

# The Leeds Insulin Pump Workbook for Children and Young People







A service for children and young people with diabetes



This project has received funding from Medtronic





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Welcome to your insulin pump workbook. It aims to offer background information to support you and your child starting on insulin pump therapy. This workbook should be used with the instructions and book issued with the pump you have chosen.

The workbook contains information on a range of topics, from what an insulin pump is to tips on diet, counting carbohydrates and travelling with the pump.

At the end of each section you'll find a worksheet section where you can enter information related to your child's diabetes, followed by questions based on the information in that section.

We hope you find this workbook useful. If you have any questions regarding its contents, or can't find a particular piece of information here, please contact your child's healthcare team to discuss it with them.



# About this workbook

Developed by Carole Gelder, Frances Robson, Dr Philip Holland, Dr Fiona Campbell and the Leeds Children's Hospital Diabetes Team on behalf of the Yorkshire and Humber Children and Young People's Diabetes Network and the Diabetes Education Network. Thanks to Mrs Penny Robinson for her review and contributions.

In part adapted from the adult insulin pump workbook by Joan Everett and Dr Helen Lockett on behalf of Diabetes Education Network.

Sponsored by the Yorkshire and Humber Strategic Health Authority as part of the Healthy Ambitions project.

The information in this workbook should be used only as a guide. It is not a substitute for consulting with your Children's Diabetes Team.

Every effort has been made to make sure the information in the workbook is correct. However, it is the responsibility of the local Diabetes team to make sure they are happy with the information in the workbook and that the information given to patients and parents is correct and in line with local recommendations.

1<sup>st</sup> Edition January 2012

#### Quick glossary

**Fast-acting insulin:** insulin that acts quickly to minimise the rise in blood glucose (sugar) that occurs after eating a meal.

**Basal rate:** rate of continuous background insulin infused.

**Food bolus:** a dosage of fast-acting insulin with a meal.

**Correction bolus:** an extra amount of fast-acting insulin to lower the blood glucose (sugar).

Long-acting insulin: insulin which acts slowly throughout the day and night to match the normal background level of insulin.

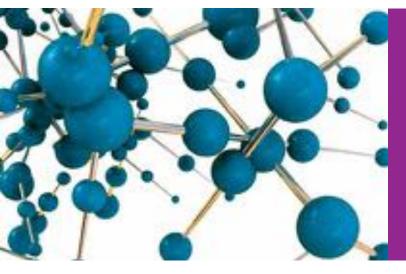
**Hypoglycaemia:** a state that occurs when blood glucose (sugar) is too low. It is sometimes called a 'hypo'.

HbA1c: your child's HbA1c (glycated haemoglobin) reading is an indicator of your child's blood glucose (sugar) levels over the previous two to three months.

**Ketones:** these are produced in association with periods of insufficient carbohydrate (missing food) and inadequate insulin (missing insulin or inadequate dose of insulin). They are associated with the need for increasing doses of insulin to correct high glucose levels (insulin resistance).



This symbol means a calculation is necessary



## Introduction

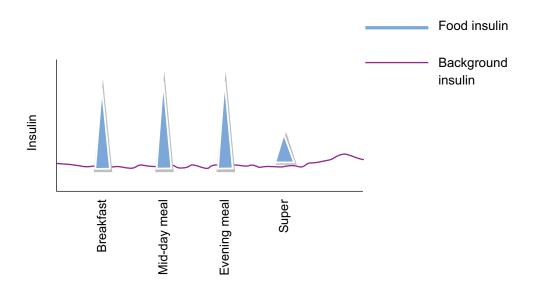
- 1.1 Why is insulin necessary?
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#### Introduction

#### 1.1 Why is insulin necessary?

The diagram below represents what happens in someone without diabetes. Background insulin is necessary to maintain blood glucose levels whether people are eating or not. The pancreas produces a small amount of insulin continually to maintain normal blood glucose levels. The pancreas automatically increases or decreases insulin production according to the blood glucose level.

When food containing carbohydrate (CHO) is eaten, the pancreas produces exactly the right amount of insulin to keep blood glucose levels within the normal range. In the diagram below the peaks show the insulin that is secreted after breakfast, lunch, the evening meal and supper. The height and shape of the peaks are determined by the amount and type of CHO eaten.



#### 1.2 Insulin pump therapy

Daily insulin requirements vary from person to person. The aim of insulin pump treatment is to mimic the pancreas by using **fast-acting insulin** to give a **basal** (background) **rate** which is pre-programmed and delivered in small pulses. In addition a button can be pressed to deliver a bolus dose of insulin to cover CHO in the food eaten (**food bolus**) or give extra insulin to correct a high blood glucose level (**correction bolus**).

Only fast-acting insulin is used in a pump. This means your child doesn't need to eat extra meals or snacks, provided the basal rate is set at the correct level throughout the 24 hours. It is possible to have a different basal pattern set for those who are very active with sport (see page 58), monthly periods in girls (see page 61), or when blood glucose levels are higher which may be seen during illness.

However, because only fast-acting insulin is used in the pump, action will need to be taken immediately if things go wrong with the insulin delivery, as there is no **long-acting** background insulin (see section 3).

#### 1.3 Benefits of insulin pump therapy

Although insulin pump therapy is usually very successful, it is important that the benefits continue in the long term. The potential benefits are:

- less frequent severe hypoglycaemia
- return of early warning symptoms of hypoglycaemia
- improved glucose control with less variability
- better quality of life.

It would be expected that your child would get a reduction in their **HbA1c** level of at least 0.5% less than their average level before starting on the pump (unless their HbA1c is less than 7.5% already).

In order for your child to benefit from the pump it is important that you are confident in:

- using the technical features of the device
- altering the amount of insulin depending on the CHO content of meals, activity or during illness
- measuring blood glucose levels so you can calculate correction doses.

We anticipate that you will see the benefits to your child after 3-6 months of using the pump. These need to be maintained in the longer term. It will be necessary to measure the benefits by checking your child's HbA1c level, their awareness of any hypoglycaemic episodes, and gauging quality of life (this may involve using questionnaires) at regular intervals.

#### 1.4 What types of insulin are used in a pump?

Only fast-acting insulin is used in insulin pumps.

The insulins commonly used are:

- lispro (Humalog)
- aspart (NovoRapid)
- glulisine (Apidra).

You will be able to obtain your child's insulin in the usual way from your GP by prescription. However, you will require **10 ml vials** of fast-acting insulin for routine use rather than the insulin cartridges used in pens. **Ensure your child's GP knows to add this to their insulin prescription.** 

#### 1.5 The basics of insulin pumps

You will first be taken through the basic functions of your child's pump by their healthcare team.

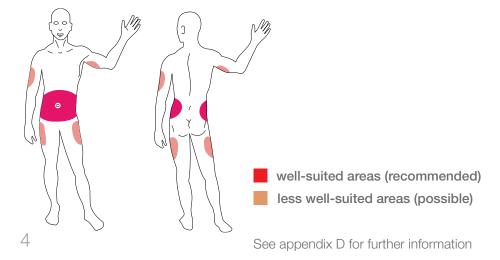
You can also refer to the pump manufacturer's instruction book.

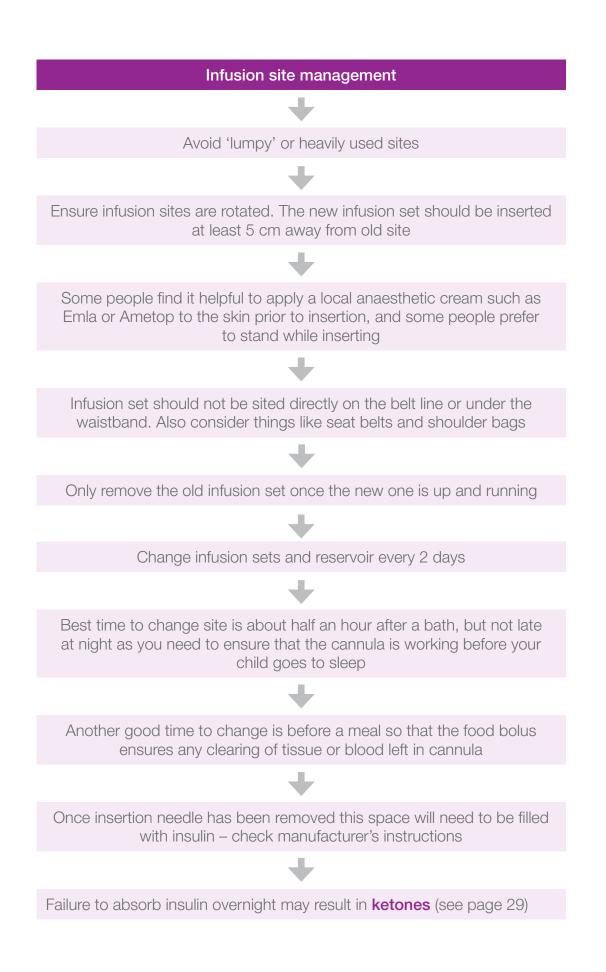
#### What will be covered?

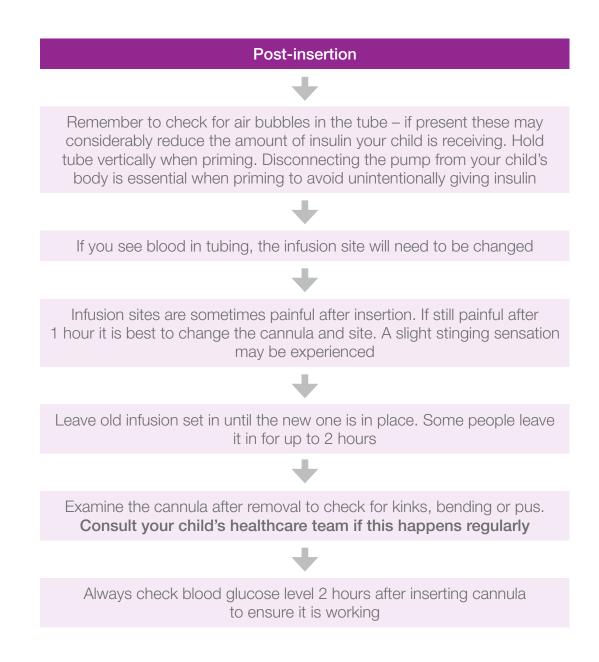
- Inserting batteries
- Setting time and date
- Switching pump on/off
- How to give a bolus
- How to set basal rates
- How to fill up a cartridge/reservoir
- How to insert a cartridge
- Different infusion sets and insertion devices

#### **Insertion sites**

The diagram below shows the best sites in which to insert the cannula. It is often better to move within one block before changing areas completely.







#### Helpful tips

- Calendula or tea tree cream is useful to help heal scars
- If infusion sets do not stick very well ask about an adhesive spray or wipes such as Cavilon
- If infusion sets are difficult or uncomfortable to remove, ask your child's healthcare team about an adhesive remover such as Lift Plus

#### **Preventing infection**

- Wash hands before opening any package
- Wash hands after touching the old site
- Use a 'no touch' technique for ends of tubes
- Change set at first sign of pain, redness or discomfort

#### 1.6 Blood glucose monitoring and HbA1c

Measuring blood glucose is an important way of monitoring your child's diabetes. By using the blood test results you can learn how different things can affect the results, such as the type of food your child has eaten, the exercise they have taken, or any illnesses and stress.

