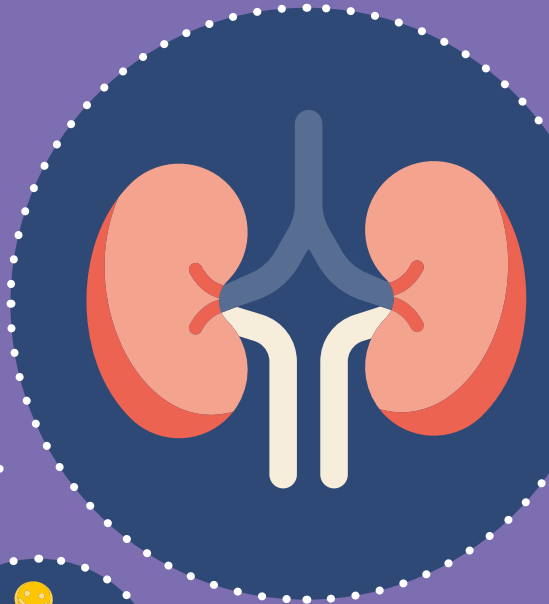


# Understanding Type 1 diabetes, kidney health and nephropathy

Developed as part of SEREN Connect diabetes education;  
supporting young people and young adults living with  
Type 1 diabetes





**Quality in Care**  
Diabetes Education Programme of the Year 2020  
**Quality in Care**  
Diabetes Judge's Special Award 2020

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SEREN Connect Diabetes Education  
c/o 1st Floor River House, Ynys Bridge Court,  
Gwaelod-y-Garth, Cardiff, CF15 9SS

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**With thanks to all who inspired, contributed,  
and believed in this programme.**

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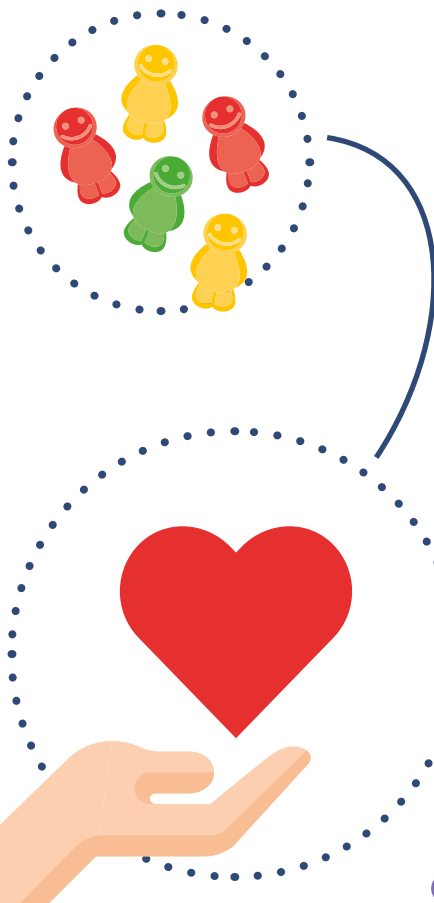
# Understanding Type 1 diabetes, your kidney health and nephropathy

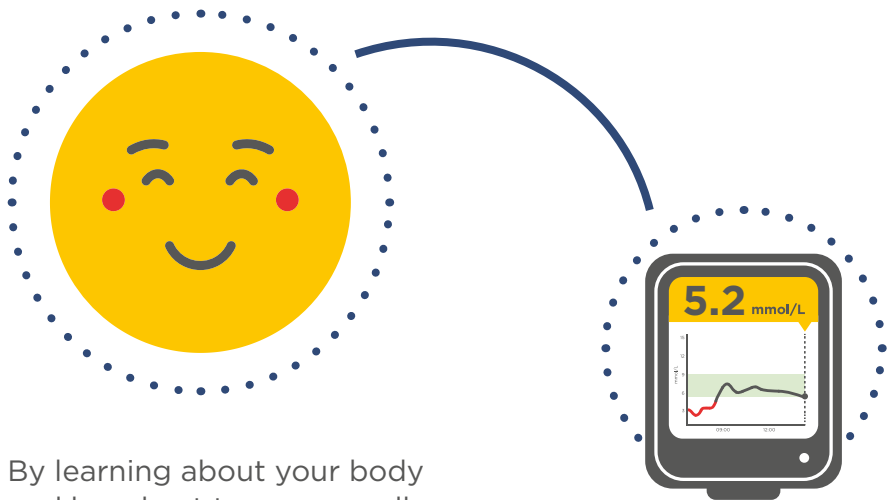
This booklet covers information to help you understand:

- Basic kidney health
- How Type 1 diabetes can affect the kidneys
- Practical steps you can take to look after your kidneys as part of your diabetes care

## Why is it important to look after my kidneys if Type 1 diabetes is linked to a problem in the pancreas?

Over time, having lots of glucose in the blood can affect the tiny nerves and blood vessels in parts of your body, including your kidneys. This stops them from being able to work as well as they should and can lead to conditions called diabetic nephropathy, or kidney disease. **This is covered in more detail on page 10.**





By learning about your body and how best to manage all aspects of Type 1 diabetes, and putting that into practice, you can help yourself stay healthy for as long as possible.

- Everyone is encouraged to learn about their kidneys
- Not everyone living with Type 1 diabetes will develop a kidney problem
- In addition, there are ongoing regular checks you should receive **at least** once a year as part of your annual review so that any signs of changes (that you wouldn't be able to notice yourself) can be picked up early, monitored closely and the best course of treatment offered to you

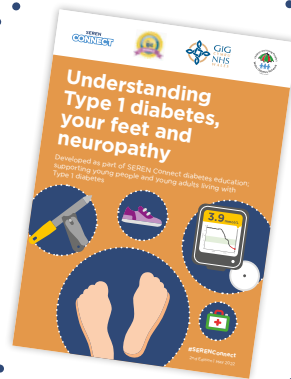
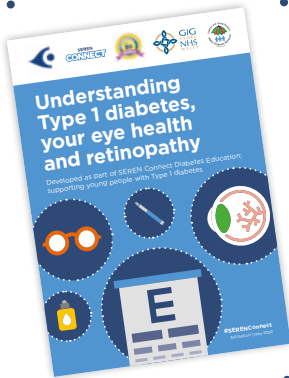
This booklet covers some of the support and treatment available when changes are detected in a person's kidney health so, if this is something you face at any point, you will know a little about what to expect. These are general points and may differ to your personal experiences or services local to you, so it's a good idea to ask questions about your local set up following this booklet if you want further information and clarity.

You can learn more about taking care of yourself, including looking after your eyes and feet and reducing your risk of associated diabetes related complications, by reading the following SEREN Connect booklets:

- **Understanding Type 1 diabetes, your eye health and retinopathy**
- **Understanding Type 1 diabetes, your feet and neuropathy**

Life gets busy as an adult but developing the habit of prioritising your health is one of the most important skills to learn.

Regularly provide your blood and urine samples to your diabetes team and/or GP as required and attend your annual review appointments where your kidney health will be checked, monitored and discussed with you by a healthcare professional.



# The basics: Who looks after your kidney health?

- First, and foremost, the best person to look after your kidneys is you. Use the information covered in this booklet as a starting point to help you understand how
- Your diabetes team (or, once you are an adult, in many places it is often your GP surgery) will check your kidney health at least once every year and answer any questions or concerns you may have. If needed (from the results of your annual review) they can refer you onto other services for further advice and/or treatment
- As your condition progresses, if your diabetes team feel they need further specialist input for your kidneys, they may refer you to a nephrologist (or a renal team) who specialises in looking after kidneys, who will offer you further advice and additional treatment options



When I was a teenager I used to hate having to provide a urine sample. I thought if they saw my bloods were higher than my team wanted, I'd be in trouble. I didn't understand or value how important those checks were for my long-term health. They weren't just measuring blood glucose or checking ketones, there's a lot more to it that really benefits me. It's worth peeing in the pot!

**Young adult living with  
Type 1 diabetes**

# What to expect from your annual kidney check

**Your routine diabetes care from your diabetes team (or your GP) includes checking on your kidney health. It makes up part of your yearly check-up/annual review.**

Each year, you can expect to have your kidney function checked in two ways (see page 8).

By having these done each year, you, and the clinicians looking after you, are able to keep your kidneys healthy for as long as possible. Changes detected early can be closely monitored and/or treated. The earlier that changes are picked up, the more treatment options are available to you to avoid further problems or slow further loss of kidney function.

Your annual review takes place either at your GP surgery (more usually, when you are an adult) or with your diabetes team (more common when you are a child). If you know that you are unable to make an appointment, make sure you let them know so that it can be rearranged for a more suitable time and they can give that appointment slot to someone else.

