hours	Give a 5 to 10% extra insulin dose. Check blood glucose and ketones again in about two hours	Give a 10 to 20% extra insulin dose. Check blood glucose and ketones every hour.
BGL 8 to 15 mmol/l	Re-check blood glucose in two hours. May fall without extra insulin. If persistently elevated, consider a 5 % extra dose of insulin	Re-check blood glucose and ketones in two hours. If persistently elevated, give a 5 to 10% extra dose of insulin	Give a 10 % extra insulin dose. Check blood glucose and ketones again in about two hours
BGL 4 to 8 mmol/l	No cause for concern. Check BGL again in 2 hours.	Ketones indicate carbohydrate and insulin deficiency. Give extra glucose / carbohydrate to maintain or increase BGL. Continue usual insulin doses. Check glucose and ketones in 2 hours.	Ketones indicate carbohydrate and insulin deficiency. Give extra glucose / carbohydrate to maintain or increase BGL. Do not stop usual insulin doses and consider an extra 5% insulin dose if ketones not clearing. Check glucose hourly and ketones 2 hourly.
BGL less than 4 mmol/l	Treat the hypo by giving sweet fluids/food and ongoing carbohydrate to maintain BGL. Check BGL in 20 to 30 minutes. Do not stop usual insulin doses, but may need to be lowered. Consider mini- dose glucagon. Hospital admission for IV fluids may be needed if BGL cannot be maintained.	Treat the hypo by giving sweet fluids/food and ongoing carbohydrate to maintain BGL. Check BGL in 20 to 30 minutes. Ketones indicate carbohydrate and insulin deficiency. Continue to give extra glucose / carbohydrate. Do not stop usual insulin doses, but may need to be lowered. Hospital admission for IV fluids may be needed if BGL cannot be maintained and ketones cleared.	Treat the hypo by giving sweet fluids/food and ongoing carbohydrate to maintain BGL. Check BGL in 20 to 30 minutes. Ketones indicate carbohydrate and insulin deficiency. Continue to give extra glucose / carbohydrate. Do not stop usual insulin doses, but may need to be lowered. Hospital admission for IV fluids may be needed if BGL cannot be maintained and ketones cleared.

## How do I decide how much extra insulin to give – 5 per cent, 10 per cent or 20 per cent?

Use the table above as a guide. In children under five years or those who seem very sensitive to short-acting insulin or are at the milder end of the ranges in the table, use the smaller dose in the range shown in the table first. You will get a feel for extra doses that your child needs for illness after you have dealt with some. If you are not sure what to do, phone your doctor, educator or hospital for advice.

#### Example of extra dose calculation

#### Usual daily doses:

Breakfast: NovoRapid 6 units, Levemir 14 units Predinner: NovoRapid 4 units Pre-bed: Levemir 6 units Total daily dose = 30 units

A 10% extra dose would be 3 units of NovoRapid (rapid-acting) i.e., 10% of the usual total daily dose

A 20% extra dose would be 6 units of NovoRapid (rapid-acting)



### Illnesses with low blood glucose levels

As discussed above, many illnesses will raise blood glucose levels, even if the appetite is less than usual. This is the most common situation. Some illnesses, however, cause blood glucose levels to be low and these are usually gastroenteritis illnesses (tummy upsets) where nausea, vomiting and diarrhoea are the main features. Blood glucose levels are low because there is less carbohydrate intake and the food that is eaten may be absorbed poorly. There may be ketones (usually small amounts) in the blood or urine in this situation – these indicate that supplies of glucose are running low in the body. The body still needs insulin in these situations as well as extra glucose from carbohydrate to correct the situation.

Electrolyte replacement solutions (e.g., Gastrolyte or Hydralyte) can be used and help to replace fluid and electrolyte losses. The solutions contain relatively small amounts of glucose, usually around 15 g or one exchange per litre, so additional carbohydrate may be needed.

In these situations, still follow the sick day guidelines as above. In some cases where symptoms persist, there is dehydration or the blood glucose level cannot be kept above 4 mmol/l, hospital admission may be required.

If things are improving but the blood glucose levels are tending to stay low, insulin doses should be reduced. Do not stop the insulin, but consider reducing insulin doses by 30 per cent or sometimes more. A reduced insulin dose may be required for a number of days as it takes some time for the bowel to recover. Insulin doses may be difficult to judge in this situation, and if in any doubt, contact your diabetes team for advice.

#### Mini-dose glucagon

Glucagon is a medication that is usually used for emergency treatment of severe hypoglycaemia in diabetes when the person is unable to safely eat or drink or is unconscious or fitting. Glucagon raises the BGL, mainly by releasing glucose from the liver and in such situations can be life-saving. All families must have glucagon at home and know how to use it.

Sometimes children with diabetes experience illnesses which are not severe, yet their BGLs are low (under 4 mmol/l) and they are reluctant to eat or drink enough to raise the BGLs up to satisfactory levels. This is especially common in young children and toddlers. While this is not classed as severe hypoglycemia it could become so and if BGLs cannot be raised it may mean a trip to hospital for IV fluids.

The mini-dose glucagon protocol has been developed as a way of raising BGLs in such circumstances until the child is eating or drinking better. It can help avoid an admission to hospital. It can be used safely and effectively provided that the guidelines are followed carefully. Mini-dose glucagon should not cause vomiting.

#### 1. Is mini- dose glucagon suitable for my situation ?

#### You MUST NOT use the mini-dose glucagon protocol if :

- Severe hypoglycemia decreased consciousness or fitting a full dose of glucagon is needed urgently as described in chapter 8.
- more than mildly unwell or has other symptoms, e.g., tummy pain
- There is persistent vomiting
- You are very worried and do not want to continue to manage at home

If you are not sure whether it is appropriate to use the mini-dose glucagon protocol or have questions, contact your diabetes educator, doctor or after-hours diabetes service.

#### 2. Mixing up the glucagon

Glucagon (Glucagen Hypokit) is mixed up as per the standard recommendations. All the fluid in the syringe is pushed into the bottle of powder. The syringe is then withdrawn and the bottle is gently swirled to dissolve the powder. Do not shake the bottle.

#### 3. Drawing up the correct dose into an insulin syringe:

An insulin syringe is used to draw up the glucagon dose.

#### Draw up 1 unit of the glucagon mixture on the insulin syringe per year of age.

e.g., for a 10 year old child, draw up 10 units on the syringe. If your child is less than 2 years, use 2 units as the dose. If your child is over 15 years, use a maximum dose of 15 units.

#### 4. Giving the mini-dose glucagon injection

Give the injection as you would an insulin injection, into any site that you would normally use.

#### 5. Monitoring the response

The BGL should be re-checked in 30 minutes. If the BGL has not risen to normal levels after 30 minutes, give another dose of glucagon of **double** the initial dose. If there is still no response after 30 minutes, then you will need to bring your child to the hospital or call an ambulance.

If the BGL rises satisfactorily, continue to encourage suitable foods and fluids to help keep the BGL up. Monitor the BGL frequently until stable.

#### 6. If the BGL falls again later

Another dose can be given, with BGL monitoring as above. If more than 2 doses are needed on the same day, then you should contact your diabetes team or come to hospital. The glucagon solution is stable for 24 hours in the refrigerator.

#### 7. Lowering insulin doses

Lower insulin doses are usually needed during these times, with dose reductions up to 30–50% often needed. Both short-acting and long-acting insulins will be reduced, but often more so the short-acting. Call your doctor or educator if you need advice.

#### 8. If a severe hypo develops

You must give a full dose of glucagon and call the ambulance. A full dose of glucagon is 0.5 mls (50 units on an insulin syringe) if less than 6 years old or 1 ml (100 units on the insulin syringe) if older than 6 years. The dose can also be given by using a second spare glucagon kit.

If using the mini-dose glucagon protocol, make sure that you always keep at least 0.5 mls of glucagon in case you need to treat a severe hypo. 0.5 mls will generally be enough for this situation in an older child or teenager.

#### 9. Glucagon supplies

Remember to replace your glucagon after using it.



## Foods and fluids for sick days

#### When the blood glucose level is above 8 mmol/l:

#### Use low calorie or sugar-free fluids, such as:

- water
- diet cordial or diet soft drink (shake bubbles out or allow to go flat)
- diet jelly

#### When the blood glucose is below 8 mmol/l:

Carbohydrate-containing foods or fluids will be required. The following list gives some foods and fluids which may be useful during illnesses. Any carbohydratecontaining foods or fluids may be used, but it is a matter of trying to use foods and fluids which your child will tolerate while sick.

Food	Jelly beans	Drink	Ordinary soft drink
	Toast or bread		Juice
	Plain sweet biscuits		Milk, with added chocolate powder
	Ice-cream, Icy Poles	;	Tea or water with honey or sugar
	Yoghurt		
	Sweet jelly		
	Banana		
	Orange		

These fluids are not generally suitable for children with significant dehydration. Any child who may be becoming dehydrated should be assessed at hospital and may require admission and an intravenous drip.

### **Surgery and anaesthetics**

Like any child, a child with diabetes may require surgery or a procedure with an anaesthetic at some time in their life. These can be performed safely, provided that appropriate precautions are taken and the diabetes is cared for during this period by staff experienced in childhood diabetes. Not all hospitals have this expertise. You should always discuss any planned procedures with your diabetes specialist who will be able to advise about appropriate arrangements. Your surgeon will look after the operation and surgical care but you need the involvement of your diabetes team to look after the diabetes.

Even minor procedures will require admission to hospital, although sometimes the stay can be for only one day. Surgery is best performed first thing in the morning. An intravenous drip containing glucose is usually required to cover the period before, during and after the operation where your child cannot eat or drink.

For minor procedures, insulin will be given by injection or a pump will continue to be used, with doses adjusted as needed. For major procedures or emergencies, an insulin infusion will be given through an intravenous drip. More frequent blood glucose monitoring is required and the blood glucose levels are likely to be more variable. The aim is to avoid major hypos, prolonged highs, dehydration or other complications.

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If you have any doubts about arrangements for surgery or a procedure, you should contact your diabetes team without delay.

### Common questions and answers



## When my son gets ear infections and has a fever, he eats much less. Should I lower his insulin doses?

Illnesses with fever and infection often make the blood glucose levels higher than normal, even if the child is not eating well. This is because of glucose output from the liver, which is exaggerated when the body is stressed and lacking in insulin. You should check the blood glucose levels more often and continue the usual doses of insulin. Sometimes extra insulin will be needed. Some illnesses make the blood glucose levels lower, especially vomiting and diarrhoea. If this happens, less insulin may be needed – monitor more often and check with your doctor or educator if unsure.



#### How do extra fluids help when my child is sick?

High blood glucose levels can cause extra fluid losses through passing more urine. Extra fluid helps replace this and helps the body clear ketones.

2	
6	

#### My daughter has only had diabetes for three months and this is her first illness since the diagnosis. We don't feel confident about giving extra inulin. What should we do?

It is natural that you will feel anxious and uncertain about dealing with sick days, especially at first. Use the guidelines in this section. If worried or unsure, call your doctor, educator or after-hours diabetes service who will guide you; this can usually be done over the telephone.



#### If my child is sick and does not feel like eating, what can I do?

Measure the blood glucose level more often. Try to give carbohydratecontaining fluids or foods that are easy to swallow (e.g., jelly, custard, ice-cream). During sick days, if the blood glucose level is above 8 mmol/l, low calorie or sugar-free fluids should be used. If the blood glucose level is below 8 mmol/l give carbohydrate-containing fluids or food.



## Do children with diabetes get ketones whenever the blood glucose is high?

No. If the child is well and the blood glucose is high from eating too much carbohydrate or perhaps because of mood or emotion, then usually there will be no ketones. It is only when there is not enough insulin in the body that ketones develop, and this is more likely at times of illness. Ketones are likely to develop if the BGL is high for more than a few hours.



#### My seven-year-old daughter with diabetes needs to have her tonsils removed. I have been advised that this can be done in our local private hospital, even though they do not have a children's section. What should I do?

Surgery on children with diabetes should only be performed in hospitals in which there is experience in looking after children with diabetes at these times. Usually this will be a major children's hospital or general hospital with a paediatric section. Your diabetes specialist needs to be involved in the planning and during the time in hospital. Contact your diabetes team for further advice about how you should proceed.

## **Chapter 11 Exercise and Sports**

## **Key Points**

- Exercise usually lowers blood glucose levels, but sometimes they rise for a short time during or just after strenuous exercise
- Measure the blood glucose before exercise and frequently during any prolonged exercise
- For exercise, there may be a need to lower the insulin doses, eat extra carbohydrate or both
- Delayed hypos can be a common problem after strenuous or prolonged exercise – measure the blood glucose, lower the insulin and eat extra carbohydrate after exercise if needed
- Planning ahead helps minimise any problems

### **Benefits of exercise**

Exercise is very beneficial and is encouraged for all children. With appropriate knowledge and precautions, exercise and sports can be undertaken without major concerns in children and adolescents with diabetes. There are a number of professional sports people with diabetes.

#### Exercise:

- helps keep the body in good shape and at an ideal weight
- helps people feel well and happy and is an important social activity
- helps keep the heart rate and blood pressure lower
- gives you more energy
- strengthens muscles
- helps you get good control of diabetes.

In infants and young children, general activities and play provide adequate exercise. As children grow older they are increasingly active and will often wish to become involved in group or individual sports. Older children and adolescents who have a tendency to be inactive and do not wish to play sports should be encouraged to incorporate some regular exercise into their weekly routine (e.g., walking, swimming). Children with diabetes should not be limited in their activities and should be encouraged to participate in sports and physical activities. Learning sports when you are young gives you skills that are much harder to develop as an adult.

### **Exercise and diabetes**

#### The following points are important to know about exercise and diabetes:

• Exercise usually lowers the blood glucose level (during and after exercise). This occurs because the exercising muscles use more glucose as fuel, but also because exercise makes the body more sensitive to insulin (i.e., the same amount of insulin has a greater effect). Lowering of blood glucose levels can occur during the exercise and for some time after, often up to 12 to 16 hours.

# Chapter

- Sometimes exercise makes the blood glucose level go up. This can happen during or just after exercise in some people because of the effect of some of the body's other hormones which rise during exercise (e.g., adrenaline) and increase glucose output from the liver. Usually later the blood glucose will fall because of the reasons outlined above. Exercise is also likely to raise the blood glucose level if people exercise when unwell. Strenuous exercise should be avoided if unwell if the blood glucose level is above 15 mmol/l or if there are ketones present.
- Exercise affects everyone a little differently. Because everyone is different in the way their body will respond to a certain activity, learning your child's own response to each type of exercise by observation and extra BGL monitoring will help avoid hypoglycaemia.

### **Guidelines for exercise and diabetes**

#### **Before exercise**

- Type of exercise: Think about how long and how strenuous the exercise will be. Short or low level exercise may require no adjustment, whereas prolonged or vigorous activity will require reductions in insulin and/or extra carbohydrate.
- Injection sites: Insulin is absorbed more quickly from parts of the body that are exercising (e.g., arms and legs). The abdomen (tummy) is the best place to have insulin injections before exercise or as a second choice the buttocks.
- Supervision: Children should be supervised by or exercise with someone who knows that they have diabetes and could help if there is a problem. It is important to let people (such as teacher, coach, Scout leader) know that your child has diabetes. Provide them with simple information and guidelines for what to do if there is a problem, which is most likely to be a hypo. Food or drink to treat hypoglycaemia needs to be available to those supervising.
- Dangerous sports: Some sports or activities are not recommended for people with diabetes or have to be approached with extreme caution. These are mainly sports which are solo or unsupervised water or air sports or any other sports where recognising or treating a hypo could be difficult.



People with diabetes should not do solo or unsupervised sports – a companion who knows about diabetes and hypo treatment should always be present. Sports which are not recommended for people with diabetes include motor racing, rock climbing, scuba diving, hang-gliding, solo flying. Some potentially hazardous sports (e.g., surfing, sailing) are possible with good planning.

• Measure the blood glucose: It is very useful to measure the blood glucose level before exercise. This helps to decide about reducing insulin or the need for extra carbohydrate before or during the exercise.

During periods of prolonged physical activity (e.g., a day of bushwalking or a swimming carnival) the blood glucose should be measured more frequently than usual. It is also important to measure blood glucose levels after exercise because of the possibility of delayed hypos.

#### How to adjust for exercise

Most forms of activity lasting more than 30 minutes are likely to need consideration of adjustment to insulin dosing or food. This can depend on many factors, such as usual activity patterns, intensity of exercise, when you are exercising, type of insulin plan and recent insulin doses.

Adjustment for exercise will require thinking about:

- 1. Reduction in insulin doses acting at the time, and sometimes after exercise
- 2. Additional carbohydrate before and during the exercise
- 3. A combination of both insulin reduction and additional carbohydrate

For planned exercise, particularly in older children, insulin reduction is an appropriate first step if possible in the individual's insulin plan. For unplanned exercise and younger children, a common first step is to give some extra carbohydrate.

Prolonged exercise will usually require a combination of insulin reduction and extra carbohydrate.

#### Insulin adjustment for exercise

Insulin reduction is often the appropriate first response to exercise. It can be combined with having extra carbohydrate if needed. Reasons for reducing insulin doses as a first step, if possible, include:

- Not wishing to eat or drink too much before sport
- Extra carbohydrate may not be enough to avoid hypos.
- Older children and teenagers are likely to exercise more intensely
- Extra food with exercise can contribute to unnecessary extra calories and excess weight gain.
- Prolonged exercise or high activity periods (e.g., sports carnival days or school camps).

However insulin reduction as a first step is not practical in all insulin plans, especially when extra exercise is spontaneous or unplanned. e.g., it may not be possible to predict that a toddler will be very active after lunch; the usual morning insulin dose may have been given and if there is no lunch time insulin dose to adjust, giving extra carbohydrate is the only way of compensating.

To adjust insulin for exercise it is necessary to have an understanding of which insulin doses are acting mostly during and after the exercise (see section 5). For those on an insulin pump, please refer to chapter 18 for specific details about adjustments.

The dose of insulin which is acting at the time of the exercise (especially rapid or short-acting) may need to be reduced by between 20 and 50 per cent. Discuss this with your diabetes team if unsure. Usually it is appropriate to reduce the rapid or short-acting insulin before exercise more than the long-acting insulin.

For some children it is necessary to have different doses of insulin on different days depending on their activity levels (e.g., lower dose on weekends with sporting activities). Extra monitoring and experimenting with dose adjustment will help work out what works best for your child. Insulin doses may also need to be reduced after exercise (see later). Your educator or doctor will also be able to guide you.

During very active periods such as school camps or diabetes camps insulin doses may need to be decreased by around 20-30 per cent for the duration. This depends on how active the camp is compared to your child's normal routine.

#### Extra carbohydrate before and during exercise

If you wish to adjust by taking extra carbohydrate, the following table is a general guide to the extra carbohydrate which should be taken before and during exercise. You may find that you modify this a little for your child after you gain some idea of their pattern with particular types of activity. If insulin is also being reduced, the extra amount of carbohydrate needed will be less. Advice for insulin pump users is based on the same principles, but is covered in more detail in chapter 18.

It is usually best to have the extra carbohydrate 20 to 30 minutes before exercise. The extra amounts are in addition to the carbohydrate your child usually has during the day.



Exercise	Blood glucose level before	Extra carbohydrate* - use extra exchanges (15g carbs) or serves according to the system you follow
Short duration	Less than 7 mmol/l	1 exchange before
(less than 50 limites) or low intensity exercise (e.g., slow walking, yoga)	More than 7 mmol/l	No extra necessary
Moderate exercise (e.g., power walking, aerobics, swimming, tennis, jogging)	Less than 7 mmol/l	<ul><li>1-1.5 exchange before;</li><li>1 exchange per 30-40 minutes of exercise</li></ul>
	7-12 mmol/l	1 exchange before; 1 exchange per 30-40 minutes of exercise
	Above 12 mmol/l	May not need extra before; 1 exchange per 30-40 minutes of exercise
Strenuous exercise (e.g., basketball, hockey,football, strenuous cycling)	Less than 7 mmol/l	<ul><li>1-2 exchanges before;</li><li>1 exchange per 20-30 minutes of exercise</li></ul>
	7-12 mmol/l	1 exchange before; 1 exchange per 20-30 minutes of exercise
	Above 12 mmol/l	May not need extra before; 1 exchange per 20-30 minutes of exercise
	Above 15 mmol/l	Strenuous exercise should be avoided if ketones are present – give a correction dose of insulin first

\* Note: less carbohydrate than this may be needed if insulin has been reduced before and during exercise

Another rule of thumb is that young adults require 1 to 1.5 grams of carbohydrate per kg of body weight each hour during strenuous exercise, unless they have reduced insulin beforehand.

Many carbohydrate foods are suitable before and during exercise, but here are some popular ones:

- juice
- milk
- sports drinks
- yoghurt
- fruit
- fruit bar or muesli bar
- biscuits
- small chocolate bar.

#### Delayed hypoglycaemia after exercise

Delayed hypoglycaemia is common for up to 12-16 hours after significant exercise. This is because the muscles can continue to use more glucose than usual and the body is more sensitive to insulin after exercise. If there has been prolonged or intense exercise throughout the day then delayed hypos are very likely. These can be prevented by insulin reduction, extra carbohydrate and extra blood glucose testing.

Test the blood glucose level before bed after significant exercise. An extra one or two carbohydrate exchanges should be given if the blood glucose is less than 6 mmol/l at bed time. It may also be necessary to check the blood glucose level later in the evening or overnight.

In some children it is necessary to reduce the evening insulin after exercise to avoid night-time hypos especially where the exercise has been vigorous or prolonged. Again, the reduction is usually in the range of 10-30 per cent but only extra monitoring will help work out what is best for your child.

#### **Exercise adjustment examples**

The following are examples of some common adjustments. Since exercise and response to it will vary so much in different children, only extra monitoring and trial and error will determine what works best for your child. Your educator and doctor are experienced in advising about these adjustments if you need help.

#### Example 1

Troy is an active ten-year-old boy. During the winter he has football training from 4 to 6 pm on Tuesday evenings and plays football on Saturday mornings from 10 to 11 am.

#### Usual insulin doses:

Before breakfast: Levemir 12 units, Actrapid 6 units Before main evening meal: NovoRapid 4 units Before bed: Levemir 7 units

#### Adjustment:

After extra monitoring and adjusting the following plan was worked out:

Before football training: eats usual afternoon tea plus one or two extra exchanges depending on BGL (not practical to reduce morning insulin here, as his BGLs would run high during the day)

Has orange juice half-way through training session.

Has pre-dinner insulin reduced to NovoRapid 2 units and reduces pre-bed Levemir to 5 units.

Eats extra exchange at supper if BGL is less than 6 mmol/l.

On Saturday mornings: has insulin reduced to Levemir 10 units, Actrapid 4 units. Eats morning tea early just before game. Has orange juice at half-time.

#### Example 2

Sarah is a three-year-old girl who attends preschool two mornings per week. She is tending to have low BGLs at preschool in the late morning because she is more active than at home.

#### Adjustment:

It was found that she is quite hungry at preschool and giving some extra carbohydrate at preschool solved the problem. If this had not been successful a reduction in the morning insulin dose on those days would need to be considered.

#### Example 3

Aysha is a 14-year-old girl who wishes to attend a dance party on Saturday night from 7 pm to 10.30 pm. She is a keen and vigorous dancer. She is on four injections a day:

#### Apidra:

before breakfast 12 units before lunch 10 units before dinner 14 units

Lantus: before bed 28 units

#### Adjustment:

Morning and lunch doses remain the same.

The pre-dinner Apidra (rapid-acting) is reduced to 10 units and dinner is eaten as usual. Aysha makes sure to have one or two exchanges of carbohydrate per hour during the party (e.g., potato chips, orange juice, cake). On returning home she checks her blood glucose and would have extra carbohydrate if her BGL is less than 6 mmol/l. She reduces her pre-bed Lantus (long-acting) to 23 units. Dad usually checks her blood glucose level at 2-3 am after a big night out.



### When is it unwise to exercise?

People with diabetes should avoid exercise if:

- unwell
- The blood glucose level is high (above 15 mmol/l) and ketones are present. Exercise at this time can raise the blood glucose and ketone levels and make your child feel more unwell. More insulin is needed at this time, not exercise. Exercise will not lower the blood glucose if the body is lacking insulin.

If the BGL is above 15 mmol/l, but the person is well and ketones are negative, mild or moderate exercise is fine (but not strenuous) and will help bring the glucose down. However, it is important to think about why the glucose is high and whether extra insulin might be needed.

### Associated video resource for Chapter 11:

#### WWYCD (Wicked) – Your Get-Up-and-Go Guide to Living with Type 1 Diabetes

ERC Media, Educational Resource Centre, Royal Children's Hospital, Melbourne, 2009.

WWYCD clearly lays out the benefits of maintaining regular exercise and, when motivation is low, encourages young people to consult the one person who can truly assist them to develop and maintain a healthy fitness regime for life.

#### View via the link at www.kidsdiabetes.org.au



## **Common questions and answers**



#### Our son tends to have hypos in the night after his athletics days, even though we give him extra carbohydrate. What can we do?

Delayed hypos after exercise are common and exercise can cause blood glucose levels to be lower for some 12 to 16 hours afterwards. Lowering the insulin on these very active days will help – lower the evening dose, or both morning and evening doses, depending on the pattern.



## My 15-year-old son is a keen surfer. I worry about him having a hypo when he is out in the water. What should I do?

Activities like surfing are potentially hazardous and require extra precautions. Always check the blood glucose level before going into the water and eat some extra carbohydrate (see the guidelines in this section). Some children will lower their insulin doses if planning a very active time. He should always surf with a buddy who knows he has diabetes and what to do for a hypo. He should come in to the beach every 30 minutes or so for extra carbohydrate (one to two exchanges). As an extra precaution, a tube of glucose gel can be tucked into the wetsuit or board shorts in case of an unexpected hypo.



#### My daughter has a school camp which is going to be very active. What should we do about her insulin doses?

Plan ahead by looking at the activity program and how active it will be. Also ask to see the menus to check for carbohydrate content and number of meals and snacks provided. If the camp is much more active than your child's usual routine, insulin doses often have to be reduced by 20 to 30 per cent overall. Extra carbohydrate will also be needed. Consult your diabetes doctor or educator before the camp if uncertain.



## What are some good extra carbohydrates for before or during exercise?

Many carbohydrate foods are suitable. Some popular ones are juice, milk, sports drinks, yoghurt, fruit, fruit bars, muesli bars, biscuits or small chocolate bars. Higher energy foods can be used at these times since the energy is burned up and does not raise the blood glucose levels so much.



#### My daughter is sometimes hypo after netball training, but at competition matches her blood glucose levels are often high. Why is this?