Blood glucose monitoring will give you information about their response to all of the above. It should help you see what's working and what's not. Take each blood glucose reading as a learning experience, and see what might be changed next time.

To achieve good results it is necessary to test blood glucose on average five times a day, and more often when aiming to improve control.

National targets for glucose levels							
Before each meal	5-8 mmol/l						
After each meal	5-10 mmol/l						
At night	4.5-9 mmol/l						

National targets for HbA1c						
HbA1c	less than 58 mmol/mol					
HbA1c (as percentage)	less than 7.5%					

If you are unsure what HbA1c means, and what your child's target reading should be, discuss it with your child's healthcare team.

#### 1.7 End of section 1 worksheet

Benefits of pump therapy:

Benefits of blood glucose monitoring:

How many blood tests should your child expect to do on the pump?

What is your child's target blood glucose level?

#### Questions

1. How often should you change your child's infusion set?

2. Which infusion set have you used?

3. How much insulin does it need to fill the space once you have removed the insertion needle?

4. At what time of day will you change your child's infusion set?

5. How long after putting a new set in would you check your child's blood glucose level to make sure that it's working?

6. Why is it important to check for air bubbles?

7. Why is it important to disconnect the pump when priming?

You can find the answers to these questions in Appendix E of this workbook.

#### **Quick glossary**

**Hypoglycaemia:** a state that occurs when blood glucose (sugar) is too low. It is sometimes called a 'hypo'.

Long-acting insulin: insulin which acts slowly throughout the day and night to match the normal background level of insulin.

**Fast-acting insulin:** insulin that acts quickly to minimise the rise in blood glucose (sugar) that occurs after eating a meal.

**Basal rate:** the rate of continuous background insulin infused.

Hyperglycaemia: a state that occurs when blood glucose (sugar) is too high.

**Insulin to carbohydrate ratio (ICR):** a ratio that tells you how many grams of carbohydrate are covered by 1 unit of insulin (e.g. one unit insulin to seven grams of carbohydrate).

**Food bolus:** a dosage of fast-acting insulin with a meal.

**Temporary basal rate:** temporary adjustment to the basal rate of insulin given in response to activity, stress or illness.

**Correction bolus:** an extra amount of fast-acting insulin to lower the blood glucose (sugar).

**Insulin stacking:** accumulation of insulin in the blood after repeated bolus doses of insulin close together (within two hours).



This symbol means a calculation is necessary





# Starting pump therapy

- 2.1 Getting started
- 2.2 Calculate and set basal rate
- 2.3 Calculate insulin to carbohydrate ratio
- 2.4 Calculate the correction dose
- 2.5 Pump failure
- 2.6 Removing the pump
- 2.7 Temporary basal rates
- 2.8 Emergency kit
- 2.9 End of section worksheet

#### Starting pump therapy

#### 2.1 Getting started

Before starting with insulin pump therapy, check that you have:

- the pump (which should have been delivered)
- fast-acting insulin in a 10 ml vial
- reservoir/cartridge
- the chosen cannula and infusion set
- blood glucose and ketone monitor
- hypoglycaemia (hypo) remedy
- a record of the total daily doses over the last week.

## How to adjust your child's last dose of long-acting insulin the day before starting pump therapy:

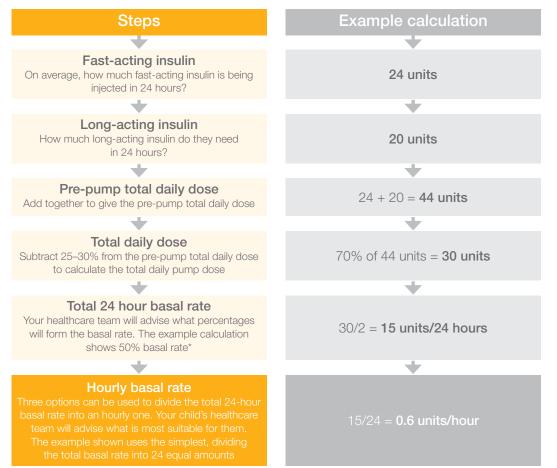
- if taken in the evening, reduce your child's long-acting insulin dose by 50% the evening before
- if taken in the morning, omit the dose of long-acting insulin on the day when you are initiating pump therapy.

Give your child fast-acting insulin with carbohydrates (CHO) for breakfast and to correct any high blood glucose levels.

#### 2.2 Calculate and set the basal rate

- The **basal rate** is the rate at which the insulin pump gives background doses of insulin. These increments of insulin are released continually over a 24-hour period. This basal rate is responsible for about 25-50% of your child's daily insulin requirement.
- Please note that in young children, particularly under 5's, only 25-30% of the new total daily dose may be required as the total basal rate.
- It's very important to get the basal rate right (see guide to calculating hourly basal rate on the next page). In theory, if it's correct your child could go all day without eating and their blood glucose level would remain more or less stable (between 5-8 mmol/l).
- Young people with diabetes will need approximately 25-30% less insulin on a pump than their present requirements on pen injections, depending on the frequency of any hypos, HbA1c levels and age i.e. 70% of pre-pump total daily dose will be needed.

#### Guide to calculating the hourly basal rate



There are 3 basic ways of calculating the hourly basal rate:

- 1. divide the total basal rate into 24 equal parts
- 2. divide the basal rate into blocks of time giving more insulin per hour early morning and afternoon/evening (see examples, page 15)
- use the ROCHE calculator. This uses different profiles for different age ranges and mimics the body's natural variation in insulin levels over 24 hours. (See graph of ROCHE calculator and Contact ROCHE for Accuchek 360 Insulin pump configuration software and to have ICON put on your computer.)

Calculate your child's hourly basal rate						
units of fast-acting insulin in 24 hours +units of long-acting insulinin 24 hours =pre-pump total daily dose						
( pre-pump total daily dose $/100$ ) x 70 = total daily dose						
total daily dose /2 = total basal rate in 24 hours						
total basal rate in 24 hours/24 = hourly basal rate						
My child's hourly basal rate is						

\*Percentage basal rate: there is some degree of variation in the ideal percentage of total daily dose which is used as the basal rate. It varies between 30-50%. BUT it is important that higher basal rates are NOT used to mask the failure to bolus with all CHO. Basal rate MUST represent the basal resting pattern and bolus MUST represent what is given with food or for corrections.

#### Confirm that the starting dose is safe

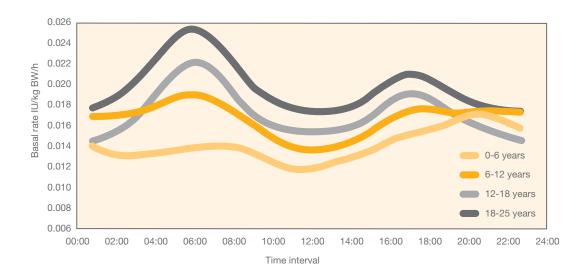
It is important that the dose of the basal rate is not too high so as to minimise the risk of hypoglycaemia. Reducing the risk of hypos helps ensure a smooth transition to pump therapy and builds the confidence of both you and your child.

#### How to check a starting dose is safe



#### **Different basal rates**

- Although the body often produces more insulin in the early morning and early evenings, a flat basal rate is usually programmed and increased at these times as indicated.
- However, if there are obvious patterns of insulin resistance or sensitivity, such as waking with hyperglycaemia or hypoglycaemia at night, then divide 24 hours into 4 or 5 blocks for more effective treatment. For more information on how to do this discuss with your healthcare team.
- The pump has the ability to deliver different basal rates over 24 hours. These will be determined according to individual needs over the first few weeks. Most young people with diabetes have between one and six different basal rates.



#### Different basal rates through 24 hours

Example 1: A 14 year old girl who is on 60 units of insulin and receiving multiple daily injections

20% reduction = 48 units

If a 50% basal rate is required then divide by 2 = 24 units basal rate over 24 hours

Time	Units/hour	Total (units)	24 hour total (units)
00:00–04:00	0.7	2.8	
04:00–07:00	1.3	3.9	
07:00–13:00	1.1	6.6	
13:00–20:00	1.0	7.0	
20:00–00:00	0.8	3.2	23.5

Example 2: A 3 year old boy who is on 11 units per day of insulin and receiving multiple daily injections

10% reduction = 10 units

If a 50% basal rate is required then divide by 2 = 5 units basal rate over 24 hours

Time	Units/hour	Total (units)	24 hour total (units)
00:00–06:00	0.1	0.6	
06:00-12:00	0.25	1.5	
12:00–20:00	0.2	1.6	
20:00-00:00	0.15	0.6	4.3

Examples adapted from Insulin Pump Therapy and Continuous Glucose Monitoring. Edited by John Pickup (2009) Oxford Diabetes Library.

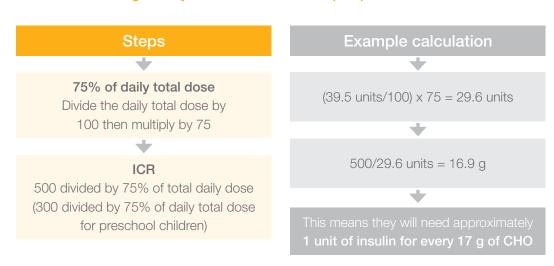
#### 2.3 Calculate insulin to carbohydrate ratio (ICR) (500/300 rule)

**Insulin to carbohydrate ratios (ICR)** ratios are used to calculate the insulin doses young people with diabetes need for specific amounts of food containing CHO. An ICR tells you how many units of insulin your child needs to cover a specified number of CHO grams (g). For example, if their ratio is 1:12, your child will need one unit of insulin for every 12 g of CHO they eat. You may already have calculated an ICR when on basal bolus insulin. This can be used in your pump settings.

- Your child may be using an ICR that is based on the number of units of insulin for each 10 g of CHO consumed. Your healthcare team will advise how to convert this to a suitable measure for your child's pump settings.
- When using a pump it's more common to have a ratio where one unit of insulin is given for a calculated amount of CHO (g). This allows more accurate **bolus dose** calculations.
- ICR should be regularly reviewed as your child grows and develops.

#### **Calculating ICR**

Calculate your child's total daily dose and subtract 25-30% (as demonstrated on page 13). Then divide this figure into 500 for 5 years and above, and into 300 for preschool children. (This will vary every day, so use an average value from a typical day. Add together both their total background amount and food/correction boluses.) **If already on a pump don't reduce by 25-30%** 



#### Guide to calculating ICR if your child is NOT on the pump

Calculate your child's ICR	
(Average total daily injection dose/100) x 75 or pump dose	-
<b>500</b> /by above figure OR	=
300/by above figure (preschool)	=
My child needs to take 1 unit of insulin for g of C	жю

#### Factors which may influence the ICR

- Time of day: the need for insulin is often highest at breakfast and the ratio may need to be higher, e.g. 1:8 instead of 1:10.
- During periods of rapid growth, particularly puberty, in some boys the ratio may be 1:4.
- Girls often need more insulin the day before or during periods.
- When your child is being particularly physically active they will need less insulin, for example you may need to change their ratio from 1:10 to 1:15 (see page 58).
- During illness and infection more insulin is often needed, so you may need to increase the basal rate and look at increasing the ratio. See page 20 to find out more about how and when to set the **temporary basal rate**, and page 30 to learn more about illness.

Your healthcare team will be able to offer you advice specific to your child and their circumstances. If you are unsure about what to do when any of these circumstances arise, contact your healthcare team before adjusting treatment.

