

# Looking after yourself with early chronic kidney disease



## Information for patients

Sheffield Kidney Institute (Renal Unit)



**PROUD TO MAKE A DIFFERENCE**

SHEFFIELD TEACHING HOSPITALS NHS FOUNDATION TRUST



## Introduction

We have written this leaflet for people who have been told they have kidney disease.

We realise that there is a lot of information to take in and understand and some of the information may seem to be complicated. We also understand that people can have busy and stressful lives with work, caring for children or parents, worries about money or studying, etc.

For many people, kidney disease is a long term condition that is present throughout their lifetime. You may hear your kidney problems called chronic kidney disease or CKD for short.

Doctors, nurses and other healthcare staff use the word chronic to mean:

- Health problems that happen gradually over time.
- That there is no cure (the disease or illness won't go away).
- That there are treatments that can help live with the illness and any problems it may cause, for example dialysis.
- The word chronic does not mean that the illness is not serious.

CKD has many different causes (for example diabetes, high blood pressure) and the disease damages both kidneys.

Here at Sheffield Kidney Institute (or Renal Unit) we treat people with kidney disease. We know that people who have long term conditions and become involved in managing their care and treatment generally:

- Feel more in control of what is happening to them.
- Have less stress and anxiety about their condition
- Have fewer complications
- Any complications that do happen develop later
- These complications may be less severe
- Have a better quality of life

Although we are experts about kidney disease, we are not experts about you – and that is where your experience and views are important.

## **What can I do to get involved in my care?**

There are several ways that people with kidney disease can become more involved in their own care, from simple things to some more complicated parts of treatment.

Examples of the ways you can become involved include:

- Preparing for your clinic appointments by thinking of questions that you would like to ask the doctors, nurses, or dietitian.
- Understanding as much as you can about your disease and CKD will mean it will be easier for you to make decisions about your care with members of the renal team. Please feel free to keep asking questions if you don't understand what you have been told or want more information.
- Learning about your medications and bringing a list to your clinic appointments.
- Learning to measure your own weight and blood pressure and recording it at home. We have a record card where you can write down the results, or you may prefer to use your own notebook or your computer. You will need to bring your results when you come to clinic. (You can buy a blood pressure machine from Boots or Lloyds or any large chemist. The staff there will be able to advise you on what may be best for you. The blood pressure machine must be the type where a cuff goes around your arm.)
- Registering for Patient View. This is a secure website where you can view your own blood results, find more information about kidney disease, etc:  
**<https://www.patientview.org/#/>**
- We have a booklet explaining in more detail about PatientView and how to get an account and a password. Please ask if you

would like a copy or you can read an electronic copy here:

**[www.sth.nhs.uk/patients/patient-information/find-a-leaflet/search-for-a-leaflet](http://www.sth.nhs.uk/patients/patient-information/find-a-leaflet/search-for-a-leaflet)**

- Coming to our patient support and learning group – Sheffield Kidney Informed Patient Programme or SKIPP for short. The group is open to you and your family and is held every 2 months in the centre of Sheffield. Please ask for a leaflet if you want to find out more about the group. You will learn more about kidney disease and treatment.

You can have copies of letters sent to your GP about your clinic visit. You will need to ask the doctor at your clinic visit if you want a copy. This will help you understand your kidney condition and keep you informed about what is happening with your treatment.

Sheffield Kidney Institute is involved with a number of research projects. If we think that a project is relevant to you, we may ask if you would like to join the project. Joining a project is voluntary; you can say no without it affecting your care.

You may be asked to read and make comments on new patient information leaflets that are being written. Taking part is voluntary; you can say no without it affecting your care.

## **How do I keep myself as healthy as possible?**

There are a number of ways you can help yourself to stay as healthy and well as possible. These include:

- Coming to all your clinic and test appointments
- Understand and take your medication exactly as it has been prescribed. Never just stop taking any medication without discussing it with a doctor.
- Follow any advice you have been given by the dietitian at the Renal Unit.

- Stop smoking: we have a leaflet “Stop smoking: improve your health” that tells you about this in more detail. Please ask if you would like a copy or you can read an electronic copy here: **[www.sth.nhs.uk/patients/patient-information/find-a-leaflet/search-for-a-leaflet](http://www.sth.nhs.uk/patients/patient-information/find-a-leaflet/search-for-a-leaflet)**
- Keep to a healthy weight: if you need help to lose weight, please ask to see a dietitian.
- Gentle exercise is recommended to reduce the chance that you put on weight and to improve your general health.
- Try to reduce the stress in your life to improve your health and well-being. There are helpful hints and tips via this internet link: **<https://www.nhs.uk/conditions/stress-anxiety-depression/understanding-stress/>**
- Keep your alcohol intake within recommended limits. You can find out more about this at NHS UK or discuss this with your GP or practice nurse if you are concerned. **<https://www.nhs.uk/conditions/alcohol-misuse/>**
- If you use recreational drugs or feel that you have become dependent on pain killers for example, you may want to think about getting some help with this. The internet link below explains how you can get help and support drug and substance issues. **<https://www.nhs.uk/live-well/healthy-body/drug-addiction-getting-help/>**

It is important to keep yourself healthy throughout the year. Below are some hints and tips on staying healthy during the winter and summer.

