



A guide to...

Adolescent Clinic: Information for Young People with Diabetes

Patient Information

Contact the diabetes team:

Clinical advice line: 01442 287 442

Email for NON-URGENT enquiries: westherts.paediatricdiabetes@nhs.net

Contact details for diabetes administration team: Telephone: 01442 287 425

If you need this leaflet in another language, large print, Braille or audio version, please call **01923 217 198** or email **westherts.pals@nhs.net**



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Ratified / Review Date	Nov 2024 / Nov 2027	© W App Pati Info
ID Number	40/2324/V1	

Welcome to the Adolescent Clinic!

Now that you're 15, you have stepped up from the Children's Clinic to the Adolescent Clinic.

The main difference will be that you will now see the children's and adult's diabetes team together in clinic. Usually either an adult diabetologist and/or one of the adult diabetes specialist nurses (DSNs) will come to your clinic appointments so you



can get to know each other and work towards getting ready to move to the Young Adult Team Clinic (YAC).

All the care you usually receive from the Children's and Young People's Diabetes (CYPD) team outside of clinic will remain the same. The way you contact us and the support you receive won't change, but when you come to clinic it'll be a little busier than before.

Usually, you'll stay in the Adolescent Clinic until you've completed your GCSEs and are ready to move to the YAC.

One of the aims of the Adolescent Clinic is to support you to become increasingly more independent with your diabetes. You will notice that the content of this booklet contains information with more adult themes. This is to enable you as a young person (YP) to make informed decisions about your lifestyle and health. The diabetes team have two checklists; one is to help us get to know you better, and the second is a tool to assess your level of independence that we can use as a guide to your educational needs over the next one to two years, before your transfer to the young adult team. See Appendix 1 and 2 for these checklists.

Moving to the adult wards

From your sixteenth birthday if, for any reason, you're admitted to hospital, you will go to an adult ward. This means that your usual CYPD team may not know you've been admitted. It is important you ask a member of the ward team to inform the adult diabetes team that you've been admitted, and they can come and see you whilst you're an inpatient, although your outpatient care will remain with the CYPD team until you move to the young adult service.

If you visit A&E, but are not admitted to the ward, we would still like to know, in case there is any way we can support you to manage your diabetes whilst you're unwell, so do inform us.

Diabetes and Young People

When you were a child, most of the diabetes education was aimed at your parent(s) or guardian(s). It is important that you understand how your day-to-day decisions affect your long-term diabetes control and your overall health.

Let's go back to basics...

- In Type 1 Diabetes the pancreas does not make <u>any</u> insulin
- In Type 2 Diabetes the pancreas makes insulin, but the body doesn't use it correctly (known as insulin insufficiency or insulin resistance)
- Insulin is an important hormone that moves the glucose that is stuck to your red blood cells, from your blood stream, into your body cells, to give the cells the energy they need
- Since you don't make insulin when you have diabetes, you can make ketones at the wrong time, and these ketones are harmful
- Ketones are acids and can cause Diabetic Ketoacidosis (DKA), which if left untreated can lead to coma and death
- It is very important for you to know how to manage ketones using your 'sick day rules' so that you can deal with ketones before they make you unwell
- Having good diabetes control reduces your risk of DKA and long-term health problems, known as diabetes complications

What is 'good' diabetes control?

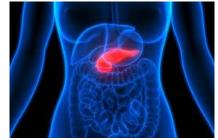
- Children and young people (CYP) with Type 1 or Type 2 Diabetes have a target HbA1c of 48mmol/mol, and so the closer you are to this the better
- We use a traffic light system:
 Green less than 58mmol/mol
 Amber between 58 and 69mmol/mol
 Red over 70mmol/mol

What is HbA1c?

- HbA1c measures the amount of glucose stuck to the red blood cells
- If you have lots of glucose in your blood stream (i.e. high blood glucose levels) sticking to the red blood cells you will have a high HbA1c
- Research has found that an HbA1c of 48mmol/mol will significantly reduce your chances of having long term complications

What are long term complications of diabetes?