#### 2.4 Calculate the correction dose (100 rule)

A **correction dose** is an extra amount of fast-acting insulin. Correction doses are sometimes referred to as an Insulin Sensitivity Factor (ISF), and are recommended in order to keep blood glucose levels within a target range (usually 5-8 mmol/l). The correction dose needed depends on your child's insulin sensitivity. You can work this out from the total amount of insulin injected each day.

#### To calculate the correction dose



This will tell you how much one unit of fast-acting insulin will lower your child's blood glucose when it's high. When correcting high blood glucose levels at meal times, you should aim to bring your child's blood glucose down to 7 mmol/l; this will take about two to three hours.

- The correction dose will need to be checked regularly. As your child grows and develops the amount of insulin required to correct high blood glucose will increase.
- To avoid insulin stacking, which can cause a hypo, don't give insulin correction doses more frequently than once every 2 hours. Most pumps have a built-in mechanism which prevents stacking, by calculating how much insulin is already active in your child's body.
- Your child's correction dose may also vary through the night, often needing less insulin to lower blood glucose always be cautious correcting at night.

Calculate your child's correction dose							
Average total daily pump dose =							
100/ Total daily pump dose =							
1 unit of insulin will reduce blood glucose level by approximately mmol/I							
How much insulin would you give, as a correction bolus, if your child's blood glucose is 10 mmol/l pre-meals and their target blood glucose level is 7 mmol/l?							
(Blood glucose level – target blood glucose )/correction dose =							
i.e. If 1 unit lowers their blood glucose by 3 (1:3)							
10 (blood glucose pre-meal) – 7 (target blood glucose) = 3 mmol/l							
3/3 = 1 unit							

#### 2.5 Pump failure

What should you do when your child's pump isn't working properly and they need to go back to injections?

- Use their usual ICR and correction doses. Deliver the fast-acting insulin (NovoRapid, Humalog (lispro) or Apidra) with a pen or syringe. Your child will probably need more corrections than usual.
- Contact the pump manufacturer, who will arrange to supply another pump for you if it's within warranty.
- If you are unable to get a replacement pump within 24 hours, calculate your child's total daily basal rate on the pump and inject this amount immediately as long-acting insulin (Lantus or Detemir).

E.g. If you are on a 24 hour basal rate of 18 units, inject 18 units of long-acting insulin. This will need to be repeated daily until you receive the replacement pump. Close monitoring is advised as this dose may need to be increased. Contact your child's healthcare team if you are unsure.

• On recommencing the pump, the long-acting insulin will still have some effect for 1-2 days, so a 10-20% temporary basal rate reduction may be needed.

Keep a written record of your child's pump basal rate for each hour and bolus ratios in case the pump fails and you need to go back to injections.

#### 2.6 Removing the pump

It's recommended that the pump is removed when your child:

- showers
- gets changed
- goes swimming
- takes part in contact sports (such as rugby).

When the pump is removed for:

- up to two hours→check blood glucose before, during, and when pump is reconnected
- more than 2 hours→check blood glucose and give food and correction bolus by injection, or reconnect pump to give appropriate insulin every two hours using normal bolus
- more than 24 hours  $\rightarrow$  long-acting insulin may be needed
- removing the pump for extended periods may cause spikes in blood glucose later on due to missed basal insulin, so you should continue to monitor blood glucose for several hours following reconnection of the pump.

In the case of exercise, like rugby, less insulin may be needed (see page 58).

#### Remember to keep the pump in a safe place.

#### 2.7 Temporary basal rates

The insulin pump also gives you the ability to set a temporary basal insulin rate, and this is most commonly used when your child is exercising, or ill. The insulin pump will later return to the original basal rate pattern after the set period of time.

#### 2.8 Emergency kit

The following equipment should be carried at all times for emergency use:						
Essential	fast-acting insulin pen/syringe and insulin					
	hypo treatment (hypo remedies, Glucogel)					
	blood glucose and ketone testing kit					
Advisable	spare infusion line					
	spare cannula					
	spare insulin					
	spare batteries					
	hypo treatment (Glucagon)					

#### 2.9 End of section 2 worksheet

- Does your child need less insulin on the pump than their previous requirements?
  Yes
  - 🗆 No
- My child injects \_\_\_\_\_ units of fast-acting insulin in 24 hours
- My child injects \_\_\_\_\_units of long-acting insulin in 24 hours
- Pre-pump total daily dose is \_\_\_\_\_units
- Total 24-hour basal rate is \_\_\_\_\_units

Time (hrs)							
My child's basal rate							

- My child needs to take 1 unit of insulin for every\_\_\_\_\_ g of CHO at breakfast
- My child needs to take 1 unit of insulin for every\_\_\_\_\_g of CHO at lunch
- My child needs to take 1 unit of insulin for every\_\_\_\_\_ g of CHO at dinner
- 1 unit of insulin will reduce my child's blood glucose level by approximately \_\_\_\_\_mmol/l

Note possible circumstances when your child might need a temporary basal rate decrease:

E.g. During or after spontaneous exercise, sport, or when fasting

Note possible circumstances when your child might need a temporary basal rate increase:

E.g. When blood ketones are present, during illness, stress, or during a long car drive.

#### Questions

- 1. When during the day is the need for insulin likely to be the highest?
- 2. In the case of pump failure, if you are unable to get a replacement pump within 24 hours, what should you do?

You can find the answers to these questions in Appendix E of this workbook.

#### Quick glossary

**Hypoglycaemia:** a state that occurs when blood glucose (sugar) is too low. It is sometimes called a 'hypo'.

#### Continuous glucose monitors

(CGMs): these are devices which are able to measure your glucose levels in the tissue by using a small probe inserted under the skin. As it is not measuring glucose in the blood there is a lag period, so they are not always good at measuring rapid hypos. There are two sorts: one where the results are stored but cannot be viewed until downloaded, and others where the result can be seen all the time – each have their own advantages.

**Food bolus:** a dosage of fast-acting insulin with a meal.

**Insulin to carbohydrate ratio (ICR):** a ratio that tells you how many grams of carbohydrate are covered by 1 unit of insulin (e.g. one unit insulin to seven grams of carbohydrate).

**Basal rate:** the rate of continuous background insulin infused.

**Temporary basal rate:** temporary adjustment to the basal rate of insulin given in response to activity, stress or illness.

**Correction bolus:** an extra amount of fast-acting insulin to lower the blood glucose (sugar).

**Hyperglycaemia:** a state that occurs when blood glucose (sugar) is too high.

**Ketones:** these are produced in association with periods of insufficient carbohydrate (missing food) and inadequate insulin (missing insulin or inadequate dose of insulin). They are associated with the need for increasing doses of insulin to correct high glucose levels (insulin resistance). **Diabetic ketoacidosis:** a condition where the blood becomes acidic due to rising levels of ketones.

Long-acting insulin: insulin which acts slowly throughout the day and night to match the normal background level of insulin.

**HbA1c:** Your child's HbA1c (glycated haemoglobin) reading is an indicator of your child's blood glucose (sugar) levels over the previous two to three months.

**Glycaemic Index (GI):** this may range from low to high and refers to how quickly glucose in the food is absorbed from the gut into your blood. Low glycaemic food is in general better and the food is slowly absorbed. Examples include wholegrain bread and pasta. High glycaemic foods are best for treating hypos as they tend to contain pure sugars and are absorbed fast from the gut.

**Dawn phenomenon:** the natural increase in insulin occurring in the early hours of the morning associated with the body's natural day/night hormonal rhythm (Circadian rhythm).

**Dusk phenomenon:** The natural increase in insulin late afternoon in association with the body's natural day/night rhythm, usually less pronounced than the dawn phenomenon.

This symbol means a calculation is necessary



## Managing pump therapy

- 3.1 Hypoglycaemia
- 3.2 Hyperglycaemia
- 3.3 Ketones
- 3.4 Illness and diabetic ketoacidosis
- 3.5 Checking basal rate
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- 3.9 End of section worksheet

#### Managing pump therapy

#### 3.1 Hypoglycaemia

Hypoglycaemia means low blood glucose and is commonly called a "hypo".

#### The most common causes of hypos are:

- too much insulin
- overestimation of carbohydrate (CHO) content of food
- more physical activity than planned
- excessive alcohol.

## When your child experiences a hypo at what level do you notice warning symptoms? What blood glucose level do you count as a hypo?

Generally a blood glucose level of less than 3.9 mmol/l is defined as the onset of hypoglycaemia. Maintaining your child's blood glucose no lower than this allows time for yourself or them to recognise any symptoms and take the necessary action.

Remember to be alert to night time hypos - clues to these may include:

- fluctuating blood glucose in the morning going from high to low
- waking up with headaches and feeling confused
- they may be asymptomatic, and it is only by testing you can check whether hypos are happening – consider continuous glucose monitors (CGMs) (see page 37) or night time glucose testing.

If you don't notice any warning signs, please discuss this with the diabetes team.

Remember, a hypo during the previous 24 hours may increase the risk of further hypos. Any hypos can lead to unpredictable blood glucose readings over the next 24 hours due to the body releasing various hormones in response to the low blood glucose level.

#### Hypo Symptoms

It is important to recognise your child's signs of hypos, and the terms they use to describe them. The commonest signs are:

- going pale and shaky and sometimes unusually quiet
- becoming aggressive and confused
- sweating
- loss of consciousness and, rarely, fits.

#### Hypos and the insulin pump

 Hypos happen for the same reasons, whether your child is receiving pump therapy or injecting insulin. However, because pump therapy only uses fast-acting insulin and you can control the delivery, there are more ways of dealing with and preventing a hypo. It's important to understand how the type of food, exercise and insulin all combine to determine your child's glucose level.

#### Tips for preventing hypos:

- calculate CHO correctly to ensure correct bolus
- check the insulin to carbohydrate ratio (ICR) is right it may differ at different times of the day
- consider doing a test meal
- split bolus or use different type/duration of bolus if larger amounts of CHO are eaten
- be careful when giving correction boluses. Work out exactly how much is needed.
  Remember, fast-acting insulin may last in the body for up to five hours so it's advisable to correct no more frequently than two hourly
- **basal rates** should ideally be tested every four to six weeks, but at least every three months to make sure they are correct.
- use a temporary reduction of basal rate when exercising
- never give a bolus of insulin for alcohol consumed unless you are sure of the effect
- always look for a pattern before changing basal, food bolus or **correction bolus**
- wherever possible use insulin pump decision-making tools (Bolus Wizard, EZ Carb, Bolus Advisor etc.).

#### Managing hypos

Check whether it is the basal rate or the bolus which is incorrect.

Factors which suggest that it is the basal rate which is wrong include:

- hypos at night and at least 3-5 hours after the last bolus (a bolus of fast-acting insulin usually only lasts 4 hours)
- repeated episodes of hypo at similar times of the day/night.

Factors which suggest amount or type of bolus is wrong:

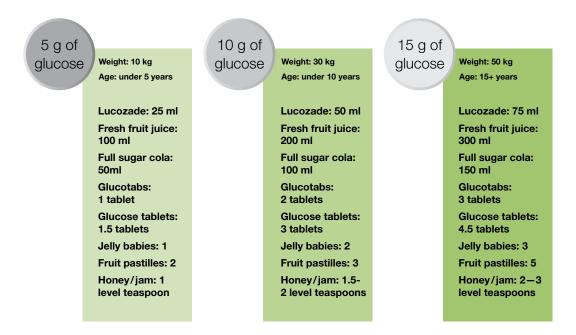
- hypo within 4 hours of the last bolus
- a large bolus given as a one-off standard bolus rather than as dual wave. Consider the type of food, does it contain slow-release CHO?