Sometimes the stress and excitement of the competition will make the blood glucose high through production of hormones like adrenaline which cause glucose release from the liver. If this affects performance, ask your doctor or educator about some possible solutions.



## My son had a BGL of 18 mmol/l immediately after basketball last week. Should we have given extra insulin then?

No. High intensity exercise can push the BGL up temporarily during the exercise and for a short period after. This is because of a 'stress hormone' response. Usually the BGL will settle with rest and some fluids. Giving extra insulin at this time is likely to cause a hypo. Check the BGL an hour or so later to make sure it is settling.



## Chapter 12 Insulin adjustment

## **Key Points**

 How you adjust insulin will depend on the types of insulin being used and the number of injections each day

- Insulin doses often need adjustment. General principles are:
  - Pattern adjustment: look for patterns that indicate a need to adjust usual insulin doses because of high or low glucose levels at certain times over a few days or longer periods? Look at this regularly
  - Day to day adjustment (flexible daily adjustment): if you are using a flexible system, think whether you need to adjust a dose or doses now or today to take into account a variation in carbohydrate intake or activity? Many people on multiple daily injections make these flexible decisions on a daily basis with their pre-meal injections
  - Corrections: think about the need for a correction adjustment, especially for correcting a BGL that is too high now
- If hypos are occurring frequently, don't delay adjustments
- Seek help from your diabetes educator or doctor if you are not sure what to do or your adjustments are not working
- Pump users also need to adjust insulin, but details are different see chapter 18

All people with diabetes need adjustment of their insulin over time and also often from day to day. At first this may seem a little confusing, but you will soon find that it falls into place and you will get a good feel for how to adjust your child's doses. Older children and teenagers will also start to think about their own adjustment and can become skilled at it. It is very rewarding and will give you a sense of control to be able to adjust the insulin doses as needed.

In some situations and for some children, adjustment remains very difficult, requiring more frequent contact with your diabetes educator or doctor. Shortly after diagnosis, very frequent adjustments need to be made and these are usually made by regular contact with your diabetes educator or diabetes doctor.



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The details of adjustments for injections and pumps are quite different; this chapter discusses injections for those on injections. Adjustments for pumps are dealt with in chapter 18.

### Why does insulin need adjusting?

Insulin doses will need adjusting gradually over time and can often need adjusting day to day. There are many reasons why insulin may need adjusting, including the following:

- As children enter a honeymoon phase shortly after diagnosis, insulin doses decrease
- As children grow, they need more insulin to maintain good control
- Insulin requirements increase more with puberty and the associated growth spurt
- Changes in activity levels from day to day
- Variation in appetite and food intake from day to day
- Change of circumstances, such as holidays, new school, camp etc.
- Sickness (see chapter 10 'Sick days')



### **Principles of insulin adjustment**

It is useful to think of three main types of insulin adjustments and think of them in this order:

#### 1. Pattern adjustments to usual doses:

These are changes to regular doses based on patterns in blood glucose readings over several days or longer. This may occur:

- when coming out of a honeymoon phase
- as the child grows and especially as they have their growth spurt with puberty or reach the end of puberty
- when the child has a general change in activity levels.

#### 2. Day to day adjustments (flexible daily or 'thinking ahead' adjustments):

These are adjustments to some doses based on what is going to happen that day. Examples of this are:

- reducing a dose or doses for sporting activity
- reducing an evening dose of insulin after a very active day to avoid delayed hypos
- adjusting a dose to plan for eating more or less at a meal.

#### 3. Corrections ("Fix-up adjustments"):

This is adjusting a dose or giving an extra dose to correct or 'fix up' a blood glucose reading that is unexpectedly high. For example:

- giving extra rapid or short-acting insulin when the blood glucose level is found to be high before a meal
- giving extra doses for high readings between meals
- adjusting for sick days.

## More detail on these three types of adjustment is given in the following sections. General points are:

- Insulin adjustment requires a knowledge of the types of insulin your child is on, particularly when they start to work and how long they work for (see chapter 5 'Insulin treatment').
- Overall insulin adjustments are generally based on the recognition of blood glucose patterns over several days, so enough blood glucose readings need to be done to allow this.
- Cautious adjustment steps are made in insulin doses until blood glucose levels in the target range are reached.
- At times of instability or illness it is necessary to do extra blood glucose readings to guide adjustment.
- Recurring hypoglycaemia requires thinking about insulin doses without delay and adjustment if needed.
- Frequent dose changes may be necessary when insulin needs are changing rapidly, in which case your diabetes educator or doctor should be aware and able to help.
- Increasingly, modern insulin plans incorporate flexibile dose adjustments on a day-to-day basis to adjust for activity and exercise; this is most suited to multiple daily injection plans but can be used to some extent in most plans.

## Because insulin adjustment differs significantly between different insulin plans, the next section is divided into:

- Adjustment for those on 2 or 3 injection per day plans, and
- Adjustment for those on multiple daily injections.

## Guidelines for insulin adjustment on 2 or 3 injections per day:

As outlined in chapter 5, injection plans that have two or three injection times per day can suit many children. Such plans are more commonly used in younger children and where it is impractical to have a lunch-time injection. Often children evolve from such plans to multiple daily injections or pump therapy later on. The major difference in these insulin plans, compared to multiple daily injection (MDI plans), is that there are less insulin injections that can be adjusted each day and specifically less opportunity for adjusting insulin doses before meals.

#### For children and adolescents on 2 or 3 injection per day plans:

- The insulin plan involves long-acting insulin being given once or twice daily (morning or evening or both), with rapid or short acting insulin being given before breakfast and at afternoon tea or dinner
- Insulin doses are set and adjusted to balance with their carbohydrate intake
- Carbohydrates are counted according to a pre-set meal plan that suits their nutritional needs and appetite; therefore they tend to have fairly similar amounts of carbohydrate (exchanges) for their various meals and snacks from day to day, in order to balance with the insulin. Usually a pattern of 3 main meals (breakfast, lunch and dinner) and 2 or 3 snacks (morning tea, afternoon tea and sometimes supper) suits well for any age with this pattern.
- Overall adjustments need to be made based on patterns over several days or longer
- There is some scope for day to day adjustment to suit the circumstances of the day (e.g., variation in appetite and exercise and correction of high BGLs), but this is much more limited than for those on multiple daily injections.

#### 1. Overall adjustment to usual doses (pattern adjustments)

- 1. Look for a pattern in BGL levels over a few days or longer (e.g., high levels before breakfast). Three days of levels above the target range or two days of levels below the target range at the same time of day should make you think about the need for adjustment.
- 2. Identify the insulin that is acting to regulate BGL levels at this time of day (e.g., the pre-breakfast level is mostly regulated by the previous evening's long-acting insulin).

Adjust the appropriate insulin (see below for a guide on how much to adjust). In general, adjust only one insulin at a time. Adjusting more than one at a time can be confusing.

Wait a few days to assess the outcome of the adjustment before making further changes.

#### Exceptions to these general guidelines are:

- Hypoglycaemia (especially if severe) or periods of increased activity or sick days may require more rapid or frequent adjustment.
- Where your doctor or educator advises more frequent changes.

#### Which insulin dose to adjust?

Here we show which doses should be adjusted for children on examples of a 2 injection per day pattern and a 3 injection per day pattern

#### Example of a child receiving three injections per day:

- combination short and long acting insulin before breakfast
- short acting insulin at afternoon tea
- long acting insulin at bed

If blood glucose readings show a high / low pattern over several days at:	Dose of insulin to increase / decrease:
Before breakfast or overnight	Evening long-acting insulin
Before morning tea or lunch	Morning short-acting insulin or sometimes morning long-acting insulin
Before dinner	Afternoon tea short-acting insulin or sometimes morning long-acting insulin
Before supper or bed	Afternoon short-acting insulin

#### Example of a child receiving two injections per day:

• combination short and long acting insulin before breakfast and before dinner

If blood glucose readings show a high / low pattern over several days at:	Dose of insulin to increase / decrease:
Before breakfast or overnight	Evening long-acting insulin
Before morning tea or lunch	Morning short-acting insulin or sometimes morning long-acting insulin
Before dinner	Morning long-acting insulin
Before supper or bed	Evening short-acting insulin

#### By how much should doses be adjusted?

Insulin adjustment is made in steps based on blood glucose monitoring. The amount by which the dose is changed depends on the current dose. For example:

- if on 4 units of Actrapid, a 1 unit increase is a 25 per cent increase
- if on 20 units of Actrapid, a 1 unit increase is only a 5 per cent increase.

Doses are usually adjusted by **about 10 per cent** of the current dose. If you are unsure, make smaller cautious changes, waiting for several days of blood glucose readings to decide on further adjustment.

Remember that during periods of insulin adjustment more frequent BGLs are very helpful (e.g., four to six per day or sometimes more).

#### General rules of thumb for adjusting insulin doses:

Dose to be adjusted	Adjust by
10 units or less	1 unit. In some children on doses of less than 5 units, 0.5 unit changes are often used
10-20 units	1-2 units
20-30 units	2 units
More than 30 units	2-4 units

Pens are available that allow half-unit adjustments and, with care, half-unit increments can also be used with syringes.

#### 2. Day to day adjustments (flexible daily adjustments)

These are changes to some doses based on what is going to happen that day. If you can anticipate that your child's insulin needs will be more or less than usual on a certain day, then making an adjustment is likely to reduce the chance of highs or lows during the day. Some of these situations are:

- Adjustment for sports and activities:
  - o This is also covered in chapter 11. Extra activity or sport usually requires a reduction in insulin doses, extra carbohydrate or both. Which insulin doses are lowered will depend on the time of the day the sport is played and which insulins are mainly acting then. For example, in a child on a 2 or 3 injection per day plan, less short-acting insulin might be given in the morning on days when there is planned physical exercise at school at 9am.
  - o For days when the activity levels will be continually high (e.g., athletics carnival, active camp, bushwalking) all doses may need to be lowered (short and long-acting insulins) and this is usually a reduction by 10 to 30 per cent, depending on the individual. Remember also after very high energy days to reduce the night time dose of insulin to avoid delayed hypos overnight.



#### • Insulin adjustments for meals:

Many younger children eat similar amounts of carbohydrate at similar times of day. This particularly suits the routines of younger children and insulin adjustment before meals often does not need consideration. However, since there are usually 2 doses of rapid or short-acting insulin each day which coincide with meals or snacks, these can be adjusted if need be to cope with more or less carbohydrate intake if that can be predicted.

For example, you may know that your child always eats more and ends up with a high blood glucose level after eating pizza for dinner. Therefore, you may find that it helps to increase the rapid-acting insulin dose before dinner on those days to give a better BGL later in the evening.

#### • Correction doses:

In a similar way, if BGL is found to be above the target range when a rapid or short-acting insulin dose is due, it is reasonable to increase this dose a little to help the BGL return to the target range. This is called a correction dose.

If you find that you are needing to make corrections nearly every day, this suggests that overall doses may need increasing (see pattern adjustments above).

#### • Adjustment for sick days:

This is covered in detail in chapter 10. Sick days can require dose increases if blood glucose levels are high and ketones are present or dose reductions if blood glucose levels are staying too low.

## Guidelines for insulin adjustment for multiple daily injections:

Multiple daily injection (MDI) plans are now widely used, which include one or two injections daily of a long-acting insulin and an injection of rapid or short-acting insulin before each main meal. In chapters 5 and 6, different ways of applying and adjusting multiple daily injections plans and carbohydrate counting were outlined, These are discussed here in further detail.

Three methods are in common use:

#### 1. Conventional MDI with consistent carbohydrate intake

In this pattern, a person has fairly consistent carbohydrate intake on a day to day basis and tends to keep the pre-meal insulin doses fairly constant from day to day. Adjustments would usually be based on overall patterns.

This pattern assumes that the person likes to have and adheres to fairly constant amounts of carbohydrate for their meals on a daily basis. Adjustments would still be made from time to time for exercise, and if needed for sick days.

This method can suit some people very well, but others find it lacking in flexibility.

#### Which insulin dose to adjust based on blood glucose patterns?

Here we show which doses should be adjusted for children on the two common examples of multiple daily injection:

#### MDI Example 1:

- Before breakfast: rapid or short-acting insulin
- Before lunch: rapid or short-acting insulin
- Before dinner: rapid or short-acting insulin
- Before bed: long acting insulin

Blood glucose showing a high / low pattern	Dose of insulin to increase / decrease
Before breakfast or overnight	Evening long-acting insulin
Before morning tea or lunch	Morning short-acting insulin
Before dinner	Lunchtime short-acting insulin
Before supper or bed	Evening short-acting insulin

#### MDI Example 2:

- Before breakfast: long-acting insulin and rapid or short-acting insulin
- Before lunch: rapid or short-acting insulin
- Before dinner: rapid or short-acting insulin
- Before bed: long acting insulin

Blood glucose showing a high / low pattern	Dose of insulin to increase / decrease
Before breakfast or overnight	Evening long-acting insulin
Before morning tea or lunch	Morning short-acting insulin or sometimes morning long-acting insulin
Before dinner	Lunchtime short-acting insulin or sometimes morning long-acting insulin
Before supper or bed	Evening short-acting insulin

#### By how much should I adjust doses?

This is the same as for 2 or 3 injections per day – see earlier in this section. Dose adjustments of about 10% of the current dose are usually made, waiting several days to assess the effects of the change.

#### 2. Flexible multiple daily injections (flexible MDI)

In this method, the principles of adjustment based on overall patterns should still be used as outlined above. However, pre-meal insulin doses are also adjusted from day to day based on variations in carbohydrate intake and activity patterns. There is no precise formula for how this is done. It is a type of "fuzzy logic" that is based on person's understanding of how food and activity affect their BGLs, judgement and past experience. Many people may use much the same insulin doses and have the same carbohydrate intake most days, with only occasional adjustments. Other people find that they adjust doses more frequently.

The pre-meal injections allow greater flexibility for adjustment, since each of those doses can be adjusted according to:

• the amount of carbohydrate that is going to be eaten;

- any planned activity; and,
- whether the current blood glucose needs correcting (i.e., is higher or lower than desired).

Diabetes education now includes discussion of how to make these adjustments and this may be done differently in different centres and by different people. It also requires a good understanding of carbohydrate counting and different effects of different carbohydrates (i.e., the glycaemic index).

In this method, a person has a good understanding of their usual carbohydrate intake for each meal and the amount of insulin usually required to cover that. They then make adjustments of pre-meal doses (up or down) according to the particular circumstances at that time (planned food intake, recent or planned activity, current BGL level) and their previous experience. Long-acting insulin doses are usually not adjusted on a day to day basis, although may sometimes be reduced if needed relating to sport and exercise (see chapter 11).

#### Example 1:

Justin is 14 years old and usually has 12 units of NovoRapid before breakfast. Today he has a BGL of 5 mmol/l, but is not very hungry and plans to eat less. Also he has Physical education class at 9am. He decides to reduce his dose to 8 units.

#### Example 2:

In the same circumstances above, if Justin's BGL had been 14 mmol/l, he probably would have taken the usual dose of 12 units, to assist the BGL to return to normal.

#### Example 3:

Emma is on a multiple daily injection plan with NovoRapid before meals and Levemir before bed. She knows that on a usual day when she eats a usual breakfast of cereal and toast, she needs 8 units of NovoRapid. However, she sometimes does not feel like eating much for breakfast and only has a glass of milk. She finds that 5 units of NovoRapid works well on these days and her BGL late morning is within target.



#### 3. Insulin to carbohydrate ratio (ICR)

This is a variation of flexible MDI for day to day adjustment in which the pre-meal insulin dose is calculated according to the amount of carbohydrate that will be eaten using individual formulas that have been calculated with your diabetes team.

The ICR is a formula for how much insulin is needed to cover 1 exchange of carbohydrate (15 grams of carbohydrate) and the dose is calculated according to how many exchanges of carbohydrate are going to be eaten that meal. A correction can also be made if needed for a high blood glucose and anticipated activity. Sometimes different ICRs are needed for different meals or for different days of the week, depending on activity levels etc.

This method is derived from the way insulin pumps work and can be applied successfully for those on injections. There is variation as to how this is done in different centres. Some diabetes centres use card or wheel calculators or PDA software programs to assist families in using ICR systems, whereas others use manual calculation methods. The exact details of these systems are beyond the scope of this book and if you are using an ICR system, your local team will advise which system they feel is best for you and teach you how to use it.

#### Example of using an ICR:

Francesca is on an insulin plan with Apidra before meals and Lantus at bedtime. Based on her food and activity records, the diabetes team have calculated an insulin to carb ratio of 3 units per carbohydrate exchange. She has also worked out a correction factor with her diabetes team for when she is high – 1 unit of insulin lowers the BGL by 2 mmol/l.

Today at breakfast her BGL is 12 mmol/l and she is going to eat 3 exchanges of carbohydrate. She calculates 9 units of insulin to cover the meal and an extra 3 units of insulin to bring the BGL back to a target of 6 mmol/l. Therefore she takes a dose of 12 units.

#### Which method ?

All of the above 3 methods of adjusting multiple daily injections can work well. There is not currently evidence that any one method gives better outcomes than another, although there are strong trends in diabetes management to use the more flexible methods that may offer benefits for lifestyle.

Often the decision comes down to the system used in your diabetes centre and your personal preference. It is important to stress that for success, all systems require attention to carbohydrate counting, good amounts of blood glucose testing and recording and thinking about adjustments.

#### **Correction doses ("fix-up" adjustments)**

Correction doses have been discussed in the context of adjustments in earlier sections, but are summarized here. A correction or "fix-up" adjustment is adjusting an insulin dose to correct a blood glucose reading that is currently higher or lower than desired. Corrections can be incorporated into most insulin plans and are more commonly part of MDI plans.

Correction involves an adjustment (increase or decrease) to rapid or short-acting insulin or an extra dose of rapid or short-acting insulin. If you need to do lots of corrections, then it usually means that the usual doses need some adjustment to prevent the problem readings in the first place. Correction adjustments are not made with long-acting insulin. The amount of correction adjustment (up or down) will vary for individuals but will usually be around 10 to 30 per cent of the rapid or short-acting insulin dose for that time. Sometimes your diabetes team may give you a formula for calculating correction doses for high BGLs which is similar to that used for insulin pumps (see also the rule of 100 in chapter 18)

When an unexpectedly high or low BGL occurs it is wise to re-check the BGL after washing the hands (if high, in case of sugar on the hands) and make sure a good size drop of blood is used so that the meter is reading accurately.

Adjustment for sick days is a type of correction and is covered in detail in chapter 10.

#### Example:

Your child is due to have their usual injection at breakfast time and the BGL is 18 mmol/l, with no ketones. If you know from previous experience that this makes the BGL high for the rest of the day, it would be reasonable to give a little extra rapid or short-acting insulin for the pre-breakfast injection.

#### Summary of insulin adjustment

Insulin adjustment is an essential part of diabetes care. Think of:

- Pattern adjustment: look for patterns that indicate a need to adjust usual insulin doses because of high or low glucose levels at certain times over a few days or longer periods. Look at this regularly.
- Day to day adjustment (Flexible daily adjustment): if you are using a flexible MDI system, think whether you need to adjust a dose or doses now or today to take into account a variation in carbohydrate intake or activity. Many people on multiple daily injections make these flexible decisions on a daily basis with their pre-meal injections.
- Corrections: think about the need for a correction adjustment, especially for correcting a BGL that is too high now.

## Insulin adjustment examples

Example 1 (pattern adjustment) Jordan, aged ten					
Current insulin doses		Morning	Afternoon tea	Bed	
	Actrapid	4 units	3 units		
	Protaphane	12 units			
	Lantus			6 units	
BGLs	Breakfast	Morning tea	Dinner	Supper	
Monday	7.5	12.0	10.5	8.3	
Tuesday	6.5	15.6	6.7	9.5	
Wednesday	8.1	13.2	4.6	7.3	
Thursday	5.8	14.1	7.4	7.9	

Below are some additional examples of adjustments as discussed above.

The blood glucose levels are generally within the desirable range except before morning tea. A one unit increase in the morning dose of Actrapid should improve the morning tea BGL.

Example 2 (pattern adjustment)		Claire, aged three		
Current insulin doses		Morning	Dinner	Bed
	NovoRapid	1 unit	1 unit	
	Levemir	5 units		3 units
BGLs	Breakfast	Morning tea	Dinner	Supper
Monday	3.6	9.0	10.5	8.3
Tuesday	5.1	11.5	6.7	9.5
Wednesday	3.0	8.6	4.6	7.3
Thursday	4.0	6.1	7.4	7.9

The blood glucose levels are generally within the desirable range except before breakfast when they are too low. A one unit decrease in the evening dose of Levemir should help the morning BGL be slightly higher and within target. Checking the BGL overnight would also be a good idea until things improve.

#### Example 3 (flexible, day to day adjustment) Adam, aged 10

Adam has a swimming carnival and is in six events during the day. He finds it hard to eat extra food when swimming a lot. His usual insulin doses are: before breakfast: NovoRapid 6 and Protaphane 16; before dinner: NovoRapid 4 with Levemir 8 units.

His mum lowers his morning dose to NovoRapid 4 with Protaphane 13 and lowers his evening dose to NovoRapid 3 with Levemir 6 to reduce the risk of a delayed hypo. She makes sure to check the BGL in the late evening also.

#### Example 4 (flexible, day to day adjustment) Louise, aged 16

Louise is having a normal day, but dinner is going to be high in carbohydrate and she is quite hungry. She is on a multiple daily injection plan with Humalog before meals and Levemir at bed. Usually she would have 8 units of insulin before dinner, but tonight decides that 10 units would be a better estimate of her insulin needs.

#### Example 5 (correction adjustment) Lok, aged 11

Lok has three injections per day. Before breakfast: Actrapid 8, Protaphane 20; before afternoon tea: Actrapid 8; and before bed: Lantus 8 units. He arrives home from school with a blood glucose level of 22 mmol/l (negative ketones). Since it is also raining and he is going to stay inside, his mother decides to give him ten units of Actrapid at afternoon tea instead of the usual 8. His mum also tries to find out if there is any reason for the high (e.g., less activity, extra or inappropriate food).

#### Example 6 (adjustment to an insulin to carbohydrate ratio) Marc, aged 13

Marc is on a flexible multiple daily injection plan – he has Lantus insulin usually 25 units before bed and uses an insulin to carbohydrate ratio for his Apidra doses before meals – 3 units of insulin per 15 g exchange of carbohydrate. He is happy with BGLs, except they always seem high at morning tea. After thinking about whether his carbohydrate estimation is accurate at breakfast, he decides to try using an insulin to carbohydrate ratio of 3.5 units per exchange for his breakfast Apidra dose.

### **Common questions and answers**



#### Why may insulin needs increase so much in puberty?

Puberty is a time of rapid growth and also hormonal changes. The body needs more insulin as it grows bigger and it is also more resistant to insulin at this time. After puberty and the growth spurt is complete, insulin doses often decrease.



## Do I always need to check with my doctor or diabetes educator before adjusting insulin?

No, only if you are not sure. Regular adjustment of insulin is a necessary part of diabetes management and you will learn to do this. After a while many families and teenagers become quite experienced in adjusting the insulin themselves and it is good to be independent. If you don't feel confident, are unsure or it just isn't making sense, contact your educator or diabetes doctor for advice. Insulin can be much more difficult to adjust in some children than in others.



#### Sometimes my child has a BGL of 18 or 20 mmol/l before bed, with no ketones. Should I give an extra dose of insulin to bring this down?

Make sure the hands are washed before any test. If the blood glucose is above 15 mmol/l, it is important to check for ketones, especially if unwell (see chapter 10, Sick days). However, if your child has not missed any insulin doses, is well and has no ketones, it is usually not wise to give extra rapid or short-acting insulin at bed time because of the risk of a hypo overnight. Often the BGL will fall by itself anyway. If you really feel that a dose is needed for a very high reading, you must check the BGL two hours later or in the late evening to make sure it has not dropped too much. (*Please note that this advice does not apply to those on insulin pumps who would need to check the operation of the pump and set and must correct the BGL without delay – see chapter 18).* 

## Chapter 13 Type 2 Diabetes

## **Key Points**

- Type 2 diabetes can occur in young people
- Important risk factors for type 2 diabetes are being overweight with an unhealthy diet and not enough exercise or generic factors
- Type 2 diabetes can often be treated with an improved healthy food plan, exercise and tablets, but insulin may also be needed

Most of this resource focuses on type 1 diabetes since most children and adolescents with diabetes have type 1 diabetes. Overall, however, type 2 diabetes is by far the most common form of diabetes in the community (80 to 90 per cent of diabetes) and predominantly affects older people. There is great concern about the global increase in the incidence of type 2 diabetes which is predominantly related to lifestyle factors. A number of factors increase the risk of developing type 2 diabetes, including being overweight or obese, family history, low physical activity and ethnic background. Obesity is the main risk factor and is related to an inactive lifestyle, being unfit and having an unhealthy diet. Unfortunately, the age of onset of type 2 diabetes is falling and we are starting to see an increase in type 2 diabetes in teenagers.

## What is type 2 diabetes?

In type 1 diabetes, the main problem is insulin deficiency, with the pancreas being unable to make insulin. In type 2 diabetes, the main problem is resistance to insulin. The pancreas is able to make insulin, often in large amounts, but the insulin is not able to work well because the cells of the body are resistant to its effects. Sometimes later in type 2 diabetes, the pancreas becomes exhausted and insulin resistance and insulin deficiency are both present.

Type 1 diabetes is often called insulin-dependent diabetes because insulin therapy is always needed. Type 2 diabetes is often called non-insulin-dependent diabetes because it can often be treated initially with a combination of weight loss, diet and exercise. Tablets and insulin treatment may also be needed.

## Why do people get type 2 diabetes?

One of the major risk factors is being overweight (obesity), which is related to lifestyle factors such as not enough exercise, eating too much and an unhealthy diet (too much sugar and fats). The people at most risk are those who have central obesity, meaning that they carry a lot of the extra weight in the tummy or abdominal region (often called 'apple shaped').

There is a genetic contribution to type 2 diabetes, which tends to run in some families. There are also some less common forms of type 2 diabetes which affect non-obese people and usually they have strong family genetic risk factors.

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It is also clear that there are certain racial and ethnic groups that have a particularly high risk of type 2 diabetes, especially if they become overweight. The highest risk groups around the world are the Pima and Canadian Indians, Polynesians, Australian Aborigines and Torres Strait Islanders. There is also a moderately increased risk in Asians, African-Americans and Mexican-Americans.

As well as seeing an increase in type 2 diabetes in teenagers, doctors are also seeing an increasing number of young people with obesity and insulin resistance which is likely to go on to the development of type 2 diabetes unless it can be controlled. This is sometimes also called the metabolic syndrome or insulin resistance syndrome or pre-type 2 diabetes. In addition to being overweight, it is also common to have a particular type of skin appearance called acanthosis nigricans. This is a dark brown, velvety marking that is most common around the back of the neck but can also occur in the underarms, groin and elbows. This skin appearance is a very strong marker of insulin resistance and risk of type 2 diabetes.