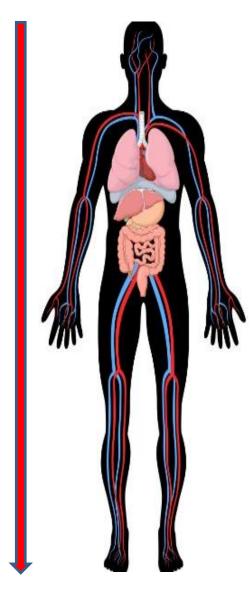
- They are health conditions due to damage to parts of the body caused by persistently high glucose levels
- If your glucose levels are mostly high, your blood will be sticky, and your blood circulation affected





- Sticky blood makes circulation through your body more difficult and so blood flow to your extremities (e.g. lower legs, feet, sexual organs) can be reduced, causing damage
- High glucose levels and reduced blood flow can damage your nerves which can reduce sensation (feeling) in your body (e.g. lower legs, feet, sexual organs)
- You might hear diabetes complications divided into; macrovascular or microvascular. This is a way to differentiate between conditions affecting large blood vessels (macro) compared to those affecting small blood vessels (micro) also known as capillaries
- This is the reason for your **annual review checks**, so that potential problems are identified, monitored and treated early

Let's look at this from head to toe...





EYES

Complication = vision impairment, blindness (retinopathy)



TEETH & GUMS Complication = tooth decay and tooth loss (gum disease)



HEART

Complication = heart disease cardiovascular disease)



KIDNEYS Complication = kidney disease (nephropathy)



NERVES

Complication = loss of sensation (neuropathy)



FEET

Complication = foot/ leg ulcers/ amputation due to reduced blood flow

Let's look at long term complications of diabetes in more detail...

EYES - It is important to have your retinal screening check every year. Retinopathy can be treated if identified early.

Retinal screening examines the 'seeing' (retina) part of the eyes and the blood vessels at the back of your eyes, to ensure the vessels are allowing enough blood flow to nourish the retina. It is more difficult for sticky blood to flow through small blood vessels and so reduced blood flow to the retina can cause damage, which can affect vision, and even cause blindness.

TEETH - People with diabetes are at greater risk of developing tooth decay, also known as caries.

Too much sugar in your blood can lead to more sugar in your saliva, and that creates the perfect breeding ground for a second group of plaque bacteria. This bacteria produces acid which attacks your tooth enamel and dentine causing cavities. The longer sugar is present, the higher the risk of tooth decay. Looking after your teeth and gums should be a basic part of how you manage your diabetes. You can prevent these potential complications by spotting them early and getting the right treatment from your dentist.

GUMS - Make sure you see your dentist regularly as untreated gum disease will always get worse.

Gum disease is a very common disease, but when you have diabetes, your risk is higher due to high blood glucose levels. Gum disease is caused by one group of bacteria in plaque that makes toxins that inflame the gums, known as gingivitis. It can cause loss of bone around your teeth and gum recession over time. This can lead to tooth loss, known as periodontitis. Gums that bleed when you brush your teeth are never normal and you should see a dentist.

HEART - Attend diabetes clinic appointments to check your blood pressure (BP) and have your cholesterol checked as part of your annual blood tests.

When you have diabetes, you are at a higher risk of developing heart disease which can lead to heart attack and stroke. You can protect yourself from heart disease by exercising regularly, optimising your glucose levels, and stopping smoking if you smoke. Ask the diabetes team or your GP if you want help to stop smoking.

KIDNEYS - It is important that you provide a urine sample and have your annual bloods done.

Diabetes can cause damage to your kidneys over a long period of time making it harder to clear extra fluid and waste from your body. This is caused by high blood glucose levels and high blood pressure. It is known as diabetic nephropathy or kidney disease.

NERVES – Attend clinic to discuss any concerns about reduced sensation in any part of your body. Always attend your annual foot check.

Some people with diabetes may develop nerve damage caused by complications of high blood glucose levels. This can make it harder for the nerves to carry messages between the brain and every part of our body so it can affect how we see, hear, feel and move. This can also lead to sexual health problems:

Sexual problems in women - Damage to blood vessels and nerves can restrict the amount of blood flowing to your sexual organs so you can lose some sensation. If you have high blood glucose levels, you are also more likely to get thrush or a urinary tract infection.

Sexual problems in men - The amount of blood flowing to your sexual organs can be restricted which may cause you to have difficulty getting aroused. It may lead to erectile dysfunction, difficulty getting or maintaining an erection.