Factors where both need to be considered:

• exercise, particularly if lasting more than 20-30 minutes, can produce hypos 24-36 hours after finishing. You may need to reduce the bolus both before and after exercise and reduce your child's basal rate for up to 36 hours.

If you are unsure about this, keep detailed records of glucose levels and contact your healthcare team.

#### An approximate guide to treating hypos



#### Extra tips:

 chocolate is NOT recommended as an effective treatment for hypos as the body takes longer to break down the lactose found in milk then it does glucose, and the presence of fat further slows the rate of absorption. Double the CHO is needed with fruit juice to get the same effect as the other treatments due to the slower rate of absorption of fructose (fruit sugar).

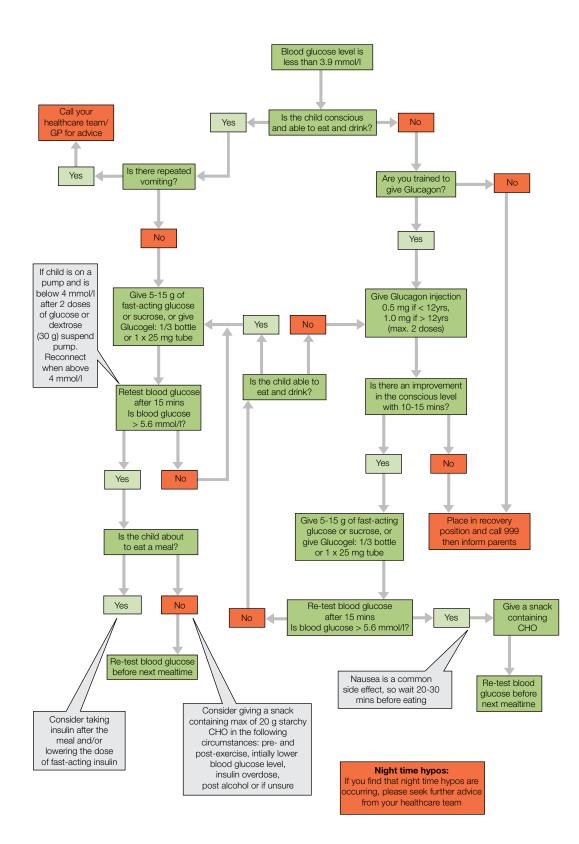
## Fill out the hypo treatment that works best for your child in the workbook at the end of this section (see page 41).

Long-acting CHO is no longer routinely recommended in addition to a hypo treatment, as it can lead to over-treatment and highs later on. However, a maximum of 20 g may be considered in the following circumstances:

- pre- and post-exercise
- insulin overdose
- post-alcohol
- if your child has had a hypo during the last 24 hours, or if you are at all unsure.

During a severe hypo your child may become unconscious. Give a Glucagon injection which will raise the glucose level and inform your healthcare team. Ask your healthcare team to explain how to give Glucagon if you are uncertain.

Check that your child's Glucagon is in date and always take it on holiday with you.



### Managing Hypoglycaemia in Type 1 Diabetes

#### 3.2 Hyperglycaemia

**Hyperglycaemia** means high blood glucose. This is generally a glucose level higher than 14 mmol/l, but symptoms may not start to become noticeable until even higher values such as 15-20 mmol/l.

#### Hyperglycaemic symptoms:

These may not be as clear as with hypos but can include:

- feeling irritable and miserable similar to hypo (test blood glucose to confirm)
- thirsty and weeing a lot day and night
- tired
- loss of weight
- smelling of ketones (pear drops not everyone can smell these)
- nausea and vomiting (if this happens seek help immediately).

#### The following may specifically cause high blood glucose during pump therapy:

#### Increased insulin requirements:

- infection/illness
- growth
- stress
- reduced exercise
- hormones
- steroids.

#### Infusion set:

- inflammation at site
- insertion into a hardened area
- left in too long
- dislodged or blocked
- blood or large air bubble in tubing
- empty cartridge
- leak
- pump failure.

#### Insufficient insulin delivery:

- basal rate too low
- forgot to give bolus
- bolus too little for the amount of CHO/under-calculated CHO content of food
- excessive CHO after hypo
- rebound following hypo
- pump stopped or forgot to reconnect pump.

What symptoms are associated with hyperglycaemia? What are the most common reasons for hyperglycaemia?

#### 3.3 Ketones

#### What are ketones?

In the absence of sufficient insulin, the body's cells cannot use glucose for energy. The cells will switch to an alternative energy source and body fat will be broken down to supply the necessary energy.

This rapid breakdown of fat can cause the build-up of molecules known as **ketones**. Eventually, the blood glucose and ketones rise to levels that cause the blood to become acidic. This is known as **diabetic ketoacidosis** (DKA), which is potentially very dangerous and will require hospital admission, particularly when associated with vomiting. The only treatment for severe DKA is insulin and fluids via a drip – subcutaneous insulin will not work with poor circulation and cold and clammy skin.

Blood ketones should be measured using a blood ketone meter. It is advisable to check the expiry date on blood strips before use.

Remember, now your child is on a pump they have no **long-acting insulin**, and ketones will be produced within four to five hours if there is insufficient insulin delivered. Your child will become unwell more quickly on a pump and action needs to be taken immediately. Checking blood glucose levels at least six to eight times a day is therefore advisable to ensure early detection.

If glucose levels are above 14 mmol/l we recommend testing for blood ketones.

As DKA can develop and progress quickly, and will make your child feel very unwell, the next sub-section gives guidelines for you to follow if your child is ill.

Remember, to help get rid of ketones your child will need to have regular insulin. Insulin is the key which helps switch off the ketone-producing mechanism in their body. To help them stop producing ketones they need CHO as liquid exchanges if they do not feel like eating. They must have insulin to correct and cover the CHO. The dose may need to be increased if there is a suboptimal response.

	Blood Ketone Guide	
Less than 0.6 mmol/l	0.6-1.5 mmol/l	Greater than 1.5 mmol/l
Green (okay)	Amber (warning)	Red (needs taking care of)
No action	Correction via pen and more frequent monitoring	As for Amber PLUS Urgent medical assistance

## 3.4 Illness and Diabetic Ketoacidosis (DKA)

Sickness can make the body more resistant to insulin, so when your child is ill they may require additional insulin. In addition, sickness can cause stress hormones to be released, and these can cause glucose levels to rise.

- All the same things will apply as before, including the need for more insulin when your child is unwell.
- Consider problems with delivery of insulin. Your child has no long-acting insulin; they are dependent on fast-acting insulin only, which, after two hours, will see levels rapidly fall if delivery stops or the needle comes out.
- Consider air bubbles in the tube.
- Consider problems with placement of needle. Has it come out?
- Remember, problems are likely to occur quickly if your child has missed insulin or is running a high **HbA1c** with poor control.
- It is even more important to check for ketones.
- Think about when you should use a pen and cartridge insulin.

#### Illness and hyperglycaemia

#### What to do when your child is ill and they have hyperglycaemia:

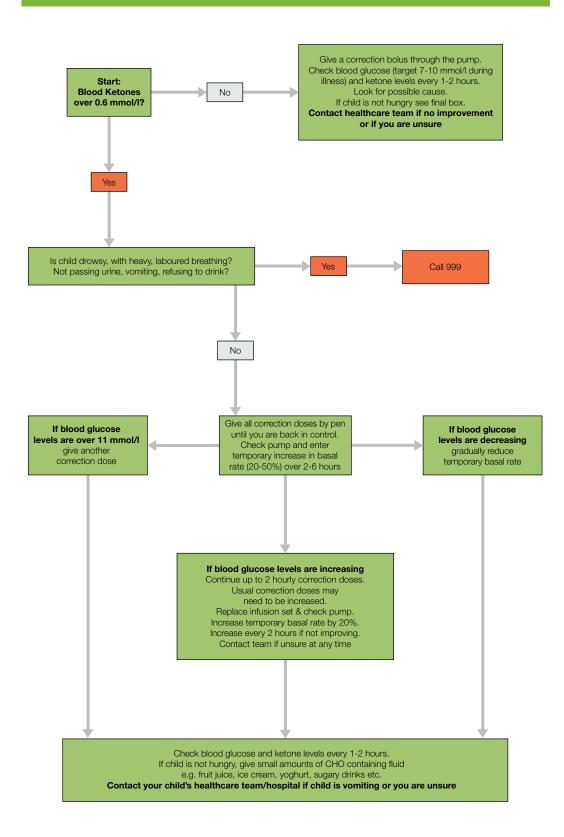
- if they have had something to eat in the last 90 minutes, re-check in one hour as they may not have taken enough insulin for the amount they ate, or a different type of bolus may have worked better for the type or quantity of food they ate
- it is recommended that your child's blood is tested for ketones if their blood glucose levels are over 14 mmol/l
- give your child their usual correction dose, but be aware this may need to be increased in the presence of ketones
- give them plenty of water or sugar-free fluid
- if they do not want to eat, offer sweetened fluid such as Lucozade or flat fizzy drinks, and give an insulin bolus accordingly

- change infusion set and check pump settings
- try to identify the cause of the high blood glucose and seek help/treatment as necessary
- test blood glucose and ketones every one to two hours and repeat the correction dose until blood ketones start to clear. Give the correction dose by pen if they are not responding and ketones are present
- most people need to increase their usual correction dose when ketones are present
- remember, if problems persist after two correction doses increase the basal rate by 20% and review every two hours as further increases may be required
- consider pre-setting an illness basal rate
- your child should not exercise if ketones are high
- contact the diabetes team if high blood glucose levels and ketones persist and/or vomiting starts.

#### Your child will need extra insulin if blood ketones are present.

- Aggressive management of blood glucose levels is necessary at times of illness.
- If blood glucose levels are allowed to get out of hand DKA can occur very quickly.
- Correct high blood glucose levels with the usual correction ratio providing your child is ketone free.
- If their blood glucose levels are very high (even if there are no ketones present) you may find the usual correction dose may not be enough.
- If ketones are present give insulin by the pen until back under control. You will need more insulin than usual. Some adults and teenagers need to double their usual correction dose.
- Use the temporary basal rate to increase in 20% steps and check your child's blood glucose levels every one to two hours to check if this needs to be repeated.
- If the basal rate won't increase any further you may need to increase the "max basal rate" for the duration of the illness. Don't forget to reduce it once your child is better.
- Setting an illness basal pattern is another alternative. Discuss with your healthcare team if unsure.
- Check the pump function and ensure the infusion set is working. Change the infusion set if in any doubt.
- Once blood glucose levels are mostly in single figures start to gradually reduce the increases in 20% steps, providing that the result was not preceded by the administration of a correction dose within the last two hours.

## Sick day rules for children on insulin pump therapy when blood glucose level rises over 14 mmol/l during illness



## 3.5 Checking basal rate

Basal rates should be checked every four to six weeks, and certainly every school holiday, to ensure your child's programmed basal rate is meeting their body's requirement for the background supply of insulin. The basal insulin dose will need to be increased as they grow and develop – the teenage growth spurt is a particularly important time.