## **Diagnosis of type 2 diabetes**

Type 2 diabetes can present with the same symptoms as type 1 diabetes, including excessive thirst and urination and tiredness and even diabetic ketoacidosis. More commonly however, unlike type 1 diabetes which develops rapidly, the symptoms of type 2 diabetes usually develop gradually. Many people with type 2 diabetes have no symptoms at all and are only diagnosed after screening on a routine medical check which finds a high blood glucose level or glucose in the urine. Because of this, people with type 2 diabetes may have had the disease for many years unknowingly and can have significant complications already present at the time of diagnosis.

## **Treatment of type 2 diabetes**

Type 2 diabetes requires careful management for life and requires healthy lifestyle choices in addition to treatments prescribed by the diabetes team. Some people with type 2 diabetes can do well with dietary measures, exercise and weight loss and may not require other treatment, at least not for a number of years.

However, most will eventually require additional treatments which can include oral medications (tablets) or sometimes insulin or a combination of both. All of these aspects are discussed on page 134.

#### Change to a healthier lifestyle

This involves becoming more active, with regular exercise and changing to a healthy, balanced diet. If the person smokes, this should be ceased as it increases the risk of vascular complications.

#### Weight control

Being overweight can make it difficult to manage your diabetes. Adults who are overweight need to lose weight and this alone will help control the diabetes. In children and teenagers who are still growing, some may need to lose weight, but in some a goal may be to maintain the same weight or gain very slowly over time. Then as they grow taller, their weight will become more appropriate for their height and the balance will be restored.



#### Food plan and healthy eating

Healthy eating is important for managing type 2 diabetes, weight control, blood pressure control and managing blood cholesterol levels. The principles of the food plan for type 2 diabetes are similar to that for type 1 diabetes (see chapter 6 "Food and healthy eating") although there are some special considerations. The healthy food pyramid gives a good guide for this. People should follow a normal, healthy, balanced food plan.

#### Meals should be based on:

- A variety of vegetables, fruit and legumes (e.g., baked beans, lentils)
- High fibre breads, cereals and grain foods (e.g., pasta, rice)

#### With smaller amounts of:

- Low fat dairy foods
- Eggs, nuts, lean meats, poultry and fish
- Fats and oils

Extra foods such as high fat snacks, takeaways, chocolates, lollies and soft drinks including diet drinks should be kept to occasional treats.



The amount and composition of the food plan should be adjusted to allow the weight goals to be achieved. It is important to have guidance from a dietitian and have regular reviews of the food plan. Carbohydrate is an important part of the food plan, however there is some evidence that in type 2 diabetes a diet lower in carbohydrate and slightly higher in protein and monounsaturated fat may result in a better control and metabolic profiles. The dietitian will discuss these aspects with you.

It is generally agreed that it is important to eat regular meals and snacks containing carbohydrate throughout the day and try to have a similar intake of carbohydrate from day to day. This is particularly important for those on insulin or tablets that stimulate insulin release, so that the glucose lowering effect of these is balanced with carbohydrate intake. Those on no medications or insulin-sensitising drugs (e.g., metformin) will have less need of between-meal snacks and do not need to be as consistent in their carbohydrate intake. Different carbohydrate foods affect blood glucose levels differently – the *glycaemic index* describes this. Try to include some low GI food in each meal and snack, as low GI foods tend to keep the blood glucose levels more steady. Limit the amount of food containing sugar, but some sugar in food is a normal part of a balanced diet.

Fat should be kept low in the diet, especially saturated fats. Most of the fat intake should be monounsaturated or polyunsaturated fats. An adequate amount of fibre intake is important and soluble fibre, such as that contained in fruit, vegetables and legumes is particularly beneficial as it helps slow the after-meal rise in blood glucose levels.

Here are 8 tips for a healthier lifestyle that can be applied for all people, including those with type 2 diabetes or pre-diabetes:

- 1. Eat regular meals, which include some carbohydrate
- 2. Have breakfast each day do not skip breakfast
- 3. Pack a healthy lunch
- 4. Choose healthy snacks
- 5. Eat slowly and stop eating when satisfied
- 6. Take care with takeaways healthy choices are possible
- 7. Choose water as a drink
- 8. Be active everyday

#### Exercise

Exercise is a most important part of the management plan for type 2 diabetes. Exercise has many benefits including weight control, increasing glucose uptake by cells, helping insulin work better and general fitness and health. Your diabetes team will discuss a suitable exercise plan with you. This should focus on regular, achievable exercise goals.

It is important to do moderate exercise regularly (preferably every day or at least four times per week) rather than doing strenuous exercise occasionally. Moderate exercise is an amount which makes you puff a bit but you should still be able to carry on a conversation during the exercise. Aim for 45 to 60 minutes of moderate exercise at least four times per week. Walking is an excellent form of exercise and is best done with a friend or other family members for companionship and safety. In teenagers it is also important to put reasonable limits on sedentary activities such as television, computers and computer games since research has shown a strong relationship with these and obesity.

Those with type 2 diabetes treated with insulin or medications that stimulate insulin secretion (e.g., sulphonulureas) need to remember that hypoglycaemia is more likely with exercise. It may be necessary to reduce insulin doses (and in some cases tablet doses) on days of strenuous exercise and/or take extra carbohydrate before and during exercise as suggested in Chapter 11. Test the BGL more frequently as a guide. Your diabetes team will advise depending on the exact details of your treatment.

Those with type 2 diabetes on no medications or on insulin sensitiser drugs (e.g., metformin) do not have a risk of hypoglycemia with exercise, so no special precautions are needed.

#### Monitoring and follow-up

People with type 2 diabetes require blood glucose monitoring, regular haemoglobin A1c checks and regular follow-up by their doctor and diabetes team. This is similar to type 1 diabetes, although the frequency of monitoring and follow-up may vary, depending on the treatment required. Target BGLs are tighter than for type 1 diabetes (usually 3.5 to 6 mmol/l before meals and up to 8 mmol/l after meals) and the target for the HbA1c is less than 7%.

#### Screening for complications - blood pressure and lipids

The diabetes team will arrange for appropriate checks for various complications such as eye, kidney, nerve and feet problems. It is also very important to have regular blood pressure and blood lipid (cholesterol) checks and have treatment of these if needed.



#### **Medications for type 2 diabetes**

It is important to remember that type 1 diabetes cannot be treated with tablets and always requires insulin therapy. For type 2 diabetes there are a range of tablets that may be effective, either as single medications or in combination. However, type 2 diabetes may also require insulin. Detailed explanation is beyond the scope of this resource, but a brief summary is given here. Your doctor will advise which is most appropriate for the individual and give full information about potential benefits, side effects and other issues. The medication recommended may change with time.

There are several types of medications used for type 2 diabetes treatment. Not all are currently approved for use in young people. Combinations of some agents are used.

- 1. Medications that make the body more sensitive to insulin: Two classes of these medications are currently available:
  - metformin
  - thiazolidinediones (e.g., pioglitazone, rosiglitazone).

These aim to overcome the major problem of insulin resistance in type 2 diabetes. This class of medication (usually metformin) is often the first choice for overweight teenagers with type 2 diabetes and can be very effective in combination with the healthy lifestyle measures described above. Hypoglycaemia is most unlikely with these medications because of the way they act.

## 2. Medications to help the pancreas secrete insulin: Two classes of these medications are currently available:

- sulphonylureas (e.g., gliclazide, glibenclamide, glipizide, glimepiride, tolbtamide)
- meglitinides (e.g., repaglinide).

These help the pancreas to secrete more insulin in order to overcome the insulin resistance and relative deficiency of insulin. Some are taken once or twice a day, others before each meal. Hypoglycemia is a possibility with these medications because they are promoting insulin release.

#### 3. Medications that alter the absorption of food:

Acarbose is a medication that slows the absorption of carbohydrate foods. This can help prevent rises in blood glucose levels and is most often used in combination with other medications.

Orlistat is a medication that blocks absorption of about 30 per cent of the fat that is eaten. This does not specifically treat the diabetes but may help diabetes management in people having major problems achieving weight control.

#### 4. GLP-I analogues (e.g., Exanitide)

These are a newer class of medications that work to control blood glucose through a variety of mechanisms and are given by injection, usually twice daily. At the time of writing this edition, they have not been used very much in children or adolescents.

#### 5. Other newer agents, e.g., DPP-4 inhibitors (such as sitagliptin)

These are another newer class of medications that are taken by mouth and may be increasingly used in type 2 diabetes, but have not yet been used much in younger people.

#### 6. Insulin

As outlined above, insulin treatment may be needed in young people with type 2 diabetes, either from the time of diagnosis or at any time. It is important not to delay the use of insulin if other treatments are not able to control the diabetes well. Insulin may be used in combination with some of the other medications.

## Sick days and type 2 diabetes

Extra care is needed if you are unwell. Similar principles apply to sick days for type 1 diabetes, especially if you are being treated with insulin (see chapter 10). Here is a summary of sick day management for type 2 diabetes:

- Check the blood glucose more frequently
- Keep taking usual insulin doses and other diabetes medications
- If you take insulin, you may need extra doses during illness if BGLs are high see chapter 10
- If you take metformin tablets, these may need to be ceased if vomiting contact your doctor or diabetes team
- Keep drinking fluid to avoid dehydration glucose containing fluids if the BGL is under 8 mmol/l and glucose-free if over 8 mmol/l
- Keep eating if possible

- Contact your doctor, diabetes team or hospital if:
  - You cannot keep the BGL below 15 mmol/l or above 4 mmol/l
  - There is persistent vomiting
  - The person is getting sicker
  - You are worried and don't know what to do

## Type 1 and type 2 diabetes (combination)

Occasionally people can have combination forms of diabetes with features like both type 1 and type 2 diabetes. These people may be treated with a combination of insulin and a medication to improve insulin sensitivity, such as metformin.

### Screening for insulin resistance and type 2 diabetes

Since progression to type 2 diabetes may be prevented, it is recommended that young people with risk factors be screened. Screening with a fasting blood glucose level is recommended every two years from the age of ten if there is obesity combined with two or more of the following:

- a close family history of type 2 diabetes
- high risk racial or ethnic group
- signs of insulin resistance (e.g., acanthosis nigricans skin changes).

Major efforts are being put into programs to prevent obesity in young people and to detect the early warning signs that will lead to a high risk of type 2 diabetes. Young people who are overweight and have the acanthosis nigricans skin appearance as described earlier should always be assessed for insulin resistance and type 2 diabetes.

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## **Common questions and answers**



# My 13-year-old son is overweight and has been diagnosed with insulin resistance. Is it inevitable that he will go on to get type 2 diabetes?

No. He has the opportunity to prevent or delay this by changing to a healthy diet, exercising more and controlling his weight. This can often be difficult to achieve so you should seek the advice of your family doctor, dietitian and other health professionals as needed.



#### My 14-year-old daughter has had type I diabetes for three years. She is on large doses of insulin and our diabetes specialist has suggested adding a tablet (metformin) to her treatment. Does this mean her type of diabetes has changed?

Your daughter probably has one of the 'combination' forms of diabetes. In these, insulin treatment is essential, but insulin resistance can be a major problem which can often be helped by adding a medication like metformin that helps make the body more sensitive to insulin. This would only be done on the advice of a diabetes specialist.



# My four-year-old son has type 1 diabetes and is on three insulin injections per day. When he is an adult will he be able to be treated with tablets instead of insulin, like his grandmother?

No. Your son will always require insulin replacement because he has type 1 diabetes in which the pancreas cannot make insulin.



#### My 15-year-old daughter has type 2 diabetes like her father, and is treated with metformin tablets. Do I need to watch for any side effects?

Metformin is generally a safe medication, provided that certain precautions are taken. You will be advised about these by your diabetes team. Metformin should not be used in people with any major liver or kidney problems. If your daughter has a significant illness (e.g., one requiring admission to hospital), the metformin should be stopped and you should contact your doctor without delay. There is a risk of a serious complication called lactic acidosis if metformin is continued during major illness. Metformin also should not be taken with some other prescription medications and X-rays with iodine contrast should be avoided. Your doctor will advise on all of these issues.



My 12-year-old daughter is 10 kg over the healthy weight range for her age and I have been told she has mild type 2 diabetes. I am putting her on a strict diet with the aim of losing the 10 kg over the next three months. Is this the best approach?

Weight control is an important aspect of type 2 diabetes management and involves exercise and diet management. However, it is unrealistic and unhealthy for your daughter to lose this much weight at this time in her life. A much better approach would be for your daughter to aim at staying the same weight or lose weight only gradually. Then, as she has her growth spurt, her weight will gradually move into the healthy range for her height.



#### My father has type 2 diabetes and is treated with tablets and insulin. His BGL is usually between 4 and 10 mmol/l. Why can't we achieve BGLs like this in my son, who has type 1 diabetes?

Your father's insulin dose is supporting his pancreas in making enough insulin, a bit like a child with type 1 diabetes in the honeymoon phase. Unfortunately, BGLs can't always be controlled this well once the pancreas isn't making any insulin at all, as in type 1 diabetes. However newer insulin plans and insulin pumps are helping to make tighter BGL control more possible in type 1 diabetes.

## **Chapter 14 School and Diabetes**

# **Key Points**

- Planning ahead helps minimise any problems with diabetes at school
- Remember the hypo pack for school
- The teacher and school need to have information about diabetes and your child
- Talk to the school and make sure they have the information they need

It is normal for parents to feel anxious about sending their child to school after a diagnosis of diabetes. You want to feel that your child is in safe hands while at school. Your child may also be worried about returning to school and especially about the management of the diabetes and being different. With planning and support, the child can participate safely in all school activities and can have a productive and fun time at school. The approach required will vary considerably depending on the age of the child.

Below are some points to think about for your child at school.

## Information and education

Teachers and office staff need to receive information about diabetes, but not too much as that can cause information overload. This should include information on food, exercise, hypos and sick days and this is provided in The Schools Pack which is distributed to all schools and available through Diabetes Australia and their website (www.diabeteskidsandteens.com.au) or through your diabetes centre. Other information is available on this website for schools, including a Webcast about diabetes and students.

The Schools Pack is comprehensive and includes:

- An information flipchart
- Diabetes Emergency Information Poster
- Duty of Care Information
- Note for Parents
- Management Plan
- Medical Alert sheet
- Schools Careline Card
- Emergency Card
- Fact Sheets for Support Persons (What is type 1 diabetes?, What is hypoglycaemia?, Physical Activity and type 1 Diabetes)

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It is important for you to go to the school and make sure they have this information and run through it with your child's main teacher and other appropriate staff (e.g., sports teacher, music teacher). It is also important to advise the child's teachers that relief teachers need to know about the diabetes. Speak to your child's teachers regularly about your child's general progress and any possible concerns related to the diabetes.

It is best to assume that the teachers will not have any knowledge about diabetes, so start with a basic summary. Common misconceptions about diabetes are that children fully understand diabetes and should be totally self-caring or that activity should be restricted. It is important for the teachers to understand that these are not true.



In general, school staff do not take on the responsibility of giving insulin or glucagon injections. They are often happy to assist with or supervise blood glucose testing once it has been explained and shown to them and may assist with supervising an insulin pump. They have an important role in ensuring that the child with diabetes is eating their food and in watching for hypos and assisting with hypo treatment.

In some circumstances the diabetes educator may do a school visit to provide education for the staff. Also diabetes health professionals often run teaching seminars for school teachers and for parents preparing their children for school.

## Hypoglycaemia (hypos)

Teachers and office staff need to know how to recognise and treat hypos. Hypo food should be readily available and hypos treated where they occur, rather than needing to send the child somewhere. A child with a hypo should never be sent alone to obtain their hypo food or left alone during a hypo. If initial hypo treatment is not effective it can be repeated each 15 minutes until the child recovers. Your child or the teacher should let you know if a hypo has occurred at school.

Make sure there are hypo packs at school (e.g., with the class teacher and in the staffroom).

#### Contents of a hypo pack

- 1. Name of the child.
- 2. List of contents.
- 3. Written descriptions of hypo symptoms in your child.
- 4. Instructions for how to treat a hypo.
- 5. Fast-acting carbohydrate such as juice boxes or jelly beans.
- 6. Slow-acting carbohydrate such as muesli bars fruit bars and biscuits.
- 7. Parents' and hospital contact numbers.

In general, school staff do not take on the responsibility of giving glucagon injections (or insulin injections). In the event of a severe hypo an ambulance will be called and this will carry glucagon.

A child with diabetes should never be sent to the sick bay unsupervised and never be left alone if they are having a hypo.

## Insulin doses and glucose testing at school

It is common for children to have insulin injections at school or to be using an insulin pump. How this is managed will depend on the type of therapy and the age of the child:

- Older children and teenagers can usually take responsibility for their own blood glucose testing and insulin injections or pump bolusing.
- Some children will require provision of a place where they can keep their testing meter and insulin pen and go for an injection.
- Younger children will need supervision with blood glucose testing and insulin injection or bolusing with a pump. School staff usually do not directly do these tasks, but are usually happy to assist or supervise with these provided that they have been appropriately briefed.
- Sometimes school staff will agree to do blood glucose testing or give injections or boluses; this requires negotiation and appropriate education and training.
- The level of assistance needed will vary and this can be negotiated with the teacher and school, with the assistance of your diabetes educator or Diabetes Australia if needed.

Add your child's photograph to the poster which is provided in The Schools Pack. This is for the school staff room and contains information on hypo symptoms and treatment . You may wish to modify this if it does not match your child's symptoms of a hypo.

## Identification

The child should always wear a medical identity necklace or bracelet, stating they have diabetes. Children may also need identification for the school bus indicating that they may need to eat on the bus.



Examples of diabetes alert wrist-bands

## Food

In younger children the teacher may need to ensure that all of the meals are eaten on time and that food is not given to, or obtained from, other children. Meals and snack times should be at the same times as other children. Occasionally an additional snack may be necessary just before going into school in the morning. With planning, your child can order lunch from the school canteen. Parents need to be informed if there is going to be a change in meal times at school for a special event.

## Exercise

Any moderate or strenuous exercise is likely to need extra carbohydrate unless you have planned with your child to reduce insulin doses (see chapter 11, Exercise and Sports). Your child will still be able to join in special events such as parties, swimming carnivals, sports days and excursions but you need to know about these events in advance so that you can plan ahead.

## Letting others know

Encourage your child to let the teacher know if they are feeling unwell or having a hypo. In general, it is best that classmates know about the diabetes, but some children prefer to have only a few friends know. This will vary between individuals and with the age of the child. Friends with some knowledge about diabetes can be excellent 'buddies' and help out with hypos and so on.

If your child requires injections or blood tests at school they may wish to do this in privacy and the school should help make arrangements for this. In general, school staff are unable to take on the responsibility for performing blood tests or giving insulin doses at school but are usually happy to supervise these if they are appropriately briefed. Careful negotiation with the school will usually result in them being very helpful. Bear in mind, that it usually works best to give the school a small amount of essential information rather than over-loading them with instructions and less relevant details.



## **Participation**

The child with diabetes should be allowed to participate fully in all activities (e.g., sports, excursions, sports days, carnivals and camps). Some of these will require special liaison and preparation by parents. The diabetes educator will help with special advice, depending on the circumstances. Staff involved in these activities should know about the child's special needs.

## **Behaviour and discipline**

The child with diabetes should be treated the same as other children, as much as possible. The child should be disciplined in the normal way; however, they should never be detained at mealtime or after school. You need to be informed if your child is going to be late home.

If they need extra snacks, to test blood glucose, to take insulin or have extra trips to the toilet, they need to be allowed the time. However, avoid drawing unnecessary attention to their condition.

# Blood glucose levels and effects on learning and examinations

Teachers should be aware that when a child has low blood glucose levels, or after low blood glucose levels, concentration, behaviour and school performance may be affected. Tiredness, irritability and lack of concentration can occur with either high or low blood glucose levels. Fortunately these problems are usually minor and occasional.

Special provisions are available for children sitting external examinations. Forms supplied by the school should be filled in well in advance. Provisions are made for blood glucose testing during exams and extra time for testing, hypo treatment and recovery if necessary. If diabetes causes major problems during an examination, students can apply for consideration under the Misadventure and Illness provisions.

## High blood glucose levels

If blood glucose levels are high, extra trips to the toilet to pass urine are often needed and the child should also be allowed to drink as much water as they like. The school should inform you if high blood glucose levels, excess urination or thirst persists.

## Sick days or emergencies

If your child becomes sick at school, you should be contacted. If you are not contactable, then the child's diabetes team should be contacted for advice.

For any emergency situations (e.g., unconsciousness, convulsions), the teachers should know how to lie the child in the coma position and call the ambulance and tell them that it is a child with a diabetic emergency. These measures are detailed in chapter 8 and in the Schools Pack.

## Associated video resources for this chapter

#### Loco parentis - Managing diabetes at primary school

ERC Media, Educational Resource Centre, Royal Children's Hospital, Melbourne, 2004.

In this video, parents, students, teachers and health professionals share their insights and tips for successful diabetes management at primary school and pose new questions about where the teaching profession is heading in terms of taking on additional responsibility for the medical needs of students.

#### View via the link at www.kidsdiabetes.org.au

#### Loco parentis - Managing diabetes at secondary school

ERC Media, Educational Resource Centre, Royal Children's Hospital, Melbourne, 2004.

This video discsuses similar issues, but in the secondary or high school environment.

#### View via the link at www.kidsdiabetes.org.au

## **Common questions and answers**



#### My son is reluctant to tell other children that he has diabetes. How should we approach this?

Children vary in this. Some children don't mind everyone knowing, but some prefer only a few close friends to know. It is good if your child can have a few close buddies who know he has diabetes and a little bit about hypos, so that they can tell an adult if there is a problem.



#### My child will be starting school soon. How do I go about making sure the teacher knows what to do about the diabetes?

Planning ahead is important. Visit the school and discuss with the teacher or head teacher. The school needs to have written information about diabetes (provided in the Schools Pack which they should have or you can provide them with), and you also need to tell them the particular details about your child's routine. Arrange for hypo packs to be at the school, arrange a poster for the staff room and make sure the school knows how to contact you. Usually this is enough, but if there are particular concerns, contact your educator who may be able to arrange a visit to the school for education.



# My eight-year-old daughter has her breakfast at 7.30am and recess is not until 11 am. She is having quite a few hypos just before recess. How can we deal with this?

More than three hours may be too long without a snack for young children on some insulin patterns. Options are to reduce the morning short-acting insulin or to have an extra carbohydrate snack just before going in to class at 9 to 9.30 am. It is best not to have to have extra snacks during class as this may make your child feel different.



#### My nine-year-old son is starting to come home with half of his lunch left in his bag, and has had low blood glucose levels some afternoons. What should I do?

Talk to your son about why this is happening. Sometimes a simple change of food choices may work – variety is important as is food that is easy to eat. Perhaps let him order lunch from the canteen some days for a change. Sometimes they are too eager to start playing and 'don't have time' to eat their lunch. You may need to visit the teacher and check that lunch is supervised, and reinforce how important it is that he eats all his lunch.



#### I worry about what will happen if my child has a severe hypo at school. The teachers say they are not able to give glucagon. Is this a problem?

Teachers are generally unable to take on the responsibility of giving injections. The school will know to call an ambulance in the event of a severe hypo and ambulance officers will give glucagon or a glucose injection.

## Chapter 15 Different age groups and diabetes

# **Key Points**

- Diabetes affects children differently throughout the age groups
- Different issues arise at different ages

## **Toddlers and preschoolers**

Preschool children are imaginative thinkers and are in what is called the trust stage and fantasy stage. During this stage parents look after all aspects of the diabetes, but a gradual increase in participation in diabetes routines is encouraged. It may be helpful to play games around the diabetes procedures, gradually letting the child help (e.g., fingerpricks, choosing the injection or infusion site, pressing the plunger during injection). Letting them practise on their dolls or teddy bears is very helpful.

Young children often have difficulty recognising hypos, but there is a gradual increasing recognition of hypo symptoms which should be encouraged by discussion about feelings at the times of hypos. Hypos are more risky during this age because the toddler is unlikely to recognise or be able to treat them and therefore the child requires constant supervision by a responsible person.

Children may have some understanding of foods they can eat, but apart from giving simple choices control needs to be taken by the parents or carers. Young children have little concept of time and their routines need to be controlled. Even toddlers and young children should have a pattern of fairly regular meals and snacks and the pattern of 3 main meals and 2 or 3 snacks per day works



well. The family should all sit together at mealtimes with minimal distraction (e.g., turn off television) and try to make meal times a positive social interaction. This often encourages better participation and eating from children.

During this time the aim is to keep blood glucose levels in the target ranges discussed earlier, however numerous factors can lead to unstable blood sugar levels (e.g., teething, immunisations, variable appetite, activity and sleeping patterns and minor childhood illnesses). Blood glucose levels are usually much more variable at this age and targets may need to be individualized.

Increasing numbers of children are going onto insulin pump therapy, including in this young age group (see chapter 18). Parents often find that an insulin pump helps reduce some of the variability at this age and allows them to cope better with the variable eating and other factors at this age. Pumps can be locked so that young children cannot activate the settings. Infusion sets are more usually placed on the buttocks, although interference with the set seems very infrequent since children gain an early understanding of the importance of their diabetes therapy.

## School-age children (6 to 11 years)

Children of this age are concrete thinkers, curious and sociable. They have also become more objective and are increasingly responsible. Participation in diabetes care increases; however, supervision is still generally required with all aspects of diabetes management. Children of this age are acquiring the necessary fine and gross motor skills but lack the maturity and knowledge to take on the full responsibility. They need to be carefully supervised in their diabetes care and adults need to make sure that insulin doses are accurate and are all given, whether by injection or insulin pump.

During this age range children usually start doing their own fingerpricks, often from quite a young age. Many will wish to start trying some of their own injections from around nine to ten years or sometimes earlier, although they should not be forced if they are reluctant. Using pens is fairly straightforward, but the ability to accurately draw up the insulin with a syringe may take longer to develop; this is usually possible by around 10 to 11 years. Children gradually become more aware of time and can learn to take greater responsibility for eating food at a set time. Knowledge about food increases rapidly. This age group is usually able to recognise hypos and seek treatment.

For children of this age on a pump, they will actively participate in set changes and some may do this by themselves, with supervision. Often from 9-10 years of age, children will also estimate their meal boluses and operate the pump themselves, although supervision is still needed.

Additional factors that can affect blood glucose control include peer influence, mood, growth, variation in food intake, sports, parties, childhood illnesses and variable routines at school.



## **Adolescents**

Adolescence is a time of major physical and psychological change and increasing independence. However, behaviour and degree of responsibility vary enormously during this period. Body image is very important and peer pressure can lead to denial, self-neglect and risk-taking behaviour.

