NHS
Royal Berkshire
NHS Foundation Trust

A guide to Type 1 Diabetes in Young People

And moving to the Young Adult Clinic

BYPDC
BERKSHIRE YOUNG PEOPLE'S DIABETES COUNCIL

Index

Introduction

What is transition?

Transition is the purposeful planned movement of young people with chronic conditions from family-centered to adult-orientated health care systems.

When you were approximately 14-15 years old, you were transferred from your current diabetes nurse to Boikie, our specialist young persons' nurse. This was to mark the beginning of the transition process. You continue to be seen in Children's Clinic until you are 16-18 years old; the age depends on your individual needs.

Your last medical appointment at Children's clinic will be with Dr Jo Spinks and Dr Fania Kavvoura. This is a chance to meet Dr Fania Kavvoura and hand over your medical care all together. Boikie can also sit in with you.

You will then have your medical appointments (see a doctor) in Melrose House, while still having access to our dietitians, psychologist and on call service until you reach your 19th birthday, when the transfer process is complete. During this time, working together we want to prepare you for living with diabetes as a young person. We are here to promote and encourage you towards more independent thinking, to develop a deeper understanding of your diabetes and become involved in treatment decisions. The aim is for you to become confident in your self-care abilities as you move into adulthood. This is especially important for young people who were diagnosed with diabetes as young children and who may not have been fully included in, or part of, any direct teaching and learning.

Paediatric Diabetes Specialist Team
Dr Jo Spinks Paediatric Diabetes Consultant (Clinical Lead)
Dr Chandan Yaliwal Paediatric Diabetes Consultant
Dr Claire Holt Paediatric Diabetes Consultant
Dr Cathy Golding Paediatric Diabetes Associate Specialist
Dr Ines Banos Consultant Clinical Psychologist
Andrea Jones 07825 434 350 (Lead)
Boikie Osupeng (Young People's Nurse): 07826 534 445
Ian Lehain 07810 833 754
Sarah Gresty 07554 117 128
Jayne Lewis 07789 617 738
Team email Paeds.diabetesnurses@royalberkshire.nhs.uk
Paediatric Diabetes Specialist Dietitians
Rachel Dcruz 07768 034 871
Kayleigh Wilcox 07825 283 706

When to contact the Paediatric Diabetes Team

If you are unwell, are vomiting or have ketones. Or

- ➔ If you notice that you are waking up with blood glucose levels below 4mmol/L or above 7mmol/L more than 4 times per week.
- ➔ If you notice that your blood glucose levels are consistently below 4mmol/L or above 7mmol/L before any meal or at any time.
- ➔ If you have any questions about your diabetes management or if you need any extra support.
- ➔ If you need the Specialist Team to write you a letter (please give us at least 6 weeks' notice to allow for postage.)

Out of hours' advice

Your Paediatric Diabetes Team runs an out of hours' advice service for urgent queries that cannot wait until the next working day.

The out of hours' service is available as follows:

Monday to Friday from 5pm to 8pm

Weekends and Bank Holidays from 8am to 8pm

From 8pm to 8am, you will need to contact the hospital switchboard on 0118 322 5111, and ask to speak to the paediatric registrar on call (if you are still under 19.)

To find out the mobile phone number of the staff member on call, please download the Digibete app and enter our clinic code ABMJL. This will tell you who is on call and has lots of useful information and videos including Sick Day Rules.

I**f you are over 19 please call 111**

Young Adult Clinic (YAC)

Once your medical appointments have been transferred to Melrose House, will need to visit the Young Adult Clinic at least four times a year as part of your regular diabetes care. These visits will to support you in your journey to enhance your self-care skills. While you may be *'followed up'* for not coming to your appointment in Children's Clinic, the resources in Young Adult Department do limit the capacity to do this. Therefore, there is an expectation that you have reached an age where the responsibility lies with you to turn up for appointments.

Your attendance in clinic is highly valued. Your appointment does not need to just be about how your diabetes has been, so even if you feel your diabetes self-care hasn't been going as well as you might like, please come. However, if you are unable to attend the clinic, please let the diabetes nurses' secretary know on 0118 322 7532. If no one is available, please leave a message. Your request will be dealt with and another appointment sent out.

You may not always see the same doctor when attending your Diabetes Clinic appointment.

However, the procedure on arriving at the clinic is generally the same:

➔ Check in at reception in the entrance.
➔ You will be shown to the YAC waiting room down the stairs.
➔ You will then be invited into a room for the usual checks to be done.
➔ Boikie or Andrea will be present during your visit to the Young Adult Clinic (YAC).

➔ An Annual Review will be carried out around the anniversary of your diagnosis. This is usually a slightly longer visit and may include urine testing.

All of the staff are there to help you, so please feel free to ask anyone any questions or queries that you may have.

Where to find the Young Adult Diabetes Clinic

Centre for Diabetes and Endocrinology
Melrose House
71 London Road
Reading RG1 5BS

Directions

Cross London Road at the traffic lights (from the main hospital), and the Diabetes and Endocrinology Centre is directly in front of you and is opposite the garage.

Parking

You can park in the North Block car park or the Craven Road multi storey car park.

Contact details

Young Adult Clinic	
Lead Consultant	Dr F Kavvoura
Consultants	Dr T Aung, Dr E Saeed, Dr G Farah, Dr N Murphy
Psychologist	Dr Alice Parfitt, Dr Vicky McKechnie
Diabetes Specialist Nurses	**Josee Winter 07721599789** (Young People Nurse 19-25yr olds) **Warin Majid** (Manager) **Justina Bangura** (Lead Nurse),Tel: 0118 322 7478 or email: diabetes.nurses@royalberkshire.nhs.uk
Dietitian	
Berkshire Young People's Diabetes Council (BYPDC) Email: bypdc.reading@gmail.com Insta: hypo_to_hero	

What to do if?

What if my meter/pump is broken?

Please contact your meter/pump provider:

Medtronic	01923 205167
Roche Pumps	0800 731 2291
Expert Meter	0800 701 0000
Omnipod	0800 092 6787
Libre	0800 170 1177
Diasend	020 779 581 91
Dexcom	0330 088 7879
T-Slim	0800 012 1560
Novo Nordisk Pen	0845 600 5055
GlucoRx HCT ketone and blood glucose meter	0800 007 5892

What if my pen is broken?

It is always a good idea to have a spare pen for both types of insulin. This still applies even if you use a pump.

You should have the novo pen on your prescription. You can also register new pens (for novorapid/tresiba/levimir) with Novo Nordisk when you first receive them. If they break within a five-year guarantee period, Novo Nordisk will replace them.

If it breaks at the weekend or at night, you can follow the advice below. You will be able to get disposable pens until you can get a replacement.

Contact your Young Adult Diabetes Team if you are over 19.

What if I run out of insulin?

➔ Consult your GP for an urgent prescription.

➔ Ring your usual pharmacist and ask if will dispense emergency supply.

➔ Speak to your Diabetes Team.

➔ Ring 111.

➔ Visit the nearest A&E.

Back to basics

What is diabetes?

The type of diabetes that you have is called Type 1 diabetes. It is also called diabetes mellitus. It happens when the body does not have enough insulin to keep blood glucose levels in the normal range pre meal (between 4 and 7 mmol/L). About 8% of people with diabetes in the UK have Type 1 diabetes.

What causes diabetes?

No one really knows what causes diabetes. We know that some people are more at risk of developing diabetes than others because of genetic factors. Something triggers the immune system to start destroying the insulin-producing cells in the pancreas. This is called an autoimmune response. This process may have been ongoing for several months. Experts think that

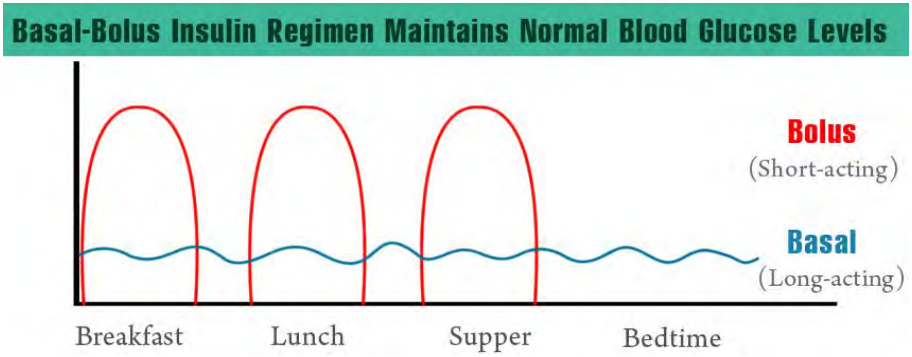
some viral illnesses may trigger the immune system to attack the beta cells in the pancreas and start a destruction process.

What is insulin?

Insulin is a hormone made in the pancreas, (which is an organ in your body that helps with digestion). We all need insulin to live. It does an essential job. It allows the glucose in our blood to enter our cells (such as muscle and brain cells) and fuel our bodies. When you have Type 1 diabetes, your body still breaks down the carbohydrate from food and drink and turns it into glucose. But when the glucose enters your bloodstream, there's no insulin to allow it into your body's cells. More and more glucose then builds up in your bloodstream.

The basal-bolus insulin regimen

A basal-bolus regime, also known as multiple daily injection therapy, involves taking a longer acting form of insulin to keep blood glucose levels stable through periods of fasting and separate injections of shorter acting insulin to prevent rises in blood glucose levels resulting from meals, snacks and drinks containing carbohydrates.



Types of insulin

Basal insulin

The long-acting insulin is called basal insulin. They are background insulins.

There are three:

➔ Levemir/Detemir is sometimes taken once a day, but is more effective in two split doses as it has the shortest acting time.

➔ Lantus/Glargine lasts up to 20-22 hours.

➔ Tresiba/ Degludec has the longest action.

They should be given around the same time each day. This time will be different for different people depending on their activities and routine. Once you have decided on a particular time, stick to it for a while. If it turns out to be inconvenient, it can be changed at a later date.

NovoRapid

This is the bolus insulin that your body needs to deal with the glucose from the carbohydrates in food and drinks. The quick action of NovoRapid starts within 10 minutes of the injection and lasts for 2-4 hours after the injection.

How is your insulin dose worked out?

Insulin to Carb Ratio:

It is the number of grams of carbohydrate covered by 1 unit of fast acting insulin. This ratio varies between people and can be different for different meals or mealtimes.

1 unit of NovoRapid insulin per X grams of carbohydrate.