Testing your child's basal rate involves fasting (no CHO) for a period of time or, if that is not possible, delaying eating for as long as possible. If their basal rate is right for them, their blood glucose level should be kept within their targets. It is important to consider when they last had a bolus and ate something, and what it was they ate, as these could still be affecting their blood glucose now.

It is not a good idea to check basal rates if your child is ill or has been doing a lot of exercise.

Don't try and do the whole day at once. Getting the overnight period right first is usually a good idea. Then breakfast until lunch, lunch until evening meal, and lastly evening meal until bed.

## General rules when checking your child's basal rate:

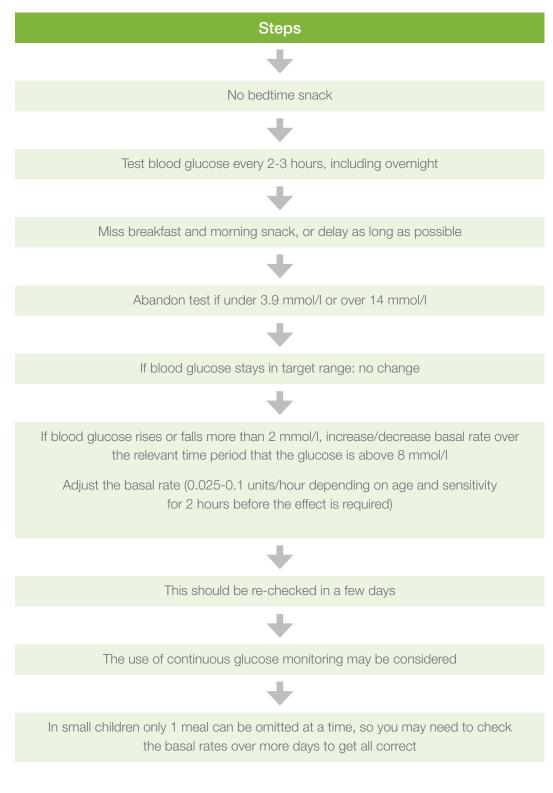
- have last CHO two hours before starting to fast and try to avoid low **glycaemic index** foods (see glycaemic index, page 46) as they can continue to affect blood glucose levels for several hours after eating
- alternatively, if unable to omit a meal, delay it or give a standard meal with known amount of CHO and high GI (e.g. toast)
- give normal insulin bolus with last meal
- your child should not eat any snacks during fast period (they can drink water)
- check blood glucose level every one to two hours during the fast
- if hypo occurs (blood glucose under 3.9 mmol/l) treat and abandon test
- if hyperglycaemia occurs (blood glucose over 14 mmol/l) treat and abandon test
- once complete, you can change your child's basal rate.

#### Checking the overnight basal rate

## If blood glucose drops below 3.9 mmol/l or rises above 14 mmol/l during fast, abandon fast for that day and treat abnormal blood glucose.

You will need to change the basal rate, look at the profile of when the rate was high or low, and go back two hours and increase or decrease basal rate accordingly. In general it is recommended to increase or decrease by 0.025-0.1 units an hour at a time depending on age and sensitivity. Repeat on another day to see if it is now correct.

Use the table in appendix B (see page 68) to fill in when you are testing your child's basal rates. Choose the time over which you want to test, and mark when you are doing the blood tests. Remember, your child has to avoid having CHO for at least 2-3 hours before doing the tests.



When the blood glucose does not remain stable within +/- 2 mmol/l, adjustments of the basal rate are recommended.

Some young people need more insulin with breakfast due to the effects of the dawn phenomenon.



## 3.6 Checking insulin to carbohydrate ratio (ICR)

If your child's ICR is right for them, their blood glucose level should be no more than 2 mmol/l higher or lower than their pre-meal blood glucose level 2-4 hours after eating. For example, if their blood glucose is 5.9 mmol/l before breakfast and 7.8 mmol/l 2 hours later, the ratio is correct.

Example 1: Andrea takes 1 unit for every 10 g CHO she eats. Here are
her blood glucose readings over a couple of days

Time	Blood glucose	Amount of CHO	Insulin for food	Correction dose	Comments
Day 1					
07:30	7.2	45 g	4.5		Normal day
10:30	3.2				Felt hypo
13:30	5.2	45 g	4.5		
18:00	6.7	60 g	6		
22:00	4	15 g			
Day 2					
07:30	6.5	45 g	4.5		Normal day
10:30	3.0				Felt hypo
13:30	6.2	40 g	4		
18:00	7.1	70 g	7		
22:00	4.1	20 g			No insulin too low for bed

Discuss with your healthcare team the changes you might make to Andrea's insulin regimen.

Time	Blood glucose	Amount of CHO	Insulin for food	Correction dose	Comments				
Day 1									
07:30	5.7	60 g	4		Normal day				
13:30	11.2	50 g	3.3	2					
18:00	7.2	72 g	5		Went for 1 hour walk				
22:00	8.9			1					
Day 2									
07:30	6.8	60 g	4						
13:30	12.3	50 g	3.3	2					
18:00	7.1	90 g	6						
22:00	11.3			2					

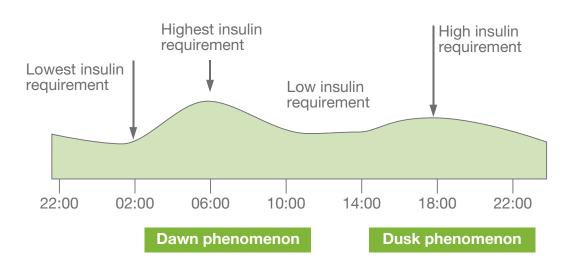
## Example 2: Sam takes 1 unit for every 15 g CHO he eats. Here are his blood glucose readings over a couple of days

You may find it helpful to perform a test meal where you give an exact CHO load, checking blood glucose at the beginning and at timepoints both two and four hours later.

# 3.7 Continuous glucose monitoring (CGM) and meter/pump downloads

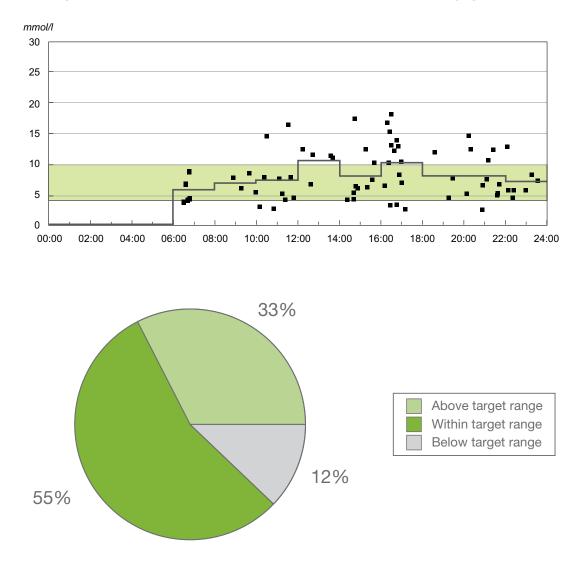
With your child moving onto the pump it becomes even more important to monitor their blood glucose. Your healthcare team should be able to offer options for using blood glucose meters, continuous glucose monitoring, downloads from the pump and meters to maximise the benefits of the pump.

Background insulin secretion in those without diabetes varies depending on the time of day and night (see below). This is particularly important in teenagers when they are going through the growth spurt. The insulin pump gives you the opportunity to try and copy this. To help you get it right it is important to examine your meter and pump readings to see what changes are required.



#### Meter downloads

All meters have the facility to download blood glucose readings so that you and your child's healthcare team can examine them. See below for an example of the information obtained from a glucose meter. This enables you to identify areas which require changing.



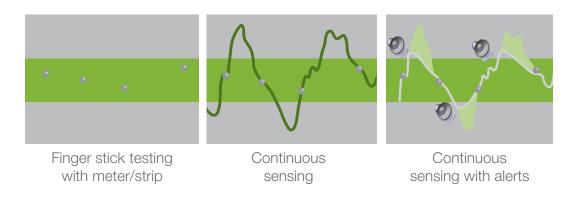
## Important things to remember to maximise information from your child's blood glucose meters

- Make sure the date and time is correct on all meters (remember to check after battery change). Don't forget clock changes in autumn and spring.
- Bring all meters to clinic to enable them to be downloaded.
- You can do this at home and then ask your child's healthcare team to review the results (discuss this with them).

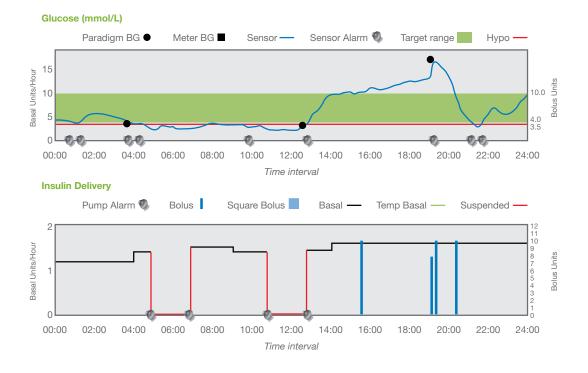
Your child's healthcare team may discuss with you the role of CGM. This is via a small cannula inserted under the skin, and will allow measurement of glucose concentrations under the skin every 5 minutes. This is particularly helpful overnight and when trying to stabilise basal rates (see example below). Some sensors are linked to specific pumps, while others are completely separate.



### Why is CGM in diabetes so important?



CGM completes the fingerstick picture. The use of alerts allows early intervention to reduce the severity and duration of highs and lows



#### Problems with glucose sensing

It is important to recognise the problems with sensing in order to use it properly:

- there is an approximate 20 minute delay when comparing blood glucose levels and glucose levels under the skin. It is therefore best at picking up trends, and will not necessarily pick up rapid hypos
- the sensor needle needs accurate calibration as per careful instructions and finger prick testing. If this is not done properly the results it gives will be meaningless
- the needle cannot be left in place for more than six days and should be taken out if it looks red and inflamed
- be careful about over-interpreting one result. Look for patterns over a few days and discuss with your child's healthcare team (see above).

## 3.8 A structured approach to interpretation of blood glucose readings

It is important to take time each week to review your glucose results and see if changes are required. Listed below are four ideas which may help you to see what changes may be required. Remember if you can get this right at the beginning it will lead to good control and make it easier to review at regular intervals and keep good control.

- Daily overlay view are there clear patterns replicated on each day or through part of each day? Consider overnight, first three hours post meals then three hours or more post meals.
- Daily summaries Are there excessive increases or decreases? Are these related to anything your child has done, such as exercise, snacks, alcohol, school or lifestyle events?

- Consider the pattern on each day after a specific event e.g. a specific meal or exercise.
  - Is this glucose profile similar on each occasion after the specific event?
  - Does the glucose profile after the specific event differ on occasion and if so what happened on this occasion that was different (e.g. insulin dose or CHO intake)?
- If no patterns are identified using first three steps, block out 4-10 mmol/l to assess where peaks and troughs are occurring.

## 3.9 End of section 3 worksheet

Fill in the details below about your child's experiences of hypoglycaemia.

How does your child feel when they have a hypo?

What warning symptoms do they have?

What blood glucose levels would you count as a hypo?

At what level do they experience warning symptoms?

What is their preferred hypo treatment?