FEET – Attend clinic appointments to have your annual foot check.

Diabetes foot problems are serious and can lead to amputation if untreated. Nerve damage can affect the feeling in your feet and raised blood glucose levels can damage the circulation, making it slower for sores and cuts to heal. That's why it's important to tell the diabetes team or GP if you notice any change in how your feet look or feel.



The good news...

- Research has found that if you have a time in range (4-10mmol/l) of 70% your HbA1c is likely to be in target, and you will reduce your risk of long-term complications
- Continuous glucose monitoring (CGM) sensors allow you to keep track of your time in range (4-10mmol/l)
- Learning how to adjust your insulin doses safely will help you to reach a time in range of 70% talk to the team about learning this skill
- Giving regular safe correction doses of insulin when your glucose levels are high will help
- The diabetes team can support any aspect of education you need help with, whether it is carb counting or dose adjustments. You have a key worker you can reach out to between clinic appointments

Conditions related to Diabetes

Since diabetes is an autoimmune condition (your own body developed antibodies to destroy the insulin making cells in the pancreas), there is a higher chance for you to develop another autoimmune condition, compared to someone without diabetes. It doesn't mean this **will** happen, just that your chances are higher. This is the reason we check for other conditions when we do your annual blood test, and this is why it is so important to have these bloods done!

What we check for...

Coeliac disease

This is where the body's immune system reacts to gluten, a protein found in wheat, rye and barley. This immune reaction damages the lining of the gut making it difficult for it to absorb nutrients from food.

Symptoms and treatment:

Diarrhoea, bloating, nausea, mouth ulcers, tummy aches, unexpected weight loss (but not in all cases), hair loss, anaemia. Once diagnosed, by removing gluten from the diet symptoms resolve.

Thyroid conditions; hyper or hypothyroidism

This is when the body either makes too much or not enough thyroid hormones, due to an autoimmune response in the body.

Symptoms and treatment for hypo and hyperthyroidism vary, and so talk to the diabetes team or visit this website for more information: <u>https://thyroiduk.org/</u>

Tips to gaining independence:



- Have open and honest conversations with your parents/ guardians about where you are going, what you are doing and show that you are responsible by carrying your diabetes kit.
- Respond to CGM alerts and treat properly so that 'followers' aren't having to remind you, as they will worry about you!
- Sit down and agree diabetes responsibilities with your parents/ guardians. It is helpful to share the responsibilities of diabetes to reduce the risk of you feeling overwhelmed. Look at the checklist (Appendix 1) and agree who does which part, who collects prescriptions, who downloads meters/ pumps, who orders equipment. If you have clear responsibilities, you will have less reason for conflict with parents/ guardians.
- Make time to look at your diabetes data once per week and discuss dose changes with your parents/ guardians or reach out to the diabetes team if you are unsure what to do.



Mental health and emotional wellbeing

At this age there are many things that can be stressful and difficult to manage. Pressure at school builds as you get closer to exams, relationships can change, and you are trying to work out what to do in the future. For many young people, this can be a time when they are more likely to notice changes in their mood and stress levels. For young people with diabetes, there is the additional need to manage your health condition more independently and this can feel like a burden or even overwhelming at times.



You can always go to your school, college or GP and ask about the support available if you are finding things difficult. When you are age 16 and over, you can access support from the Hertfordshire Wellbeing Service, who have professionals trained in supporting people who have long-term conditions. Your diabetes key worker (PDSN/ diabetes nurse) is always happy to talk to you and find the right support for you, so feel free to reach out to them for assistance.

Below are some useful websites aimed at young people who might be experiencing mental health difficulties, which might also be useful:

www.kooth.com www.youngminds.org.uk www.nspcc.org.uk www.getconnected.org.uk www.mindful.org

Driving

Learning to drive

Can't wait to get behind the wheel? Take a second to read this before you put on those 'L' plates. As long as your diabetes is well controlled and your doctor confirms this if asked, there's no reason why you shouldn't be issued with a licence. People with Type 1 Diabetes get a licence for one, two or three years, which can then be renewed.