It is very common for a person's insulin to carb ratio to change as they get older. This is why it is important to review blood

glucose levels regularly at home so the diabetes team can update your regime as your body changes.

For example: The carb ratio is **1 unit for 15g carbohydrate**, and your meal contains **60g carbohydrates**.

1 : 15

X : 60

60 ÷ 15 = 4

This means that the insulin dose needed for this example meal is **4 units of Novorapid**.

Insulin sensitivity

Insulin sensitivity is also known as your correction. This number varies between people and can be different for different meals or mealtimes.

1 unit of NovoRapid insulin per X mmol/L glucose.

It is the number of mmol your blood glucose will fall by when you give 1 unit of fast-acting insulin.

It is very common for a person's insulin sensitivity to change as they get older. This is why it is important to review blood glucose levels regularly at home. **Remember:** look out for patterns in your blood glucose levels! Your diabetes specialist will calculate your insulin sensitivity during clinic – so make sure you talk to the Diabetes Team when you notice a change.

How is insulin correction worked out?

It depends on:

➔ How many units of insulin you need to correct your blood glucose.

➔ Your current blood glucose level.

➔ Your target range pre meal is (usually 4.0 - 7.0 mmol/L) and when using a target for correction it is usually 5.5/5.6.

You will need to work out:

➔ How much insulin you need for the carbohydrates you are about to eat using your Carb Ratio.

➔ How much insulin you need for correction using your Insulin Sensitivity.

➔ Add those doses together to give you the total dose of insulin you need to give.

For example: Your meal contains **60g carbohydrates**, and your **carb ratio is 1u for 15g carbohydrates**. Your blood glucose level is **13.5 mmol/** Your target is **5.5 mmol/L**. And your Insulin Sensitivity is **1u for 4 mmol/L.**

60 ÷ 15 = 4 - meaning 4 units of insulin is needed for the carbohydrates.

13.5 - 5.5 = 8 - meaning you are aiming to have your blood glucose level drop by 8mmol/L.

8 ÷ 4 = 2 - in order to reach your target, range you need to take 2 units of insulin.

4+ 2 = 6 - your total dose for this meal is 6 units of insulin.

Whilst it is useful to understand the math's behind your doses, there are plenty of resources that mean you won't have to do any of this math's! The Aviva Expert Meter does all of the calculations for you if your insulin regime is multiple daily injections. Pump meters come with insulin calculators and the MySugr app can also calculate your insulin.

"The main take away from this is to test your blood glucose levels! I remember falling into the habit of increasing my correction doses every meal and eventually all of the intricate maths the diabetes team used to calculate my insulin sensitivity was lost! Hindsight is 20/20 but now it is obvious I should have asked for help sooner and keep track of my patterns. Instead, I had to reset all my ratios based on my weight alone and had to restart all over again." Sam, BYPDC

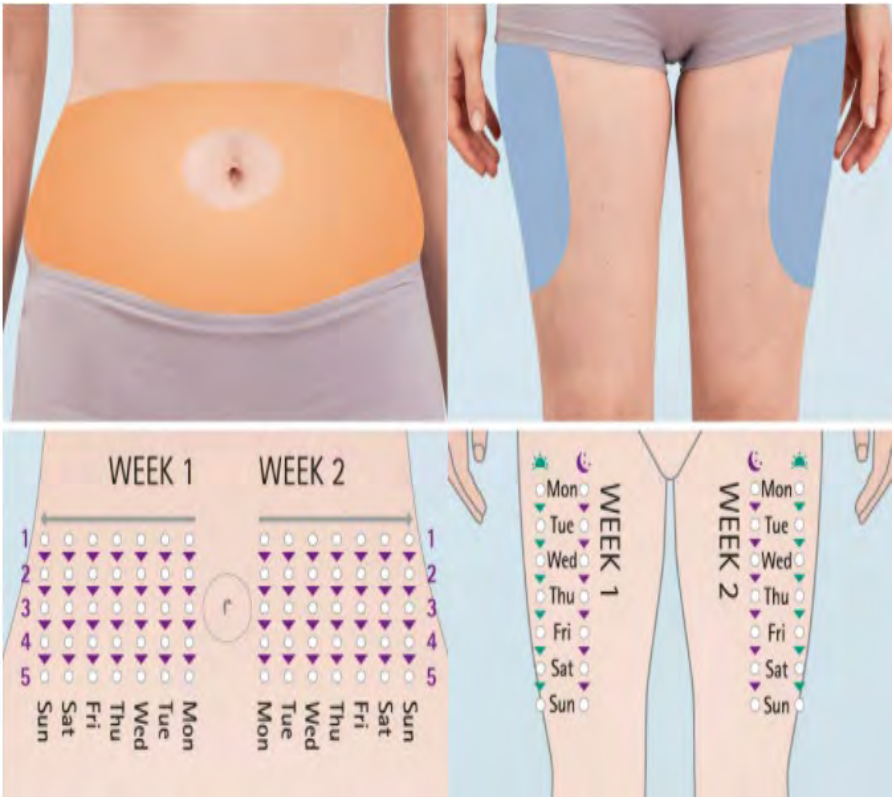
Injections

Giving injections becomes a normal part of your daily routine. The first few injections may feel tricky, but most people manage to give them. If you do have any problems, please discuss with the team so we can help find a solution.

Where do you inject insulin?

Insulin is not given into a vein: it is injected into the fatty (subcutaneous) tissue under the skin and can be given in several different sites. Injections must be given into the subcutaneous tissue to ensure the insulin is reliably absorbed. It should **not** be given into the muscle below nor just below the skin surface.

Insulin is absorbed fastest in the abdomen then the arms. It is slowest in the thighs and buttocks. We recommend long acting (basal) insulin is given in thighs and buttocks.



Problems with injection sites

It is important to rotate the injections around the various sites to prevent one part becoming lumpy. The lumps are not insulin; they are an accumulation of fat. Insulin makes fat cells grow in size if given in the same place repeatedly. Injections into lumps will usually result in a slower and more erratic absorption of your insulin, which can cause variable blood glucose readings.

They can take anything up to 6 months to disappear so it is best not to get them in the first place. If you can't feel your injection, you are injecting into a lump so you need to move!

Insulin pumps and Continuous Glucose Monitoring (CGM) and Flash Glucose monitoring (FGM)

Insulin pumps are devices attached to the body that continuously deliver of rapid or short-acting insulin via a catheter, called a cannula, inserted under the skin. As well as a continuous flow of very small amounts of insulin that you can adjust to meet your needs, depending on activity, illness or stressors, you also need to enter the carbohydrates of every single food or drink that you eat to obtain a bolus of insulin.

CGM and flash glucose systems are different methods of measuring glucose. The sensors measure the glucose in your interstitial fluid – the fluid in and around your body's cells. This is different to blood glucose. CGM/FGM can be used whether you wear a pump or use injections for your insulin delivery.

- ➔ **CGM systems** work 24 hours a day and can include alarms to indicate when your glucose levels are too high or too low. To be eligible for funding for a CGM system you will need to fulfill certain criteria and this can be discussed further with your diabetes team.
- ➔ **Flash Glucose Monitoring (FGM)** (currently in the UK; Freestyle Libre 1 and 2) is a way of monitoring glucose levels. A sensor is placed on the upper arm for 14 days, measuring interstitial glucose. The sensor is scanned with a reader or mobile phone providing current glucose reading, a trace for the previous eight hours, and importantly trend

direction arrows depicting whether glucose levels are going up, down or stable.

With both systems, there will still be occasions when you need to test your blood glucose with a finger prick. This will be discussed when you start the system.

If you are interested in any devices, speak to your consultant and/or your nurse.

Those who already have these devices will continue to be supported as normal. By this time in your diabetes walk, we would expect that you can manage these on your own or with some support.

"I always had trouble testing my blood sugar. I more often than not a high number would make me feel like I was failing at diabetes. I now have CGM, which is amazing because it warns me before I get high, and I am confronted with my blood sugar whether I want to know or not. It has really helped me gain control of my diabetes.

I use the Medtronic 670G with the Guardian 3 sensor. This pump has a feature called auto-mode, which automatically adjusts my basal insulin to keep me in range. I was always terrible at using temporary basal rates, so to have a pump that does it for me is massively useful.

I had options with CGM and pump options. The way I did this was mostly YouTube videos and blog posts. The BYPDC has put together Peer Support Champions who can answer questions you have about pumps and/or CGM. It's a great resource so don't be afraid to use it!" Sam, BYPDC

Peer Support Champions

Email: bypdc.reading@gmail.com **This is not for clinical advice**

Keeping in range

In order to keep blood glucose (BG) levels in range you may need to change insulin doses in between clinic visits. These tips help you to know what to do and when.

- ➔ Ideal BG levels are 4 - 7 mmol/L pre meal
- ➔ BG levels are information to help you stay in range - not grades. Having raised or low blood glucose is not a failure, but rather indication that something needs to be altered.
- ➔ Give a correction dose if BG levels are more than 10 mmol/L **2 or more hours** after a meal. But **also think about if you have exercised or plan to exercise**. NovoRapid has an action time of between 2 - 4 hours depending on the food eaten, time of day, site injected and individual person.
- ➔ Regularly look at your data to spot patterns. Try to do this on a weekly basis.
- ➔ If BG levels are raised at certain times 4 days or more in a week check
- ➔ If you have raised BG levels before a particular meal, increase the insulin dose for the meal eaten before the raised levels. If you have raised BG levels before bed, increase the evening meal dose in the same way.
- ➔ If you have raised BG levels in the mornings and these are not because of raised levels before bed, or treating nighttime hypos, increase basal (long acting insulin) or overnight basal rates, think about what you are eating before going to bed

and speak to the team if you need further support to explore why this may be occurring.

➔ If you have 10 - 20 units of, increase by 1 unit at a time (wait 5 days for your body to adjust to the change.)

➔ On a pump, increase basal rates overnight by a total of 0.05 - 0.1 units per hour overnight. Consider basal rate testing.

➔ If you are not sure what to change, or would like some discussion, then please don't hesitate to call your nurse. **Remember to note any changes you make and why. This will be useful for your next clinic.**

Hypoglycaemia

Hypoglycaemia or a hypo is a low blood glucose level of less than 4 mmol/L. You may have low hypo awareness, but the symptoms usually are:

Always check your blood glucose level if you have any of these signs or symptoms and treat if the blood glucose level is below 4 mmol/L

Hypoglycaemia needs to be treated urgently to ensure that blood glucose levels return to the desired range.