Your child's illness correction dose is:

#### **Fasting record sheet**

Use a chart to record your child's blood glucose while they are fasting, then re-assessing their basal rate. You may find it helpful to mark the boxes with a red asterisk (\*) where you are planning to test blood glucose (for some you may elect to stop earlier than midday):

#### Overnight and morning testing:

- your child should not eat from 8 pm until midday the next day (finish earlier if needed)
- they should miss breakfast. State time of last meal and last bolus.

TIME (HRS)	MIDNIGHT	01:00	02:00	03:00	04:00	05:00	06:00	07:00	08:00	09:00	10:00
	FASTING (water only)										
BGL	BGL * * * *										

BGL = Blood glucose level

#### Morning and early afternoon testing:

- early breakfast
- start blood testing from 10 am 6 pm
- miss lunch.

TIME (HRS)	08:00	09:00	10:00	11:00	12:00	13:00	14:00	15:00	16:00	17:00	18:00
	FASTING (water only)										
BGL	BGL * * * * * *										

BGL = Blood glucose level

#### Afternoon/evening test:

- no eating from midday until 10 pm
- state time of last meal and last injection/bolus.

TIME (HRS)	12:00	13:00	14:00	15:00	16:00	17:00	18:00	19:00	20:00	21:00	22:00	23:00
	FASTING (water only)											
BGL	BGL * * * * * *											

BGL = Blood glucose level

## Questions

1. What symptoms are associated with hyperglycaemia?

2. Tom has been using a pump for 2 months. He has woken up feeling very unwell with a sore throat. He has just tested his blood glucose and it is 25 mmol/l. He has tested for ketones and has 3 mmol/l

What should his parents do?

3. Amy's mum is surprised when she tested her blood glucose level and it was 18.8 mmol/l. She has no ketones.

What are some of the possible reasons for her high blood glucose?

4. What is the maximum length of time for which a glucose sensor needle should be left in place?

You can find the answers to these questions in Appendix E of this workbook.

## **Quick glossary**

**Food bolus:** a dosage of fast-acting insulin with a meal.

**Basal rate:** the rate of continuous background insulin infused.

**Temporary basal rate:** temporary adjustment to the basal rate of insulin given in response to activity, stress or illness.

**Glycaemic Index (GI):** this may range from low to high and refers to how quickly glucose in the food is absorbed from the gut into your blood. Low glycaemic food is in general better and the food is slowly absorbed. Examples include wholegrain bread and pasta. High glycaemic foods are best for treating hypo and tend to contain pure sugars and are absorbed fast from the gut.

**Insulin to carbohydrate ratio (ICR):** a ratio that tells you how many grams of carbohydrate are covered by 1 unit of insulin (e.g. one unit insulin to seven grams of carbohydrate).

**Hypoglycaemia:** a state that occurs when blood glucose (sugar) is too low. It is sometimes called a 'hypo'.

> This symbol means a calculation is necessary



# Diet

- 4.1 Carbohydrate counting
- 4.2 Glycaemic Index
- 4.3 Advanced bolus options
- 4.4 End of section worksheet

## Diet

## 4.1 Carbohydrate (CHO) counting

For your child to get the best results from their pump, you need to count CHO. This is particularly important if you are planning to use the 'bolus calculator' on their pump – if you put the wrong information in, you will get the wrong information out. CHO is counted in grams (g) for pump therapy. Even if you have been CHO counting for a while, it is worth having a refresher session with your child's dietitian before starting with the pump to make sure everything is up to date.

## What foods need to be counted?

#### Those containing starchy CHO

- Bread
- Potatoes
- Pasta
- Rice
- Chapat
- Breakfast cereals
- Noodles
- Bread products and things containing flour
- Couscous
- Quinoa
- Bulgar wheat
- Yams
- Cassava
- Plantain
- Squashes
- Sweet potato
- Parsnips
- Pastry
- Crackers
- Pulse vegetables (baked beans, mushy peas, other beans, peas, chickpeas, dahl, lentils)

#### Those containing natural sugars

- All fruits
- Fruit juice
- Fruit smoothies
- Dried fruit
- Milk
- Yoghurt
- Fromage frais
- Drinking yoghurt
- Milkshake
- Custard
- Rice pudding

#### Those containing added sugars

- Biscuits
- Cakes
- Muffins
- Cookies
- Brownies
- Doughnuts
- Sweets
- Chocolate
- Chocolate biscuits
- Ice cream
- Mousse
- Trifle
- Cheesecake
- Other desserts

**Those not counted include:** plain proteins and fats, although they may affect how CHO is absorbed.

#### How to count CHO

- use food labels
- weigh foods
- use nutritional books
- use phone apps.

#### 1. Food labels

Use the nutritional labels on a product, giving values per 100 g and/or per portion. You need to use the 'total carbohydrate' figure, NOT the 'of which sugars'. The 'traffic light' labelling on the food packaging only gives the sugars value.

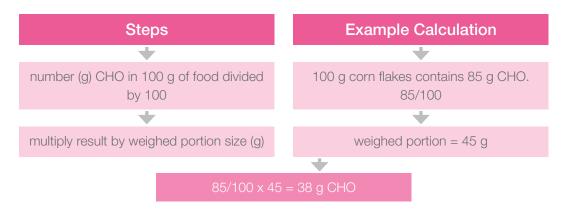
Nutrition Information	n			Guideline daily am				
Typical values Cooked as per instruction	Carbo- hydrate per 100 g	Carbo- hydrate per 1/3 Pizza	% for a typical % GDA Adult	Women	Men	Children (5–10) years		
Energy	1001 KJ <b>238 Kcal</b>	1977 KJ 470 Kcal	23.5%	2000 Kcal	2500 Kcal	1800 Kcal		
Protein	9.3 g	18.4 g	40.9%	45 g	55 g	24 g		
Carbohydrate	28.7 g	56.7 g	24.1%	230 g	300 g	220 g		
Of which is sugars	2.7 g	5.3 g	5.9%	90 g	120 g	85 g		
Of which is starch	25.9 g	54.2 g	-	]-	-	-		
Fat	9.6 g	19.0 g	27.1%	70 g	95 g	70 g		
Of which saturates	3.7 g	7.3 g	36.5%	20 g	30 g	20 g		
Mono-unsaturates	4.0 g	7.9 g	-	-	-	-		
Polyunsaturates	1.6 g	3.2 g	-	-	-	-		
Fibre	2.3 g	4.5 g	18.8%	24 g	24 g	15 g		
Salt	1.0 g	2.0 g	33.3%	6 g	6 g	4 g		
of which sodium	0.40 g	0.79 g	32.9%	2.4 g	2.4 g	1.4 g		
You may want to keep an eye on your <b>salt</b> intake as too much may increase your blood pressure. It's important to watch your <b>calorie</b> intake, as without regular exercise too many may lead to weight gain. A diet low in <b>fat</b> , particularly <b>saturated fat</b> , could help to maintain a healthy weight and healthy heart. To maintain a healthy lifestyle, we recommend aiming for at least 30 minutes of moderate exercise each day, such as brisk walking.								

If you are weighing food, you can use the 'per 100 g' figure. The 'per portion' value is useful for quantities you can easily count, e.g. per slice of bread, per biscuit, per fish finger, etc.

### 2. Weighing foods

This is the most accurate way to count CHO in foods without labels, or when the portion size varies. Foods that are good to weigh include pasta, rice, potatoes (roast, mashed, chips, jacket), couscous, noodles, breakfast cereals, homemade recipes and fruits.

You can buy scales that come with the nutritional values of foods pre-programmed, and will calculate the CHO value based on the weight of food. However, these are quite expensive and you only end up using a small amount of the data you are paying for. A pair of digital scales and some maths will do the same job!



Once you have weighed a portion, keep a record of your child's portion sizes of different foods to avoid having to reweigh each time. However, children's portion sizes change as they grow, so reweigh portions every three to six months to check the new CHO contents.

## 3. CHO books

Many books are available to help. As they tend to be aimed at people losing weight, they count calories but also contain CHO values. Some books give values per 100 g (useful for weighing), some per portion (useful when you and your child are out or away from home), and some have photos to show different quantities. Below are examples of each:

- Collins Gem, *Calorie Counter* (ISBN: 978-0007211500): Values per 100 g and per portion
- Carolyn Humphries, *The Hugely Better Calorie Counter* (ISBN: 978-0572034818): Values per portion
- Chris Cheyette and Yello Balolia, *Carbs & Cals: A Visual Guide to Carbohydrate & Calorie Counting for People with Diabetes* (ISBN: 978-0956443052): Photographs of different portion sizes displaying CHO and calorie values for each
- Chris Cheyette and Yello Balolia, Carbs & Cals & Protein & Fat: A Visual Guide to Carbohydrate, Protein, Fat & Calorie Counting for Healthy Eating & Weight Loss (ISBN 978-0956443076): Photographs of food and drink items displaying CHO, calorie, protein and fat values for each.

All are available from online retailers, or can be ordered from bookshops.

#### 4. Phone app

The *Carbs & Cals* book is also available as an app for the iPhone, available via the Apple App Store.

#### Calculating CHO when using recipes

Work out the whole recipe then divide by number of portions:



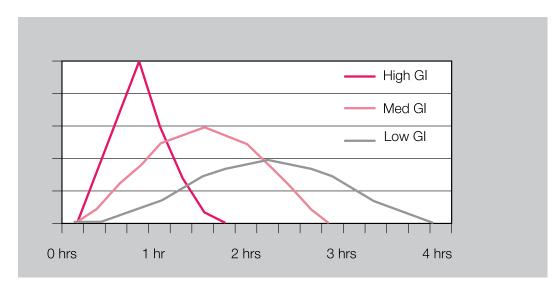
#### **Dietary fats**

Recent studies have suggested that dietary fats may contribute to delayed increases in glucose levels. We recommend that once you have achieved good control with your child's **basal rate** and bolusing with meals, you may want to fine tune that control by looking at meals specifically high in fats (e.g. fish and chips, pizza, creamy curries and pasta dishes, some puddings). You may find that their blood glucose stays higher than you would have predicted for a longer period of time after these types of meals. If this is the case then discuss with the dietitian and look at a different **bolus** type or a **temporary basal rate** increase for up to 8 hours.

## 4.2 Glycaemic Index (GI)

**Glycaemic Index** (GI) is a term that describes the different rates at which carbohydrate (CHO) foods break down and release their sugar into the bloodstream. Each CHO food is tested in a laboratory and given a value. High value GI foods are broken down very quickly, causing a rapid increase in blood glucose levels. Low value GI foods take a longer time to break down, causing a slower more steady increase. Fat and protein, in a food or as part of a meal, slow the release of sugar from CHO foods and reduce the GI.

For more information on GI look at www.glycemicindex.com (spelt the American way, without an 'a')



#### How does the GI of the food affect the pump?

Things to think about:

- on a pump, different bolus patterns should be used with mixed meals to slow the insulin delivery to match the release of sugar from CHO foods. Most main meals (which contain protein and fat) would benefit from using a dual or combination wave bolus over one to four hours
- some meals containing both quick and slow release CHO would also benefit from a dual wave bolus. This delivers some insulin quickly and some insulin over the delayed time (one to four hours). The percentage of quickly and slowly delivered insulin depends on what you set, but usual combinations are 50:50, 70:30 or 30:70
- if your child is eating a meal that contains fat, protein and low GI CHO, then you may need to extend this even longer over four to six hours, e.g. 30:70 or 50:50. Getting this right requires trial, error, and good record keeping! **Discuss this with your child's dietitian to get the best match.**

#### Food ideas for smoothing out blood glucose readings

Look at the ideas below and fill in your own suggestions in the workbook at the end of this section (see page 55). Including more naturally low GI foods in your child's diet will help smooth out your child's blood glucose readings and maintain energy levels between meals.