Adolescents should be increasingly taking over responsibility for their diabetes care but continue to need help and supervision. Often during early adolescence, further education is required, directed primarily at the adolescent, rather than at the parents. Additional education about things such as alcohol, puberty, sexuality, drugs, smoking and complications is necessary. Adolescents should increasingly recognise the importance of good blood glucose control to prevent complications and should be more willing to have multiple injections. Pumps are also very suited to adolescents and they are often capable of quite independent operation of the pump, although teamwork with the family and general supervision are still always advised.

If the diabetes was diagnosed at a young age, often the initial education was mainly directed to the parents. It is important to have some formal education directed to the adolescent at this time so they are equipped with the information to move gradually towards increasing self-care and independence.

#### Adherence and general management issues

Some adolescents begin to resent routines. Also, poor or variable cooperation with food, insulin injections or pump boluses and testing can become a problem. Unfortunately it is common to see adolescents doing little or no glucose testing and becoming variable in their routines. Faking or fudging of blood glucose levels is not uncommon as the adolescent tries to 'satisfy' their parents and health professionals by having some reasonable readings in their book. Usually this is temporary and is discovered when the blood glucose meter is downloaded or the HbA1c is out of keeping with the recorded blood glucose readings. It can be a difficult time for families as questions over trust and honesty arise.

Insulin omission (forgetting or deliberate) is also reasonably common at this age. With insulin pumps, it is often the food boluses that are missed, particularly at school. Insulin omission is obviously quite serious as it leads to poor control and risk of serious illness with diabetic ketoacidosis.

Remember that poor adherence to diabetes management is not always directly linked to diabetes issues. Sometimes children and adolescents may be angry or sad with other areas in their life, such as, poor body image, lacking school performance, conflict with significant relationships and low self esteem. Additionally some children and adolescents may manipulate insulin doses and other routines in an attempt to control weight. This is not the right way to achieve weight loss and can cause more problems with the diabetes.

Parents and adolescents need to continue working as a team with the diabetes through the teenage years. This is strongly encouraged, although a more subtle, hands-off approach is needed than in childhood. Studies have shown that handing over total control too early and lack of involvement with diabetes by parents in the teenage years is associated with poorer control and other difficulties, including 'burnout' in adolescents. Clearly the degree of involvement will be differently negotiated for different families. Compromise is needed on many issues at this age, including diabetes. Keeping lines of communication open between parents and teenagers is important. The diabetes team will work to support and guide teenagers and their families and may tend to be listened to more than "nagging parents". Even though negotiation and reasoning is important, if dangerous practices such as insulin omission, poor insulin dose decisions or insufficient BGL testing are occurring at any age, parents or caregivers need to take control and directly supervise and monitor all aspects of diabetes care. Sometimes it is even necessary to take over some of the diabetes procedures, just as at the time of diagnosis. Your diabetes team will provide support as best possible, but they cannot take over the parental role.

These certainly can be difficult years for diabetes management and control may not be optimal. However, there is light at the end of the tunnel and with greater maturity in later adolescence there will hopefully be improved motivation, interest and cooperation with the diabetes management. Remember also that many young people with diabetes sail through the teenage years with no major problems.

#### Transition to independent adult care and adult diabetes services

This process is usually started in the clinic when your teenager starts seeing the doctor or other health professionals without a parent. By late adolescence, it is necessary for the person to have gained independence and confidence in looking after their diabetes. In late adolescence (usually between 16 and 18 years), it will be necessary and appropriate to move from a children and adolescent diabetes service to an adult service. It is important that this step be well planned and successfully made.

Your diabetes team will advise and assist at the appropriate time and discuss the various options in your locality.

#### **Appropriate career options**

Some professions (such as the defence forces, commercial pilot, police, fire brigade) are not usually open to people with diabetes and they need to know this when considering career options. Organisations such as Diabetes Australia and JDRF can assist with further current information.

#### **Growth and puberty**

The growth spurt and changes of puberty result in much higher insulin requirements and it is important to try to keep up with this by appropriate monitoring and insulin adjustment. The insulin treatment plan may change over time, with a different pattern of insulin injections or use of an insulin pump. Adolescent girls may have higher and more variable blood glucose levels around the time of the menstrual period, but appropriate monitoring will guide the necessary insulin adjustments.

#### Weight issues

It is often during adolescence that concerns arise about excessive weight gain, especially in girls but also in boys. Teenagers are very conscious of body image and this is contributed to by peer influences and the media. Sometimes teenagers will manipulate their insulin doses in an attempt to avoid weight gain or lose weight. This is a poor strategy which usually fails and leads to poor diabetes control and long-term weight gain. Your diabetes team are aware that this is a very important issue at this age and want to work with young people to avoid this.



The diabetes team try to take a preventative approach and it is important that there is not an overt focus on diet or weight as this can worsen the problem. Growth will be monitored and if concerns occur with weight there are a number of effective strategies. These include additional advice about the food plan, changes to types and patterns of insulin and increasing exercise.

From time to time teenagers, more commonly girls, start to restrict the amount of food they eat because of concerns about body image and weight. Any such concerns should be discussed with the diabetes team who will reinforce concepts of healthy, sensible eating and normal body image. Additional help will be sought if needed, but hopefully the situation can be contained before it becomes more serious.



#### Smoking

Smoking needs to be actively discouraged from an early age. Smoking is a health risk to all people, but particularly to those with diabetes because of the increased risk of diabetes complications, particularly vascular disease. Children and adolescents are more likely to take up smoking if adults in their home smoke.

#### Drugs

Illicit drugs or unprescribed drugs are damaging to the health of all adolescents, but represent an added danger in those with diabetes through their effects on conscious level, insight and judgment, appetite and body metabolism.

Mind-altering drugs make it difficult for people to recognise hypoglycemia and to have correct judgment about treating hypos, food and insulin doses. Some drugs increase appetite, causing high blood glucose levels.

#### Alcohol

Alcohol can be dangerous and unhealthy for adolescents. For people with diabetes there are additional problems with alcohol. Delayed hypoglycaemia is a risk because alcohol blocks glucose production by the liver. Impairment of the senses by a combination of alcohol and hypoglycaemia is very dangerous. Alcohol can also contribute to excess weight gain and increased blood lipid levels.

Discussion about alcohol will be included at an appropriate time in diabetes education. Alcohol intake cannot be condoned below the legal age limit; however, it is recognised that teenagers will often experiment with alcohol at an earlier age. Young adults who choose to have alcohol should be advised how to do this responsibly and minimise risks:

• Drink in moderation only; one to two drinks maximum at any session and avoid drinking daily.

- Select beer or dry wines in preference to other things. Low alcohol beer is a preferable option. Avoid sweet wines, fortified wines, spirits and liqueurs.
- Always eat some carbohydrate before drinking and continue to have a regular carbohydrate intake during the period of drinking and afterwards.
- Blood glucose levels should be checked regularly, especially before going to bed and overnight if concerned. Ensure a level above 6 mmol/l before bed and if below this or borderline, eat extra carbohydrate. A reduction in overnight insulin is often appropriate to avoid overnight hypos after drinking alcohol.
- Arrange for a responsible person to wake the person the next morning at an appropriate time, to see that all is well.

#### Contraception

This is an important general issue in adolescence and will be discussed by the healthcare team at an appropriate time. If contraception is required, condoms are recommended for both contraception and protection against sexually transmitted diseases. Intra-uterine devices are not recommended for young women with diabetes. The oral contraceptive pill can be used by young women with diabetes without significant extra risk, unless there are certain complications such as high blood pressure, lipid abnormalities, vascular disease or blood clotting disorders. Unplanned pregnancies in women with diabetes pose major extra risks to their own health and the health of their baby.

These comments are of a general nature only and if contraception is required, the issues should be discussed in detail with your GP, diabetes doctor or educator.

#### Driving

Unpredictable or severe hypoglycaemia is the main hazard to driving however the authorities also need to know that there is adequate general diabetes care and that there are not serious complications that would make driving hazardous. On applying for a learner's permit, forms will be issued to take to the doctor for a medical report and medical examination. The wish to obtain a licence will sometimes be an incentive for adolescents to improve aspects of their diabetes care. Doctor's have a legal obligation to recommend against the granting of a licence if the requirements are not being met. A report from the diabetes doctor is usually needed every two years for a standard licence renewal.

With a responsible attitude, driving is generally safe. The blood glucose level should be checked immediately before driving and food for treating hypoglycaemia must be available in the vehicle.

#### **Diabetes alert identification**

All people with diabetes should wear a bracelet or necklace indicating that they have diabetes. A variety of alternatives is available so an acceptable style can usually be found. At the very least, a card should be carried in the wallet or purse indicating that the person has diabetes. Teenagers often need to be reminded about this.

#### Ear piercing, body piercing and tattooing

These are choices for individuals and their families to make. Skin infections and infection of piercing sites are much more common if BGLs are high and diabetes is in poor control. Aim to have good BGLs before considering this and have it done by professionals only. See your doctor or diabetes team if you have questions before or after.

### Associated video resources for this chapter

#### Here we go 'round the Mulberry bush – Positive parenting of toddlers with diabetes

ERC Media, Educational Resource Centre, Royal Children's Hospital, Melbourne, 2002.

This video focuses less on the physiological aspects of the condition and more on the issues of coping day to day with a toddler with diabetes. It is recommended viewing for parents, families and friends of young children who have been recently diagnosed.

#### View via the link at www.kidsdiabetes.org.au

#### Loco parentis - Managing diabetes at primary school

ERC Media, Educational Resource Centre, Royal Children's Hospital, Melbourne, 2004.

In this video, parents, students, teachers and health professionals share their insights and tips for successful diabetes management at primary school and pose new questions about where the teaching profession is heading in terms of taking on additional responsibility for the medical needs of students.

#### View via the link at www.kidsdiabetes.org.au

#### Loco parentis - Managing diabetes at secondary school

ERC Media, Educational Resource Centre, Royal Children's Hospital, Melbourne, 2004.

This video discsuses similar issues, but in the secondary or high school environment.

#### View via the link at www.kidsdiabetes.org.au

#### GYST - a life guide for young people on the move

ERC Media, Educational Resource Centre, Royal Children's Hospital, Melbourne, 2006.

GYST' is a fresh, new holistic approach to the complex process of transition. It's a comprehensive 'life guide' covering all the most important aspects of getting set up in adult life with specific information for young people living with diabetes. It is packed full of valuable information that every young person needs to know.

#### www.gyst.org.au

## **Common questions and answers**



#### My two-year-old's blood glucose levels seem to vary a lot. I think this is because some days he eats really well and other days just doesn't seem interested in food. What can we do?

This is common at this age and blood glucose levels do vary more. Offer simple choices if not eating well, or carbohydrate-containing fluids. Avoid the temptation to offer treats instead of healthy choices – give simple choices of acceptable foods e.g., Would you like yoghurt or banana? Sometimes if your child goes through a phase of less appetite, lowering the insulin dose may be necessary – discuss with your diabetes team. Insulin pumps may be helpful in smoothing control in such situations.



## My eight-year-old is not showing any interest in giving her own injections. How should I encourage this?

Proceed gently. Children vary in the age that they feel ready to start doing injections or inserting pump sets. Usually they will do their own fingerpricks earlier, but many don't start giving injections or pump related procedures until nine or ten or sometimes later. It is important they are involved in diabetes routines from early on, even if it is just helping with some part of a procedure. Gradually, involvement in practical procedures can be increased and they start to take more direct responsibility, with continued supervision. Accurate drawing up of insulin or use of an insulin pen may take a little longer in some cases and needs to be closely supervised.



#### I was shocked when our educator said that our 14 year-old son was writing down fake blood glucose readings in his record book. He has always been so reliable. Where have we gone wrong?

You haven't gone wrong. Having diabetes can be particularly difficult in adolescence. Attention to the diabetes may wane and it is more difficult to supervise. Adolescents are striving for independence but are not quite ready for it, especially as far as the diabetes is concerned. Sometimes false readings are written down to try to please parents or stop them from worrying. Try to establish some agreement with your son about how you may cooperate to help with the diabetes. Sometimes the diabetes team can help negotiate this, since teenagers will often listen more to them than 'nagging parents'. Hang in there – things will improve!



# At what age should my teenager start seeing the diabetes team by himself?

There are no definite rules for this and it is a question of when individuals feel comfortable about it. It is usually harder for the parent! Usually in the early to mid teenage years the diabetes team will start to recommend seeing the young person by themselves first as this is important in the transition to independent adult living. The parent or parents are usually seen with the teenager afterwards and relevant issues discussed.



#### I don't want to encourage my daughter to drink alcohol but if she does, I want her to do it safely. How can I approach this?

These types of dilemmas are faced by all parents of teenagers. The diabetes team will usually raise the issue of alcohol at an appropriate time, since many teenagers will experiment with it. While not encouraging alcohol, it will usually be explained that adults can have alcohol in moderation in a safe manner by following certain rules. Then, if or when the teenager does try alcohol they have some information about how to do it with minimal risk. It is important to discuss the issue of alcohol in education.

## Chapter 16 Follow-up visits and long-term management

## **Key Points**

- Your child needs review by your diabetes team approximately every three months, or sometimes more often
- A diet and education review should occur each year, or more often if needed
- A haemoglobin A1c test should be performed approximately every three months to assess overall control
- Maintaining good long-term control will minimise the problems and complications that diabetes may cause
- Transition to adult services needs to be planned at the appropriate time

The first phase of your diabetes education aims to give you the basics about caring for diabetes at home. Sometimes this will occur during a stay in hospital of several days or may be done as part of a day care program where you spend the nights at home and return to the hospital each day for the first few days.

Moving on from this first phase can feel like a big step and will naturally cause some anxiety. However you will get plenty of support and guidance from the diabetes team, especially in the early stages. Your diabetes team is always willing to help, but it is important that you actively seek help from the team when you are concerned or have questions. Otherwise the team may assume that "all is well".

## Moving on from the first phase

Your diabetes team will assist you in all of these important steps that will prepare you for looking after diabetes at home.

- **1. The first phase of education will be completed:** The aim over the first few days is to give you your child and family the basic education about diabetes management. There is a lot to learn and it is impossible to do this all at once. The diabetes team will put a plan in place for further education sessions.
- **2. Diabetes supplies obtained:** You will need a range of supplies for diabetes management. Your diabetes team will advise about any different options and where to obtain them. The main requirements are:
  - blood glucose meter
  - blood glucose strips
  - finger pricker and lancets
  - ketone test strips for urine or blood (some meters)
  - diabetes record book
  - insulin and insulin prescriptions

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- syringes and/or insulin pens (those with pens need syringes also in case of pen malfunction and for possible use of mini-dose glucagon)
- glucagon (GlucaGen hypokit)
- medical alert bracelet or necklace
- sharps container
- Insulin and glucagon require a prescription your diabetes doctor or family doctor will supply these when needed.
- Supplies for insulin pump therapy, for those using insulin pumps
- 3. Arrange to join the **National Diabetic Services Scheme** (NDSS) which allows people with diabetes to obtain supplies at concessional prices through NDSS approved pharmacies Diabetes Australia or their Diabetes Centre. The diabetes team will provide you with a form for this. Supplies such as syringes, needles, testing strips and lancets are obtained at concessional prices.
- 4. Obtain information about joining local **diabetes organisations** such as Diabetes Australia and Juvenile Diabetes Research Foundation.
- 5. **Insulin doses:** You will be advised of the doses of insulin to have at home by the diabetes team and when to phone to get further advice about doses. Insulin doses are likely to change rapidly in the first few weeks and frequent advice from the educator or doctor is usually required to adjust doses.
- 6. **Contact numbers:** Phone, fax and e-mail are all useful ways to communicate with the diabetes team. The diabetes team will supply these.
- 7. Follow-up arrangements:

**Telephone follow-up:** Usually there will be fairly close follow-up by telephone. This gradually decreases as time goes on, insulin changes become less frequent and you feel more confident about the home management of diabetes. Remember that if you are concerned, diabetes advice is available at all times from your hospital or diabetes centre.



**Finishing education:** During the first few weeks, appointments will be made for you to return to the diabetes centre for more education checks on progress and adjustment of diabetes management. You will have frequent contact with the diabetes team in these early weeks. It is particularly important for the food plan and insulin doses to be reviewed and adjusted if needed during these early days.

## Long-term follow-up

#### **Regular visits**

Regular follow-up visits are important for diabetes. You will get to know your diabetes team well and children will often look forward to visits to the team that they know so well. After the more frequent visits near diagnosis, routine follow-up for most children is three to four times per year. At clinic visits, the diabetes doctor will discuss any questions or concerns you have, look at blood glucose and other records, examine your child and discuss any adjustments or other management that may be needed. You will also see other members of the diabetes team as needed at these visits (diabetes educator, dietitian or social worker/psychologist), but not necessarily at every visit.

A HbA1c should be performed at each clinic visit (three to four times per year).

#### **Annual review**

Usually once per year there will be a more major review paying particular attention to growth, development and puberty, blood pressure, nutrition and checking for any other problems or complications. Once each year it is also recommended that there be a full review session with the diabetes educator and dietitian. Visits may need to be more often for children under five or where there are special concerns about the diabetes.

Most diabetes centres also recommend an additional blood test once every year or two to check that there are no problems developing, such as thyroid problems, coeliac disease or high cholesterol. Alternatively these tests may be included as part of diabetes complications screening. Your diabetes team will explain this to you.

#### **Complications screening**

After five years of diabetes in younger children or two years in older children and teenagers, it is usually recommended to start screening for diabetes complications. Again, your diabetes team will advise about how this is done and more details are given in chapter 19 'Complications'.

#### **Recommended minimum follow-up for diabetes:**

- Visits to your child's diabetes doctor and team three to four times each year. More frequent visits will be required just after diagnosis and later if there are concerns about progress.
- Diet and education review yearly with interim advice as needed.
- Haemoglobin A1c test performed three to four times each year.

## Diabetes outreach and shared care

Children living in or near the major cities usually see a children's diabetes specialist for regular review 3 or 4 times per year, as well as other members of the diabetes team as needed. Country children will usually see their local paediatrician or physician for routine review. Also, diabetes specialists from one of the major children's hospitals may visit regional areas and can see you and your child for a consultation if needed. For regional families, the aim is for your child to have expert local care as well as periodic review by specialists from the children's hospitals if needed. These arrangements work through the close cooperation of the diabetes teams from country areas and children's hospitals.

### Other diabetes supports: workshops, seminars and

#### diabetes camps

In addition to the support and education you have from your diabetes team, there are other avenues for learning about diabetes, updating knowledge and sharing experiences.

Hospitals or diabetes organisations will often run workshops, seminars or other education programs. Sometimes these will cover a wide range of topics but sometimes are more specific (e.g., toddlers diabetes support group, seminar for teachers, education session for grandparents and other carers). Details of these are available through your diabetes centre and organisations such as Diabetes Australia and Juvenile Diabetes Research Foundation.

Diabetes camps are also a great way of learning more and helping your child to adapt to diabetes in a fun environment. For younger children, parent and child camps are available in some states and older children and teenagers attend camps by themselves. More information on camps is in chapter 17.

### Goals for long-term management and control

The overall goals of diabetes management are to have:

- normal growth and development
- good social and psychological adjustment
- full participation in school and other activities
- healthy eating patterns
- blood glucose levels in the target range as much as possible
- minimal hypoglycaemia or no serious hypoglycaemia
- long-term metabolic control as good as possible as measured by haemoglobin A1c
- reduced risk of long-term complications.

## What does the haemoglobin A1c (HbA1c) tell you?

The HbA1c gives a measure of overall blood glucose control over the last two to three months. While blood glucose tests give important information about daily variations in blood glucose levels, the HbA1c gives important information about long-term control.

The HbA1c level should be measured approximately every three months when you visit your doctor or diabetes centre.

As red blood cells move around in the bloodstream, the haemoglobin they contain picks up glucose. The amount of glucose picked up depends on how much glucose there is in the bloodstream. If the average blood glucose levels are high over a two to three month period, lots of glucose will stick to the haemoglobin and the HbA1c will be high. If blood glucose levels are mostly within the target range the HbA1c will be in the desirable range. If blood glucose levels are swinging from high to low, the HbA1c may be reasonable, but this is not a good balance. The HbA1c is a little more influenced by recent readings than earlier readings in the two to three month period.

Daily blood glucose levels and regular HbA1c measurements (approximately every three months) are important in monitoring diabetes control. Diabetes control is judged by both the HbA1c and the blood glucose levels.

## **Recommended control targets**

The closer the HbA1c is to the non-diabetic range the better, provided that there is not too much hypoglycaemia. Below are realistic recommendations for target blood glucose levels and HbA1c.

Recommended ranges for blood glucose levels and HbA1c in type 1 diabetes	
Blood glucose range*	HbA1c*
<ul> <li>Target ranges for blood glucose levels are generally</li> <li>o Before meals 4 to 7 mmol/l</li> <li>o After meals 5 to 10 mmol/l</li> <li>o at bed time 6 to 10 mmol/l</li> <li>o at 3am 5 to 8 mmol/l</li> </ul>	Less than 7.5% (all ages)
*Individualized targets may need to be set for some individuals	

People without diabetes have an HbA1c of 4 to 6 per cent but people with diabetes usually experience too much hypoglycaemia if their HbA1c is maintained in this range. Therefore, the HbA1c with diabetes runs higher than the non-diabetic range. The HbA1c can come into the non-diabetic range in the 'honeymoon phase' following diagnosis, but later is likely to run a little higher.

People often feel frustrated when they can't get all of the blood glucose levels in the target range. This is rarely possible. The aim is to get the majority of readings within or close to the target range, but realistically often only 60 to 80 per cent of readings will be in the target range.

While the above glucose and HbA1c targets are desirable, they will not be possible for some children at certain times. The aim, however, is always to be moving towards the targets – any degree of improvement of control is beneficial.

## Relationship between blood glucose levels and

## HbA1c

The HbA1c is not an average of blood glucose levels. However, there is a good relationship between average blood glucose levels and HbA1c which is approximately as follows:

HbA1c	Estimated average BGL (mmol/l) over last 8-12 weeks
6%	7.0
6.5%	7.8
7%	8.6
7.5%	9.4
8%	10.1
8.5%	10.9
9%	11.8
9.5%	12.6
10%	13.4

It is evident from this table that to have a HbA1c in the recommended target range of under 7.5%, average BGLs need to be under 9.5 mmol/l.

## **Problems with control**

The following are signs that there are problems with diabetes control and that a review of management is needed. Refer to chapter 7 'Monitoring diabetes control' for an approach to unstable blood glucose levels. If the solution is not clear, your diabetes educator or doctor should be contacted for further advice.

#### Signs indicating problems with diabetes control

- 1. Blood glucose levels are often falling outside the recommended range.
- 2. More than 3 or 4 mild hypos per week especially if the reason is unclear.
- 3. Hypoglycaemia unawareness; that is the child is not aware of hypos they are only noted on testing or by others.
- 4. Any episode of severe hypoglycaemia (e.g., fits or unconsciousness).
- 5. HbA1c above the recommended range or rising over the last two measurements.

The nature of diabetes is such that there will be periods when blood glucose levels will be stable and other more difficult periods when they fluctuate (see the section on blood glucose levels in chapter 7). Sometimes, despite everything you do, there will be ups and downs that cannot be explained. This can be frustrating, but usually improves with time.

## Insulin omission and other control problems

Diabetes is a challenging condition for young people, their families and health care advisors. It has a unique set of attributes:

- It is a long-term condition with no cure yet possible.
- It requires time-consuming and complicated management from day to day.
- It makes young people feel different from their peers.
- It reduces lifestyle flexibility.
- Problems can develop rapidly if there are management problems (e.g., severe hypoglycaemia or diabetic ketoacidosis).
- There is a risk of long-term complications which cannot be predicted for individuals but is greater if control is not optimal.

It is not surprising that some young people at times find this condition overwhelmingly difficult and become unable or unwilling to adhere to management recommendations, even though they are aware that this is not in the best interest of their health. It is important that young people, their families and health care advisers are aware of the difficulties that can sometimes arise, so they can help get through these times. These problems are more commonly encountered in teenagers who are starting to be more independent, but elements of them are also seen in younger children. The psychological aspects of diabetes in children and adolescents require much more research and understanding.

#### Problems that may be encountered are:

- insulin omission (forgetting or missing doses)
- problems with blood glucose monitoring
- problems with food
- diabetes 'burnout'

#### Insulin omission (forgetting or missing doses)

Omission or missing of some doses of insulin is common in teenagers or younger children who are taking responsibility for some or all of their own doses. It is a major contributor to poor diabetes control and a common factor in teenagers admitted with diabetic ketoacidosis. Sometimes this is due to being forgetful or over-busy or distracted. It can be a problem with either insulin injections or insulin pump therapy. The injections or boluses most commonly omitted are those at school. Sometimes the omission is deliberate. Reasons for this may be misguided attempts to control weight, not wanting to appear different at school or psychological disturbance and attention-seeking.



If insulin omission is a problem, the diabetes team will explore the possible contributing factors in order to change the pattern. Re-education or counselling may help. Sometimes multiple injection routines are changed back to simpler routines if it is felt that acceptance will be improved. Sometimes pump users take a break from the pump and return to an injection plan for a time. Frequently, the diabetes team will ask parents to work much more closely with the young person with diabetes and supervise and assist with all aspects of diabetes management until the situation can be turned around.

#### **Problems with blood glucose monitoring**

After many years of blood glucose monitoring, teenagers will sometimes lose motivation and do less or no monitoring. Clearly, this makes diabetes management difficult and contributes to poor control. There may be a tendency to write down false readings in the record book so as to satisfy parents and the diabetes team, but this will be uncovered when the meter is downloaded or the haemoglobin A1c is found to be high. Unfortunately, non-invasive blood glucose monitors are not yet a reality and good diabetes management requires frequent BGL readings. Continuous glucose monitoring is likely to be used increasingly, but still requires significant user input.

Helpful strategies can include compromise on the number and timing of BGLs, re-education and counselling, ensuring that a modern, rapid blood glucose meter is available and teamwork with parents or other family members.

#### **Problems with food**

Problems with the diabetes healthy food plan are common and a major contributor to difficulties with diabetes control. Common problems are overeating, excessive treats and snacks and irregular timing of meals and snacks. Food binges may occur and there is an increased tendency to eating disorders in diabetes, such as anorexia nervosa or bulimia. Weight is often a concern in teenage girls and there is sometimes manipulation of food and insulin in an effort to modify this.

These problems require a team approach with special input from the diabetes dietitian. It is important to normalise the food plan as much as possible and help teenagers to sensibly and realistically address any concerns they have about food issues and weight.