It is always worth letting people around you know what to do if you have a hypo.

Treating hypoglycemia

Stage One – you are hypoglycemic.

Give 15g-25g of fast acting glucose (you may need more depending on your body size), for example:

➔ 220ml Lucozade Energy (this is a lot of fluid to get down)
➔ Whole Lift bottle (15g)
➔ 6 glucose tablets this would be 24g with most tabs
➔ 200ml pure fruit juice (not really ideal due to fibre)
➔ Skittles (1g) each
➔ Large jelly babies 4-5
➔ **Do not use chocolate, as it is high in fat and releases glucose too slowly.**

Wait 15 or even 20 minutes if using Flash Glucose Monitoring or Continuous Glucose Monitoring, wash hands and repeat blood glucose level check. If above 4 mmol/L go to Stage Two, if not repeat Stage One

Stage Two – if you use injections, have a snack containing 15g slow-release, starchy carbs, for example, 3 rich tea biscuits.

If you are on a pump or within 30 minutes of your next meal, you should continue as normal. If you are on a pump and are having persistent hypos, you may want to use a temporary basal rate.

What your support system (friends/family) must do if you cannot treat the hypo yourself

Unco-operative but conscious

➔ Squirt 2 tubes of Glucogel (1 tube is only 10g of fast acting glucose) slowly into both sides of the mouth between gum and cheek, a little at a time.

➔ Recheck blood glucose in 15 minutes, if you haven't reached 4mmol/L but can now safely use your normal treatment you can do so.

➔ Once your B/G is above 4mmol/s you can have a snack.

➔ It is advisable to check blood glucose levels every 15 minutes if you have had a hypo where someone has had to help you. (Assisted hypo).

Unconscious

Tell people to never attempt to give Glucogel or food or drink to an unconscious person, as this is a **choking hazard**. Someone needs to Dial ***999***.

It is important that the person ringing 999 tells them that you have Type 1 diabetes and if you have been drinking alcohol.

Glucagon will not work if the hypo is due to alcohol, so alternative treatment may need to be given.

If you have a Glucagon Injection Kit, the person with you can prepare the Glucagon injection by adding all the liquid to the powder, following the simple picture instructions in the lid of the box.

They need to inject all of the prepared solution into the upper, outer muscle of the thigh. The ambulance operator can talk the person through the procedure.

Once you are awake and co-operative, follow **Stage One**. Check blood glucose every 15 minutes for a least an hour afterwards – it is common for the glucose to fall again. Nausea, vomiting and a fast heart rate may occur following an injection of Glucagon. If recovery has not taken place within 10-20 minutes, then an intravenous infusion may be required from the ambulance crew

Actions after a hypoglycemic episode

Avoid physical exercise and activity for a while after all symptoms have disappeared. If the blood glucose level is greater than 10mmol/L after the hypo, do not be tempted to give a corrective dose of insulin at the next meal. This will increase your risk of another hypo. **Remember to contact your diabetes nurse if you are having frequent hypos (over 3 hypos each week) or if you have needed to use gel or Glucagon injection.**

Causes of hypoglycemia

➔ Errors in the counting of carbohydrates in a meal or snack
➔ Your appetite being temporarily poor due to illness
➔ Not finishing your meal
➔ Too much insulin
➔ Your carb ratio being needing adjustment
➔ The incorrect dose of insulin being given accidently
➔ Unplanned exercise or activity
➔ Increased insulin absorption. This could be due to warm weather or activity

➔ Alcohol reduces blood glucose as there is a reduced ability for your liver to release glucose as it deals with the alcohol. **This worsens the hypo you experience.** More on this in the 'Alcohol' section.

Hyperglycemia

To remain healthy, anyone with Type 1 diabetes should aim to keep their blood glucose levels between 4 and 7mmol/L pre meal. Hyperglycemia occurs when blood glucose levels are 10 - 14 mmol/L. Above 14 mmol/L is dangerous. In the short term, hyperglycemia can cause excessive thirst and tiredness. In the longer term, it can increase the risk of infection and cause serious damage to the blood vessels (including those around the heart, kidneys, eyes and nerves). It is important to try to identify the cause of hyperglycemia in order to prevent further episodes from taking place. If you're having lots of hypers, try looking for a pattern - that can really help when trying to figure out what's going on.

Causes of hyperglycemia

➔ Errors in the counting of carbohydrates in a meal or snack.
➔ Snacking without insulin
➔ Not enough insulin
➔ Your carb ratio needs adjusting
➔ You missed injections at mealtimes or snack times
➔ Your body is fighting an infection
➔ Your insulin being out of date
➔ Your insulin has been stored incorrectly (at room temperature for over 4 weeks or at temperatures above 25

degrees Celsius or at temperatures below 2 degrees Celsius or exposed to strong sunlight).

➔ Forgetting to prime your insulin pen with a 2 unit ‘air shot’ prior to the injection

➔ Forgetting to count slowly up to 10 seconds after the start of the insulin injection

➔ A bubble or kink in your pump tubing

➔ Your cannula being bent

➔ Injecting insulin into a lumpy site

➔ Your cannula site is too close to the last one

Sick / High Day Rules

The body’s natural response to illness is to raise the blood glucose levels. You will need your usual amount of insulin and may need even more when unwell. Therefore, act immediately when you feel unwell and seek prompt treatment for infections. Do not wait for your blood glucoses to be persistently low/high before seeking help.

Illness generally causes the blood glucose level to rise and you may develop ketones.

Here are some simple rules:

➔ Don't panic – contact the Diabetes Team who will help you if you have any queries or if you are unsure about what to do.

➔ Keep taking insulin, long- acting and short acting or basal rate (if you are on the pump) – even if you don't feel like eating.

➔ Even if you do not eat, your body continues to produce glucose from its stores. If you stop taking insulin you could become very ill.

- ➔ Measure blood glucose and ketone levels at least every 2 hours. Be prepared to increase the insulin dose as needed.
- ➔ Stay hydrated – have plenty of sugar free drinks, and eat little and often.
- ➔ Check your ketones even if your blood sugar level isn't high.
- ➔ Keep eating or drinking – if you can't keep food down, try snacks or drinks with carbohydrates in to give you energy. Try to sip sugary drinks (such as fruit juice or non-diet cola or lemonade) or suck on glucose tablets or sweets like jelly beans.

Always check blood ketones when blood glucose is above 14 mmol/L. Also check blood ketones when you're vomiting or feel sick, even if the blood glucose level is low or between 4 - 14 mmol/L.

Blood Ketone Level	**Action needed**
Between 0.0 and 0.9 mmol/L	Acceptable range - give correction as per meter/device guidance.
Between 1.0 and 2.9 mmol/L	Start following sick day rules. If still under 19 years old use on call system. If 19 or over Inform the Diabetes Team on 01183227478 during working hours and 111 out of hours. (correction dose.).
Over 3.0 mmol/L	As above but consider going to the Emergency department if your ketones don't come down under 3 following extra insulin. Ring 999 if you have excessive vomiting/tummy pain or your breathing seems different

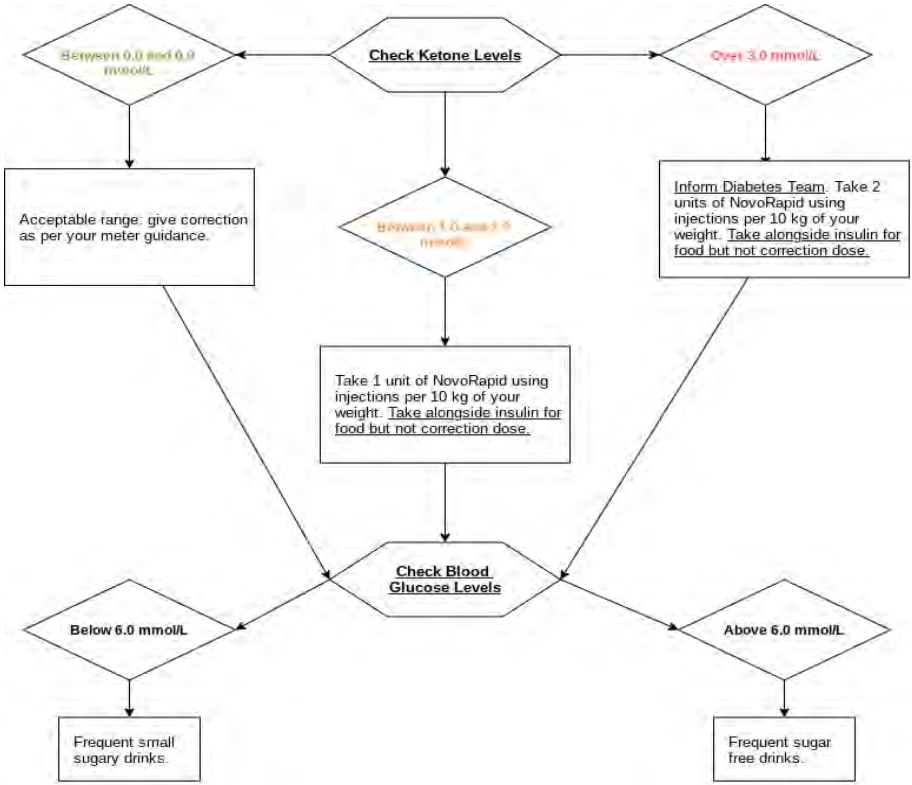
Ketones and low blood glucose levels

This occasionally occurs, especially with diarrhoea and vomiting. If your blood glucose levels are low and ketones are high, then follow the sick day rules (below) but be sure to consume sweet drinks and food as follows:

- ➔ If you are unable to eat normally, and you Blood glucose levels are 6 or less then replace starchy carbohydrate food with fluid such as full sugar squash, full sugar lemonade, cola, Lucozade, etc. Alternatively, eating sucking sweets or lollies if the fluid is making you vomit.
- ➔ Drink plenty of extra sugar free fluids such as water
- ➔ With diarrhoea and vomiting plenty of sugar free drinks plus sugary fluid containing 5g carbohydrates every 15 minutes or sweets containing 5g carbohydrates every 15 minutes.

Take a picture of the Sick Day Rules handout (see overleaf) and keep on your phone and know your approximate weight in KG.

Look on the Digibete app where there is a copy of our Sick Day Rules as well as general principles. They are also on our Royal Berkshire Hospital website page.