If something happens on the day and you are unable to make it, call to explain so that you can be given another appointment, **as this may not happen automatically if you didn't attend.**



**Usually, two weeks before your annual review appointment you'll need to take some time out to provide the following samples:**

- A blood sample taken from your arm
- A urine sample (the first urine of the day tends to give the most clear results)

This allows enough time for your results to come back and you can discuss them at your annual review appointment.

This blood sample is usually taken at the same time as the blood sample you would provide to get your HbA1c measurement, if you had it taken from your arm. From the level of serum creatinine in your blood, your estimated glomerular filtration rate (eGFR) can be calculated by using a mathematical equation that also takes into account your age, sex and race. This gives you information on your level of kidney function and is a key indicator of any sign of kidney disease. **This is covered in more detail on page 10.**

From your urine, your albumin-creatinine ratio (ACR) is calculated. Your urine is checked for a type of protein called albumin, which indicates early signs of kidney disease. Your first urination of the morning gives the best accuracy. When albumin is in your urine, it's called albuminuria and **there's more information on page 10.**

Take time to understand the local set-up in your area (especially if you were diagnosed under paediatrics as it can feel quite different to what you've been used to). You need to know what to expect and where to go; how to make appointments and get your results.

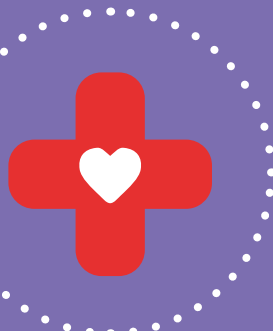
**Making sure you don't miss out on important parts of your ongoing care is so important for your long-term health, and developing this habit early will really help you in the long run.**



Your kidneys are bean shaped organs (think kidney beans) about the size of a fist. Most people have two kidneys, although it is possible to live a healthy and active life with just one. They are located just below your rib cage, with one on each side of the spine.

You can get a rough idea of where your kidneys are by following these steps:

- Put your hands on your hips
- Turn your hands and feel towards your spine until your fingertips almost meet
- That's roughly where your kidneys are but you can't feel them



## What do your kidneys do?

Kidneys are made up of millions of nephrons, which each contain a filtering unit of tiny blood vessels. They filter your blood, have several functions that are vital for your body, and they produce hormones that affect how other organs in your body work too.

### Their main functions include:

- Removing waste products and excess fluids from the body through urine
- Cleansing the body of toxins (e.g. alcohol and drugs)
- Keeping vital chemicals (e.g. potassium and sodium) in your body balanced
- Releasing hormones that regulate blood pressure
- Producing an active form of vitamin D that promotes strong and healthy bones
- Controlling the production of red blood cells

High blood glucose (also known as hyperglycaemia) over time can cause damage to the blood vessels, which means that a diabetes diagnosis puts you at a higher risk of developing kidney problems such as nephropathy. Learning how to manage your diabetes and making decisions that protect your health are the best tools you have in keeping this risk as low as possible.

**It's important to be aware of other factors that increase your risk of developing kidney disease so that if they apply to you, you can make informed decisions around your lifestyle and health choices.**



### **These include:**

- If you have high blood pressure (also known as hypertension) that isn't treated
- If you have high blood cholesterol
- If you smoke (there's support available if you need help to quit, speak to your GP)
- If you have a family history of diabetes and kidney disease
- If you have a high BMI score
- If you have other kidney issues e.g. kidney stones



I remember feeling like the list of potential complications that came with diabetes felt never-ending, especially when I became an adult. It all felt a bit much. I wanted to ignore it all, but I soon realised there is so much I can do if I took the time to learn and make space for it. Ironically, it takes up less headspace now I understand a lot more about it.

**Young adult living with  
Type 1 diabetes**

If your kidneys are healthy and working well, your urine won't contain any protein called albumin and your estimated glomerular filtration rate (eGFR) would measure 60% or higher. If you have high levels of albumin in the urine and/or your eGFR measures 15%-60% then you have indications of kidney disease and you would need further tests to confirm this and then possible treatment.

You may need to repeat some of these tests several times over a specific period of time to build up a picture of what is happening and to see whether your results are stable or changing.