#### **Diabetes 'burn-out'**

It is not surprising that the relentless demands of diabetes over long periods can lead to a situation of burn-out in young people with diabetes and their families. Features include a lack of motivation, a lowering of aims and targets, missing or avoiding follow-up appointments and a feeling of helplessness in being able to change the situation. There is an element of burn-out in most of the problems mentioned earlier in this section. All of these things can lead to anxiety, stress or even depression and it is important to address these. Depression can be more common in people with diabetes and is important to act on signs of this, so that the situation can be helped.

There is no easy solution to burn-out, but helpful strategies can include simplifying diabetes routines where possible, sharing the load with family members, re-education, counselling and sometimes psychological intervention. The diabetes team will try to maintain closer contact in order to help motivation. It is also important for young

people to have positive diabetes role models and an understanding of advances in diabetes management that will give them hope for easier management and possible cures, provided these are realistic. Attending diabetes camps can help re-motivate some young people.

For all of these issues, the diabetes team take a non-judgmental approach and bring in other health professionals to help if needed. Diabetes requires a lot of compromise in people's lives, especially in the teenage years. Often the difficulties are only temporary and are overcome with time.

### Transition to adult care

All young people will need to transition to care in adult diabetes services at some time. This should be a planned process in which there is appropriate preparation and time for adaptation.

Your diabetes team will guide you about local transition recommendations and arrangements. Here are some important points in the transition process:

- Transition will often occur between 16 to 18 years of age. However this may depend on whether a young person has left school, availability of local services and their own preferences.
- Transition should not be a sudden event, but a planned process over a period of time which allows education and knowledge to be reviewed and for the young person to adapt to the upcoming change
- Adolescents transitioning need to be a given a range of possible options for the adult service they could attend and participate in that decision; for example preferred location, hospital clinic or private service. Some services run joint young adult clinics (with adolescent and adult diabetes specialists) as a way of facilitating transition.
- The diabetes service will arrange for a transfer of relevant medical information to the new adult diabetes team, with the young person's consent
- It is important that young people do not get "lost" in the transition process, through either not attending the suggested adult service or dropping out early because it is different to what they are used to or because they feel disconnected from their long-term diabetes team. Parents and caregivers have a role in helping to ensure that young people have their appointments and attend them, especially early in the process. Your diabetes team will also have mechanisms in place to monitor the transition process and to try to ensure that successful transition has occurred.
- If there are problems in the process of transition, you should contact your child / adolescent diabetes team to discuss. Sometimes a different centre or doctor may need to be tried, since different services suit different people.

### Associated video resource for this chapter

#### GYST - a life guide for young people on the move

ERC Media, Educational Resource Centre, Royal Children's Hospital, Melbourne, 2006.

'GYST' is a fresh, new holistic approach to the complex process of transition. It's a comprehensive 'life guide' covering all the most important aspects of getting set up in adult life with specific information for young people living with diabetes. It is packed full of valuable information that every young person needs to know.

#### www.gyst.org.au

## **Common questions and answers**



#### How can I get advice about diabetes problems if I am worried?

The first step is to contact your usual diabetes educator, dietitian or doctor, depending on the question. If you can't contact them and the question is urgent, the major children's diabetes centres have a 24-hour telephone service for urgent advice.



# We live in a country town a long way from a major children's diabetes centre. How should our child be followed up?

It is a widely accepted recommendation that children with diabetes should see a doctor with specialist experience in children's diabetes about every three months. In country centres the appropriate doctor is usually a specialist paediatrician, or may be an adult physician for older teenagers. Teams from children's hospitals diabetes centres visit some regional areas and your doctor may recommend you see them for review. Country centres usually also have a diabetes educator and dietitian with experience in children. Find a follow-up pattern that suits you and your child.



#### Can the haemoglobin A1c be too low?

Yes. A low haemoglobin A1c can be achieved by having lots of hypos, but this is definitely not a good thing. Severe hypos with fits or unconsciousness or hypoglycaemia unawareness become an increased risk if the HbA1c is too low.



#### What should I do if I am not happy with the advice I am given by my doctor or someone else in the diabetes team?

This can sometimes be awkward, but as a parent you need to address this. If you feel you can, discuss the matter with your doctor or educator or other member of the team and often this will help sort things out. If there are still worries, it is always your right to seek another opinion from whomever you choose. Remember that diabetes is a long-term condition and you and your child need to find a doctor and other advisers who suit you. Your health professionals need to be experienced in caring for children with diabetes.



#### My child's diabetes is quite difficult to manage and we can never seem to get the haemoglobin A1c in the recommended target range. What should we do?

The recommended range is the ideal but, for a variety of reasons, not everyone can reach this. The most common reason is that blood glucose levels are higher than ideal at those times of the day when you are not testing. It may also be that the insulin types or timing are not the most suitable for your child at this time. Your diabetes team will be able to help with these issues. Remember that any improvement in haemoglobin A1c is of benefit in reducing the risk of complications (e.g., improving from 9.6 per cent to 9.1 per cent, even though it is not in the target range).



#### My 15-year-old son made the switch to four injections per day about a year ago, and was doing well. Now his control has deteriorated; he seems to be doing less testing and it seems he is often forgetting his lunch-time injection at school. What can we do?

It sounds like there are some elements of diabetes burn-out. Explore the reasons for difficulty with the lunch-time injection. Sometimes this is something simple that can be overcome (e.g., lack of privacy or not enough time). The diabetes team will assess if they can re-motivate your son or if there are other particular issues. A review by the social worker or psychologist may help. They will also consider whether it may be appropriate to go back to three or two injections a day for a while. Work with your son in a team effort so he is not carrying all of the load of day-to-day management. It is important for parents to stay involved in assisting with diabetes care, even during the teenage years.


## Chapter 17 Travelling, holidays, camping and other special situations

## **Key Points**

- Travelling and holidays should not be restricted because your child has diabetes
- Planning ahead will help prevent any problems and ensure that travel and holidays are safe and enjoyable
- See your diabetes doctor and educator before the trip especially for overseas trips
- Changes to timing and routines can be dealt with by planning ahead
- Diabetes camps help many kids with diabetes and are fun!

## **Preparing for travel**

#### Things to consider

Before travelling it is important to think about:

- length of journey
- possibility of delays
- timing of insulin
- availability of carbohydrate food
- access to medical services and diabetes supplies
- care of insulin and diabetes equipment
- customs regulations in different countries
- changes in types of foods
- changes in activity levels
- changes in medication and sleep routines
- the prevention and management of sickness away from home
- carrying letters from your diabetes team in case they are needed at customs or security checks

#### Review by the diabetes team

A review by the doctor and educator is advisable about one month before the trip. This is especially important for overseas trips. Diabetes control will be assessed and adjustments made if needed. Appropriate letters will be supplied and advice given about coping with time zone changes. Other issues such as insulin adjustments for activity changes, overseas medical facilities and so on can also be discussed.

#### **Letters and contacts**

- Obtain a letter from your doctor summarising medical information about your child in case you need to seek medical advice away from home. For overseas trips and domestic flights, obtain a letter stating that you will be carrying supplies such as insulin and syringes; this is so you avoid any problems at customs or security inspections.
- Ask your doctor about suitable diabetes services at your destination. Usually some contact names addresses and phone numbers can be provided for most parts of the world.
- Make sure you have the contact phone, fax number and e-mail address of your usual diabetes doctor and educator in case you or others need to contact them about your child.

#### Immunisations

Ensure your child is up to date with immunisations and has any special immunisations required for travel to particular countries. Allow at least two months for this in case special immunisations are required – your GP will be able to advise about this.



#### **Travel insurance**

Obtain travel insurance well in advance. As the insurer will usually require information from your doctor, sufficient time needs to be allowed for this process. Diabetes Australia can provide information about companies providing suitable medical and other travel insurance. It is a good idea to shop around.

#### **Contact with the airline**

Advise the airline that your child has diabetes and find out approximate meal times and whether extra snacks are available. It is best not to ask for a 'diabetic diet' as this is often low in carbohydrate and not the type of food kids like. Ask for a kids' meal or normal meal and if there is not enough carbohydrate ask for more or use some of your own food.

#### **Supplies**

- Make sure you have enough supplies insulin, glucagon, syringes, insulin pens, blood glucose meter and spare batteries, blood and urine test strips, diabetes bracelet or neck chain, insulin pump supplies etc. It is a good idea to have a spare blood glucose meter or a bottle of blood glucose strips that can be read by colour change without a meter (visual test strips) as a back-up. The insulin glucagon and blood glucose meter need to be protected from extremes of temperature; if these are likely to occur on the trip use an insulated container or packing. If you are travelling with an insulin pump, make sure that you have a supply of insulin pens as a back-up in the event of pump failure.
- Make sure your child is wearing a diabetes ID necklace or bracelet.
- During the trip, essential diabetes equipment needs to be divided between two separate hand luggage bags in case one is lost. Supplies should not be packed in your luggage in the cargo hold as they may be exposed to extreme temperatures or get lost at the airport.

# Chapter

#### Preparation in case of sick days

- Prepare a kit for sick day management.
- Revise information on sick day management and hypoglycaemia management.
- Obtain supplies of easy-to-eat carbohydrate for treating hypoglycaemia as well as enough extra carbohydrate in case of delayed meals. For a long flight always have sufficient carbohydrate foods for two to three meals. Be prepared for long and unexpected delays. Carry supplies of bottled drinks and water if allowed, although there are limits on carrying liquids on some flights.
- For trips to countries where English speaking is uncommon, it may be advisable to have medical letters translated into the local language and also some translations for important requests (e.g., I need to find a doctor I need sugar quickly). Making contact with the Australian consulate may also be advisable for longer stays or in the case of any difficulties.

#### Food and hygiene issues

Like all travellers in overseas countries, you need to be extremely cautious with food hygiene. In countries where water supplies and general hygiene are suspect, drink only bottled water, avoid ice cubes and salads and avoid street food sellers and market stalls.

#### **Reference information**

Take this book "Caring for Diabetes in Children and Adolescents" with you or you can access it on-line at **www.kidsdiabetes.org.au**.

## Changes to timing and routines

Adjustments can be made when needed to cope with changes in diabetes routines. In general, diabetes control will be smoothest in children when routines are fairly regular; however, there will often be times when routines have to change. In all of these situations, extra blood glucose monitoring and thinking about patterns of insulin action and meal times will usually help you work out what to do.

Insulin pumps allow the greatest flexibility for changes in routines, although adjustments are still relatively easy on multiple daily injection plans (MDI).

#### Overseas flights and time zone changes

Insulin adjustments for flights crossing time zones need to be individualised, taking into account:

- the duration of the flight
- number of hours of time zone change
- timing of meals, snacks and stop-overs
- usual pattern of insulin doses
- time of arrival at destination and plans for that day (e.g., sleeping or active).



Your educator can help you work out a detailed plan and when possible you should allow one month's notice of travel if you want help in working out a plan. General principles are:

- Never omit insulin on flights.
- Do extra BGL testing.
- Keep one watch on local departure time and one on destination time.
- Set an alarm or arrange to be woken to avoid over- sleeping on the plane or after arrival.
- Be prepared to give extra doses of rapid or short-acting insulin whenever BGL is above the target range.
- Be prepared for unexpected hypos
- Carry plenty of additional carbohydrate in case there are delays late meals and so on.
- Higher BGLs are more likely during flights because of inactivity.
- Low BGLs are more likely if care is not taken to avoid more than the usual overlap of long-acting insulin doses or if less food is eaten because of sleeping more than usual.
- No significant adjustments are required for predominantly north-south travel with less than a two-hour time shift (e.g., Sydney to Tokyo).
- When travelling west, the travel day is extended (e.g., if you leave eastern Australia in the late afternoon you arrive in London at breakfast time after travelling about 24 hours).
- When travelling east, the travel day is shortened (e.g., if you leave eastern Australia in the morning you arrive in Los Angeles earlier the same morning after travelling for 14 hours).

Adjustments are easiest for people on multiple injections (usually rapid or shortacting insulin before main meals and long-acting insulin before bed or twice-daily). Continue to take short-acting insulin before main meals (about every four to five hours). For long-acting insulin, the options are:

- If you usually take long-acting insulin twice daily, continue to take it approximately every 12 hours. If your morning and evening doses vary significantly, you can readjust the ratios at your destination. Use extra BGL monitoring to guide dose decisions.
- If you usually take one injection per day of long-acting insulin, options are:
  - Give the next long-acting dose approximately 24 hours after the previous one, but at a reduced dose, so that you can resume your usual time of day injection at the destination. The time intervals will vary according to your destination, but the first dose at the destination will also need to be reduced if the dose given in transit was significantly less than 24 hours ago. The principle is that you will need about the same amount of long-acting insulin each 24 hours, whether you split it or not.

Or,

• Give the next dose of long-acting insulin at your usual time of day (morning or evening) at the destination, which could be up to 36 hours after the last long-acting injection. This will work satisfactorily, provided that rapid or short-acting doses continue to be taken regularly before meals with top-ups as needed if high. If it is less than 24 hours after the last long-acting injection, give a reduced dose to avoid overlap.

#### Adjustments for those on two or three injections per day:

- This will vary considerably, depending on the pattern of your insulin plan and the type and number of long-acting insulin doses
- Start by thinking about your long-acting doses; whether you have this once or twice per day
- If you have long-acting insulin twice per day, plan to have doses about 12 hours apart; the ratios may need changing at your destination because of time shift
- If you have long-acting insulin once per day, the options are the same as for multiple daily injections above
- Short-acting insulin should be given with the long-acting insulin doses that are given before meals. Additional short-acting doses may be required especially if BGL rises above 12-15 mmol/l.
- Some people decide to change to four injections per day (MDI or basal-bolus plan) during their travel to make things simpler and more flexible and this is quite a good idea.

#### Adjustments for those on an insulin pump:

• Adjustment is simple. Usually the basal rate is left the same during the flight and boluses are given for meals and to correct high BGLs. At the destination the clock on the pump is changed to local time.

### **Sleeping in**

Sleeping in is part of the enjoyment of weekends and holidays. No particular changes need to be made if the later injection time is within 1-2 hours of the usual time.

Unfortunately though, diabetes does not allow your child to sleep in for a long time. Sleeping in for longer can cause problems with low blood glucose levels if overnight insulin is still acting or high blood glucose levels if insulin action is running out. If your child wants to sleep in longer, then you need to check the blood glucose level to ensure that this is safe and then arrange to wake at a set time later. It is generally not advised that the usual routine be altered by more than two hours. Never take insulin doses in bed and do not go back to bed between taking insulin and eating breakfast. Giving the insulin later than usual in the morning can cause overlap with the evening insulin, so if you do this you should compensate by either moving the entire day's routine later or reducing morning long-acting insulin and/or evening short-acting doses.



## **Getting up earlier**

No changes usually need to be made to insulin doses or food plans if the injection time is an hour or less different from the usual time. For earlier starts than this, you can:

- give an extra morning tea if all other meals are to be given at the usual times or
- bring the whole day's routine forward with extra testing in the evening to assess the need for any extra food and best insulin dose.

## Going to bed later

Usually eating an extra supper during the evening is sufficient; the amount depending on what your child is doing at the time. Checking the pre-bed blood glucose level is recommended and it needs to be above 6 mmol/l. The alternative is to reduce the evening insulin if you know in advance that your child will be up later than usual, especially if they are planning an active evening such as a school dance.

## **Eating out late**

If you are going out for a meal at a restaurant or will be eating at a later time, you can give your child supper or a snack at their usual dinner time and their usual evening insulin and evening meal at the restaurant.

### Staying over at a friend's house

Children love to stay over at a friend's house, but with diabetes this can create practical difficulties and anxiety. Some planning can make this possible without problems. The age of the child will make a difference in the planning that is required. If your child stays regularly with friends or relatives, arrange for some diabetes education or for them to read a resource like this one.

If your child can do blood testing and can use pens or draw up and give insulin with a syringe, usually all that is required is that the host family receive simple advice about meal requirements and timing and hypoglycaemia. They need to know how and when to contact you or the diabetes team. They also need advice about what to do if an emergency arises.

If your child uses syringes and can give an injection, but cannot draw up the insulin, insulin pens for those occasions are the best option.

## **Diabetes camps**

Children or adolescents who have diabetes are often very dependent on their parents in caring for the diabetes and often do not know others of the same age with diabetes or do not mix with them. It is not uncommon for children who have had diabetes for a number of years to have never spent a night away from their parents. Diabetes camps are good for children and adolescents for the following reasons:

- They meet make friends and socialise with other children with diabetes. They will also realise they are not the only person in the world with diabetes.
- They learn to become more independent in diabetes care a stepping stone toward independent adult living. Children and adolescents learn how to care for themselves and adjust their diabetes care for situations such as increased activity. This often leads to children participating in other camps (e.g., school or sports camps) and being able to have holidays away from their parents.
- They learn more about diabetes in general. All camps have an educational component whether this is formal or informal learning.
- They increase their confidence in social and physical activities in a well-supervised environment.
- They participate in a safe quality and fun recreational program.

Another important function of camps is to provide some respite for parents from the daily responsibility of looking after their child with diabetes. Many children require encouragement to go to camp initially, but end up having a wonderful time and gain great benefit. Despite the name, camping does not usually involve staying in tents.

A variety of camps exist in different regions and catering for different age groups.



Children do not normally attend camp alone under the age of nine years. For younger children (less than nine or ten years) there are weekend camps where the child attends with one parent.

Diabetes Australia has established camping standards guidelines to ensure that camps are run in a safe and professional manner. Camps have professional staff with diabetes training. For information about camps that would be suitable for your child, contact your diabetes educator, Diabetes Australia or the Juvenile Diabetes Research Foundation.

### School camps

Most children in primary and secondary school will want to attend school camps or overnight excursions, which are usually two to five days long. This often makes people worry about the diabetes care.

Most of these camps do not have any nursing staff, but medical facilities are usually close by. Some parents attend camps as helpers and this may work well, but sometimes children will not want this. Planning ahead should allow your child to attend camp without any major problems.

#### **Preparing for camp**

#### Here are guidelines for preparing for camp or overnight excursions:

- Revise and refresh diabetes skills for your child (e.g., using pens, drawing up and injecting insulin, blood glucose monitoring, testing for ketones, changing a pump set). Children need to have basic diabetes skills to attend camps. In some cases where children are not confident in drawing up or injecting, automatic injection devices or insulin pens are a good option. Your educator will arrange extra education before the camp if needed.
- Obtain the activities and meal program for the camp as early as possible and discuss this with your diabetes educator or diabetes doctor. In most cases activity levels will be higher than usual and lower insulin doses will be necessary. This is usually in the range of 10-30 per cent less than usual doses.
- Discuss the food and meals with the camp organisers. Arrange for extra carbohydrate food to be available so your child can treat hypos and prepare for exercise.
- Provide teachers and/or supervisors with information about diabetes before the camp (see chapter 14 'School and diabetes"). It is also useful if your child has one or two friends who know about diabetes and hypos and can act as buddies to alert teachers if there is a concern.
- Try to identify one teacher or supervisor who will take responsibility for any extra supervision that your child needs.
- Arrange for a hypo pack or packs to be available at the camp, with instructions for teachers and/or supervisors about its use (see chapter 14). Usually there will not be staff at such camps who would be able to give a glucagon injection for severe hypoglycaemia but if this occurs the Ambulance Service would be called and ambulance officers would give glucagon or a glucose injection.
- Make arrangements so your child or a teacher can contact you (or their educator) to discuss blood glucose levels and insulin doses while at camp.

## Fasting, e.g., religious or other reason

Healthy nutritional plans and most diabetes management plans rely on regular carbohydrate intake. However, sometimes there is a wish to participate in periods of fasting. Examples include the religious activities of Ramadan and Yom Kippur, or charitable and advocacy activities such as the "40 hour famine".



People with diabetes or other significant medical conditions are usually excused from fasting by their religions, but some people will still make a personal choice to fast. Fasting is not recommended for younger children. For teenagers and adults this can usually be done safely, following the following principles:

- Fasting for more than 12 hours is not recommended
- Think about your insulin plan and in particular which insulin doses are covering food intake
- For people on insulin pumps, the approach is usually simple. Continue the pump at the usual basal rates. Take meal boluses only when eating and use corrections if needed. If BGL tends to run low while fasting, use a lower temporary basal rate.
- For those on a multiple daily injection plan, continue your usual basal or long-acting insulin. Sometimes this may need a small reduction if total daily food intake is less. Use injections of rapid or short-acting insulin only when eating or if needed for corrections. Be careful about large doses of rapid or short-acting insulin just before sleeping, since this can increase the risk of night hypoglycaemia if the dose is misjudged.
- For those on an injection plan with 2 or 3 injections per day, both short and long-acting insulins cover food through the day and will need to be reduced. Extra doses of short-acting insulin may be needed when food is taken.
- In all cases, extra BGL monitoring is important to guide adjustment and to guard against the increased possibility of hypoglycaemia

### Associated video resource for this chapter

#### Spreading our wings - the diabetes camp experience

ERC Media, Educational Resource Centre, Royal Children's Hospital, Melbourne, 2005.

Experiences of diabetes camps told from the parents and child's or adolescent's perspective

#### View via the link at www.kidsdiabetes.org.au

## **Common questions and answers**



#### What should we do if our child gets sick when overseas?

Use the information in this resource on sick day management. If things are not getting better you will need to see a doctor. You may have been given a contact by your diabetes team before leaving home. Otherwise, find the nearest children's hospital, or large hospital with a children's department. If none is available nearby, ask for help to find an Englishspeaking doctor or a doctor who speaks your language. Remember also that you can phone home to your diabetes team who may be able to help over the phone.



## What should we do if our blood glucose meter is lost or breaks down when we are overseas?

Consider taking a spare meter. Alternatively, take some spare testing strips with you which can be read by eye. These are less accurate than a machine but will give a good guide. A few brands of these are available. In many countries it will be possible to purchase a replacement machine, but the meter might read the blood glucose in different units than you are used to (1 mmol/l = 18 mg/dl).



#### My nine-year-old wants to sleep over at a friend's house. He can give an injection but cannot reliably draw up. How can we handle this?

It would be best to use insulin pens for this situation, which he should be able to dial up or his carers can easily be taught to dial up or supervise.

## **Chapter 18 Insulin Pumps**

## **Key Points**

- Insulin pumps are now widely used in the management of type I diabetes and are a core therapy with evidence of significant benefits
- A pump is another way of delivering insulin under the skin, although it may not suit all children or teenagers
- Progressive technology improvements are expected to add further benefits
- Your diabetes team will discuss pump therapy with you and the potential suitability

This chapter explains details of using an insulin pump for diabetes management. However, as there are a number of different brands of insulin pump, the information here cannot be brand specific. When you or your child starts an insulin pump, additional individual information and education will also be given to you by the diabetes team. Remember that information in other chapters of this book is also relevant for insulin pump users.

## What is an insulin pump?

An insulin pump is a small computerized device that delivers regulated amounts of insulin continually under the skin. The pump is programmed to give small background doses of insulin (**basal insulin**) continuously throughout the day and night depending on the individual's needs. Each time the person eats carbohydrate, they activate the pump to give a burst of insulin (**meal bolus**) to cover the amount of carbohydrate that they are going to eat. An extra bolus (**correction bolus**) can also be given to treat a high blood glucose level. In this way the insulin pump simulates more closely the way the pancreas would normally deliver insulin.

The insulin pump has a syringe in it which is loaded with **rapid-acting insulin**. No long-acting insulin is used. The syringe is driven by the computerized pump mechanism. This is attached by a plastic tube to a special plastic needle **(cannula)** which is inserted under the skin usually of the abdomen or buttock region. This cannula has to be changed every 2 or 3 days which is easily done at home. The pump can be disconnected for short periods e.g., to have a shower, swim or play football, but in general it remains attached to the person 24 hours a day.

It is important to remember that current **insulin pumps are not automatic.** They have to be programmed by the user based on at least 4 to 6 blood glucose levels per day and careful thinking about food and exercise patterns. Young children require parents or carers to operate the pump, but older children and teenagers become increasingly independent in operating the pump. In general, a pump requires more work and thinking about diabetes than do injections, but with a number of potential benefits. It is important for the person with diabetes to be motivated themselves to go on a pump rather than being talked into it by others. Your diabetes team will discuss with you if your child may be a suitable candidate for a pump and help you to consider possible advantages and disadvantages. It may come down to personal views and preferences as to whether people with diabetes like the idea of an insulin pump. It is important to remember that modern insulin injection plans can still give most people good diabetes control if they concentrate on the routines and management of their diabetes.

## Outline of insulin pump therapy

In general, people on insulin pumps manage their diabetes as follows:

- Basal rates (background insulin rates) are established that suit different time periods throughout the day. Most people have between 4 and 6 different basal rates, but occasionally more. The pump delivers this insulin continuously.
- Bolus insulin doses are given for meals and snacks. The amount of carbohydrate that is eaten for a meal or snack needs to be fairly accurately estimated in grams or exchanges. This amount is entered into the pump, allowing the pump to calculate the amount of insulin required.
- Correction doses can be given at meal times or other times if the BGL is higher than desired at the time. The BGL is entered into the pump, and the pump helps calculate the correction dose.
- The blood glucose level should be tested at least 4 to 6 times per day, or at any other time there is concern. Continuous glucose monitoring systems (CGMS) can be used with some pumps and are likely to be increasingly used.
- High blood glucose levels must be taken very seriously and action taken quickly to correct this, because there is no long-acting insulin being used.
- The pump can be disconnected for short periods throughout the day e.g., contact sport, shower, swim, but usually not for more than 2 hours.
- The insulin syringe, tubing and infusion cannula need to be changed every 3 days, but sometimes more often.
- Frequent contact with the diabetes team is needed initially, but this later settles into a standard 3 monthly review if all is going well.
- Record keeping is important to monitor progress and to recognize the need for adjustments. A variety of methods are available, including the increasing use of electronic records and internet communication.



An insulin pump and tubing

## Potential advantages of insulin pumps

For people who successfully make the change to a pump, there are a number of potential advantages. These are discussed below.

#### Better blood glucose control and HbA1c

Many people experience smoother blood glucose levels and a fall in HbA1c with pump therapy, but not all. Hypoglycaemia is less common in general with pumps, although it remains a significant risk. Pumps may help stabilize diabetes for people who work hard at their diabetes yet have difficult and unstable blood glucose control.

#### More accurate insulin delivery

The pump delivers insulin very accurately and simulates more closely the way a healthy pancreas works. Insulin absorption is much more predictable than with insulin injections. The pump can be accurately programmed to match the changing needs of any individual. Only rapid-acting insulin is used in pumps.

#### Flexibility and lifestyle benefits

The insulin delivery of the pump can be altered to allow for many variations in routine, eating patterns and exercise. This allows the times and amounts of meals to be more flexible and allows sleeping in and other variations in routine to a much greater extent. It also more easily allows for adjustments on sick days if the person is not eating or is needing extra insulin. Many people enjoy how easy and discreet pumps are for delivering insulin, compared to giving insulin injections with a pen or syringe.