When to contact the Diabetes Team:

- If you become increasingly unwell
- you have ketones over 3 mmol/L or that persist for over 6 hours
- Vomit more than twice
- In need of a second extra dose of insulin
- Unable to maintain Blood Glucose above 4
- Worried for any reason

Office number: 0118 322 8922

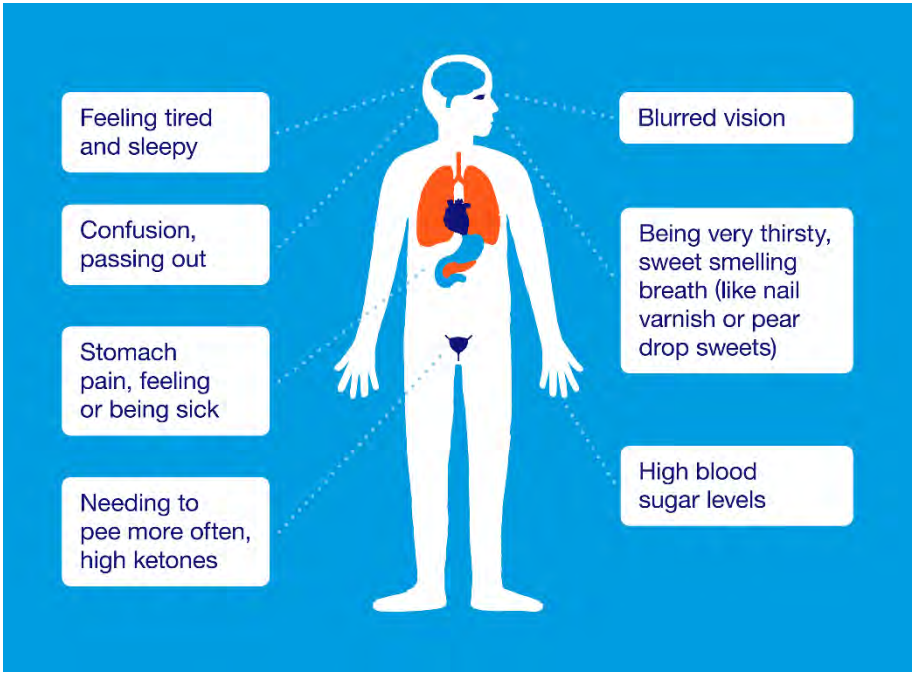
The out of hours service is available from Monday to Friday from 5pm to 8pm and weekends and bank holidays from 8am to 8pm

To find out the mobile phone number of the staff member on-call, please contact 0118 322 8922.

From 8pm to 8am, you will need to contact the hospital switchboard on 0118 322 5111, and ask to speak to the Paediatric Registrar on call (if you are still under 19).

In an emergency contact 999

Diabetic Ketoacidosis (DKA)



DKA happens when there is a severe lack of insulin in the body. This means the body can't use glucose for energy, and starts to use fat instead. When this happens, chemicals called ketones are released. If left unchecked, ketones can build up and make your blood become acidic – hence the name acidosis. DKA is very serious and must be treated in hospital quickly. Left untreated, it could lead to a life-threatening situation, permanent brain damage or death. If you suspect, you have DKA it is important to get medical help straight away.

You can avoid DKA if you act on high B/GS and ketones immediately.

“This is something that may seem something that would only happen to a handful of people but it can happen easier than you think. I have been borderline DKA three times and it is a scary experience and one that I would hate to happen again. When in DKA you will start to get a lot more tired and drink excessive amounts of water. This will lead to you having to use the bathroom a lot more. All these indications are of the usual high bloods, which are why it is always good to check your ketones as well to make sure that they are okay. If your ketones are running high, you will start to feel nauseous and may even throw up. Ways to help bring them down are to give yourself more insulin and also to drink water, this will help you to urinate more which will then flush the ketones out of your system.

However, in some cases the ketones are too high for you to manage on your own, which is when you will be sent into hospital. The doctors will then keep an eye on you and help to bring them back down to a normal level. DKA is something I only truly learnt about after I had it the first time. And is also something I wish I knew more about at an earlier stage, it's the small things that help you stay healthy. To keep safe just remember that if your blood sugars are above 14, it's always safer to check your ketone levels (which should be 0 - 1 mmol/L).” Tyler, BYPDC

HbA1c

This measures how much glucose is attached to a part of your red blood cells called haemoglobin. This is the part that carries oxygen to all cells in the body. A red blood cell lasts for around 120 days in your bloodstream before it is broken down and replaced. During its lifetime, each red blood cell will collect molecules of glucose from your blood. The HbA1c check shows how much glucose on average has been attached to your red blood cells for the past 2 to 3 months.

If your blood glucose levels are mostly above range, then your HbA1c result will also be above range.

Your red blood cells are being replaced by new cells all the time so the HbA1c result is like a snapshot. The check needs to be repeated every time you come to the clinic.

What is a healthy HbA1c level?

The HbA1c check is not like a test that you can pass or fail. The goal is to help you aim for an HbA1c of 48 mmol/mol (6.5%) or lower.

HbA1c in mmol/L (%)	What this means
Less than 50 (6.5%)	**Right on the mark**
50 to 54 (6.5 to 7%)	**On track** – some small changes may be needed
55 to 64 (7 to 8%)	**Slightly out of ideal range** – some changes need to be made.

HbA1c in mmol/L (%)	What this means
65 to 79 (8 to 9.5%)	**Out of range** – some immediate action is needed. You should keep in touch with your diabetes specialist nurse between clinic appointments to let them know how your blood glucose levels are doing.
80 to 99 (9.5 to 11%)	**Worrying** – immediate action is needed along with more frequent clinic reviews and regular contact with your diabetes specialist nurse
100 or more (above 11.3%)	**Very worrying** – an admission to hospital may be advised to get your diabetes back on track and the Diabetes Team will work closely with you to help overcome any difficulties you have been having with diabetes.

Complications

Research shows that the risk of complications from diabetes is reduced if your HbA1c levels are consistently within the target range. You can do this by keeping in regular contact with the team, reading articles online, checking out online groups and forums, or linking up with the BYPDC. An HbA1c level of less than 48 mmol/mol (less than 6.5%) over the years can minimises risk of complications. Every 11 mmol/mol (1%) you can bring the HbA1c down will cut the risk of complications by about 10%.

If blood glucose run high a lot of the time, small blood vessels are more likely to become blocked. This may affect many

different organs in the body – but especially the ones outlined below. All of these complications can sound very frightening. However, it is important that you know about them, because the risk of getting these complications can be significantly reduced by having blood glucose control within the target range and leading a healthy lifestyle.

Kidney disease (nephropathy)

The kidneys are the organs that filter and clean the blood. They get rid of any waste products by making urine. They help to control blood pressure by regulating the amount of fluid and various salts in the body. Kidney disease is when the kidneys start to fail. As with many of the other complications of diabetes, kidney disease is caused by damage to small blood vessels in the kidneys. This damage can cause the vessels to become leaky or to stop working making the kidneys work less well. **People with HbA1c levels consistently above 75 mmol/mol (above 9%) have about a 1 in 3 risk.**

How does the diabetes team check for kidney disease?

Kidney disease can be a very serious condition, which is why it is very important to detect it early. Everyone with diabetes will have an Annual Review. This check will include a urine test. This test looks for tiny particles of protein in the urine, called 'microalbuminuria'. These appear during the first stages of kidney disease as the kidneys become 'leaky' and lose protein. At this stage, kidney disease can often be treated successfully, so this test is very important.

Eye disease (retinopathy)

Diabetic retinopathy is a complication of diabetes that affects the retina. The retina is the layer at the back of the eye, which is sensitive to light. Diabetes causes the tiny blood vessels in the retina to become blocked. This may then lead to leakage or cause the growth of extra new vessels, which may be prone to bleeding. This can cause damage to sight and may lead to blindness. **Having a HbA1c levels consistently above 75 mmol/mol (9%) leads to about a 1 in 3 risk**.

How does the diabetes team check for eye disease?

If eye disease is caught early it can be treated. This is arranged by your GP surgery – please check that you are on the “diabetic retinopathy screening list” at your GP surgery (especially if you change GP at University).

Cardiovascular disease (CVD)

People with diabetes are 2 to 4 times more likely to develop CVD, making it the most common diabetes related complication. The term CVD applies to all diseases of the heart or blood vessels, including: high blood pressure, heart attacks, strokes and the narrowing or blocking of the arteries.

CVD is caused by the blood vessels becoming blocked with fatty deposits. In the brain this can cause a stroke and in the blood vessels supplying the heart it can cause a heart attack. It can also cause narrowing of the arteries to the legs, resulting in poor blood supply to the feet.

How does the diabetes team check for CVD?

We will check lipid (fat/cholesterol) levels in your blood once a year at Annual Review, and check blood pressure regularly.

Nerve damage (neuropathy)

The most common type of neuropathy that affects people with diabetes is known as *sensory neuropathy* and it generally affects legs and feet. This means that the nerves may start not to sense things as well as they did before.

The symptoms of neuropathy are:

➔ tingling in toes and feet
➔ pain, which can be quite severe, in both feet and legs
➔ a burning sensation, pins and needles or shooting pains
➔ loss of feeling in the feet which can lead to unnoticed injuries and eventually ulcers

Looking after feet is absolutely vital:

➔ keep blood glucose levels in range
➔ wear shoes that fit well
➔ cut toenails straight across
➔ dry in between toes after swimming
➔ if feet get wet change into dry socks
➔ if you get athlete's foot or verrucas, go to your GP or ask to see a podiatrist.

How does the diabetes team check for neuropathy?

We will examine your feet once a year as part of their Annual Review. We will check the sensation in their feet and we will check that you can feel vibration normally. We may also refer you to podiatry for an assessment.

Other complications

If you have an HbA1c level above the target range a lot of the time, you are also at risk of other complications including skin conditions such as acne and fungal infections like thrush (can apply to males and females). There is also a higher risk of osteoporosis (poor bone density) and sexual dysfunction. HbA1c levels above range over long periods of time are associated with a reduced life expectancy.

"I'm going to start by introducing myself, I am Faye and I've had diabetes for three years now. This time a year ago my HB1C was above 14%, I know yikes. I'm pleased to say that currently my Hbc1 has gotten down to 7.8%.

Meanwhile, I'm definitely not perfect and I'm still working on my blood sugar, I've come a long way. For me guilt was a big factor that motivated me to sort it all out along with having to deal with the consistent thirst headaches and nausea that I tried to ignore for a while but for you it could be different could be the fear of later on health complications etc.