You must get insurance and tell your insurance company that you have diabetes. If you don't, it may make your insurance invalid, which would be a disaster if you need to claim. Your premium should not be increased because of your diabetes, and if it is, move your business elsewhere.

Getting into first gear

You'll need a provisional licence before you can start taking driving lessons. And there will be a part on the form to fill out about your diabetes.

It's a good idea to tell your driving instructor that you have diabetes as you'll need to check your blood glucose levels before you drive.

The hypo-highway code

Having a hypo while you are driving a car (or riding a motorbike) can be fatal, not only for you, but for others as well. The DVLA advise you to:

- Check your blood glucose level less than two hours before getting behind the wheel, then again when two hours have passed from your pre-driving check once you have started driving. You will then need to stop and check again every two hours whilst driving. If it's less than 5mmol/l eat some carbs. If it's less than 4mmol/l don't drive
- Don't delay or miss a meal or snack
- If you feel like you are going hypo, stop driving as soon possible. Switch off the engine, remove the keys from the ignition, leave the driving seat, then test your blood glucose levels. Treat your hypo, and don't start driving again until 45 minutes after your blood glucose level has returned to 5mmol/l or more
- Held up? You can't predict traffic jams, but you can pre-empt them by carrying snacks and hypo treatment just in case
- It's obvious, but: never drink and drive

Information taken from Diabetes UK, Living my Life - Driving: <u>https://www.diabetes.org.uk/guide-to-diabetes/teens/me-and-my-diabetes/living-my-life/driving</u>

Please ask a member of the diabetes team for *'Diabetes, driving and the law'* leaflet for more in depth information or visit: <u>https://www.gov.uk/diabetes-driving</u>

Sexual health

It's always a good idea to tell a new partner that you have Type 1 Diabetes, so they know what to do in case of an emergency and understand that you might need to treat a hypo during sex. Remember that sex is an exercise, keep hypo treatment nearby in case of a hypo and make sure your partner knows how to support you.



If you are sexually active, then there is a risk of catching a sexually transmitted infection (STI), but you can help reduce this risk. First of all, make sure you always use a condom, whatever form of contraception you're using, as this will help protect you against STIs. Another option is for both you and your partner to have a test for STIs before you start having sex.

All infections, including STIs, are trickier and may take longer to get rid of when you have Type 1 Diabetes. If ignored they can have serious consequences and you may pass it on to your partner. So, it is a good idea to get yourself checked out if you have any worries. For information on where to get free contraception, STI tests and loads more information see the "Contact Information for local services" section below.

You can find out more about sex and relationships on the Diabetes UK website: <u>www.diabetes.org.uk/theone</u> Information from: <u>https://jdrf.org.uk/knowledge-support/living-with-type-1-diabetes/university-toolkit/universi</u>

Contact Information for local services

If you are looking for any more information on sexual health the following services are a useful place to start:

Sexual Health Hertfordshire – provide clinics or a drop-in service for information on contraception, emergency contraception, STI screening, advice and specialist care for psychosexual problems and much more. You can contact them at: http://www.sexualhealthhertfordshire.clch.nhs.uk/ or call on 0300 008 5522

YC Hertfordshire – provide a drop-in service offering free condoms (c-card scheme), free chlamydia testing, free pregnancy testing, healthy relationships programme, sexual and general health advice. You can contact them at: <u>https://www.servicesforyoungpeople.org/support-for-young-people/sexual-health-services/</u> or call on 0300 123 7538

Switchboard LGBTQIA + Helpline – an information, support and referral service for lesbian, gay, bisexual, transgender, queer, intersex and asexual + community. You can contact them at: <u>https://switchboard.lgbt/</u> or call on 0800 0119 100

What the diabetes team can help with:

At your appointments with the diabetes team, we are happy to discuss any concerns or questions you might have regarding sexual health. Although we cannot prescribe contraception, emergency contraception or provide STI screening we can help you find local services if you need this support. We are always happy to talk.

Pregnancy

If you're planning on trying for a baby, it is important to start planning before you start trying to conceive. For women, becoming pregnant with diabetes requires careful planning and tight blood glucose control to ensure a healthy baby and healthy pregnancy. Accidental pregnancies are therefore not advisable so always use contraception. It is vital that you contact your diabetes team if you are planning a pregnancy.