Meal time	High GI Options	Low GI Options
Breakfast	Cornflakes Weetabix Bagels, crumpets White bread	Oat/Bran-based cereals Whole fruit Milk/Yoghurt Granary bread
Lunch	White bread, baguette, wraps Jacket potato	Granary Bread Pasta salad Yoghurt Whole fruit
Snacks	Rich Tea biscuits Pretzels	Fruit, oatcakes Popcorn, crisps Oat cereal bars
Dinner/Main meal	Mashed/boiled potatoes White rice	Pasta, sweet potato Beans, peas Basmati rice

## 4.3 Advanced bolus options

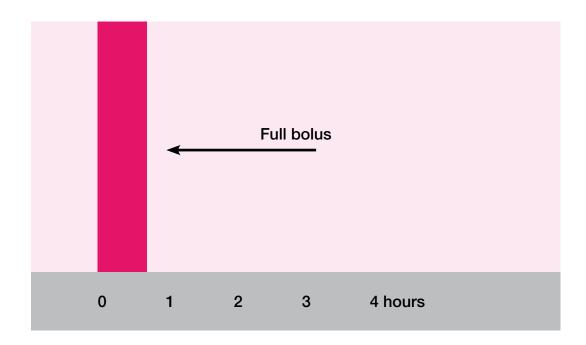
Another advantage of insulin pump therapy is the ability to have different choices when giving boluses. The names may differ according to the pump you are using.

#### Normal or Standard

This is when the whole of the bolus is given straight away.

If you do not know how much food your child is going to eat, you could give two normal boluses close together; some before they eat, and then a top up when they have finished eating and you know how much more to give.

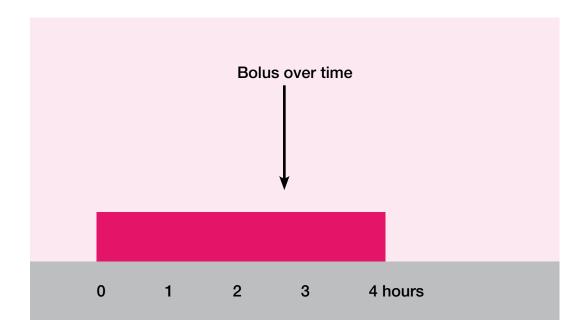
A ham sandwich, non-oat cereal and milk, snacks in general.



#### Extended or Square Wave

This is where the total bolus is spread out over time. The whole dose is evenly spread over the choice of time (15 minutes to eight hours). It can be stopped at any time and is useful for long spread out meals, buffets, and meals with either a very high fat or low glycaemic index content.

A high-fat meal takes longer to be absorbed, therefore this option can be programmed to more closely match the rise in blood glucose, e.g. pasta (with cheese sauce), fish and chips, curries especially with rice and naan bread, pizza (especially with meat or extra cheese topping).

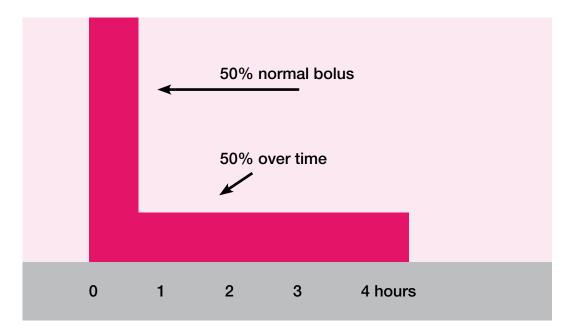


#### Multiwave, Dual Wave or Combination

This is a combination of the normal and extended wave, when a chosen amount is given immediately and the rest over time. This is useful for most meals containing protein and fats as well as CHO.

Whether this is given as half immediately and half over a period of time (50:50 over 1 hour), or another ratio (30:70, 70:30), is usually a matter of trial and error.

Any main meal containing all three food groups (CHO/protein/fat) e.g. sweet and sour Chinese food, pasta with a tomato sauce, ham sandwich with oat-based cereal bar.



Fill in a list of foods that may need these various bolus types in the workbook at the end of this section (see page 54).

#### **Bolus calculators**

All pumps now have a bolus calculator. Your child's personal settings can be programmed into the pump.

#### Settings include:

- blood glucose target
- insulin to CHO ratio (ICR)
- insulin sensitivity factor (ISF)
- insulin on board (IOB) or 'active insulin' this is the amount of insulin still working.
  By taking this into account the risk of a hypo is reduced.

Remember, the bolus calculator can have different settings for different times of the day.

#### You still need to:

- do a pre-meal blood glucose test
- calculate and enter the amount of CHO
- a dose will be suggested but...

#### You still need to think about:

- type and amount of CHO
- environmental temperature
- exercise
- individual variability in absorption.

In children and young people these settings need to be reviewed every three months, or whenever the family starts to feel less confidence in the advice given by the bolus calculator. Bolus calculators are an effective way of ensuring consistency as your child gradually takes on more responsibility.

Ask your child's healthcare team to show you how to set this on your child's pump.

## 4.4 End of section 4 worksheet

#### Advanced bolus options

Foods that may need normal or standard bolus:

Foods that may need extended or square bolus:

Foods that may require a multiwave, dual wave or combination bolus are:

### Food ideas for smoothing out blood glucose readings

Fill in the table below with your food ideas.

Meal time	High GI options	Low GI options
Breakfast		
Lunch		
Snacks		
Dinner/Main meal		

## Questions:

- 1. Do fat and protein in food slow the release of sugar from CHO foods and reduce the GI?
  - 🗆 Yes
  - 🗆 No
- 2. 100 g cooked rice contains 30 g CHO. If my weighed portion of cooked rice is 230 g, how much CHO is in my portion?

You can find the answers to these questions in Appendix E of this workbook.

## Quick glossary

**Basal rate:** the rate of continuous background insulin infused.

**Fast-acting insulin:** insulin that acts quickly to minimise the rise in blood glucose (sugar) that occurs after eating a meal.

Long-acting insulin: insulin which acts slowly throughout the day and night to match the normal background level of insulin.

**Correction bolus:** an extra amount of fast-acting insulin to lower the blood glucose (sugar).

**Food bolus:** a dosage of fast-acting insulin with a meal.

**Temporary basal rate:** temporary adjustment to the basal rate of insulin given in response to activity, stress or illness.



# Life

- 5.1 Exercise and activity
- 5.2 Travel
- 5.3 School/College and social life
- 5.4 Illness
- 5.5 Menstruation
- 5.6 Alcohol
- 5.7 Admission to hospital
- 5.8 Continuation of funding
- 5.9 Insurance
- 5.10 Identification of a medical issue
- 5.11 End of section worksheet

## Life

## 5.1 Exercise and activity

Activity is often associated with the need for less insulin, and therefore the option to decrease the **basal rate** (see page 20) is useful. Adjusting insulin rates for increased extra activity is often a process of trial and error, as each individual reacts differently. The table on the following page has some suggested insulin dose adjustments.

Things to think about:

- will your child need to take their pump off to participate in the activity?
- if they are wearing their pump, will their basal rate need to be reduced during the activity?
- will their basal rate need to be reduced after the activity, and how long for?
- will they need an extra activity snack, or can it be managed by reducing their insulin dose with the meal bolus beforehand?

For every hour of above average activity 10-20 g of extra carbohydrates (CHO) are usually needed. For more competitive athletes this could be 15-30 g/hr.

	Light activity	Medium activity	Heavy activity
Examples	Walking, trampolining, short bike riding	Swimming, football, cricket, rugby, dance class	Weekend hiking, school residential trips, sports tournaments
Bolus	No reduction	Approx. 50% reduction	50% reduction Discuss with healthcare team
Basal during	10-30% reduction	Approx. 50% reduction	50% reduction & eat CHO
Basal after	No reduction	No reduction	30-50% reduction for up to 12 hours, occasionally longer

Consider reducing the meal bolus if exercising within 90 minutes of eating.

## All-day activity may require a 50% reduction in the basal rate during the day and 25% that night.

Things to remember:

- competitive sport can raise blood glucose due to adrenaline surge, and extra insulin may be needed before but reduced afterwards
- more frequent blood glucose testing will help to clarify what's needed
- if your child does a lot of sport/exercise it may be best to record what they do and when, and see how it is related to meals and the time of day. Then plan what you are going to do with their food, their basal rate and their bolus.

Lots more information and helpful advice about exercise, sport and activity can be found at www.runsweet.com

## 5.2 Travel

Now that your child has an insulin pump things will be a little different when they travel. You'll find answers to the most common questions below.

### Can my child go through security wearing their pump?

Yes, but do not let your pump go through the baggage X-ray machines. Ask for a letter from your child's healthcare team.

### Should they have a letter with them about the pump?

Yes, their healthcare team should provide a letter.

#### What else should they take with them?

When travelling your child should always have plenty of supplies, including **fast-** and **long-acting insulin**, and a means of taking it (pen or syringe).

#### Bearing in mind security requirements, where should my child store their insulin?

Your child's insulin and equipment should be stored in hand luggage on board aeroplanes. It should not be packed in a suitcase, as it is too cold in the hold and might also go missing.

#### Make sure your child has travel insurance covering their pump!

Most pump companies have a holiday loan scheme so that your child can take a second pump on holiday – contact their helpline for more information.

#### Time zones

Think about the changes that will need to be made if your child is flying to a different time zone.

- If the new time zone is less than four hours different, adjust your child's pump clock on arrival.
- If the time zone is more than four hours different you can either:
  - adjust your child's pump clock by four hours on departure and then gradually adjust further over the next few days

or

- use the lowest flat basal rate during flights, use correction doses if necessary, and change time on departure or arrival according to preference.
- Give **boluses** with meals as usual.
- Monitor blood glucose levels regularly and correct high and low readings as needed.

## 5.3 School/College and social life

#### School & college

Starting with an insulin pump is planned in advance, so it's always a good idea to show the staff at your child's school the pump itself ahead of time. You or your child's diabetes nurse will explain what it is, how it works, and the key differences compared to an injection regime particularly when more immediate action is required. They will also run through the recommended list of supplies that should be kept at school.

#### Social life

Please ask your child's diabetes team about the additional options available for managing situations such as music festivals, friends and intimate relationships while on insulin pump therapy. It is often important to include close friends/partners in understanding how to manage your child's diabetes and insulin pump.

If your child is going to be involved in a new situation such as a music festival, travelling abroad etc, it is important to think how you will handle it in advance. If necessary, discuss any concerns you might have with your child's healthcare team.

## 5.4 Illness (sore throats, chickenpox, colds etc.)

Infections associated with a temperature often increase blood glucose, resulting in the temporary need for more insulin (see section on ketones, page 29). In these circumstances, if bolus correction has failed and your child's glucose levels remain above 14 mmol/l then consider increasing the basal rate over four to 12 hours (sometimes longer) to 120%. In some circumstances it may be necessary to gradually increase in steps up to 200%. You may find it useful to set a second basal pattern with an increase of 20% for times of illness.

## 5.5 Menstruation

Monthly periods are often associated with an increased need for insulin. You may find it useful to either set a second basal pattern or use the **temporary basal rate** increase to help keep your child's blood glucose in single figures. **Please discuss this further with your child's healthcare team.** 

## 5.6 Alcohol

Alcohol can affect blood glucose levels so it is important to ask the healthcare team to explain this to you and your child once your child is consuming alcohol. The team can help them to manage alcohol safely.