If you're in a similar position or feel like you could be doing better with your current blood sugar I would start off by making a small goal or target for example your next appointment HB1C as that will help you to stay consistent and motivated. Reminder that even if you're not happy with your blood sugar today, do not beat yourself up about it as tomorrows a fresh start." Faye (Young person with Type 1 Diabetes)

Experiences with diabetes by the BYPDC

This booklet was put together by members of the Berkshire Young People's Diabetes Council alongside members of the Paediatric and Young Adult clinics. We all agreed that having diabetes as a young person can be difficult and comes with many unspoken battles. These are some experiences members of the council have faced that will hopefully make you feel less alone. We hope this booklet is not only a good educational resource, but also a relatable anecdote into living with diabetes. After certain sections you will see accounts in blue speech bubbles. These are personal experiences and have been written by members of the council.

"I never thought that I would want or need to see a Diabetes Psychologist. I had been diabetic for about 9/10 years when I really started to struggle. I was keeping my blood sugars really high because I was scared of having hypos. It was starting to affect my hypo awareness and eventually I was told that if I kept going the way I was, even for only a few years, I was going to have serious issues with my eyesight, feet etc. within the next 10ish years.

It wasn't until a family member suggested that I talk to someone outside of my family and friends. Speaking to a psychologist completely changed how I looked after myself, it took a while, but eventually I had better control and a better relationship with my diabetes." Phoebe, BYPDC

Mental wellbeing and diabetes

"The International Society for Paediatric and Adolescent Diabetes and the NICE guidelines recommend that young people and their families receive psychological support as part of their diabetes care." (Delamater et al, 2014; NICE, 2015) Having a chronic illness is categorised as a form of trauma – seeking help is vital, not just after your diagnosis, but rather as a continuous process.

Diabulimia or disordered eating and diabetes

Disordered eating in relation to diabetes is an eating disorder that affects people with Type 1 diabetes, male or female. It is when you stop or reduce the insulin you need to take. Insulin allows your body to access the energy from the food you eat. Without any insulin your body gets energy from its reserves – fat. This is why you lose weight when not taking insulin. However, the breakdown of fat produces ketones, without insulin to break down the toxic byproduct your blood acidifies. This can have life-threatening consequences. There is more detail on this in the 'Ketones' and 'DKA' sections. You are also much more likely to develop diabetes related complications.

"My diabulimia resulted from years of body dysmorphia and body image issues, all of which were escalated by my poor relationship with type 1 diabetes. I was being weighed on a constant basis at appointments and having to inject even more insulin due to insulin resistance. This only increased as I gained weight and I entered a vicious cycle - I felt trapped and ashamed of my body. My relationship with my condition and my body continued to deteriorate. My mental health was very poor and I was still incredibly angry about my diagnosis two years before….

...To gain some sense of control over my body, I injected less and then eventually stopped altogether to 'lose weight'. In reality, my body was going into survival mode and was digesting my own muscles for energy as it had no access to the energy from the food I ate. I would turn to stress eating carbs to feel better, which only worsened things as I was constantly experiencing hyperglycemia. I would avoid talking about my diabetes if anyone asked or would just say I was fine, believing that if I ignored it, it didn't exist.

Deep down, I was incredibly lonely and sad, as I knew no one else with diabetes, and felt too far gone with denial and lying to speak to anyone about it. This eventually resulted in me having a stroke and developing sepsis, and was put in an induced coma in hospital. Afterwards, I felt so scared to be honest with others that I was struggling but realised that bottling things up had led me right to where I was. My family and I started at 'square one' again with my diabetes, so we could learn together how to cope healthily with it; I also started seeing a Diabetes Psychologist which was perhaps the best thing to ever happen to me.

Diabulimia is more well known about now within the medical community and can have long lasting damage to those suffering. If you are having issues with your body and diabetes, speak to your diabetes team and psychologist, they are here to help you, not shame you.

Struggling with your diabetes and mental health is incredibly common, but being honest about it can still be daunting; don't be afraid to speak to any member of your diabetes team or the BYPDC about your worries, as we are here to assist you in any way we can to make it easier for you to be healthy and happy." Hannah, BYPDC

Moving from the Children's Clinic to the Young Adult Clinic:

"Personally, I found the transition from the Children's Clinic to the Young Adult Clinic pretty seamless; all of the staff were so welcoming and happy to walk me through any questions that I had. They have also been very supportive with any issues I've encountered. For example, I was experiencing a lot of discrepancies and inaccuracies with my Continuous Glucose Monitoring (CGM) system, and with the support of Dr Kavvoura and Chandra, we managed to get a new CGM system set up to solve these problems.

The standard of care and support in the Young Adult Clinic is just as great as the Children's Clinic, with the added bonus of the waiting room being a lot quieter! Transitioning to the Young Adult Clinic also provides you with the chance to gain complete independence in managing your diabetes. It is quite freeing to be fully in control of your diabetes, whilst having the security of knowing that you always have access to support from the team."
Clara, BYPDC

Living with diabetes

University and college

Going to university or college usually means moving far away from those who have been supporting you, such as your friends and most importantly your parents or guardians. This can be an exciting time for you and your family. It can also be filled with anxiety for you.

Things you may need to consider:

- ➔ Suitable accommodation.
- ➔ Asking your Diabetes Team for your Disabled Students Allowance (DSA) letter to accompany your application.
- ➔ Consider that you keep your medical care at RBH by booking clinics for holiday period.
- ➔ Registering for your medical exemption card (see your GP).
- ➔ Ensuring that your supplies are directed to your new address.
- ➔ Communicating with your GP (becoming a temporary patient during visits).
- ➔ Changing GPs and pharmacies.
- ➔ Getting in touch with BYPDC for peer support and further insight into preparations for University.

The Young Adult Clinic offers video consultations. These clinics will really help you plan your schedule. Through these we hope that your time could be saved and you can receive specialist attention regularly without missing your appointments.

"Having been diagnosed with diabetes in Year 12, I had gone through GCSEs without the worry of fluctuating blood sugars. I had to be my own advocate when I arrived at college and had decided that a separate room would be beneficial to me whilst sitting my exams. It is really important that you organise any special requirements as soon as possible with the college exams office so that by the time exams come around you are ready to go. It is one of our rights to have access to a separate room, so if you face difficulty getting your exams office to understand this, as I did, then persevere with arranging this requirement and don't be shy or ashamed about asking for one. In most colleges you will be placed with other people that also use access requirements when sitting your exams." Olly, BYPDC

Working

Diabetes is nearly always covered by the Equality Act 2010. This act says an employer needs to make reasonable adjustments so that someone with a disability (like diabetes) can do their job.

Reasonable adjustments might be making sure you have your breaks at set times, so you can keep on top of their blood glucose levels. Reasonable adjustments don't have to cost money – they are more about taking a flexible approach to work. Like anyone, your stress levels are likely to be higher at

work than at home, which can make managing your diabetes more challenging. Make sure you take time out to relax throughout the day. And talk to your manager about flexible working options, which can make it easier to manage your diabetes and do your work.

Diabetes UK have a helpline you can access for support accessing your rights at work: 0345 123 2399. Or you can contact Citizens Advice, who offer free, independent, impartial and confidential advice: 03444 111 444

Parties

Young people have every right to enjoy themselves – with the right preparation you should be able to minimise any potential problems. At a party, try to eat more of the savory foods. You may wish to bring your own sugar free drinks. There is more information on drugs, sex and alcohol below.

Festivals

Festivals, especially large ones that involve camping can be hectic for anyone that goes. Even people without diabetes have to be prepared.

Important items such as money, your phone, insulin, blood glucose testing kit, hypo treatment need to be kept safe on your person. Pouch packs (bumbags) that go around your waist, under your clothing are the best option for keeping your valuables safe. If your blood glucose meter is too large for this, ask at the clinic before you go for a small one just to take to the festival with you. It’s tempting to keep items in your pockets but pickpocketing is a huge problem at festivals.

Check on the festival website before you go if there will be lockers available to store away spare insulin, needles, meter and strips, hypo treatment and water. If you are on a pump remember to take spare cannulas/insulin and also a pen with NovoRapid in. Carry this with you.

Think about your feet! You will do a lot of walking and maybe dancing. Wellies and flip flops can rub very badly, a pair of older boots or pumps/trainers that you can throw away after are a much better idea. Take plasters!

Festival restrictions

You are not usually allowed to take any fluids into the main arena from the campsite. You will be patted down on entry to check you haven't hidden away items you are not supposed to take in. It is likely they will find your diabetes kit so you will need a medical ID or a letter confirming you have diabetes in case they don't believe you when you explain what you have with you and why. You should discuss going to a festival with the team beforehand so they can give you advice and a letter. Make sure you have hypo treatment like sweets or Glucotabs to replace drinks you might usually use.

Camping

Try to ensure you take your insulin, particularly your long acting insulin at your usual time. If this is going to be inconvenient, e.g. just at the time the headliners are due on stage, change the time for a few days before you go. Having long acting insulin a bit earlier, perhaps around 5 – 6pm or even in the morning when you are likely to be eating as well and also having NovoRapid may be a good time. This helps to ensure it does

not get forgotten. If you leave your long acting insulin or spare pump insulin in your tent then ensure it is in a Frio bag as tents get really hot and insulin becomes spoiled and unusable.

You are likely to get very tired over the weekend so you may find your blood glucose levels are lower than usual. Stock up on Glucotabs and other non-liquid hypo treatment to keep on you.

Even if you are planning on drinking don't stop taking all your insulin, talk to the team on how to make manage alcohol.

Taking your insulin is important to avoid DKA and hyperglycemia.

Medical facilities

All festivals will have a medical tent where you can get help if you need it. Make sure you and your friends know where it is (find it on the first day) in case you need help, advice or support. They sometimes have a fridge where you can store spare insulin.

In an emergency, if you are wearing a medical ID, medical staff will look for this and so be alerted to your diabetes and not just think you are drunk! Even if you don't normally like to wear ID this is a good time to wear it. Also, remember to in case of emergency (ICE) numbers on your phone.

Alcohol

When anyone, with or without diabetes, drinks alcohol the blood glucose level falls and the body tries to correct this by releasing glucose from the liver stores into the bloodstream. When you have Type 1 diabetes, alcohol prevents the liver from doing this and therefore dramatically increases the risk of hypoglycaemia.

The more alcohol you drink, the greater the risk of hypo is and this risk can last up to 16 hours after you stop drinking alcohol. Initially drinking alcohol may make your blood sugar go up, however, due to the higher risk of hypoglycaemia do not correct.