If you think you are pregnant you should contact the diabetes team immediately, as we need to advise you on monitoring your diabetes during your pregnancy. If you don't want to be pregnant, or are not sure you want to be, you can seek advice from your GP or school nurse. However, please still do make the diabetes team aware, as we would like to support you during this time.

https://www.diabetes.org.uk/guide-to-diabetes/life-with-diabetes/pregnancy

Alcohol

How does drinking alcohol affect your diabetes?

Having diabetes does not mean you can't drink alcohol, but it can affect your diabetes control. Your liver has many jobs including releasing glucose into the blood, gradually throughout the day. Alcohol can hinder the liver's ability to release glucose, increasing the likelihood of having a severe and prolonged hypo. Drinking alcohol can affect your liver for up to 24 hours, including overnight and the following day.

Sometimes drinking alcohol can temporarily increase your blood glucose levels (hyperglycaemia). This is because some alcohol contains carbohydrates, for example beers, ciders and spirits with sugar-containing mixers. However, we know that in the hours following consumption of alcohol, blood glucose levels will fall quite significantly. Therefore, it is not advisable to give correction doses of insulin for hyperglycaemia when drinking alcohol.

Keeping safe when drinking alcohol

- 1. Do not give insulin for alcohol
- 2. Always eat starchy carbs for/ during the meal before drinking; never drink on an empty stomach
- 3. Consider choosing sugar-free mixers
- 4. You may need to eat some starchy carbs (e.g. bread, potato, rice) during the evening to keep your blood glucose levels up (depending on choice of alcohol and activity levels)

- 5. Tell at least one person you are with that you have Type 1 Diabetes, and make sure that they know your signs of hypo and carry medical ID
- 6. Always carry hypo treatment with you and your blood glucose testing kit
- 7. Eat a starchy snack before you go to bed e.g. toast, cereal, chips, pizza, kebab
- 8. Drink plenty of water before you go to bed to keep yourself hydrated
- 9. Always check blood glucose levels regularly, the feeling of being drunk may be similar to your symptoms of hypo including the next morning as symptoms of a hypo could be mistaken for a "hangover" e.g. headache, nausea, shaking etc.
- 10. Always eat breakfast it will help maintain your blood glucose levels
- 11. If you are feeling ill, please refer to your 'sick day rules' and speak with your diabetes team for further advice.
- 12. Set limits and stick to them have sugar-free soft drinks in between alcoholic drinks
- 13. Remember being more active e.g. dancing can also increase the risk of a hypo
- 14. Do not forget to take your background insulin (if taking injections)

It is illegal to purchase and drink alcohol under the age of 18 years. The following information has been taken from the current government Change for Life programme: "It can be a bit tricky to understand and remember how much alcohol is in drinks, and how this can affect our health. The low-risk guidelines can help with this if you choose to drink. No-one can say that drinking alcohol is absolutely safe, but by sticking within these guidelines, you can lower your risk of harming your health if you drink most weeks: 1) men and women are advised not to regularly drink more than 14 units a week, 2) spread your drinking over three days or more if you drink as much as 14 units a week". Information from "*EoE CYP Dietetic Resource Alcohol*"

Drugs

Although we would recommend that you avoid drugs, we have included a section on drugs here for your knowledge and hope you find it helpful.

It's OK to say no to drink or drugs. Most young people offered drugs choose not to take them.

Staying safe

- Remember no drug is a safe drug. There are risks associated with any drug you take
- Drugs are illegal and there are heavy penalties for possessing and supplying them
- Make sure you have some diabetes ID on you and the people you're with know about your diabetes
- Have regular soft drinks and water if you're clubbing
- Have some carbohydrate-based food before you go out and when you get in. You might also need to snack during the evening
- Don't mix drink and drugs
- Make sure you know exactly what you are taking
- Make sure you keep sufficient money to get yourself home at the end of the evening.

Drugs mainly fall into the following categories:

Downers (or depressants) e.g. sleeping pills, heroin, methadone or cannabis Downers slow your body down, including your thought processes, heart rate and breathing. The relaxing effect of downers might mean that you forget about or can't be bothered to take your insulin or do a blood test. The first dose of heroin and methadone can cause vomiting. Also, if you inject you run the risk of skin infections that won't heal properly.