## Winter health

- Make sure you have a flu vaccination every year.
  - Kidney patients are at higher risk of catching the flu virus and developing complications from flu.
  - Having the flu vaccination can reduce the chances of you getting flu.

- Look out for information in early autumn about the flu vaccination on the television or at your GP surgery.
- Make sure you find out how you can get the vaccine at your GP surgery. You will not have to pay for this.

Remember: **Flu can kill!** We have a leaflet that explains about flu and the flu vaccine in more detail. Please ask if you would like a copy or you can read an electronic copy here:

**[www.sth.nhs.uk/patients/patient-information/find-a-leaflet/search-for-a-leaflet](http://www.sth.nhs.uk/patients/patient-information/find-a-leaflet/search-for-a-leaflet)**

- Avoid visiting sick relatives and friends, for example if they have a cold or diarrhoea and vomiting.
- Take extra care if the paths, pavements and roads are icy because of an increased risk of broken bones if you fall.
- Follow any advice about your diet you have been given and try to eat as well as possible.
- Keep to any fluid allowance you have been given.
- Make sure you have a good supply of all your medication at home so you don't run out.
- Keep yourself and your home as warm as possible. There are some hints and tips on the internet pages below.

**[www.nhs.uk/Livewell/winterhealth/Pages/KeepWarmKeepWell.aspx](http://www.nhs.uk/Livewell/winterhealth/Pages/KeepWarmKeepWell.aspx)**

## Summer health

- Check the weather forecast regularly for warnings of hot weather.
- Don't sit out in the hot sun for long periods, especially between 11.00am – 3.00pm.
- Keep yourself cool; wear loose cotton clothes, sit in the coolest part of the house, have a cool bath or shower for example.
- Always use sun cream; this is especially important if you take medicines that suppress the immune system.

- Be aware that you still need to follow any fluid allowance you have been given.
- Make sure that you store food safely and cook it properly. This is especially important if you are planning a barbeque.

**<https://www.nhs.uk/live-well/healthy-body/heatwave-how-to-cope-in-hot-weather/>**

## **Planning a family**

If you are thinking about having a baby you should be aware that some of the medication for CKD can affect the unborn baby. This is true for both men and women. If you are planning to have a baby you must discuss this with your kidney doctor - don't just stop taking your medication. Your kidney doctor will be able to discuss the risks with you and if any alternative treatment is available.

## **What do I do if I become unwell now I have kidney disease?**

It is important you know where to get the right sort of help if you become unwell. The same choice of service is available to you as before you had kidney disease (for example, your local chemist, Minor Injuries Unit, NHS Walk-in Centre, your GP).

Please note:

- You must tell the member of staff at the service you use, that you have kidney disease.
- It is also important that you get help and advice straight away so your problem doesn't get any worse.
- Don't leave any problem until your next visit to outpatient clinic or the Renal Unit.

If the service you use is unsure how to advise or treat you, they can always call the Renal Unit for advice.

If your problem is an emergency (for example chest pain, breathlessness), phone 999. You should be aware that the ambulance will take you to the nearest Emergency Department not the Renal Unit, even if your emergency is caused by your kidney problem.

As we said at the start of the leaflet, we realise that there is a lot of information to take in and understand and some of the information may seem to be complicated.

We also understand that people can have busy and stressful lives with work, caring for children or parents, worries about money or studying.

While there are things to consider and choices to make, don't feel under pressure to learn or do everything at once. It will take time to make these decisions especially if you want to involve your family or friends. The support of other people can help reduce the pressure you may feel.

## Remember:

- Patients with more advanced CKD may need to make decisions about long term treatment such as dialysis or having a kidney transplant. If this is the case with you, staff at the renal unit will support you and help make the best decision for you.
- **The more involved you are with your care, the better the results from your treatment.**

## Contact

Renal Assessment Unit (Sorby Renal Outpatients): **0114 271 5320**  
Monday - Thursday: 8.30am - 4.00pm. Friday: 8.30am - 3.30pm

Alternative formats can be available on request.

Please email: [sth.alternativeformats@nhs.net](mailto:sth.alternativeformats@nhs.net)

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