What to drink

What you enjoy drinking is personal preference, but some drinks will affect your blood sugar more than others. Drinks that taste sweet are generally are the worst offenders – sourz, Wetherspoon's pitchers, dark fruits and cocktails. The more alcohol you drink the more likely you are to have issues with your blood glucose

How much to drink

Drinking too much alcohol is not good for anyone's health. Safe limits for adults are 14 units per week. You should have two or three days per week when you do not drink any alcohol.

One unit of alcohol is: Half a pint of ordinary beer, lager or cider (3 – 4% alcohol) or 1 standard glass (125ml) of wine (red, white

or rose) or 1 pub measure (25ml) of spirit e.g. gin, whisky, vodka. However, alcohol affects everyone differently.

Food and alcohol

Never drink alcohol on an empty stomach. Always eat extra carbohydrate before, during and after drinking alcohol.

Long-acting carbohydrates before drinking alcohol will help provide the reserves in the liver that the body uses to prevent hypoglycaemia. Long-acting carbohydrates taken whilst drinking prevents the blood glucose from falling too low. A carbohydrate snack taken with every other drink is a good idea, like a packet of crisps.

It is very important to eat a snack containing long-acting carbohydrates after drinking alcohol and before you go to sleep- do not bolus for this. Even if your blood glucose level is higher than normal at this time, it may still fall significantly overnight.

Getting a kebab and chips is common practice after a night out or making a pile of toast after getting in is not unheard of!

Insulin and alcohol

➔ Take your usual insulin for meals before drinking alcohol.

➔ Do not take extra insulin with the snacks that you eat whilst drinking.

➔ If your blood glucose is high after drinking, you still need a snack before you go to sleep but do not give any insulin for the snack and do not correct your blood glucose at this time. If your blood glucose is still high in the morning, you can correct this with your breakfast insulin dose.

Exercise and alcohol

Exercise taken during the day before going out in the evening, will reduce the amount of glucose you have stored in the liver. This, combined with drinking alcohol, will reduce the liver's ability to put glucose into the blood if the blood glucose level falls too low. This makes it even more important to be eating before, during and after drinking. Always eat a snack before going to bed after drinking.

Other important tips

- ➔ Hypoglycaemia and being drunk can be confused with each other. Make sure people who are with you know about hypos.
- ➔ Make sure you know what you are drinking. Beware of spiked drinks - never drink from a cup you have put down. Always know where your drink has been.
- ➔ Alcohol can have a delayed effect causing hypoglycaemia many hours after drinking.
- ➔ Also be aware that glucagon injections may not work effectively to raise blood sugar since glucagon hormone stimulates the liver to release glucose and alcohol impairs that process.
- ➔ Each alcoholic beverage takes one to one and a half hour to process in the liver. For that entire time the risk of a hypo exists. There are online calculators that can tell you when the alcohol is likely to have left your system. The more the alcohol consumed, the bigger the risk for serious hypo.
- ➔ Never drink and drive.
- ➔ Always eat carbohydrates with meals and snacks before, during and after alcohol.

➔ Test your blood glucose level after drinking and eat a good bedtime snack.

If drinking early in the day, consider taking long acting before they start drinking. For pump users; consider starting a TBR if you know you are going to go low but shouldn't start one if they have been drinking as may make a mistake in dosing.

Smoking

People who live with Type 1 diabetes and smoke cigarettes/roll ups have higher HbA1c's. Smoking also significantly increases your risk of complications linked with Type 1 diabetes; eye disease, heart disease, stroke, nerve damage and kidney disease.

As an example if you smoke, you have a 43% higher chance of developing retinopathy and a 36% higher chance of getting kidney disease. You also have the risks of developing the various cancers associated with smoking.

On a positive note, research suggests that if you stop smoking as soon as possible your risks will reduce to that of a non-smoker with Type 1 diabetes.

If you want to talk about stopping or cutting down smoking then speak to anyone at clinic or your nurse, or you can contact: https://www.nhs.uk/better-health/quit-smoking/ directly.

Drugs

Drugs are generally classified as legal or illegal. Legal drugs include tobacco, caffeine, codeine, pharmaceutical medications and alcohol. There are usually regulations governing the price, quantity, quality and availability of these drugs. For example, they cannot be sold to people under the age of 18.

Illegal drugs are all drugs for which there are no regulations or quality controls, or which are obtained outside of these regulations.

There is no safe level of drug use, especially with illegal drugs as you never really know exactly what you are taking. **All drugs have the potential to cause harm or even death.**

Many drugs may be addictive and have a negative effect on your diabetes. You should **never take an unfamiliar substance**. If you come across any drug, legal or illegal, and you are not sure how it may affect you or your diabetes, talk to your nurse.

Drug use or abuse can affect all areas of your life including family and relationships, work or school, legal, financial, and sexual health, affect driving ability and increase the risk of accidents.

Illegal drugs often contain impurities or may be mixed with other additives or bulking agents. Therefore, the effect on your blood glucose will always be very variable. What happens one time you take an illegal drug may not be the same as the next time. What will always happen is that your brain function will be affected which then impairs ability to make safe decisions about anything including about your diabetes. Your eating may become erratic, and you may eat either too much or not enough. This, in combination with the effect of the drug(s) can have a negative effect on your diabetes and cause your blood glucose to become uncontrolled.

Some drugs can make diabetes-related complications worse; for example, stimulants like cocaine or amphetamines can raise blood pressure, which can lead to a stroke or heart attack.

Although it is never recommended to take drugs, if you decide to do so, it is important to talk to your diabetes team and understand the impact that these may have on you, your blood glucose and diabetes.

It is also a good idea to have an agreement with friends that should you end up needing medical assistance they tell the crew/nurse what you have taken. **This could save your life.**

Stimulants (uppers)

Uppers speed up the central nervous system and increase neural activity to the brain. They Increase your blood pressure, heart rate, respiratory rate (how quickly you breath), reduce your appetite and give you an increased sense of energy.

Cocaine

Amphetamines (Speed)

Cocaine

Ecstasy

MDMA

Crack

Metamphetamine (Crystal Meth)

Ritalin

Dexedrine

Anabolic Steroids

Khat

Nicotine

Caffeine

Depressants (downers)

Downers cause the brain and central nervous system to function in slow motion. They affect balance, coordination, concentration and most importantly breathing. They slow down a person's ability to respond to situations. In small quantities, they can make a person feel happy and relaxed, and less shy or inhibited. They do not necessarily make a person feel depressed. However, many people feel anxious and uneasy, drowsy, light headed or sick after taking them. They can also often cause hunger (munchies). In larger quantities, they can cause unconsciousness, respiratory depression (your breathing stops), vomiting and death.

Examples of downers:

➔ Alcohol
➔ Cannabis (marijuana, weed, pot)
➔ Anti-anxiety medication or tranquilisers (benzos, valium, xanax
➔ Opiates and opioids, e.g. morphine, codeine, methadone, pethidine, heroin
➔ Some solvents and inhalants
➔ GBH (liquid anaesthetic liquid)
➔ Pregabalin

Effects on diabetes

Downers make you feel spaced out so you lose track of time and space. You may forget your insulin, or inject the wrong amount. You may also get the munchies and eat too much or too quickly, causing your blood glucose to rise rapidly. Conversely, you may forget to eat your regular meals or snacks, causing your blood glucose to drop. There is then a danger that

you will not recognise your hypo symptoms or be able to treat them in time. **Do not take insulin for munchies - it is highly likely you will get the wrong dose. Wait until you are sober to correct.**

Hallucinogenic drugs

Hallucinogens affect perception and distort reality. People who have taken them may believe they see or hear things that aren't really there, or what they see may be distorted in some way. The effects of hallucinogens vary a great deal, so it is impossible to predict how they will affect a particular person at a particular time. Some effects of hallucinogens include dilation of pupils, loss of appetite, increased activity, talking or laughing, euphoria, sweating, stomach cramps and nausea. They can also cause panic, paranoia, loss of contact with reality, and irrational or bizarre behaviour. The effects can last for hours and can be unpleasant and sometimes very scary. People can experience flashbacks to these trips in the following weeks or even months and they can trigger more serious mental health problems.

Examples of hallucinogens:

➔ LSD (tabs, flash, acid)

➔ PCP (angel dust)

➔ Magic mushrooms (shrooms)

➔ Cannabis if super strength (weed, skunk, bud)

➔ Ketamine (ket, special k,)

Effects on diabetes

Since the effects of hallucinogens can last for several hours, this greatly increases the chances of your blood glucose becoming uncontrolled. You may forget your insulin, (this is

very common) or inject the wrong amount, or your mind may play tricks on you, so for example, you believe your insulin is poison and don't want to inject it. You may not eat or drink properly and you may not be able to recognize the signs of being hyper or hypo, all of which can be really dangerous.

Top tips

➔ No drug is a safe drug.
➔ Some drugs are illegal there are heavy penalties for possessing and supplying them.
➔ Make sure you have some diabetes ID on you, and that the people you're with also know you have diabetes.
➔ Have regular soft drinks and water, especially if you are clubbing.
➔ Have some carbohydrate-based food before you go out and when you get in.
➔ It's okay to say no to drugs, most people don't take them.
➔ Don't mix alcohol and drugs.
➔ Make sure you know exactly what you are taking if you decide to take something.
➔ Make sure you keep enough money to get yourself home.
➔ Stay with someone, don't go exploring on your own.
➔ If you are feeling pressured into taking drugs or you have started and want to stop, find someone you can talk to.

Sexual health

Diabetes and sexual health is a very personal and individual issue. We run yearly workshops for Young People and we are available for advice and are able to signpost you to someone

else who can support you if you have things that you would like to discuss or find out more about, even if not directly related to your diabetes.

Find more information about workshops in the ‘Other resources’ section or speak to a member of the team.

Males with diabetes

There are a variety of ways that diabetes affects sexual health, many of which are also associated with the effects of aging. For men, the most common are erection or ejaculation problems. There are several reasons for this, some being that to get and maintain an erection blood flow increases to the small blood vessels. If you have had or have a high HbA1c for a prolonged period, it affects the small blood vessels and can impair erections. Nerve damage caused by high blood glucoses can also cause retrograde ejaculation where the semen travels to the bladder.