### Potential disadvantages of insulin pumps

There are a number of potential disadvantages of insulin pumps for some users.

#### Being permanently attached to a 'machine'

Some people do not like the thought of having to be attached to the pump almost constantly. The pump can be worn on the belt, kept in a pocket or concealed under the clothing in a pouch. A quick-release connection allows the pump to be disconnected easily for short periods e.g., a shower, swim etc. Nevertheless some people cannot adapt to this permanent dependence on a machine.

#### More blood glucose testing

Pump users need to be prepared to do 6 to 8 blood glucose tests a day, sometimes more. This is needed to ensure that the pump rates are correct and to help work out how much of a bolus dose to give at meal times and to minimise the risk of high blood glucose levels and ketones developing. Continuous glucose monitoring systems are now available for use with some pumps, which give greatly increased blood glucose information and can reduce the amount of finger-stick testing.

#### More rapid development of ketones or ketoacidosis

When a problem occurs with insulin delivery by the pump, ketones and ketoacidosis can develop much more quickly because there is no reservoir of long acting insulin in the body. Pump users are taught to watch for this and how to respond. This is another reason why more frequent BGLs need to be done by pump users. In case of pump malfunction, people always need to have insulin pens available to switch temporarily to at any time needed.

#### Skin infections or irritation

Because the cannula is left under the skin for up to three days, irritation or infection at the site can sometimes occur. This can be minimised by appropriate and careful technique. Occasionally, some people are sensitive to the adhesive or tapes which can cause skin irritation.

#### Cost

Your diabetes team will discuss how pumps may be accessed through private health insurance or government subsidies. Partial subsidies are now available from the Commonwealth Government for pumps purchase as well as NDSS subsidy of consumables.

### Diabetes management on a pump is a team effort

Most older children and teenagers adapt to the pump very quickly and are often quicker to grasp new technologies and gadgets than their parents. However it is very important that parents or other carers stay closely involved and interested in their child's diabetes. Just having a pump does not mean that more responsibility for diabetes management can or should be shifted onto the child or teenager.

The degree of involvement of parents and other family members will vary between different families. It may seem rather obvious to state these things but sometimes teenagers or parents perceive starting on a pump as a handover of responsibility for care to the teenager themselves. This is not the case and this needs to be a gradual process over many years with parents maintaining an active role and interest. In general parents should continue to have a role in:

- Checking and assisting with techniques of syringe filling and infusion set insertion
- Assisting with adjustment of basal and bolus doses, including adjustments needed for exercise
- Ensuring that adequate BGL monitoring is being done and recorded and that other record keeping is maintained
- Assistance at times of high BGLs or sick days
- Assisting with assessing carbohydrate content of foods and other aspects of food planning
- Assistance with ensuring that an insulin pen with rapid-acting insulin is available and carried at all times
- Assistance with management of hypos and ensuring adequate provision is taken to avoid or minimize risk of hypos
- Assistance with communications with pump team and in organising and attending hospital visits
- Assistance with maintaining adequate supplies of insulin (including availability of long-acting insulin) , infusion sets, tapes etc
- Any other general aspects of diabetes and health management

## Steps in commencing insulin pump therapy

#### Suitability for a pump:

This will be discussed with you by the diabetes team and it is important for you to find out as much as you can in preparation. The diabetes team will provide you with

information and the internet is another good source. Remember that some people with diabetes may not be suitable for pump therapy for a variety of reasons. You and the diabetes team will need to make a joint decision about whether or not to start on an insulin pump. Ultimately, it is your diabetes specialist that makes the recommendation for commencing a pump, so they must be involved in your discussions.

Two important factors for suitability are a demonstrated ability to monitor blood glucose levels at least 4 to 6 times per day and a motivation to achieve and maintain good diabetes routines and control.

#### Preparation for starting on the pump:

Once you and your diabetes team have decided that you are suitable for a pump, the diabetes nurse educator will assist with the arrangements which need to include:

- Discuss with the pump team how arrangements will be made for purchase of the pump and ongoing supplies. If this is going to be through your health fund, then you will have to contact them to arrange pre-approval.
- Arrangements will be made for pre-pump education with your diabetes team. You may be given specific tasks to complete (e.g., reading or on-line education) before the date of the pump start.
- A date will be arranged for the pump start. Usually this is done as a day-only hospital admission, but sometimes may require a longer stay. The person with diabetes and at least one parent, guardian or partner need to be present also. Much of the time is spent with technical training about the pump and pump therapy.
- The diabetes team will set the starting doses of insulin for the basal and bolus doses; these will be adjusted, especially over the first few days as things are settling in.
- See your general practitioner and arrange to discuss your plans to go onto the pump and arrange a referral letter, if needed

## Wearing the pump

You will receive full instruction on the operation of your pump during your pump start. Details are all contained in the instruction guide that comes with your pump and you should keep this for reference. You will soon become very familiar with all of the commonly used features on the pump.

It is important that the pump wearer is comfortable in where and how they wear the pump. The various options will be discussed with you by the pump educator. Various cases, pouches and accessories are available, including:

- Belt pouches and clips
- Pouches that are worn under the clothing, including waist pouch, thigh pouch, leg pouch, bra pouch and sports guard pouch
- Pouches can also be sewn into clothing, e.g., pyjamas

Remember that the pump will have to be accessed to give boluses for eating and the site needs to be accessible to check for any problems. Some pumps are available with remote controls which may be preferred by some.

Many children simply carry the pump in their pocket and this is simpler and more convenient than using pouches etc. This is possible by making a small hole in the seam of the pocket through which the tubing can be passed.

#### Infusion sets and tapes

The pump delivers insulin via an infusion set which has a cannula on the end of it and is inserted beneath the skin. The insulin, syringe and infusion set need to be changed at least every 3 days, sometimes more often.

Your pump team will advise on the most appropriate type of infusion set for you. There are a variety of sets available from different manufacturers with different features, cannula lengths and tubing lengths.

It is usually most convenient to insert a new set after a bath or shower, when the skin is clean and dry. This should be at least 3 hours before bed. The reason for this is so that there is adequate time before bed to ensure that the new set is working properly and BGLs are satisfactory.

Full instructions on loading insulin and inserting the particular set type will come with each set and will be taught by your educator. Please note the importance of hand-washing and a clean environment for changing a set. It is best to change a set in a relaxed and unhurried environment.

#### Site selection and rotation

The abdominal (tummy) area is a good area since insulin absorption tends to be most consistent. Avoid the belt-line and waist-line, any place that clothing would rub and avoid a circle of about 4 cm around the umbilicus (belly button). Other sites can be used including the upper, outer buttock or the thigh.

The site needs to be changed every 3 days at least, or sooner if there is any redness, irritation or suspected problem with insulin delivery. Move well away from the previously used site.

#### Disinfecting the skin and avoiding infection

Before inserting the infusion set it is important to wash your hands well with soap and water and thoroughly disinfect the skin area using the recommended antiseptic. It is important to use careful technique not to contaminate the insertion site after it has been cleaned or any of the equipment. Infection at the site is a risk if appropriate precautions are not taken. Any soreness, redness or swelling at the infusion site indicates a need to insert a new infusion set at a new site without delay and remove the old set. Full instructions are included with each infusion set. Make sure you clean the top of insulin bottles with an alcohol swab when filling a new syringe.

#### Tapes and skin preps

Special skin preps and tapes are available for people who have sensitive skin or if you need the tape to be extra sticky. It is important for the infusion set to be well secured to avoid accidental dislodgment.

#### Infusion site and site problems

With care, infusion site problems can be kept to a minimum. However, most people will experience a problem at the infusion site at some time. Possible problems include:

#### 1. Dislodgment, blockage or kinking of the cannula

This will happen from time to time, again more commonly with vigorous activities and especially after direct knocks to the cannula site. You may see the tape or cannula dislodged or sometimes leakage of insulin. Often the first indication that something has happened to the site is high BGLs. Unexplained high BGLs always requires a full check of the insulin syringe, pump, tubing and site. When no explanation is evident, the insulin, syringe and infusion set should be changed anyway as this is the most likely cause of the problem.

#### 2. Sets not adhering well

Vigorous activities and sweating make this more likely. Some special preparations are available if needed to help tapes stick more strongly. Different types of sets and tape will sometimes stick better on some people. For any set adhesion problems consult your Pump User Manual or your diabetes team.

#### 3. Infection

Tenderness, redness, swelling or pus at the cannula site may all indicate infection. If this occurs the site must be changed without delay and you should contact your doctor or diabetes team. Antiseptic or antibiotic creams may be required or sometimes oral antibiotics. The chance of infection is minimised by careful handwashing and disinfecting when inserting the cannula and keeping the area generally clean.

#### 4. Irritation or allergy to tapes

The tapes used have low allergic potential, but some people may be sensitive to them. Different sets and tapes are available if this is the case.

#### 5. Air bubbles in the infusion tubing

It is important that the insulin is at room temperature prior to filling the syringe. Make sure you spend time tapping the air bubbles out during the filling and priming procedure. Check that the tubing is well attached to the syringe and that the Quick-release is properly tightened. Tiny bubbles (like champagne bubbles) do not affect the BGLs. One inch (2.5 cm) of air in the tubing is equal to approximately 0.5 units of insulin, so unless there is a lot of air, there is no need for concern. The air itself does no harm; rather it is the insulin that is missed when air is infused that can cause the problems.

#### 6. High blood glucose levels after a set change

If after a set change, blood glucose levels become high or a correction bolus does not work, it is likely that there has been a problem with the insertion of the set. Check the site for any insulin leakage, blood in the first part of the set or other problems. Check that the tubing does not have large amounts of air in it and that the quick release was done up properly. Check for any error messages on the pump and that the pump is operational. Sometimes in lean people at certain sites, where there is not much of a fatty layer beneath the skin, the cannula tip may hit up against the muscle layer and this stops proper delivery of insulin. Pain at the time of insertion and afterwards will often occur if this is the case. Some people who are too lean on the abdomen will use the upper buttock where there is more of a fatty layer.

If no other easily fixed problem is found, the set must be changed again. When in doubt, change the set.

#### Disconnecting and reconnecting the pump

#### 1. Disconnecting

Most infusion sets contains a quick release feature that allows the pump to be disconnected for short periods e.g., vigorous sport, shower etc. Ordinarily the pump should not be disconnected for longer than 2 hours, unless the pump team have advised otherwise.

The pump must be disconnected for taking a bath as the temperature of a bath will damage the insulin in the pump. The pump is usually disconnected for very vigorous sports, contact sports and swimming. A completely waterproof pouch is available for other watersports.

When disconnecting the pump for a bath or shower, leave the pump running and keep the pump in a place that is safe, clean, cool and dry. Do not plug the infusion set if the pump is left running.

When disconnecting outside the home the pump should be **suspended** and the pump end plugged with the stopper or cover, if your set type comes with one. At the skin, if your set type has a cover, use that when disconnected.

#### 2. Reconnecting

When reconnecting, make sure the pump is re-started if it was suspended. If any of the connections have become contaminated during disconnection, wipe with an alcohol wipe before reconnecting. No priming dose is needed when reconnecting, whether or not the pump was suspended.



## Insulin types

Rapid-acting insulin is used in the pump, currently either **NovoRapid (Novo Nordisk)** or **Humalog** (Eli Lilly), although other similar insulins may also become available. This means that there is no long-acting insulin reservoir in the body and this is why a pump or infusion set problem can lead quickly to rising BGLs if not detected.

The rapid-acting insulin that is infused by the pump forms only a small reservoir under the skin which is almost all absorbed over 3 to 4 hours. Unless a bolus of insulin has recently been given this will be only a very small amount of insulin.

Your pump contains a feature that allows the estimated duration of action of insulin to be set for each individual, as part of the insulin on-board and bolus wizard features (see later). Usually this is set at 3 to 4 hours and your diabetes team will advise what is best for you, taking into account your individual circumstances and pump model.

## Setting the pump rates

The pump team will program your initial pump settings, including adjustment of any alarms and safety features required. A maximum bolus dose and maximum basal rate will be programmed for each individual to prevent the possibility of accidentally giving too much insulin; these will need to be changed over time as a child grows and needs more insulin.

In the following sections, details and examples of calculating pump doses are given. Initially these calculations will be done by your pump team. With experience, you will get a feel for how to adjust pump rates yourself.

#### Starting rates and total daily dose of insulin

Your starting doses will be individually set by the diabetes team, however the following gives a guide as to how this is calculated. The pump delivers **basal insulin** continuously 24 hours per day for background insulin requirements. On top of this **boluses** or bursts of insulin are given to cover carbohydrate food intake (carbohydrate bolus or carb bolus) or to correct high blood glucose levels (correction bolus).

The total daily dose that the person is having on injections often needs to be reduced by approximately 20%, because the pump is a more efficient method of delivery insulin. Between 40 and 50% of this is given as basal insulin over 24 hours and the rest becomes the bolus doses for food (see calculation below).

#### **Basal insulin**

Most people have about 40-50% of their total daily insulin requirement given as basal insulin. At first this can be divided evenly across the whole day with the same amount given every hour, but usually we start with a pattern that has 4 or 5 basal rates which takes into account small variations in the need for basal insulin at different times of the day. The individual basal pattern needed is strongly influenced by age and puberty.

## When setting and adjusting basal rates an important principle is that the basal rate needs to change 3 to 4 hours before the desired change in insulin effect.

Example of basal insulin calculations:

- A person is having 60 units of insulin per day in total while receiving injections.
- For changing to a pump, the dose is reduced by 20% = 48 units. This is called the **total daily dose (TDD)**.
- Basal insulin 45% of TDD = 22 units per day = 0.9 units per hour (or your team may set a number of basal rates which vary slightly around this rate)

It is important to remember that you will not have to make these calculations. They will be made for you and programmed into your pump. This information is presented here so you understand the principles of how your pump is programmed. Also, some individuals may have a basal insulin requirement outside the 40-50% range, depending on their age and other particular circumstances.

Modern pumps also allow a number of different basal profiles to be set and after a person is established on a pump, extra profiles may be programmed. For example – a 3 year old child may have one basal program with lower basal doses set for the 3 days he attends pre-school when he is very active, and a second one that he uses on less active days at home. The use of such advanced pump features will be advised by your diabetes team if needed.

#### **Bolus doses**

On top of the basal doses of insulin, boluses or bursts of insulin are needed. There are 2 types of bolus:

- 1. **carbohydrate bolus** (also called carb bolus or meal bolus) to cover the amount of carbohydrate that is going to be eaten
- 2. correction bolus an extra bolus to correct a high BGL back down to target levels

#### Boluses for meals and snacks (Carbohydrate boluses)

Prior to starting on a pump you will see a dietitian to review your food plan. Often this will change since the food plan you have been on may have been adjusted to suit your injection pattern rather than your true dietary needs. On a pump, people will often choose to have less between meal snacks and total carbohydrate requirement may be a little less.

The "500 rule" is initially used by the diabetes team as a guide to calculate the insulin to carbohydrate ratio required to cover meals or snacks for each individual. This determines how many grams of carbohydrate 1 unit of insulin will cover. This works as follows:

Divide the total daily dose of insulin that has been decided as the starting dose (TDD) into 500. The answer to this is the number of grams of carbohydrate that 1 unit of insulin will cover.

Example:

- TDD = 48 units.
- 48 divided into 500 = 10.4
- Therefore 1 unit of insulin will cover approximately 10 grams of carbohydrate (thus the **carbohydrate/insulin ratio** = 10). This is often just called the **carb ratio**.
- This figure is programmed into the pump
- Thus if the person was going to eat 45 g of carbohydrate for lunch, a bolus of 45 / 10 = 4.5 units would be offered by the pump.

Some people find that this ratio is different at different meals. The commonest variation is people who find that they need a stronger insulin to carbohydrate ratio for their breakfast compared to other meals. In the above example, a 10% stronger carbohydrate ratio would be 1 unit covers 9 g of carbohydrate. Also, the "500 rule" does not work well for all people, especially the very young and other special circumstances.

It is important to remember that you will not have to make these calculations. They will be made for you and programmed into your pump. This information is presented here so you understand how your pump is programmed.

These will be the starting doses for your meal carb boluses which will then be modified if needed as you monitor and gain experience with the pump.

The pump allows different types of boluses to be set for certain circumstances. Most people will use a **normal bolus** in which the bolus is all infused almost immediately, usually over a minute or so. This bolus is still only absorbed into the body over 3-4 hours. However the pump can also be programmed to give a **dual wave bolus** (sometimes also called **combination bolus**) or a **square wave bolus**. A dual wave bolus gives a specified percentage of the insulin immediately with the remainder given over a longer period of time. A square wave bolus spreads the total amount of bolus evenly over the time specified. This is discussed in more detail later.

Before any bolus it is wise to check, if possible, that your pump syringe has plenty of insulin and there are no problems with your tubing or site by taking a quick look at all of these. This ensures that you check these things regularly.

#### Correction boluses (using the insulin sensitivity factor)

A correction bolus is an extra bolus given at any time to correct a blood glucose level that is unexpectedly high. Often this is given before a meal or snack as this is when the BGL is done, in which case the **correction bolus is added to the meal bolus**. In most pumps these calculations are done by the bolus calculator / correction wizard and the amount of insulin to bring the BGL down to a preset target (usually set at 6 mmol/l) is calculated by the pump.

It is important to check that there are no problems with the pump and infusion site and to check for ketones when the BGL is unexpectedly high (see sections later on High BGL and Sick Days).

#### The "100 rule"

Correction boluses are initially calculated by the diabetes team using the "100 rule" which determines the insulin sensitivity factor (sometimes called ISF, sensitivity factor or correction factor). This works as follows:

Divide the total daily dose (TDD) into 100. This is an estimate of the number of mmol/l that the BGL will fall by giving 1 unit of insulin.

This gives a starting point from which adjustments can be made by you and the diabetes team. It is also possible in modern pumps to set different correction factors or targets for different periods of the day. For example, a gentler correction factor may be desired overnight when a young child may be more sensitive to insulin.

#### Example:

TDD = 48 units

48 divided into 100 = 2.1 (= insulin sensitivity factor or correction factor)

Therefore the BGL should fall by 2.1 mmol/l for every unit of insulin given

Thus if the BGL was 20 mmol/l and you wanted to bring it down to 6 mmol/l, this would require 14/2.1 = a 6.7 unit bolus (this is the calculation the pump would do).

It is important to remember that you will not have to make these calculations. They will be made for you and programmed into your pump. This information is presented here so you understand what your pump is doing. Also, the "100 rule" does not work well for all people, especially the very young and other special circumstances.

#### **Negative correction**

If the BGL before a meal or snack is lower than desired, the same formula will be applied by the pump to reduce a bolus.

Following on from the above example:

If the BGL was 4.5 mmol/l pre-meal and you would like it to be closer to 6 mmol/l. This is a desired rise of 1.5 mmol/l.

The pump calculates that giving 0.7 unit less will raise the BGL by 1.5 mmol/l, therefore the pump subtracts 0.7 units from the planned meal bolus.

Again, it is important to remember that you will not have to make these calculations. They will be made for you and programmed into your pump. This information is presented here so you understand what your pump is doing.

#### Insulin-on-board (also called active insulin)

Modern pumps assist by keeping track of how much insulin has been delivered that is yet to act. i.e., Insulin sitting under the skin that is to be absorbed and act over the next 3 to 4 hours. The computer algorithms that do this are slightly different in the different pump brands, but the principles are similar. The key is setting a factor that suits the individual for estimated duration of insulin action – usually in children this is set to 3 or 4 hours, but sometimes outside this range for certain circumstances. It is important to understand that the characteristics of the insulin cannot be changed – this setting reflects how long the insulin acts for an individual which can vary accordingly to age, size and other factors. Your diabetes team will advise the suitable settings here. Some pumps have additional settings which will be discussed with you by the diabetes team

Thus, when using a **correction bolus**, the pump will take into account when the last correction bolus was given and how much of that will still be acting (i.e., will the BGL still be falling without the need for an extra bolus). This will allow an adjustment of the correction bolus to be made to avoid the BGL dropping too much and causing a hypo (i.e., will avoid what is termed 'insulin stacking')

As an approximation, 25-30% of a rapid-acting insulin bolus dose is absorbed each hour. Therefore after 1 hour 30% is absorbed , after 2 hours 60% and after 3 hours 90%.

#### Example:

If in the previous example the person had a correction bolus of 5 units given 2 hours before the BGL was found to be 20 mmol/l. Insulin duration has been set for 3 hours in this person's pump. The pump then calculates that approximately 60% of this previous dose has been absorbed, therefore 40% (=2 units) is still to act. Thus the pump would suggest reducing the next correction bolus by 2 units. (This example presumes that you have checked there is not an insulin delivery or site problem and that the carb bolus was correct).

#### The bolus wizard or bolus calculator - examples

We have discussed how the pump software assists the calculation of a bolus dose to cover a the carbohydrate in a meal and also a blood glucose correction. Here are some more examples of how the pump calculates for 3 common situations:

#### 1. Correction bolus, not eating at the time

The current BGL is entered.

The wizard calculates how much insulin is required to bring the BGL down to the target (usually set at 6 mmol/l) using the sensitivity factor (correction factor) set in the pump.

The wizard will then deduct any insulin-on-board or active insulin that has recently been delivered and is yet to act.

A dose will be offered which usually the user will accept, but this may be modified by the user if desired (e.g., may not want to have a full correction just before sport)

#### 2. Eating and correcting of BGL if above target

The current BGL is entered.

The amount of carbohydrate about to be consumed is entered.

The wizard calculates how much insulin is needed to cover the amount of carbohydrate, using the carbohydrate factor set in the pump for the individual.

The wizard also calculates how much insulin is required to bring the BGL down to the target if needed and deducts any insulin-on-board.

A dose will be offered which is a carbohydrate bolus plus correction. Usually the user will accept this dose but it can be modified by the user if desired.

#### 3. Eating and a negative correction if the BGL is below target

If the BGL is less than the target e.g., say 4.5 mmol/l and target is set at 6 mmol/l, the pump calculator will subtract a small amount of insulin from the meal bolus to assist the BGL to drift back up to target. This is often called a negative correction.

The current BGL is entered.

The amount of carbohydrate about to be consumed is entered.

The wizard calculates how much insulin is needed to cover the amount of carbohydrate, using the carbohydrate factor set in the pump for the individual.

The wizard also calculates how much insulin should be subtracted to have the BGL rise back to target

A dose will be offered which is a carbohydrate bolus, with the **correction subtracted**. Usually the user will accept this dose but it can be modified by the user if desired.

#### Practical example:

James has the following settings in his pump:

Carb factor of 15 g (meaning 1 unit cover 15 g of carbohydrate)

Correction factor (or ISF) of 3 (meaning 1 unit lowers the BGL by 3 mmol/l) Target BGL 6 mmol/l; duration of insulin action 3 hours

He does a BGL which is 9 mmol/l. He is going to eat 45 g of carbohydrate. He has not had a correction bolus in the last 3 hours.

For the 45 g of carbohydrate, the pump calculates 3 units; i.e., 45/15

To correct from 9 mmol/l to 6 mmol/l, the pump calculates 1 unit; i.e., (9-6)/3

The pump offers a dose of 4 units which James can accept (usually) or manually over-ride (only if special circumstances, e.g., he is about to play sport)

If in the last 3 hours he had also had a correction, the pump would have subtracted any active insulin (also called insulin-on-board) from the correction.

### Adjusting the pump rates

The pump rates that you start on are likely to be adjusted over the first few days or weeks and then from time to time depending on age, growth, changes in activity and diet etc. The aim is that you will gain experience in making these changes and your diabetes team will always be available to guide you.

Adequate blood glucose testing and keeping good records is essential to allow adjustment of insulin pump therapy. Records can be kept manually, but there is increasing use of computerized pump and blood glucose records through software provided by pump manufacturers. Your diabetes team will advise you about these. Continuous glucose monitoring (CGM) can also assist with pump adjustments and may be recommended by your diabetes team.

#### **Adjusting basal rates**

Most people will end up on more than one basal rate for the 24 hour period. This takes into account different basal insulin requirements at different times of the day. The total daily amount of basal insulin is usually between 40 and 50% of the total daily dose (TDD), sometimes a little higher or lower in certain circumstances. If your total daily basal insulin is outside this range you may have an imbalance and

should consult your pump team. Basal rates will be tested in the first few days that you start the pump and at subsequent times when patterns of highs or lows suggest a need to test and change.

**A basal rate that is too high** is suggested by frequent lows at a similar time of day, a drop in BGL when a meal is skipped, the need for excessive food intake to avoid frequent hypos or excess weight gain.

**A basal rate that is too low** is suggested by frequent highs at a similar time of day, a rise in BGL when a meal is skipped or by the need for frequent correction boluses for high BGLs.

Basal rates can be checked in a systematic manner if needed by using **basal rate tests**.

When testing the basal rate, the aim is to find a rate that keeps the BGL steady or falling only slightly when no carbohydrate-containing food is eaten. Basal rates are tested before boluses are given and should be done on a fairly typical day where there have not been unusual hypos or high BGLs.

#### To test the night time basal rate:

Start at bedtime, which needs to be at least 4 hours after your last insulin bolus and only if the bedtime BGL is in the target range of 6-10 mmol/l. Skip supper or have no carbohydrate. Test the BGL at bed-time, 2 or 3 am and on waking. A good basal rate will keep the BGL level overnight or drop it only 1 to 2 mmol/l.

#### To test the basal rate during the morning:

Start the test when your BGL is between 4 and 8 mmol/l. Skip breakfast (or have no carbohydrate) and therefore have no breakfast bolus. Test at the start and every 1-2 hours for 5 hours. A good basal rate will keep the BGL level or drop it only 1 to 2 mmol/l over this period.

#### To test the basal rate during the afternoon:

Start the test when your BGL is between 4 and 8 mmol/l. Skip lunch (or have no carbohydrate) and therefore have no lunch bolus. Test at the start and every 1-2 hours for 5 hours. A good basal rate will keep the BGL level or drop it only 1 to 2 mmol/l over this period.

#### To test the basal rate during the evening:

Start the test when your BGL is between 4 and 8 mmol/l. Skip dinner (or have no carbohydrate) and therefore have no dinner bolus. Test at the start and every 1-2 hours for 5 hours. A good basal rate will keep the BGL level or drop it only 1 to 2 mmol/l over this period.

- If the blood glucose rises above target during any of these tests, increase the basal rate covering that time slightly, usually by about 10% of the existing rate (usually 0.025 to 0.05 units per hour adjustment in smaller children and 0.05 to 0.1 units per hour adjustments in older children and teenagers) and retest on another day.
- If the blood glucose falls more than slightly (1-2 mmol/l) during any of these tests, decrease the basal rate covering this time slightly, usually by about 10% of the existing rate and retest on another day.
- Remember that **changes in basal rates need to be made 3 to 4 hours before the desired change in insulin action** because of the lag in effect of absorption from under the skin.