## 5.7 Admission to hospital

What to do about your child's pump if they are admitted to hospital:

- if it is a planned admission, make sure you discuss it with hospital staff/your child's healthcare team beforehand
- if your child is having a minor operation it may be possible for them to keep their pump on with the agreement of the anaesthetist
- you may have to adjust your child's basal rate before admission. Often a 10-20% reduction from time of starvation is advised. **Please discuss with your healthcare team**
- if your child is having a major operation they will need to take off their pump and be given insulin intravenously
- if your child is admitted with high blood glucose levels or ketones, they will be asked to take off their pump and be given intravenous insulin until the problem has been resolved
- if your child is capable of looking after their diabetes for themselves they should continue using their pump while in hospital, provided they have the agreement of the medical team caring for them
- if your child is not able to look after their insulin pump themselves, you will need to use other methods to give insulin. Hospital staff will advise
- make sure your child's pump is stored safely if taken off.

## 5.8 Continuation of funding

The pump is expensive and requires renewal after four to five years. This requires your child's diabetes team to write and request permission for funding again. In the submission they require evidence that it has been useful and effective in helping your child manage their diabetes. Although **HbA1c** being below 58 mmol/l (7.5%) is not the only criterion, it is an important one, and is viewed very positively when it comes to refunding. Issues such as not working with the healthcare team, misuse of the pump or repeated failure to attend clinic will be viewed very negatively and may result in the withdrawal of funding for the pump.

## 5.9 Insurance

We strongly recommend that you put your child's pump on an appropriate insurance policy. It is often cheaper to put it on a comprehensive home insurance policy.

If the pump is lost or stolen then the pump company may decide not to replace it until the natural end of the warranty. If the pump stops working properly it will be renewed by the company.

## 5.10 Identification of a medical issue

We recommend that all children/teenagers wear an ID bracelet/necklace. This is for emergency use and is a simple and safe way to alert the emergency services to the fact that your child has diabetes. You can obtain bracelets/necklaces from:

Medic alert foundation - www.medicalert.org.uk

Or much more cheaply from:

County engraving - www.countyengraving.co.uk

Medical Tags - www.medicaltags.co.uk

Angel Bear Pump Stuff - www.angelbearpumpstuff.com/sticky-jewelry.cfm

We also recommend that you enter any appropriate contact numbers onto your child's mobile phone, if they have one, under ICE (In Case of Emergency).

Ambulance crews tend to search mobile phones for contact numbers, and they will look under ICE.

## 5.11 End of section worksheet

What temporary basal rate is your child going to start with for exercise and for how long?

What bolus reduction will you give them before exercise?

What extra CHO and what type of CHO might you give them to eat before exercise?

What are your main concerns about the management of your child's insulin pump while they are at school?

If your child's blood glucose was over 14 mmol/l at school what action should be taken?

What would you do if the pump stopped working while your child was at school?

## Questions

- 1. Can my child go through airport security wearing their pump?
  - 🗆 Yes
  - 🗆 No
- 2. When travelling on a plane, should your child's insulin and equipment be stored in hand luggage or the hold?
  - □ In hand luggage
  - $\hfill\square$  In the hold
- 3. When does the average pump require renewal?
  - □ Every year
  - □ After 2-3 years
  - □ After 4-5 years
  - □ After 10 years

You can find the answers to these questions in Appendix E of this workbook.



## Appendices

Appendix A: Record of insulin pump settings Appendix B: Adjusting basal rate charts Appendix C: Useful websites/books and support groups Appendix D: Needle information Appendix E: End of section worksheet answers Appendix F: Glossary

## Appendices

## Appendix A: Record your child's insulin pump settings

Data				loo: dia	looutin
Date	Insulin CHO ratio	Insulin CHO ratio lunch	Insulin CHO	Insulin	Insulin
		ratio iunch	ratio evening	sensitivity	sensitivity
	breakfast		meal	day	night

## Pump supplies

It's a good idea to think ahead and always make sure you have enough supplies before holidays.

Name of pump company:	
Telephone number:	
E-mail:	
Emergency number:	
Pump serial number:	
Checklist:	
Infusion sets:	
Batteries:	
Inserters:	

## Insurance

The pump is your responsibility. If it's stolen or lost you may have to pay for a replacement or return to injections. A pump is valued at around  $\pounds2,500-\pounds3000$ . We recommend you apply for a comprehensive insurance policy, and that you check your home contents insurance policy to see if the pump is covered.

## Appendix B: Adjusting basal rate chart

Use the blank forms to write in the time period and then mark times for blood glucose testing with a cross.

Time (hrs)									
	Fasting (water only)								
BGL									

Time (hrs)									
	Fasting (water only)								
BGL									

Time (hrs)									
	Fasting (water only)								
BGL									

Time (hrs)									
	Fasting (water only)								
BGL									

Time (hrs)									
	Fasting (water only)								
BGL									

BGL = Blood glucose level

## Appendix C: Useful websites/books

#### Insulin pump accessories

www.diabete-ezy.com www.pumpwearinc.com www.angelbearpumpstuff.com www.funkypumpers.com

## Pump support groups

www.childrenwithdiabetesuk.org www.insulin-pumpers.org.uk/support www.input.me.uk www.diabetesnet.com/diabetes\_control\_tips/bolus\_on\_board.php#axzz18NwKp1pF www.jdrf.org.uk/schools www.integrateddiabetes.com

## Tutorial website

www.integrateddiabetes.com

### Pump schools online

pumpschool.minimed.com/index.tpl http://bit.ly/s0YsYs www.animas.com/about-insulin-pump-therapy/kids-and-pumps

## Pumps and exercise

www.runsweet.com

## Books about insulin pump therapy

- Pumping Insulin: Everything You Need for Success on a Smart Insulin Pump. John, D.B.A. Walsh, Ruth Roberts. The best guide book for insulin pump users or professionals who teach insulin pumping. The book is extremely comprehensive. Numerous "workspaces" help you calculate various numbers for pumping, such as your total daily dose. Many tables and charts are used to illustrate each topic, helping readers to grasp what are sometimes complex subjects. There is a chapter about the use of insulin pumps in children and teens. If your child has an insulin pump and you want to help them get the most from it, we recommend this book.
- Using Insulin Pumps in Diabetes: A Guide for Nurses and Other Health Professionals. Jill Rodgers.
- Insulin Pump Therapy and Continuous Glucose Monitoring. J Pickup.
- Type 1 Diabetes in children adolescents and young adults. R Hanas.
- Think like a Pancreas. Gary Sheiner.
- Diabetic Athlete's Handbook, Your Guide to Peak Performance. Sheri R Colberg.
- Human Kinetics. Sheri R Colberg.

Pump	Infusion Set	Length (mm)	Angle	Prime Volume	Inserter
		6 mm	90°	0.3	Complete unit
	Inset II	9 mm	90°	0.5	Complete unit
Animas Pump	Inset 30	13 mm	45°	0.7	Complete unit
	Comfort Short	13 mm	45°	0.7	No
	MIC	6 mm	90°	0.3	Complete unit
	MIO	9 mm	90°	0.3	Complete unit
Medtronic	Quick Set	6 mm	90°	0.3	Yes
Pump	QUICK SEL	8 mm	90°	0.5	Yes
	Silhouette	13 mm	45°	0.7	Yes
	Siniodette	17 mm	45°	0.0	Yes
	Flexlink	8 mm	90°	1.0	Yes
	Rapid D	6 mm	90°	No Fixed	No
Roche Pump	Παρία Β	8 mm	90°	Prime	No
	Tender	13 mm	45°	0.5	No
	CLEO	6 mm	90°	0.2	Complete unit

## Appendix D: Needle information

## Appendix E: Question answers

## Section 1 – Introduction

- 1. Every two days
- 2. Varies for user (see Section 1)
- 3. Varies according to set used (consult manufacturer's handbook)
- 4. The best time to change site is about half an hour after a bath, but not late at night as you need to ensure cannula is working before your child goes to sleep
- 5. Two hours.
- 6. Because these may reduce amount of insulin your child is receiving.
- 7. Disconnecting the pump from your child's body is essential to avoid unintentionally giving insulin.

## Section 2 – Starting pump therapy

- 1. 0.4 units/hour
- 2. At breakfast, or between approx. 5 am-9 am (the 'dawn phenomenon')
- 3. Inject the total daily basal rate with long-acting insulin

## Section 3 - Managing pump therapy

- 1. High blood glucose, high levels of sugar in the urine, frequent urination, increased thirst
- 2. Correction via pen and more frequent monitoring
- 3. See section 3.2 for list of possible reasons for hyperglycaemia
- 4. Six days

## Section 4 – Diet

- 1. Yes
- 2.69 g

## Section 5 – Life

- 1. Yes
- 2. As hand luggage
- 3. After four to five years

## Appendix F: Glossary

Basal rate: the rate of continuous background insulin infused.

Continuous glucose monitors (CGMs): these are devices which are able to measure your glucose levels in the tissue by using a small probe inserted under the skin. As it is not measuring glucose in the blood there is a lag period, so they are not always good at measuring rapid hypos. There are two sorts: one where the results are stored but cannot be viewed until downloaded, and others where the result can be seen all the time – each have their own advantages.

Correction bolus: an extra amount of fast-acting insulin to lower the blood glucose (sugar).

Dawn phenomenon: the natural increase in insulin occurring in the early hours of the morning associated with the body's natural day/night hormonal rhythm (Circadian rhythm).

Diabetic ketoacidosis: a condition where the blood becomes acidic due to rising levels of blood glucose and ketones.

Dusk phenomenon: The natural increase in insulin late afternoon in association with the body's natural day/night rhythm, usually less pronounced than the dawn phenomenon.

Fast-acting insulin: insulin that acts quickly to minimise the rise in blood glucose (sugar) that occurs after eating a meal.

Food bolus: a dosage of fast-acting insulin with a meal.

Glycaemic Index (GI): this may range from low to high and refers to how quickly glucose in the food is absorbed from the gut into your blood. Low glycaemic food is in general better and the food is slowly absorbed. Examples include wholegrain bread and pasta. High glycaemic foods are best for treating hypos as they tend to contain pure sugars and are absorbed fast from the gut.

HbA1c: Your child's HbA1c (glycated haemoglobin) reading is an indicator of your child's blood glucose (sugar) levels over the previous two to three months.

Hyperglycaemia: a state that occurs when blood glucose (sugar) is too high.

Hypoglycaemia: a state that occurs when blood glucose (sugar) is too low. It is sometimes called a 'hypo'.

**Insulin stacking:** accumulation of insulin in the blood after repeated bolus doses of insulin close together (within two hours).

**Insulin to carbohydrate ratio (ICR):** a ratio that tells you how many grams of carbohydrate are covered by one unit of insulin (e.g. one unit insulin to seven grams of carbohydrate).

Ketones: these are produced in association with periods of insufficient carbohydrate (missing food) and inadequate insulin (missing insulin or inadequate dose of insulin). They are associated with the need for increasing doses of insulin to correct high glucose levels (insulin resistance).

Long-acting insulin: insulin which acts slowly throughout the day and night to match the normal background level of insulin.

Temporary basal rate: temporary adjustment to the basal rate of insulin given in response to activity, stress or illness.