Females with diabetes

Women may have sexual response problems due to nerve damage in the clitoris and genital area. You may also experience lubrication issues. If you imagine how your mouth feels when your blood glucoses are high, this is the same all over your body. This can increase your risk of getting sexually transmitted infections or small tears to your vaginal wall. Furthermore, bladder problems and infections in the urinary tract are more common amongst people with diabetes. Keeping your blood glucoses in range can make all the difference in lowering sexual and urologic risks.

Pregnancy

Having Type 1 diabetes and pregnancy is something you really need to understand before you get pregnant. Having a high HbA1c can lead to increased risks of miscarriage, birth defects and stillbirth, so contraceptive care and planning a pregnancy is very important. If you do get pregnant unexpectedly, then please tell your diabetes team ASAP so they can help you. There is lots of support for pregnant women with Type 1 diabetes.

Top tips for everybody

- ➔ Sex is exercise – keep this in mind when planning your insulin. Always have hypo treatment to hand! If you wear a pump and take it off remember to put it back on before you go to sleep.
- ➔ Always stay hydrated, if you have high blood sugar you may already be dehydrated.
- ➔ If you have been drinking or using drugs, you may not make brilliant decisions about what you are doing and who you are doing it with. Keep this in mind!
- ➔ Use appropriate lubrication, especially with high blood sugar, to avoid injury.
- ➔ No means no – the only way to have sex is with consent.
- ➔ If you have unprotected sex, get checked out ASAP.

Find sexual health services in the 'Other resources' section.

Driving

If you have diabetes and intend to drive the law requires you to do the following;

➔ Inform the DVLA about your diabetes, how it's treated, if you experience hypos

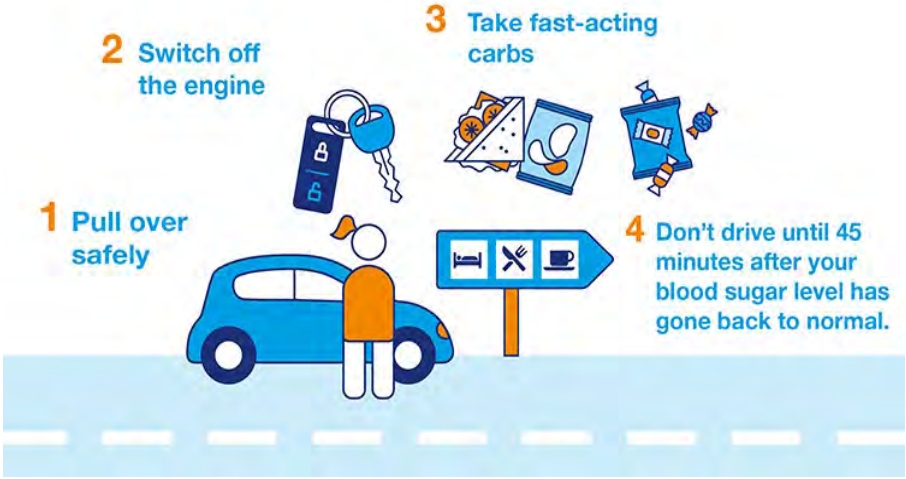
➔ Inform your insurance company. Failure to do this could invalidate your cover in the event of a claim. Failure to notify DVLA can also affect your insurance cover.

Driving and hypoglycemia

The DVLA asks a series of health related questions when you apply for a license and will normally seek advice from your doctor. If your diabetes is well-controlled there should not be any objection to you holding a license.

Hypoglycemia is a common worry for people with diabetes but with the right preparations, it can be properly managed. Keep snacks in your vehicle, test before starting and every 2 hours during the journey.

If you start having a hypo while driving, **it is the law that you must stop**. And it's what you must do to avoid any risk of an accident. So find somewhere safe to pull in as soon as possible.



Insurance

➔ Inform your insurance company that you have diabetes

➔ With the introduction of Disability Discrimination Act 1995 there should be no increase in premiums unless there is evidence of increased risk in a particular group of people. National records do **not** show that people with diabetes to be at a higher risk than people without diabetes.

➔ If you need assistance call Diabetes UK careline on: 03451232399

Accidents and diabetes

If you are hypo when you have an accident, the police will charge you with driving under the influence of a drug (insulin), driving without due care and attention, or dangerous driving. You should have a record of the checks you have done on your meter/cgms/fgm.

"When learning to drive, I found that my instructor and examiner were not very experienced with diabetes, which is completely understandable. Driving probably won't be the first time that you have had to explain diabetes to someone else, but just making sure that they know what can happen takes the pressure off of both you and your instructor. Learning to drive can be stressful enough, and I experienced a lot of anxiety around having to balance my diabetes with this, but fortunately my instructor was very supportive. However, if your instructor doesn't take your condition seriously, or is making you feel more anxious, please don't be afraid to find another one that can provide you with the support you need.

Once I'd passed my test and started driving more on my own, I found that some areas of driving also need more attention than others to account for diabetes. One example is the introduction of smart motorways. By removing the hard shoulder on the motorway, it means that there are only a few Emergency Refuge Areas (ERAs) available to stop in if you start to experience a hypo between two junctions, which is particularly scary if your vision starts to deteriorate from hypo-awareness. It's an important reminder of your responsibility as a driver and a diabetic to follow the two-hourly testing rule and not skip it on long journeys…

…Alternatively, it can be very easy to just glance at your phone or meter to see your Continuous Glucose Monitoring or Flash-Monitoring readings. However, this is still obviously against the law, and it's a clear reminder that diabetes can be a constant distraction.

I think driving has been one of the areas of my life that I have really noticed the impacts and potential dangers of my diabetes. Although needing regular blood testing on long journeys or constantly wondering whether you are creeping into a hypo can be frustrating, it's okay to feel this way. Furthermore, (like a lot of areas of life with diabetes) it does just take practice, and the freedom that driving gives you is completely worth the extra preparation that your diabetes requires." Clara, BYPDC

Tattoos and piercings

Having diabetes does not necessarily stop you from getting a tattoo or having a piercing, but there are things to consider to try to prevent your new accessory from causing problems with your diabetes.

Useful tips

➔ Use a reputable and licensed place.
➔ Ask friends and family to confirm particular shops.
➔ Ensure the shop knows you have diabetes.
➔ Make sure you have eaten something an hour before this is done to reduce chances of a hypo or simply fainting through being squeamish.
➔ Take someone with you, ask questions as you tour the shop.

- ➔ There are no legal restrictions on age you can have your ears or other body parts pierced. However, some establishments may require parental consent, or operate under local authority guidelines.
- ➔ It is against the law to get a tattoo if you are under 18, whether you have your parents' permission or not.
- ➔ High blood glucose levels or illness increase the risk of infections after the piercing or tattoo has been done. Wait until you are feeling better and your blood glucose are back in range.

Infections

Anytime the skin is broken, there is a risk of an infection with piercing and tattoos. You may be at risk of catching infections transmitted in the blood (such as hepatitis and HIV) if the equipment has not been sterilized or cleaned properly. Skin infections may lead to serious problems such as DKA or blood poisoning if not treated quickly. There is also a risk of scarring (keloids) with piercing.

Afterwards

The person performing the piercing or tattooing should give you advice on how to look after yourself after having these done. Follow this advice. Ask them before undergoing this, if they cannot give you any recommendations then find somewhere else to go.

A lip or tongue piercing will make eating and drinking uncomfortable and difficult for a few weeks. This may also lead to unsteady blood sugars. If the area around the piercing becomes red, painful, swollen or you notice any sticky yellowish

or greenish discharge then the area is likely to be infected. Seek medical attention immediately

If the area becomes infected, then you might have to remove the piercing. Leaving it in will make the infection harder to treat.

Test your blood glucose more often if the piercing is infected, test your ketones and follow Sick/High Day Rules. Don't forget to contact your diabetes nurse.

Going on holiday

There is no reason why you should not enjoy holidays away from home like everyone else. With the right preparations, you will minimise any potential problems. Ask your diabetes nurse for advice several weeks before departure so you can all plan ahead.

Checklist

- ☒ Insulin – make sure you carry it in your hand luggage (as insulin may freeze in the hold of a plane). And if your luggage gets lost you will have none.
- ☒ Take extra insulin, pens and needles – you will need double what you normally need just in case.
- ☒ Blood glucose monitoring equipment and test strips – double up again.
- ☒ Hypo treatment – make sure that you carry plenty of your hypo treatment foods and drinks (both the fast release and slow release carbohydrates) in your hand luggage.
- ☒ Dextrogel or Glucogel.
- ☒ Glucagon.
- ☒ Extra snacks in case your journey is delayed.
- ☒ Diet drinks or water.

- ☒ Ketone testing equipment – check the expiry date and ensure that they have not been opened for more than 6 months.
- ☒ Sick/High Day Rules – just in case.
- ☒ Contact details of the Paediatric or Young Adult Diabetes Teams.

Going abroad

If you are going abroad, ask your Paediatric Diabetes/Young Adult Team for a letter, stating that you will be carrying insulin, needles and pens on the flight. Here are some other things you will need to consider:

- ➔ **Insurance:** Check in advance that your travel insurance covers you for any treatment required as a result of diabetes. It may not be sufficient just to declare that you have diabetes. You may also require a letter stating that you're fit to travel.
- ➔ **Time zones:** Consider whether the country that you are travelling to is in a different time zone to the United Kingdom. It is a good idea to keep your injections and meals to your own watch time and do the same when flying home. This may not be possible with long haul so change your meter/pump time settings when flying out. Remember to change back on return. Contact your paediatric diabetes specialist or young adult nurse if you need any advice before you go.
- ➔ **Information in other languages:** You may find it helpful to look at the Diabetes UK website for leaflets about diabetes with translations.
- ➔ **Hot weather:** Extremes of temperature can affect blood glucose levels because of the way in which insulin is

absorbed. In very hot weather, insulin tends to be absorbed quicker.

➔ **Storing insulin:** Hot weather will damage insulin. If you are travelling to a hot country, discuss ways of storing the insulin safely with your paediatric diabetes specialist or young adult nurse before you go.

➔ **Activity:** If you expect your activity levels to be higher than normal blood glucose levels may be much lower and less insulin may be needed.

➔ **Shopping:** Many hotels or bars abroad will not sell sugar free diluting juices, but they may be available in supermarkets.

➔ **Medic alert information:** It is important that you wear a medic alert bracelet or necklace or carry some form of diabetes identification in case you become ill whilst away.

➔ **Being dehydrated** can increase your blood glucose levels – drink water!