Uppers (or stimulants) e.g. speed, ecstasy, cocaine

Some people use uppers when they're clubbing, to give them more confidence. Uppers give you a high, and if you are dancing continuously, this can cause dehydration as your body loses fluid. However, once the high wears off you can feel depressed, irritable and tired. Heavy users can get run down and suffer from poor skin, weight loss and mood swings. Uppers can suppress appetite, and this can cause hypos, especially if combined with dancing. It's really important to eat carbohydrate-based foods regularly or drink sugary non-alcoholic drinks and drink plenty of water.

Hallucinogenic e.g. cannabis, LSD, magic mushrooms

Cannabis is probably the most common drug and makes you feel happy, relaxed and sociable. However, after taking it many people feel anxious and uneasy, or even light headed, faint and sick. It can also give you the munchies, causing your blood glucose levels to rise or make you feel spaced out and forgetful so you might forget to take your insulin. Cannabis increases the heart rate and can affect blood pressure and there's also increasing evidence of a link between cannabis and mental health problems such as schizophrenia. If you use cannabis frequently, it can reduce a man's sperm count and suppress ovulation in women.

LSD and, to a lesser effect, magic mushrooms can cause hallucinations which can last up to 12 hours. They might be unpleasant or even terrifying, and you can have flashbacks to them in the following weeks and months.

More information about drugs:

https://www.diabetes.org.uk/guide-to-diabetes/youngadults/drugs#:~:text=Some%20drugs%20can%20also%20slow,for%20a%20few%20days%20af ter

https://www.talktofrank.com/

References & Other Useful Resources:

Diabetes UK, Diabetes & Young Adults: <u>https://www.diabetes.org.uk/guide-to-diabetes/young-</u> <u>adults#:~:text=Diabetes%20UK%20Helpline&text=You%20can%20talk%20to%20us,us%2C%2</u> <u>Owe're%20here</u>.

Diabetes UK https://www.diabetes.org.uk/

Diabetes practical education videos: https://www.digibete.org/essentials/

Goals of Diabetes - Age banded Diabetes Education Goals: https://www.digibete.org/wp-content/uploads/2018/01/GoDe_Book_v7_INTERACTIVE.pdf

Juvenile Diabetes Research Foundation (JDRF) https://jdrf.org.uk/

<u>JDRF university education toolkit:</u> <u>https://jdrf.org.uk/knowledge-support/living-with-type-1-diabetes/university-toolkit/</u>

NICE guidelines: https://www.nice.org.uk/guidance/ng18

Appendix 1 - TRANSITION CHECKLIST – Paediatrics to Young Adult Service (YAC)

Patient	Plans to start	Needs practice	Independent	Comments
Describes their condition				
Feels confident asking questions in clinic				
Has knowledge of insulins and ratios/doses				
Has knowledge of insulin adjustments for meals and correction				
Independently inject/cannula insertion				
Understands the need for rotating injection sites				
Checks BG and is able to interpret result				
Recognises hypos and treats appropriately				
Recognises hyperglycaemia, when to check BK and treats appropriately				
Has written sick day rules				
Understands the effect of exercise/parties/events and plans appropriately				
Can count carbs with confidence in all situations				
Knows how to plan for holiday and travel				
Knows how to plan for driving				
Requests all prescriptions independently				
Knows how to book own medical and other appointments				
Understands the importance of screening for complications				
Understands the implications of their diabetes on daily life (e.g. smoking, drug and alcohol use, college, work etc.)				
Knows how to access contraception +/-, pregnancy planning information				
Knows how to contact diabetes team to seek medical advice including emergencies and out of hours				
Has transition information leaflet				

Appendix 2 – INSIGHTS – Optional

All you about you:	Insights:
Who do you live with?	
Are you in school, college, university or working?	
What are you studying?	
What are your future career plans?	
Who is important to you? Family/ friends/	
partner/ pet 😳?	
Do you have any mental health support?	
Do you have any social care support, or have	
you had any support in the past?	
Are you happy with how your diabetes is	
managed or are you interested in other	
technologies, pumps?	
Do you receive the right level of diabetes	
support from school, college, university, work,	
at home?	
Can we support you with this?	
What are your preferred pronouns?	