**The rate at which kidney disease has progressed is broken down into five stages using GFR measures:**

Stage	Explanation	GFR
<b>Stage 1</b>	Kidney damage present but normal kidney function	90% or above
<b>Stage 2</b>	Some loss of function (mild reduction related to normal range)	60-89%
<b>Stage 3a</b>	Mild to moderate loss of kidney function	45-59%
<b>Stage 3b</b>	Moderate to severe loss of kidney function	30-44%
<b>Stage 4</b>	Severe loss of kidney function	15-29%
<b>Stage 5</b>	Kidney failure	15% or less

GFR is Glomerular Filtration Rate and it is a key indicator of renal function. eGFR is estimated GFR and is a mathematically derived entity based on a patient's serum creatinine level, age, sex and race. (UK Kidney Association).

The reason why having your eGFR and ACR tests done every year is so important is that they are able to pick up changes in your kidney function far earlier than physical symptoms your body may display. Physical symptoms (listed right) are not usually noticeable until stages 3-4 when the condition is more advanced. The earlier you know about any changes, the sooner you can be offered treatment that can often help slow down the progression.

### **Signs and symptoms of chronic kidney disease (CKD):**

- Loss of appetite
- Weight loss
- High (or worsening) blood pressure
- Swollen ankles, feet or hands (as a result of water retention often called oedema)
- Shortness of breath
- Tiredness/fatigue
- Protein and/or blood in your urine
- Increased need to pee (particularly during the night)
- Difficulty sleeping (insomnia)
- Itchy skin
- Muscle cramps
- Nausea and/or vomiting
- Headaches
- Risk of variable glucose readings and a higher risk of hypos

**If you have any of the above symptoms make sure you contact your GP or diabetes specialist straight away so that they can discuss your symptoms and arrange for you to have further investigations.**

# Six steps that can help you look after your kidneys

**Whilst a diagnosis of Type 1 diabetes is out of your control, there are lots of things you are still able to do to positively influence your health. This can help organs like your kidneys to function better, and can help manage any existing kidney damage you may have developed already.**

## STEP 1: Stay hydrated

Dehydration isn't good for your kidneys, so drinking plenty of fluids (such as water) can help them to function properly. Be mindful anytime where you've been sweating a lot e.g. during hot weather, when travelling in hotter countries or when exercising strenuously, you'll need to drink more to make up for fluid loss.



## STEP 2: Eat a healthy balanced diet (and learn how to carbohydrate count)

A balanced diet ensures your body is getting the right amount of vitamins and minerals that it needs to function. Eating plenty of fruit and vegetables, and reducing the amount of added sugar, salt or fatty foods you eat is a good place to start. Your dietitian will be able to discuss all things nutrition with you, including helping you understand food labels or securing you a space on an education programme that can help develop your carb-counting skills. This can be extremely beneficial if you've not been on one before as an adult or if it's been a while since you've refreshed your skills and knowledge.



## You can further help to keep your blood pressure lower by:

### **STEP 3: Watch your blood pressure**

Getting your blood pressure monitored regularly is another important part of your annual review as high blood pressure can cause problems for your kidneys and/or heart. As high blood pressure doesn't have any symptoms you likely won't know about it increasing without regular checks. If it's too high, you'll be offered advice on lifestyle changes or, if necessary, be medication to lower it. The target for adults living with Type 1 diabetes is 135/85mmHg (NICE Guidelines).

### **STEP 4: Avoiding smoking (or access support to help you quit)**

There are lots of well documented health issues related to smoking but in relation to your kidney health, it raises your blood pressure which on top of the risk you have in living with diabetes, is one of the most common causes of kidney disease. If you already smoke and you are

finding it difficult to quit, your GP can offer you additional support to help with this.

### **STEP 5: Limiting the amount of alcohol you drink**

Although you need to understand how alcohol affects Type 1 diabetes and how to manage your blood glucose when drinking, small quantities of alcohol every now and again doesn't have serious side effects. But drinking too much, too often is harmful, and if you already have kidney disease it can cause it to get worse too.

### **STEP 6: Building regular exercise into your routine**

Exercise has multiple benefits when looking after your kidneys. It can improve muscle function, lower blood pressure, lower cholesterol, help maintain a healthy body weight (being overweight also raises blood pressure) and improve sleep. It's recommended that you aim for at least 150 minutes of moderate-intensity exercise e.g. walking, cycling or swimming every week.

**With lots of emphasis on eating healthily, staying active and being a healthy weight it's not uncommon to feel overwhelmed, which can sometimes lead to mental health problems.**

If living with, and managing, your diabetes is causing you high levels of anxiety or distress, please mention this to your healthcare team or your GP so they are aware and can get you the most appropriate form of support to help you.