#### Adjusting carb boluses

Your diabetes team will give you initial settings for your carbohydrate factor i.e., the setting in your pump that indicates how many grams of carbohydrate is covered by 1 unit of insulin This may have to be adjusted from time to time depending on how well it is working.

A correct carb or meal bolus is that which returns the BGL to within 2 mmol/l of the starting BGL after about 3 hours.

If a low occurs within this period then a weaker carb bolus setting is needed. If the low occurs within 1 to 2 hours of the bolus a larger change will be needed than if it occurs between 2 and 4 hours after the bolus. Generally, make a change of about 10-20% of the current carbohydrate factor and then evaluate that over several days.

Remember that the lower the carbohydrate factor, the stronger is the bolus for the same size meal, for example:

Carbohydrate factor 10 g (means 1 unit covers 10 g of carbohydrate) – if 40 g is eaten, 4 units of insulin is given

Carbohydrate factor 12 g (means 1 unit covers 12g of carbohydrate) – if 40 g is eaten, 3.3 units of insulin is given

## It is very important that you understand which direction to adjust the carbohydrate factor if needed. If in doubt, check with your diabetes team.

Sometimes people find they are more or less sensitive to boluses at a certain time of day. If this is the case a different carb ratio may be required for this meal, although it is usually unnecessary to have multiple carbohydrate factors.

#### Example:

Sam is 14 and his current insulin to carbohydrate ratio is 10 (meaning that 1 unit of insulin covers 10 g of carbohydrate). He finds that his blood glucose levels are generally fine 2 to 3 hours after meals, except after breakfast when his blood glucose levels are generally elevated, around 9-13 mmol/l. He adds a second carbohydrate factor (about 10% stronger) to cover breakfast and makes this 9 (meaning 1 unit of insulin covers 9 g of carbohydrate)

To understand the effect of this adjustment: for a 45 g carb intake, the wizard will now calculate 5 units at breakfast time and 4.5 units at other times for Sam.

#### Adjusting the correction factor or insulin sensitivity factor (ISF):

These settings will also be made by your diabetes team at the time of the pump start, but will need to be adjusted from time to time.

An appropriate correction factor will bring a high BGL down to target within 2 to 3 hours, without causing hypoglycaemia.

If the BGL is not coming down adequately with one or more corrections, this suggests that a stronger correction factor is needed. If the BGL comes down too much or too quickly, this suggests that a weaker correction factor is needed. Generally, make a change of about 10-20% of the current carbohydrate factor and then evaluate that over several days.

Remember that the lower the correction factor or ISF, the stronger is the correction, for example: A 4 year old might have a correction factor (ISF) of 8 (meaning that when correcting, 1 unit of insulin lowers the BGL by 8 mmol/l. Therefore, to come down from 20 mmol/l to 6 mmol/l, the pump would suggest (20-6)/8 = 1.75 units of insulin.

A 15 year old might have a correction factor (ISF) of 2 (meaning that when correcting, 1 unit of insulin lowers the BGL by 2 mmol/l. Therefore, to come down from 20 mmol/l to 6 mmol/l, the pump would suggest (20-6)/2 = 7 units of insulin.

## It is very important that you understand which direction to adjust the correction factor (ISF) if needed. If in doubt, check with your diabetes team.

#### Example:

6 year old Sam's corrections seem too weak and his blood glucose level is not falling enough after corrections. His current correction factor (ISF) is 7 (meaning that 1 unit of insulin lowers the glucose by 7 mmol/l). His mum changes this to 6.3 (meaning that now 1 unit of insulin lowers the BGL by 6.3 mmol/l, a strengthening of about 10%).

To understand the effect of this adjustment: to correct from a BGL of 14 mmol/l to his target of 6 mmol/l

Before adjustment - the pump wizard would have calculated 1.14 units

After adjustment - the pump wizard will calculate 1.27 units

#### Keeping a record of pump rates and changes

Pump settings will change from time to time and it is important that you keep a written or electronic record of these. This is because if the pump is damaged or fails, you need to know what to program into a replacement pump when it arrives. We suggest that you keep a written record of settings and changes in a book at home or regularly use the electronic downloading facility of your pump to keep these records.

## Monitoring and target ranges

#### **Blood glucose monitoring**

Successful use of a pump requires an adequate amount of blood glucose monitoring, usually 6 to 8 per day minimum but preferably more. This information is required to know how to adjust pump doses and to detect unexpected high readings and possible insulin delivery problems.

A variety of blood glucose monitors are suitable, however it is preferable for insulin pump users to have a meter that can also measure blood ketones.

It is important to keep a **detailed diary record** of blood glucose levels, ketone tests, basal rates and boluses, carbohydrate exchanges and exercises. This can be achieved in a number of ways:

- 1. Blood glucose diaries
- 2. Computer spreadsheets
- 3. Software that comes with the pump that allows electronic records to be kept, and in some cases, allows communication via the internet with your diabetes team.

Your diabetes team will recommend the methods most suitable for you, but in general there is a strong move towards using electronic and internet based technologies to aid the recording and analysis of pump settings and BGLs.

All BGLs need to be entered into the pump or pump system (depending on the type of pump), even if no bolus is about to be given. This allows the pump software to contain a full BGL history which is important for reviews and adjustments.

At first **up to 8 BGL readings will be required routinely per day**, with extra readings if something of concern is happening. The usual times will be:

- Before breakfast
- Before morning tea or 2 hours after breakfast
- Before lunch
- Before afternoon tea or 2 hours after lunch
- Before dinner
- Before supper or 2 hours after dinner
- Late evening
- 3am

Later this may be able to be reduced to 4 to 6 BGLs per day by omitting routine 3 am readings and one or more of morning tea, afternoon tea and supper. It is essential however to always test the BGL before main meals so that you can ensure that the correct bolus (carb bolus ± any correction bolus) is given.

#### **BGL** targets

Target ranges for BGLs for pump users are generally as follows. These are a little lower than for most patients on injections, although will be individualized by your diabetes team as needed.

Before meals and snacks	4 to 7 mmol/l
2 hours after a meal	5 to 9 mmol/l
Bedtime	5.5 to 8 mmol/l
3am	5 to 8 mmol/l



#### Continuous glucose monitoring systems (CGMS)

Continuous glucose sensors are now available which can be used alone or integrate with some pumps. These sensors are placed under the skin, much like a pump set is inserted, and sense the glucose level in the layer under the skin. This is then converted to a blood glucose value and is displayed on the device. Sensors now last up to 6 days before they need replacing. When CGMS is used with a pump, this is termed 'Sensor-augmented pump therapy'.

When people use continuous blood glucose sensors, less fingerprick BGLs may be required, but at least 2 to 3 per day are still needed. It is important to remember that the CGMS measure is not as accurate as a finger-prick BGL and there may be delays in recording changes in glucose levels, especially if BGL is rising or falling rapidly. The most important information that can be obtained from CGMS is about patterns and trends.

CGMS devices also allow high and low alarms to be set and this can be useful as a warning. We are likely to see an increase in the use of CGMS as technology improves and costs reduce. Currently, some people use CGMS regularly or continuously, while some use it intermittently to check on their patterns and make adjustments and rely on more fingerpricks at other times.

Your diabetes team will discuss with you the way in which you may be able to use and access CGMS.



Insulin pump with CGMS device which communicates wirelessly with the pump

## How to interpret and respond to CGMS information (information from Medtronic – REAL-Time methodology for starting patients on continuous glucose monitoring):

At the time of printing, one CGMS system is currently available in Australia (Medtronic CGMS), but more are likely. The Medtronic CGMS device records the glucose level every 5 minutes, so in effect this is a total of 288 readings per day. CGMS often reveals patterns that people have not been aware of; for example, rapid rise after some meals. It is important to understand when and how to respond to these. The following is a basic guide to interpreting CGMS information only, and you will be given more information and training if you start CGMS.

While the actual BGL is of interest, the trend is the most important thing. The Medtronic CGMS device gives an indication if the BGL is rising slowly or rapidly or falling slowly or rapidly by the use of one or two arrows. The time of day and relationship to food, exercise and insulin doses are important factors in interpreting the data.

CGMS arrow indicators	Overnight	Pre-meal (about to eat, more than 3 hours since last meal)	After meal (early, first 90 minutes)	After meal (late, second 90 minutes)
	Take action	Probably fine	Probably fine	Probably fine
<b>↓↓</b> BGL falling quickly	Take action quickly	Take action	Take action	Probably fine
★ BGL rising	Probably fine	Probably fine	Probably fine	Take action
<b>↑↑</b> BGL rising quickly	Take action	Probably fine	Probably fine	Take action

Probably fine: no action needed except normal surveillance

**Take action:** watch carefully, check again soon with fingerstick BGL; extra glucose or insulin may be needed

**Take action quickly:** confirm with a finger stick reading and treat with glucose or insulin as needed

- ✤ Indicates BGL has decreased 1.1 to 2.2 mmol/l over the last 20 minutes
- ↓↓ Indicates BGL has decreased more than 2.2 mmol/l over the last 20 minutes
- ↑ Indicates BGL has increased 1.1 to 2.2 mmol/l over the last 20 minutes
- ↑↑ Indicates BGL has increased more than 2.2 mmol/l over the last 20 minutes

#### Other important principles with CGMS:

- It takes time to gain experience and understanding of CGMS
- Initially people are often surprised at how much fluctuation in BGL they see
- Don't over-react to changes
- Initial recommended settings for the low alarm is 4.5 mmol/l and for the high alarm is 13.3 mmol/l

#### Hemoglobin A1c targets

Recommendations are the same as for patients on insulin injections and is less than 7.5% at all ages. However, the lower the better, provided that there are not significant hypoglycaemic episodes occurring.

Even if this target cannot be achieved at times, any lowering toward this is associated with significant reduction in risk of long term complications.

## **Measuring ketones**

It is important to measure ketones whenever the BGL is 15 mmol/l or above, or during any illness. High blood glucose with ketones indicates insulin deficiency which needs to be acted on without delay (see later). In these situations continue measuring ketones every 2 to 4 hours until they disappear.

Ketones are best measured in the blood using particular blood glucose meters that measure BGL and can also measure blood ketones with separate test strips. The measurement of blood ketones is preferred as this gives a much earlier warning of ketosis and changes in ketone levels. Ketones can also be measured in the urine using ketone test strips if blood ketone testing is not available.

## Food and carbohydrate counting

It is s a good idea for all people starting on a pump to be reviewed by the diabetes dietitian before the start date and there will usually also be dietary education during the pump start process.

#### There are some particular points about food for pump users:

#### Carbohydrate counting

- Counting carbohydrate quantities (in grams or exchanges) is particularly important for people using pumps. It is very important to know how many grams of carbohydrate or exchanges (one exchange = 15 grams of carbohydrate) you are about to eat, since the bolus of insulin is adjusted accordingly. In general, all carbohydrate eaten should be bolused for, unless there is a specific reason not to, e.g., when treating a hypo or before sport.
- To assist with precision of carbohydrate counting, it is recommended that you use standard household measures (measuring cups, spoons and kitchen scales) to help work out serving sizes when you first start on a pump. Afterwards, it is still a good idea to measure foods sometimes to make sure that you are estimating correctly, especially as your child grows and eats more.
- Try to estimate as accurately as possible even a 5 g amount of carbohydrate can make a difference and should be estimated.
- Some meals are hard to quantify the amount of carbohydrate, especially restaurant meals and others where you cannot know the ingredients. All you can do in this situation is make an estimate (under-estimate if anything) and make a correction later if needed.
- It is important to have a good knowledge of reading food labels
- Your pump will be programmed with your carbohydrate factor/s and you will generally use the bolus calculator or wizard to assist in determining the bolus dose to cover a given amount of carbohydrate

#### Square and dual-wave boluses

- You will probably notice that different carbohydrate-containing foods have different effects on your BGLs and this is the concept of glycaemic index (discussed in chapter 6).
- A low glycamic index meal (i.e., carbohydrate is absorbed slowly and over a longer period of time) may be best suited to a **dual wave (also called combination wave) bolus**. In this type of bolus, a proportion of the calculated insulin dose is given immediately and the remainder is delivered gradually over a longer period. Low GI / high fat meals are often in this category.

Example: Justin knows that when he has pizza on Friday nights, a standard bolus tends to make him have a low BGL early on and then a high BGL hours later. This is because the pizza meal is high in carbohydrate, but low in GI. His dietitian advises him to try a dual wave bolus. He tries a dual wave bolus with 50% of the insulin given immediately and the remaining 50% over the next 4 hours. He finds this keeps his BGL smoother and nearer to target. The parameters chosen could be adjusted as needed and might need to be different for other people or other meals. Your dietitian wll advise.

• **A square wave bolus** delivers the calculated insulin bolus over a longer period of time as set by the user, without an initial bolus immediately. This can be useful for a long meal or extended snacking and is also helpful for some individuals with delayed gastric emptying (rare in young people).

#### Flexibility with food intake on a pump

- Pump users do not have to eat between meal snacks (mid-meal snacks) and often this suits teenagers and young adults. Your dietitian will advise.
- Meals and snacks can be more flexible, but avoid the temptation of having no routines as this will make good control difficult to maintain.
- Be careful of the temptation to eat lots of extra snacks. Even though with a pump these can be covered with extra insulin boluses, they will lead to excessive weight gain.
- Healthy balanced eating and regular exercise are important in assisting with blood glucose control and maintaining a healthy weight.

### High blood glucose levels and sick days

#### High blood glucose levels

High blood glucose levels will occur from time to time and have to be taken very seriously in pump users, more so than people on injections. This is because pump users do not have any background reservoir of long-acting insulin and diabetic ketoacidosis can develop more quickly.

## It is essential for pump users to always carry rapid-acting insulin in a pen or with a syringe that can be given if there are problems with the pump or infusion set.

Reasons for high blood glucose levels may include:

- 1. Problems with the infusion site, cannula, tubing, syringe, insulin or pump ALWAYS CHECK FOR THESE FIRST
- 2. Extra carbohydrate intake, not adequately covered by a carb bolus
- 3. A missed carb bolus
- 4. Illness e.g., infection, causing BGLs to rise
- 5. Basal rates or carb boluses too low

#### In the event of an elevated BGL (15 mmol/l or above), do the following:

1. Immediately check for problems with the pump or delivery system. Starting by checking the infusion site for redness, swelling or leaking. Check along the infusion line for kinks or leaks. Check that there is still insulin in the pump syringe and check the pump for error messages. The operation of the pump can be checked by DISCONNECTING your infusion set and setting a priming dose of 5 units and watch for drops coming out of the line.

If there is any doubt about the insulin (e.g., temperature damage), infusion set or cannula, change these and insert in a new site without delay. If you don't think your pump is working, remove the pump and infusion set and proceed to give an injection of rapid-acting insulin with a pen or syringe.

- 2. Check for ketones (blood preferred, or urine) if BGL is 15 mmol/l or above.
- 3. How you proceed will depend on the ketone result:

If ketones are negative or small	If ketones are moderate or high (urine)
(urine) or less than 0.6 mmol/l	or more than 0.6 mmol/l (blood), or
(blood)	you don't think your pump is working
<ul> <li>Try a correction bolus with the pump.</li> <li>Test the BGL hourly</li> <li>Drink extra low calorie fluids</li> <li>If BGL is lower after 1 hour, recheck again in 1 to 2 hours to decide if another correction bolus is needed</li> <li>If the BGL is not improved 1 to 2 hours after the first bolus proceed to give an injection with a pen or syringe (see column 2). i.e., do not attempt multiple corrections with the pump if the BGL is not falling - use a pen or syringe injection so you know 100% that the insulin is getting in.</li> </ul>	<ul> <li>You may have a pump delivery problem or be developing a significant illness</li> <li>Use injected insulin given with a syringe or pen to correct the blood glucose level. The dose can be calculated as either: <ul> <li>10-20% of total daily dose (use the 20% dose if ketones are moderate to large in the urine or &gt;1.5mmol/1 in blood), or;</li> <li>By calculating a dose using the correction factor that your pump uses (sometimes with the addition of an extra 10-20% of the calculated dose because the body is less sensitive to insulin in this situation, especially if moderate to large ketones are present*)</li> </ul> </li> <li>Extra rapid-acting insulin doses can be given every 2 hours if needed.</li> <li>Drink extra, low calorie fluids or water</li> <li>Test the BGL hourly</li> <li>Replace the insulin in your pump and infusion set and cannula, but until the situation is under control you cannot use or rely on your pump</li> <li>If after 2 hours there is no improvement or you suspect a significant illness call your diabetes team or doctor</li> <li>If after 2 hours the BGL is improved you can resume the use of your pump. Remember if you now use the pump. Remember if you now use the pump. If within 3 hours of a pen injection you may need consider reducing the correction bolus suggested by the pump.</li> </ul>

\* You may find that during periods of illness you need larger boluses than your "usual" correction boluses to overcome the insulin resistance that can occur or use temporary higher basal rates.

#### Example:

10 year old Kate tests her BGL on waking and finds the level to be 21 mmol/l and her ketones 1.5 mmol/l. On checking, she finds that her set has become dislodged. Her TDD on the pump averages 32 units and her correction factor is 3.5 (meaning that 1 unit of insulin lowers the BGL by 3.5 mmol/l when correcting). She needs to give a pen injection and can calculate this in one of 2 ways which usually gives a similar suggested dose:

- 1. 10-20% of TDD. Since ketones are only moderate she opts for a dose of 4 units, which is between 10 and 15% of her TDD, or
- 2. using the correction factor from the pump, to bring the BGL down from 21 to 6 mmol/l, calculates as (21-6)/3.5 = 4.2, so again 4 units.

#### Sick days

Most pump users will have previous experience of dealing with sick days, and general principles are covered in chapter 10. Important points are summarized here, especially as they apply to pump users:

- Illnesses can cause *high blood glucose levels* (usually viral or bacterial infections with fever), or low blood glucose levels (usually gastroenteritis illnesses)
- Have a *sick day kit* available which should include: extra supplies for BGL and ketone testing, rapid-acting insulin and pen or syringe, glucagon for injection, sugar-containing and low calorie fluids, a thermometer, medication for fever, e.g., paracetamol, contact numbers for your doctors and pump team
- **Never omit insulin.** Even if you are unable to eat you still need to have some insulin (see below for adjustments). Keep the pump on unless you have switched to insulin via injections.
- Test the blood glucose more often, every 2 hours or so during the illness
- Test for ketones in the blood (preferred) or urine whenever the blood glucose is above 15 mmol/l and continue checking every 2 to 4 hours until ketones are cleared
- Treat the underlying illness see your doctor if the cause of the illness is unclear or you are very unwell or becoming sicker
- Drink more fluids (water or low calorie) if the BGL is high and/or ketones are present. This will help the BGL fall and ketones to clear.
- Parents or partners should take over or assist with management and decision making if the person on the pump is too unwell to make appropriate decisions

#### • If blood glucose levels are high (above 15 mmol/l)

Give extra boluses of insulin to bring the BGL down – use pump or pen depending on whether significant ketones are present as outlined in the earlier table. Extra doses may be required as often as every 2 to 3 hours. It will often be necessary to also increase the basal insulin rate during an illness where BGLs are tending to be high. Use the temporary basal rate to increase the basal to 125 to 150% of the usual basal; set this for 4 or 6 hours initially and then review, based on BGL progress.

#### • If blood glucose levels are low

Treat hypos in the usual way. If you are eating and drinking less your meal boluses will be less anyway. If you are not absorbing food well because of the illness, carb boluses may need to be even less than your usual ratio – consider weakening by 25% in the first instance. If BGLs continue to trend low, it may be necessary to reduce the basal rate. Use the temporary basal rate to decrease the basal rate to 50 to 75% of the usual basal rate; set this for 4 or 6 hours initially and then review, based on BGL progress.

- Call for help or go to the hospital if:
  - Persistent nausea or vomiting or becoming more unwell
  - Unable to clear ketones
  - Unable to keep BGL below 15 mmol/l or above 4 mmol/l
  - You are worried, exhausted, too unwell to decide on doses or just don't know what to do next.

#### Sick day examples:

#### Example 1:

Sarah is unwell with tonsillitis. Despite eating little her BGLs are running high. Corrections have partially worked.

Her mum runs a temporary basal rate of 150%, initially for 4 hours, with frequent BGL monitoring.

#### Example 2:

Mario has gastroenteritis. Vomiting has stopped and he is drinking but still has some diarrhea. He sips Gastrolyte during the day.

His mum finds that adequate BGL is maintained using temporary basal rate of 50% until he starts feeling better that evening.

## Hypoglycemia

All people with diabetes will have hypoglycaemia (hypos) at times. Hypoglycaemia can occur for the following reasons:

- Too much insulin
- During or after exercise
- Eating too little carbohydrate or overestimating the carbohydrate content of food
- Using large or frequent boluses to bring down high BGLs
- After alcohol intake

Overall, most successful pump users have less hypoglycemia, particularly less episodes of severe hypoglycemia. However hypos are still a very important issue. **Pump users may experience more subtle symptoms of a hypo**, thought to be because of a reduction in overall BGLs and less extreme BGL swings. Most also find that less carbohydrate is needed to treat a hypo, compared to when they were on injections, however this partly depends on the cause of the hypo.

#### Treating a mild hypo

The amount of carbohydrate will depend on the size of the person and the reason for the hypo episode; hence a range is given as was also discussed in chapter 8 'Hypoglycaemia'. Slightly lower amounts of carbohydrate treatment for hypos are suggested for pump users, but it is important that you learn what you or your child needs for their individual circumstances.

1. Take 8 to 15 grams (half to one exchange) of fast-acting carbohydrate, such as:

- Glucose tablets 8 to 15 grams
- Fruit juice, ordinary soft drink or cordial 100 to 200 mls
- Lucozade 50 to 100 mls
- 2-3 teaspoons of sugar or honey
- Jelly beans: 3 to 5 large or 6 to 10 small (note jelly beans vary in size)

(Note: avoid the use of glucose tablets, jelly beans or other sweets in children under 5, because of choking risk)

- 2. Repeat the BGL in 15-20 minutes. If not above 4 mmol/l, repeat the treatment
- 3. Often it is not necessary to have additional slow-acting carbohydrate since this may make the BGL overshoot. This will depend on whether a meal is due soon and the circumstances of the hypo. If vigorous exercise was a contributor, there has been more than one hypo that day, the BGL was very low or a significant bolus has been recently given, it is wise to eat extra slow-acting carbohydrate as well
- 4. If a hypo occurs close to when a meal is due, treat the hypo first and recheck the BGL. Provided that the BGL has come up and there is no known reason to suspect further lows, usually the normal carbohydrate bolus for the meal would be given. If the BGL is slow to come up, it is wise to delay the meal bolus and consider reducing it a little.

#### Treating a severe hypo

In the event of a severe hypo with coma, seizure or where the person is too drowsy to safely eat or drink, a glucagon injection must be given and the ambulance called. The pump should be disconnected (using the quick release) if possible, but this is not essential. The diabetes team should be contacted without delay.

#### Frequent or recurrent hypos

This will usually mean that there is a major problem with basal rates or bolus doses. Reduce your total daily dose (TDD) by 10% by reducing your basal rates and weakening your carbohydrate bolus and correction factor (insulin sensitivity factor) all by about 10% and contact your diabetes team for further advice. A recalculation of your basal rates and bolus doses will be needed.

#### Hypoglycemia unawareness

As mentioned above, hypo symptoms may not be as obvious in pump users but should still be present and easily recognised. If you find that you are not recognising lows that are only evident on testing or when pointed out by others, this is hypoglycaemia unawareness. You should discuss with your diabetes team without delay. You will be able to continue with the pump, but target blood glucose levels will be raised for safety and to allow hypoglycemia awareness to return.

### Exercise

Since exercise generally lowers the blood glucose during and after, adjustments are made by having less insulin, more carbohydrate, or a combination of both. The amount of adjustment required depends on the duration and intensity of the exercise. Clearly, mild exercise and short duration will require less or perhaps no adjustment compared to intense exercise and long duration which may require major changes.

Adjusting for exercise is very individual and doing extra BGL tests before, during and after exercise will help guide you. Remember that high intensity exercise for short periods sometimes puts the BGL up temporarily due to a "stress or adrenaline response", but this usually falls afterwards without the need for a correction dose.

The pump is best left on for exercise with adjustments as below, but for vigorous, contact or water activities the pump will need to be disconnected.

#### Pump-on, reduced basal rate, ± extra carbohydrate

This is the strategy that tends to be most useful. A useful starting point is to **reduce the basal rate to half the usual rate** for the duration of the exercise and for one hour after, using the temporary basal rate feature. If the exercise is planned, the basal rate can also be reduced for 1 to 2 hours beforehand. After vigorous and prolonged exercise a **reduction in the overnight basal rate** may also be needed by 20-30% or sometimes more.

During the exercise, **additional carbohydrate** (which is not bolused for) may also be needed e.g., 8 to 15 grams (half to one exchange) every 30 minutes or so, often best in the form of juice or sports drinks.

#### Bolus insulin adjustment with exercise

If vigorous exercise is going to be performed within 2 hours after a meal, a reduction in that pre-meal bolus may also be needed. Start with a 25 % reduction and make adjustments from there on the basis of what you learn from BGLs.

#### **Pump-off for exercise**

Most sets allow the pump to be easily removed for contact and vigorous sports or for swimming. An alternative is to use a Sportguard case which protects the pump from any damage.

The pump **can usually be disconnected for up to 2 hours if exercising**, without problems. After one hour the BGL needs to be checked. If the BGL is rising then the pump can be reconnected and the previous hours basal insulin given as a manual bolus and the pump then disconnected for the next hour. On reconnecting again the same may need to be done again. Unless exercise is mild only, the basal amounts of insulin used here should be 50% of the usual doses.

Some people find it necessary to give a small bolus before disconnecting – the starting point for this is also to give 50% of the basal insulin that would be infused over the time period (1 or 2 hours).

#### **Exercise examples:**

#### Example 1:

Alison does 2 hours of dancing on Tuesday evening. Despite using 50% temporary basal during, she still goes low during or afterwards. So, in addition she has 15g of her dinner carbohydrate unbolused and uses 50% temp basal rate for 4 hours. This works well for her for this activity.

#### Example 2:

When Tom goes bushwalking all day with the Scouts he finds it works well to reduce to temporary basal of 60%, eat regular CHO, but only bolus for approximately half of it.

#### Example 3:

Michael does basketball on Tuesday nights. He is often high at the end of the game and corrects. Even though he has an extra snack before bed he is having late evening hypos.