Exercise

Your body takes glucose from your bloodstream to redirect it to your muscles to be used for energy. You may need extra carbohydrate to prevent a hypo (glucose level below 4mmol/L).

Timing of the exercise

Exercise within 2 hours of a meal

Make sure you eat a good amount of carbohydrate at your meal (around 1 gram of carbohydrates per kg of bodyweight. So if you weight 60kg aim for a meal containing 60g carbs). You

could include a pudding, small chocolate bar, small slice of cake or plain biscuit.

Exercising over 2 hours after a meal

You may need an extra snack before you exercise. Try some fast-acting carbohydrates, such as dried fruit / sweets / Lucozade Sport. A comprehensive list can be found in the 'Other resources' section.

Duration of the exercise

Short-lasting exercise (less than 30 minutes)

You should not need a snack before you exercise as long as your blood glucose level is above 7mmol/L before the exercise.

Long-lasting exercise (over 30 minutes)

You may need a snack before you exercise, up to 15g fast-acting carbohydrate for every 30 minutes of exercise.

- ➔ 15g carbohydrate snack if exercising for 30 minutes to 1 hour.
- ➔ 30g carbohydrate snack if exercising for 1 hour to 1 hour 30 minutes.
- ➔ 45g carbohydrate snack if exercising for 1 hour 30 minutes to 2 hours.

Intensity of the exercise

Gentle exercise:

You should not need a snack before your exercise, as long as you have had a good amount of carbohydrate with your meal

before the exercise, and as long as your blood glucose level is above 7mmol/L.

Moderate to vigorous exercise:
You will need 15g fast-acting carbohydrate for every 30 minutes of exercising.

Planned exercise can be managed by reducing your insulin dose – ask the Diabetes Team for advice. Exercise can have a lasting effect on blood glucose levels and you may need more carbohydrate after the exercise as well.
Make sure you have a meal containing starchy carbohydrate (pasta / potato / rice / bread) afterwards and a supper before bedtime.

General health

General anaesthetics

If you have been scheduled to have a procedure needing an anaesthetic, please contact the Paediatric Diabetes Team if you are under 19 or the Young Adult Diabetes Teams if you are over 19. Any patient needing an anaesthetic, will need to go several hours without food or fluid beforehand. It is sensible to time the procedure for early in the day when you would already have an empty stomach.
For uncomplicated minor surgery, delay the morning dose of Novorapid until after the procedure and monitor the blood glucose levels throughout. The dose of insulin given may be different from your child's usual dose, but the Paediatric or Young Adult Diabetes Team will adjust this as required,

depending on circumstances at the time. If the reintroduction of food and/or fluid is likely to be delayed, it may be necessary for you to have fluids and insulin intravenously.

Immunisations

You should have all the routine immunisations offered to all young people. In addition, we advise that you should have a flu vaccination every year and one extra pneumococcal vaccination.

Optician

You should have a review every two years with an optician to check your vision. This is different from the retinal screening you will need every year.

Glossary

Blood glucose level	The level (or concentration) of glucose in the blood.
Carbohydrate	One of the three major nutrients found in food, and the body's main source of energy. Composed from sugars and starches.
Glucagon	A chemical messenger that increases glucose levels in the blood
Glucose	A sugar, which is the main source of energy for the body.
Glycosuria	The presence of glucose in the urine.

HbA1c	A check of your blood that measures how much glucose is stuck to the red cells in the blood. It gives a measure of the average blood glucose level during the previous 8-12 weeks.
Honeymoon period	The length of time during which the pancreas of someone who has recently been diagnosed with Type 1 diabetes continues to make some insulin.
Hormone	A chemical produced in one of the glands in the body and carried by the blood to have a specific effect on the functioning of other cells in the body, for example insulin.
Hyperglycaemia	High blood glucose level (above 7 mmol/l).
Hypoglycaemia Or Hypo or Low	Too low a level of blood glucose (below 4 mmol/L).
Incidence	The number of diagnosed cases per year of a particular disease.
Insulin	A hormone produced by the beta cells of the pancreas. Insulin lowers blood glucose levels by helping to transport glucose from the blood into the cells of the body. Insulin allows the cells to use glucose for energy.
Ketoacidosis (DKA)	A serious condition that develops when there isn't enough insulin in the body. This stops the cells from using glucose for energy and forces them to

	use fat instead. Using fat for energy produces poisonous chemicals called ketones (which can be detected in the blood). These ketones can cause the build-up of acid in the blood, which in turn can cause the symptoms of DKA (including vomiting, tummy pain, deep or fast breathing, tiredness, confusion, falling unconscious).
Ketones	Poisonous chemicals produced by the body when cells have to use fat instead of glucose for energy. This usually happens when there isn't enough insulin in the body.
Microalbuminuria	Very small amounts of protein in the urine.
Pancreas	A large gland situated near the stomach, which makes insulin, digestive enzymes and other hormones.
Subcutaneous	Under the skin.

Other resources

BYPDC

Run by young people with diabetes for young people with diabetes. This group seeks to empower every young person and work with the healthcare providers to improve the lives of young people with diabetes. They will be running workshops, peer advice and support. Feel free to email the BYPDC for advice, support and suggestions.

BYPDC PODCAST

The podcasts are recorded at Royal Berkshire Hospital Radio by members of BYPDC. They cover day-to-day living experiences by other young people. Also includes, guests, celebrities who may be professionals or have Type 1 diabetes themselves. Follow them on Spotify and other social media outlets. For Instagram: ***hypo_to_hero***

Reading and surrounds T1 parents Facebook group

This group is run by parents who organise social meet ups on a regular basis.

Diabetes UK

Diabetes UK is a charity dedicated to supporting children and adults with diabetes. Their website is a very useful and comprehensive source of information: www.diabetes.org.uk

They have a site for teenagers that encourages them to find out about growing up with diabetes: living with diabetes day to day, dealing with relationships and going out.

www.diabetes.org.uk/guide-to-diabetes/my-life

Juvenile Diabetes Research Foundation (JDRF)
www.jdrf.org.uk

Disability Living Allowance.
0800 121 4600
Phone and ask for a DLA form. The nursing team will give you advice on completing the form and a letter to support it.

DigiBete
www.DigiBete.org
DigiBete is a video platform and social enterprise created in partnership with the Diabetes Team at Leeds Children's Hospital. It contains training videos to share with family, friends, school and community to support you and your family. It has Key Stage specific resources to help schools. There are also films of other families at every age managing diabetes at home, recipes and sports and exercise resources. You will also find national documents and downloadable resources on the site.

Mylife App
The mylife App lets you manage your diabetes discreetly at any time and any place and documentation becomes a matter of ease! You can manage blood glucose, meals, insulin delivery and much more with the mylife App and all your values are available at a glance at all times. The mylife App offers the choice how insulin on board is handled in bolus calculations.
https://www.mylife-diabetescare.com/en-GB/products/therapy-management/mylife-digital.html

Young Minds
You can also visit the https://youngminds.org.uk/ helpline

Reading Sexual Health Services

Reading Sexual Health Services

21a Craven Road, Reading, RG1 5AN
https://www.royalberkshire.nhs.uk/florey-sexualhealth.htm

Monday	7am-7pm: all services 4pm-6.30pm: LGBT+ clinic
Tuesday	7am-7pm: all services
Wednesday	7am-7pm: all services 8am-10am: Gauge clinic (for men who have sex with men)
Thursday	7am-8am, 9am-7pm: all services
Friday	7am-7pm: all services
Saturday (not open on bank holidays)	9.30am-11.30am - all services

West Berkshire Sexual Health Services

West Berks Community Hospital, London Road, Thatcham, RG18 3AS

Monday	4pm-6:30pm: Contraception (under 26) only
Thursday	4pm-6:30pm: Contraception (under 26) and sexual health check-ups for people with no symptoms
Saturday (not open on bank holidays)	9.30-11.30am: Screening (all ages) and contraception (under 26)

Users of Medtronic Pumps

These systems require a personal account to be set up by visiting https://carelink.minimed.eu/app/login

You will receive an email notification from your clinic requesting you to share your data.

Workshops

The Team runs an annual Young People and Parents Workshop around July time.

We cover Sick/High Day Rules, exercise, diet and adjusting insulin, driving and how to manage during festivals. The BYPDC also runs a Transition Open Day where you will be given a tour of the Young Adult Clinic.

Workshops	Who can attend	Dates
Young People Workshop	All 15 to 19 year olds	July
Parents Workshop	All parents of 15 to 19 year olds	July (runs concurrently with Young People Workshop)
Exams Workshops	All 15 to 18 year olds	February and October half terms

Sharing your data with the Paediatric Clinics

Contact your nurse for the specifics on uploading your data based on your Insulin Delivery system

- **Diasend: 99-12297**
- **Libreview: 0088375**
- **Dexcom: Email invite**

Uploading to the Young Adult Clinic:

Glooko: Download App and use Proconnect; ukreadadu

Dexcom: diabetes.nurses@royalberkshire.nhs.uk *(You will receive an invite to join)*

Libreview share code: 07086602

Sharps collection

Bracknell Forest Council

The GP or diabetes team need to have referred the patient and given a sharps box.
Complete clinical collection form online at:
http://www.bracknell-forest.gov.uk/bins-and-recycling/clinicalwaste
or phone 01344 352 000

Wokingham Borough Council

Call 0118 974 6307 for collection on the following Wednesday. New one will be supplied. No referral needed.

West Berkshire Council

Provide an ad hoc sharps collection service
Email: customerservices@westberks.gov.uk
or call 01635 551 111

Reading Borough Council:

Referral needed by GP or diabetes team (letter or email)
Contact on 0118 937 3787
Collection on a Tuesday

Notes

Thank you

Thank you to the BYPDC for putting together this booklet:

1. Hannah Wetten, Phoebe Greenway, Olly Staines, Sam Dedman, Tyler Cruickshank, Clara Fidler-Brown.
2. Thank you to the Paediatric Diabetes Specialist Team and the Young Person's Clinic.
3. Dr J. Spinks (Lead Paediatric Diabetes Consultant and Dr F. Kavvourra (Young Adult Diabetes Consultant).
4. Andrea Jones (Lead for PDSN).
5. Mcculloch Chandrawati (Lead for DSN).
6. Boikie Osupeng for organizing and assisting the creation of this booklet.
7. All other Young People who have shared their personal stories.

To find out more about our Trust visit www.royalberkshire.nhs.uk

Please ask if you need this information in another language or format.

RBFT Paediatric Diabetes Team/Young Adults Team, January 2025
Next review due: January 2027