And a few extra tips for when you have to manage Type 1 diabetes too:

- Take time to learn about your condition and how it affects you
- Ensure you are taking the recommended amount of insulin at the recommended times to suit your needs
- Take an interest in your annual review results. Don't be afraid to ask if there are results you would like explained to you
- Attend your healthcare appointments or rearrange any that you can't make
- Ask your diabetes team for additional help if there's anything you don't understand



# Accessing support

Living with (or even in fear of developing) diabetes related complications can often be scary, and feel quite isolating. If this is something you're experiencing you may want to consider reaching out for some 'peer support.' This is where you're able to learn about others' experiences, connect with and chat to other people living with diabetes and/or similar conditions to you.

If you prefer face-to-face interactions, ask your team if they are aware of any support groups or events happening in your area, or close enough that you could travel to them.

If you have access to the internet you can connect with others living with diabetes on a global scale, using social media platforms.



Searching for specific hashtags and key words can help you find posts that are relevant to the online diabetes community, posted by others for you to see.

Try searching for the #DOC which stands for the diabetes online community or the #GBDOC (which will bring up tags from those living in England, Scotland and Wales as part of Great Britain's Diabetes Online Community) and see what people are posting about.

**Please note:** Peer support can be a valuable resource to help people feel less isolated and/or help with emotional support when living with long-term health conditions, but **it does not replace trusted, medical advice from healthcare professionals.** You are strongly advised not to take medical advice from anyone who does not hold a professional license, and to consult with your diabetes team before making changes to your diabetes management.

## Useful links and contacts

You can find out more about diabetes from the following organisations:

Diabetes UK

**[www.diabetes.org.uk](http://www.diabetes.org.uk)**

JDRF

**[www.jdrf.org.uk](http://www.jdrf.org.uk)**

BeyondType1

**[www.beyondtype1.org](http://www.beyondtype1.org)**

You can find out more about kidney health by contacting Kidney Wales or by visiting **[www.kidneywales.cymru](http://www.kidneywales.cymru)** or outside of Wales you can check out Kidney Care UK using their **[www.kidneycareuk.org](http://www.kidneycareuk.org)** website.



# Notes

## Other SEREN Connect Resources

**Drinking alcohol with Type 1 diabetes**  
Developed as part of SEREN Connect diabetes education supporting young people and young adults living with Type 1 diabetes.

5.9 mmol/L

Icons: smartphone with graph, beer, glass of wine, insulin pen, NHS logo.

SEREN Connect Diabetes Education Team 2023

**Learning to drive and driving safely with Type 1 diabetes**  
Developed as part of SEREN Connect diabetes education supporting young people and young adults living with Type 1 diabetes.

Icons: steering wheel, road sign, car, 'L' plate, keys, insulin pen, NHS logo.

SEREN Connect Diabetes Education Team 2023

**Managing Type 1 diabetes: post-school, at university and in the workplace**  
Developed as part of SEREN Connect diabetes education supporting young people and young adults living with Type 1 diabetes.

5.9 mmol/L

Icons: smartphone with graph, hand, insulin pen, building, NHS logo.

SEREN Connect Diabetes Education Team 2023

**Pregnancy, parenting and Type 1 diabetes**  
Developed as part of SEREN Connect diabetes education supporting young people and young adults living with Type 1 diabetes.

Icons: ultrasound, baby, insulin pen, NHS logo.

SEREN Connect Diabetes Education Team 2023

**Sex, relationships and Type 1 diabetes**  
Developed as part of SEREN Connect diabetes education supporting young people and young adults living with Type 1 diabetes.

Icons: rainbow heart, insulin pen, NHS logo.

SEREN Connect Diabetes Education Team 2023

**Travel, events and festivals with Type 1 diabetes**  
Developed as part of SEREN Connect diabetes education supporting young people and young adults living with Type 1 diabetes.

5.9 mmol/L

Icons: insulin pen, passport, airplane, NHS logo.

SEREN Connect Diabetes Education Team 2023

**Understanding Type 1 diabetes, your eye health and retinopathy**  
Developed as part of SEREN Connect diabetes education supporting young people and young adults living with Type 1 diabetes.

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Icons: eye, insulin pen, NHS logo.

SEREN Connect Diabetes Education Team 2023

**Understanding Type 1 diabetes, your feet and neuropathy**  
Developed as part of SEREN Connect diabetes education supporting young people and young adults living with Type 1 diabetes.

5.9 mmol/L

Icons: insulin pen, foot, NHS logo.

SEREN Connect Diabetes Education Team 2023