Advice – it is very important not to correct highs immediately after sport; often this is a temporary high related to the adrenaline effect of sport and it settles by itself after 30 to 60 minutes after cooling off and having some water. Giving a correction bolus at this time is usually not needed and can cause a major hypo. It is decided also to use a temporary basal rate of 70% for 8 hours and adjust this as needed over the next few weeks based on monitoring.
# Pump discontinuation – using injections again

If you need to remove or stop using your pump for any reason, you need to start having insulin injections by syringe or pens. This will be both rapid or short-acting and long-acting injections, so you need to have these available for when they may be needed.

All people on pumps need to carry rapid-acting insulin with a syringe or pen at all times. Long-acting insulin needs to be readily available but not necessarily carried with you.

It is very important that you keep a written or electronic record of your current pump settings somewhere in case the pump breaks-down and has to be replaced. You need to know these settings to re-program the pump. We give the following disconnection advice:

#### 1. Short periods of disconnection:

If disconnection from the pump is only going to be for part of a day, use doses of rapid acting-insulin via a pen every 2 to 3 hours in a dose that gives you your basal requirements for the next 2 to 3 hours, covers your carbohydrate intake and gives any correction that is needed. In this case, use the rates and formulas from your pump.

#### 2. Longer periods of disconnection:

If disconnection is necessary for a longer period, you will need to switch to a combination of **long-acting** and **rapid-acting insulin**. You must always have supplies of these available. Lantus or Levemir are both suitable long acting insulins. Remember that these have a duration of action approaching 24 hours, so if you reconnect your pump within 24 hours of a long-acting dose, basal rates may need to be run at or close to 0 until the injected long-acting insulin effect has worn off (use temporary basal rate feature, for example at about 10% temporary basal).

There are 2 ways to choose from. Calculations are made from the usual average total daily dose (TDD) on the pump:

#### 1. The preferred method, especially if pump will be resumed soon

- Give a dose of long acting insulin (Lantus or Levemir) once every 24 hours to cover the **basal insulin** needs. This can be either before bed (usually better in teenagers) or before breakfast (younger children). The long acting insulin dose is about 40-50% of the usual average total daily dose (TDD) on the pump.
- For *carbohydrate and corrections* use a rapid acting insulin pen (NovoRapid or Humalog) with the dose calculated using the carbohydrate and correction factors that you use in your pump.
- 2. Alternate method; more suited if there will be a longer period of not using the pump
- Use long-acting insulin to cover the basal needs, calculated in the same way as above.
- The remaining 50-60% of the insulin total daily dose (TDD) is split into 3 pre-meal injections of rapid-acting insulin, as follows:

	Pre-breakfast	Pre-lunch	Pre-dinner	Usually once daily - pre-bed OR pre-breakfast
Rapid insulin				
NovoRapid or Humalog	15-20% of TDD	15-20% of TDD	15-20% of TDD	
Long-acting				40-50% of TDD

- This is a starting point only and adjustments are then made according to monitoring, food intake, exercise etc. Extra monitoring is essential to guide these adjustments, including overnight monitoring initially, since this is a significant change to therapy.
- Some people find it necessary to split the total amount of the long acting insulin into two doses (morning and night), but the above is a good starting point.
- Consult your diabetes team if you are not sure or having trouble adjusting the doses.

## Most frequent challenges for pump users

Having type 1 diabetes presents many challenges for young people and their families. Here is a list of the commonest issues that arise with pump therapy. Knowing these might help you avoid some problems.

#### 1. Bolus problems - missed, late or poorly estimated

Forgetting to bolus is the commonest problem we see in insulin pump therapy, especially in teenagers. There are many reasons for this relating to human nature and behaviour, which need to be explored for each person. Missed boluses are a major reason for poor diabetes control and families need to work to ensure optimal bolusing. Every time a food bolus is missed, this is also a missed opportunity for a correction bolus. If diabetes control is suboptimal and there are significant missed boluses, this can lead to inappropriate adjustment of pump basal rates or other settings – usually the bolusing problem should be addressed first before making any other adjustments.

#### 2. BGL testing

Not enough BGL testing is a common issue. A minimum of 4 BGL tests per day is recommended, but preferably more. Testing before eating main meals is always important because it allows a correction bolus to be added to the meal bolus. Remember always to do extra testing around exercise, sick days and occasionally at night. There is strong evidence that people who do more BGL testing have better diabetes control.

Continuous glucose monitoring systems (CGMS) are now available which can offer great benefits in profiling BGLs and reduce the number of finger-stick BGLs required, although cost is currently a limiting factor.

#### 3. Record keeping fatigue

Whichever pump is being used, it is important that BGLs and changes to pump settings are being recorded somewhere. This may be electronically via a pump download, on a computer spreadsheet or in Diabetes Record book. Any of these methods can work well. The key reason for recording well is so that you can detect patterns or problems as they emerge and make appropriate adjustments and also so your diabetes team can advise you based on accurate and complete information.

#### 4. Pump setting adjustments

Sometimes it can be difficult to know which settings need adjustment in your pump over time – basal rates, carbohydrate boluses or correction boluses or perhaps all. In general, as children grow, all insulin dose settings need to be increased proportionally (i.e., increased basal rates, stronger carb ratios and stronger ISF or correction settings). You will gain experience with this over time and your diabetes team will continue to guide you. An important principle to remember is that most settings and ratios should not vary widely from those discussed earlier and most individuals do not require complicated rate settings.

#### 5. Response to hyperglycemia and sick days

It is very important to have a practiced response to high BGLs and sick days, as covered in other sections. This is important to avoid diabetic ketoacidosis and other problems and hospital admissions.

#### 6. Exercise

Unstable blood glucose levels (highs or lows) around exercise are a common problem, but can be minimized with thought and planning according to the principles outlined earlier. Extra BGL testing or CGMS around exercise will help you fine-tune the approach for your particular activities. Your diabetes team can help you with this too.

#### 7. Site and set issues

The most common problem is forgetting to change the set every 3 days. Data shows that 3 days is the optimal time to leave a set in and then it should be changed. After 3 days, insulin absorption characteristics change and BGLs become less stable. If there are problems with the sets not sticking well or skin reactions, your diabetes team can advise on other options.

#### 8. Back-up plan for acute events

Have a plan for when something goes wrong. This includes knowing how to respond quickly to high levels, sick days, hypoglycaemia etc. It also involves knowing who to call if your pump fails and how to temporarily change over to injection therapy. For pump technical issues, contact the pump company. For diabetes management and health issues, contact your diabetes team.

### Obtaining supplies and service back-up

Mostly supplies will be obtained via the NDSS through your Pharmacy or Diabetes Australia. The supplies that will be routinely needed are:

- infusion sets
- reservoir syringes
- alcohol wipes
- pump batteries (some models don't use standard batteries)

Some people may purchase additional special tapes if needed for sensitive skin etc. Supplies are readily available and shipped quickly but try to always keep at least a month ahead with your supplies to avoid running out. Insulin is provided on prescription via your doctor and pharmacy as usual.

In the event of pump breakdown, damage or other malfunction you need to revert to insulin injections without delay as per the "Pump Disconnection" information. Contact the insulin pump company as soon as possible for technical support. Usually it is possible to obtain a loan pump fairly quickly while your pump is being repaired.

## **Common questions and answers**



My 15-year-old son is erratic with his routines, often forgets his blood glucose testing and has overall poor diabetes control. Should we buy him an insulin pump in an attempt to improve his control?

No. Your son has difficulties with the basic routines of diabetes which are unlikely to be helped by a pump. Using a pump is likely to be more risky for him under these circumstances. Pump users need to be highly motivated and prepared to do four to six BGLs per day or sometimes more, and to work harder at their diabetes than average. Work with your diabetes team to improve your son's basic diabetes routines in an attempt to get improved control on his insulin injections.



#### My 11-year-old daughter works hard at looking after her diabetes and usually has a HbA1c around 8 %. Her doctor is very happy with her progress. She read about insulin pumps on the Internet and would like to go on a pump. Should we do this?

Your daughter sounds well motivated and would be a good candidate for an insulin pump. While her control level is reasonable, it is above the recommended target. It is possible that this could be improved with a pump and there would be other potential advantages in terms of flexibility of routines, meals and lifestyle. Ask for more information from your diabetes team. Even if she chooses not to go on a pump she should be able to achieve good diabetes control with insulin injections.



Our son is now 13 and he has had unstable diabetes control for the 12 years that he has had it. We have worked really hard at attempting to stabilise things and our doctor and diabetes team have tried many different insulin combinations and doses. He is always prepared to do as many tests as needed and is generally good with his food. Could a pump help us?

You should discuss this with your doctor and diabetes team, but your son sounds like a person who could benefit from a pump as long as he felt this was good idea.

# **Chapter 19 Complications**

# **Key Points**

- The risk of diabetes complications can be minimised by having good long-term diabetes control
- Screening for complications is important to allow early detection
- Smoking increases the risk of complications

In this section we discuss the long-term complications that can occur with diabetes and what can be done to reduce the risks. Older children and adolescents should be made aware of these gradually, at a level appropriate to their understanding. Risk of diabetes complications increases with longer duration of diabetes, poor blood glucose control, high blood pressure, smoking and if there is a history in the family of diabetes with complications. Complications are rare in children, but it is believed that good diabetes control from early on is important and helps establish good long-term habits. It is hoped that modern diabetes management techniques will mean that the rate of complications will be much lower, but serious complications are still sometimes seen in young people, especially when diabetes control is poor for long periods.

## Minimising the risk of complications

- Try to keep the blood glucose levels within the recommended range as much as possible.
- Ensure that your child has a haemoglobin A1c measurement approximately every three months, as a guide to long-term control. There is now strong evidence that for every degree of improvement in diabetes control, the risk of complications will decrease.
- Make regular visits to your diabetes doctor or clinic. These should be every three months but sometimes more often if control is not good.
- Your child should be physically active and maintain a healthy food plan.
- Discourage smoking. Smoking adds substantially to the risk of diabetes complications.

## **Complications screening**

Your doctor or diabetes educator will advise when this screening should start, but a common guideline is :

- Once a child turns 9 years old and has had diabetes for 5 years
- 11 years and over and has had diabetes for 2 years

This is often a comprehensive screening program through one of the major paediatric and adolescent diabetes centres and is usually recommended every 1 to 2 years. Complications screening allows the detection of very early signs of complications. If these are detected early, changes can be made to management that can stop them progressing or even reverse the complications. Early detection and prevention are very important.

## Long-term complications

Complications occur in diabetes because of the effects of higher than normal blood glucose levels on small blood vessels and nerves in the body and also because of the long-term effects on large vessels. It is not fully understood how diabetes causes complications but it seems to relate to effects of glucose binding irreversibly to small vessels and nerves and affecting the way they work (a process called glycosylation). Some brief information is provided here on possible long-term complications.

#### Eye problems

#### Retinopathy

The retina is the thin layer of tissue at the back of the eye which contains small blood vessels and nerve endings for vision. Retinopathy refers to damage to the retina. Minor changes to the retina are very common after 10 to 15 years of diabetes (non-proliferative or background retinopathy), but this does not impair vision. Of more concern is where there is progression to new blood vessel formation (called proliferative retinopathy). This can threaten vision. The progression of retinopathy is related to poor diabetes control and long duration of diabetes. It can be treated by laser treatment or may require surgery for complications.

Screening for retinopathy is done by an eye doctor (ophthalmologist), optometrist or a specialized diabetes complications service.



#### Temporary blurred vision associated with changes in blood glucose levels

Large changes in blood glucose levels can cause blurred vision and difficulty in focusing. This is common at the time of diagnosis when blood glucose levels which have been running high are brought under control or after a period of stabilisation where blood glucose levels are improved. The blurred vision does not last long and usually disappears after a few weeks. It does not cause any long-term damage. Any change in glasses prescriptions should be delayed for a while after large changes in blood glucose levels.

# Chapter

#### Cataracts

Cataracts are a clouding of the lens and are more likely to occur in people with diabetes but usually only in older people. These can be successfully treated by surgery.

#### Kidney problems (nephropathy)

The kidneys filter waste products from our bodies and pass them into the urine. Diabetic nephropathy refers to kidney damage that can be associated with diabetes, which again is a greater risk for people with poorly controlled diabetes over long periods. Risks are greater in those with high blood pressure or who smoke. Advanced nephropathy can cause kidney failure, requiring dialysis or kidney transplantation.

Major advances in detecting nephropathy mean that it can be detected at an early stage and treated effectively. Screening is done by testing urine samples for leakage of microscopic amounts of protein (called microalbuminuria). If early kidney damage is detected, the treatment is to improve diabetes control as much as possible and medications are given to slow or stop further kidney damage and to control blood pressure.

#### Nerve problems (neuropathy)

Diabetic neuropathy refers to nerve damage associated with diabetes. Again, the risks are highest in those with poorly controlled diabetes over long periods. Symptoms can include numbness or pins and needles, especially in the feet and lower legs. Neuropathy is uncommon in young people, but sensitive tests can detect minor neuropathy in young people with only fairly short periods of poor control. In the early stages neuropathy can be reversed with improved diabetes control. Screening for neuropathy is part of some complications screening programs and is always recommended if there is poor diabetes control.

#### Vascular disease

Older people with diabetes have an increased risk of heart attacks and strokes due to narrowing of or blockages in large blood vessels. Risks are greater in people with untreated high blood pressure, high blood cholesterol levels or who smoke. Large vessel narrowing can also occur in the penis, causing impotence (problems getting an erection) and in the legs, causing circulation problems.

Adolescents with type 2 diabetes or combination type 1 and type 2 diabetes are at a greater risk of vascular disease at an earlier age.

Blood pressure should be measured at least annually and screening for high cholesterol levels should occur every 1 to 2 years as part of complications screening.

#### Foot problems

Foot problems (due to decreased blood flow or nerve problems) do not occur in children and adolescents. However, children with diabetes should protect their feet from injury because scarring and other damage could cause problems in later life.



Foot injuries, plantar warts, calluses, corns and in-grown toenails may be more of a problem in children and adolescents with diabetes, since infections are more likely in a high glucose environment and will be slower to heal. Proper care of the toenails is important and shoes should be worn for sports and outside play. Any scarring on the soles of the feet can increase the risk of long-term foot problems. Any foot injury needs to be cared for properly.

It is important that problems with foot alignment (such as flat feet or high arches) are detected in children with diabetes, since these may lead to an increased risk of later foot problems and can be corrected if discovered early. A podiatrist assists with any such problems.

# Medical conditions that are of higher risk with diabetes

People with diabetes are at an increased risk of some other conditions, particularly thyroid gland problems, coeliac disease and more rarely, other autoimmune disorders such as adrenal disease and rheumatoid arthritis. These are all conditions with a similar cause to diabetes, where the body forms antibodies against certain tissues and causes them not to work properly (called autoimmune conditions).

#### **Thyroid problems**

An underactive thyroid gland (hypothyroidism) occurs in 3 to 8 per cent of children with diabetes. Symptoms and signs may include tiredness, weight gain, poor growth, problems with diabetes control and an enlarged thyroid gland (goitre). It may be difficult to detect without a blood test. If hypothyroidism occurs it is easily treated by giving replacement thyroid medication in tablets.

Overactivity of the thyroid gland (hyperthyroidism) is also a slightly increased risk with diabetes. Symptoms and signs may include weight loss, nervousness, increased appetite, tremor, problems with diabetes control and an enlarged thyroid gland (goitre). This also can usually be corrected by medications taken in tablets.

Most diabetes centres screen for thyroid problems with a simple blood test every 2 years in children with diabetes.

#### **Coeliac disease**

Coeliac disease occurs in about 5 per cent of children with diabetes and is another antibody-related (autoimmune) condition in which the body forms antibodies against the protein gluten which is found in the grains wheat, rye, barley, oats and triticale. These antibodies cause damage to the bowel lining which may cause poor absorption of food, poor growth, unstable diabetes and possible development of bowel tumours in later life. In many children, no symptoms may be evident except unstable diabetes control so most diabetes centres screen for coeliac disease at the time of diabetes diagnosis and with a blood test every 2 years or so.

Coeliac disease can be treated by diet changes which involve avoiding the grains containing gluten. This treatment is very effective, but adds an extra difficulty to diabetes care. Advice from a dietitian experienced in the area is essential.

## **Common questions and answers**



# My seven-year-old has had diabetes for two years. Does he need his eyes checked?

An eye check is generally not recommended in children under 9 years until they have had diabetes for five years. If your child has eye symptoms at any time, a check should be done, but these would be unlikely to be due to diabetes. Sometimes temporary blurring of vision can occur when blood glucose levels are changing a lot, but this soon goes away.



#### My 15-year-old daughter has had diabetes for ten years and poor control for two years and has some early eye changes and slight nerve changes in the feet. Is this serious?

These are warning signs of the diabetes starting to affect the body and these could progress to become more serious. The good news is that early problems can often be stopped or reversed if control is improved, so this is the most important thing. Any improvement in control, even if only small, is of benefit.



#### My 16-year-old son asks why he should work hard at his diabetes when he is going to get complications anyway.

This is a rather pessimistic attitude, and is sometimes used as an excuse to avoid good diabetes care. Be open and honest with your son. You need to say to him that diabetes complications can occur with long duration of diabetes or poor control, but that risks are minimised with good control and can be decreased with any improvement in control. Also be optimistic that with modern diabetes management, long-term complications are expected to be less, and that major improvements in management or even a cure are real possibilities in the next decade or so.

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# Chapter 20 Research and Future of Diabetes Management

Around the world, major research efforts and funding are being invested in diabetes, with the aims of:

- finding a cure for diabetes
- identifying those at risk for diabetes and preventing the onset of diabetes
- improving management techniques until a cure is found. This includes:
  - development of new and better insulins
  - development of better ways of giving insulin (insulin delivery)
  - development of better blood glucose monitoring equipment, including non-invasive blood glucose monitoring (i.e., measuring the blood glucose without having to do a finger prick) and more use of continuous glucose monitoring
  - minimising the risk of long-term complications.

# Finding a cure for diabetes

A cure for diabetes would be a treatment method that replaced the insulin-producing capabilities of the pancreas. This would mean that insulin injections would no longer be required and blood glucose levels would be able to stay in the normal range.

Currently, the most promising research is in cell replacement in which insulin producing cells would be injected into people with diabetes. These take over the glucose-sensing and insulin-producing functions of the pancreatic beta cells. These replacement cells could be beta cells from humans or animals, or may be newly created (bio-engineered) cells with the properties of beta cells. There is much interest in the potential of stem cell research as a source of these cells for a diabetes cure.

Much progress is being made in this field, but the main problems are with long-term survival since the cells are easily rejected. Beta cell transplantation is still a highly experimental area and is not yet suitable for trial in children or adolescents. Bio-engineered cells and stem cells are showing promise but also require much more development.

Other areas of research include using immune modulating drugs to try to extend the remission phase ("honeymoon period") by preventing ongoing destruction of the remaining beta cells immediately after diagnosis.

The artificial mechanical pancreas has also been a dream of modern technology and some progress is occurring in this area, particularly with external systems. Limiting factors to be overcome are the reliability and accuracy of continuous glucose monitoring systems, the time taken for insulin to be injected and start to act and the lack of other adjusting (counter-regulating) hormones such as glucagon. Implanted artificial systems have the additional problems associated with any long-term implanted devices.

Whole pancreas transplants are possible, are often successful and may lead to people coming off insulin injections. However, this procedure has significant risks of permanent health problems or death. It is usually only available to adults with advanced diabetes complications with kidney failure who also require a kidney transplant. Long-term anti-rejection drugs are needed that can have many sideeffects. As yet, it is not a suitable option for children and young people.

# Chapter

## **Diabetes prevention**

Medical researchers have aimed for a long time to identify people who may be at risk of diabetes (pre-diabetes) and find a way of preventing diabetes developing. This research involves finding out more about the cause of diabetes, finding ways to predict who may get diabetes and trying treatments that could prevent the onset of diabetes.

Most studies have concentrated on screening relatives of people with diabetes by antibody tests and other blood tests. Where high risk factors are found, experimental treatments have been tried to prevent diabetes. At present, no preventive treatment has been proven to be safe and effective. Some are showing promise and active trials are continuing. Routine testing of relatives of people with type 1 diabetes is likely to become more routine. Screening of all children would be a much more difficult task, but may be possible in the future.

You should discuss with your diabetes specialist the pros and cons of having other children in your family tested for diabetes risk. This is likely to be a rapidly developing area of research.

### Improving management techniques

Until a prevention and cure are available for diabetes, it is likely that there will be many improvements in the way it is treated. These are likely to include:

- New insulins: Manufacturers are continually working on new insulins that work better or have more suitable action profiles. New rapid-acting insulins (Humalog, Novorapid and Apidra) and new long-acting insulins (Lantus and Levemir) have been released over the past few years and been helpful for many people. Other new insulins are under development.
- Inhaled insulin: Techniques have been developed that allow short-acting insulin to be inhaled into the lungs. These have been under clinical trial in patients with both type 1 and type 2 diabetes and results have shown equivalence in diabetes control, however concerns remain about the long-term effects upon lung function, cost and convenience of use.
- Insulin pumps: Insulin pumps are discussed in chapter 18. Improved pump technology and knowledge are making this an increasingly popular form of therapy although it does not suit everyone. Pump manufacturers are making major efforts to develop and refine technologies in which continuous or frequent automatic blood glucose readings feed into insulin pumps and make a semi or fully automated system.
- Blood glucose measurement technology:

#### Continuous glucose monitoring (CGM)

Technologies that allow very frequent or continuous BGL readings have been developed and are currently available as discussed in chapters 7 and 18. Users can receive information about their tissue glucose levels every 5 minutes. Much greater information is provided on blood glucose profiles and alarms can be set for rate of change and high and low BGLs. Currently, the cost of these technologies is relatively high, although we can expect to see greater use and further technical advances over the coming years.

#### Non-invasive blood glucose monitoring

Major efforts are being put into new and easier ways of testing the blood glucose. This is called non-invasive or minimally invasive blood glucose monitoring. It would be able to measure the blood glucose levels without having to prick the finger and may be a reality within a few years.

- Prevention and treatment of complications: New drugs and other ways of preventing and treating diabetes complications are in constant development.
- Information and education: It is a continuing goal in Australia and other countries to provide better information and education for people with diabetes.
- Psychological research: More research is needed about the way psychological aspects interact with diabetes management and the psychological impact of chronic conditions such as diabetes.



# **Chapter 21 Resources**

A wide variety of sources of additional information are available. Your diabetes team will advise you which additional resources they recommend.

Here are some commonly used sources of information:

# **Diabetes organisations**

#### **Diabetes Australia**

Diabetes Australia is represented in all states of Australia – contact numbers can be obtained from your diabetes centre or telephone directory services. A number of support services are available.

#### Juvenile Diabetes Foundation Australia (JDFA)

JDFA is represented in all states – contact numbers can be obtained from you diabetes centre or telephone directory services.

#### Your local hospital health information unit and diabetes centre

Your local team will advise of which resources are recommended and where to obtain them

# **The Internet**

There is a large amount of information about diabetes on the Internet. Much of this is useful and interesting, but be aware that the quality of information can be very variable. Always look at the organisation that is running the site as this will be a guide to how reliable the information is likely to be. For example, sites such as the American Diabetes Association, Juvenile Diabetes Foundation or those of major children's hospitals or universities are likely to be of high quality. A lot of what you may read on the Internet will apply to type 2 diabetes, so be careful to distinguish this.

If you come across material you don't understand or that disagrees with what you have been told, discuss this with your diabetes team. If you don't have access to the Internet, don't worry. New developments and information are always available through your diabetes team who keep in close touch with the latest information and technology from around the world.

Some have already been listed in the relevant sections of this resource and we have listed a number below. You will find many others if you look.

#### www.diabeteskidsandteens.com.au

The Diabetes Australia NSW website for kids and teens with type 1 diabetes

#### www.jdrf.org.au

The Juvenile Research Foundation of Australia website

#### www.diabetes.org

The American Diabetes Association website

#### www.diabetes.niddk.nih.gov

The National Diabetes Information Clearinghouse of the USA. A service of the National Institutes of Health.

www.diabetes.org.uk The website of Diabetes UK.

#### www.kidsdiabetes.org.au

The website of this book.

#### www.sweet.org.au

Sweet is an on-line site designed to assist with transition from paediatric to adult services.

#### www.gyst.org.au

Another website for those approaching transition. The various life issues at this stage are covered in a fun award-winning video with a great soundtrack showcasing some latest Australian musical talent.

### Books

Numerous books are available about all aspects of diabetes and its management. Your diabetes team will advise which they recommend for local use.

# Videos / DVDs

Several on-line videos which you may find useful are referred to in this resource and are summarized here:

#### **Diabetes Type 1 and Insulin Production**

Etsuko Uno and Drew Berry, Walter and Eliza Hall Institute of Medical Research, 2009

This animation illustrates how insulin is normally produced in the body and how its production is destroyed in type 1 diabetes

www.wehi.edu.au/wehi-tv/dna/index.html

# Here we go 'round the Mulberry bush- Positive parenting of toddlers with diabetes

ERC Media, Educational Resource Centre, Royal Children's Hospital, Melbourne, 2002.

This video focuses less on the physiological aspects of the condition and more on the issues of coping day to day with a toddler with diabetes. It is recommended viewing for parents, families and friends of young children who have been recently diagnosed.

View via the link at www.kidsdiabetes.org.au

# Chapter

ERC Media, Educational Resource Centre, Royal Children's Hospital, Melbourne, 2004.

In this video, parents, students, teachers and health professionals share their insights and tips for successful diabetes management at primary school and pose new questions about where the teaching profession is heading in terms of taking on additional responsibility for the medical needs of students.

View via the link at www.kidsdiabetes.org.au

#### Loco parentis - Managing diabetes at secondary school

ERC Media, Educational Resource Centre, Royal Children's Hospital, Melbourne, 2004.

This video discsuses similar issues, but in the secondary or high school environment.

View via the link at www.kidsdiabetes.org.au

#### GYST - a life guide for young people on the move

ERC Media, Educational Resource Centre, Royal Children's Hospital, Melbourne, 2006.

GYST is a fresh, new holistic approach to the complex process of transition. It is a comprehensive 'life guide' covering all the most important aspects of getting set up in adult life with specific information for young people living with diabetes. It is packed full of valuable information that every young person needs to know.

www.gyst.org.au

#### WWYCD (Wicked) - Your Get-Up-and-Go Guide to Living with Type 1 Diabetes

ERC Media, Educational Resource Centre, Royal Children's Hospital, Melbourne, 2009.

WWYCD. clearly lays out the benefits of maintaining regular exercise and, when motivation is low, encourages young people to consult the one person who can truly assist them to develop and maintain a healthy fitness regime for life.

View via the link at www.kidsdiabetes.org.au

#### Spreading our wings - the diabetes camp experience

ERC Media, Educational Resource Centre, Royal Children's Hospital, Melbourne, 2005.

Experiences of diabetes camps told from the parents and child's or adolescent's perspective

View via the link at www.kidsdiabetes.org.au