



# Low clearance clinic

## Information for children, families and carers

We have given you this factsheet because your child has been referred to the low clearance clinic. It explains what the low clearance clinic is, what to expect at your child's clinic appointments and how to prepare for these appointments. We hope it helps to answer some of the questions you may have. If you have any further questions or concerns, please contact us using the details at the end of this factsheet.

## What is the low clearance clinic?

The low clearance clinic is a specialist kidney clinic at University Hospital Southampton NHS Foundation Trust (UHS) that cares for children and babies who have advanced chronic kidney disease, also known as CKD (a long-term condition where the kidneys do not work as well as they should) and need additional support.

The kidneys play several key roles in the body, including:

- removing water and waste products from the blood
- · regulating blood pressure

- keeping bones strong
- · helping make red blood cells

There's no cure for CKD, but early treatment can help:

- relieve your child's symptoms
- improve your child's quality of life
- stop the disease getting worse
- prevent other health issues developing

As CKD may not make your child feel unwell, it is important that they attend all their clinic appointments so that we can monitor their condition and act as soon as possible if there are any changes.

### What are the aims of the clinic?

We aim to:

- ensure your child receives the most appropriate treatment to delay the progression of CKD
- · improve your child's symptoms by making changes to their medications and diet
- provide advice on managing CKD (for example, lifestyle changes and treatment options)
- provide information on treatments your child may need in the future, such as dialysis (a procedure to remove waste products and excess fluid from the blood when the kidneys stop working properly)

## How should I prepare for my child's clinic appointments?

You should bring the following items with you to your child's clinic appointments:

- a list of the medications your child is currently taking, including names, strengths and doses or your child's green card (unless we ask you to bring your child's medications in with you)
- a urine (pee) sample (their first pee of the day)
- a three-to-five-day food diary (ideally recorded using the Libro app your child's kidney dietitian will provide you with a link to this app)
- a family member or friend for support (if needed)

## What will happen at my child's clinic appointments?

We will:

- · test your child's urine sample
- take a number of measurements (including your child's weight and height)
- take your child's blood pressure
- perform a blood test

The results of these tests and observations will help us monitor your child's condition.

Your child will be seen by several different members of the kidney multidisciplinary team (MDT) at these clinic appointments. The kidney MDT is a group of healthcare professionals who work together to provide care for people with kidney conditions. The team includes:

- **Kidney consultants** The kidney consultants will assess and manage your child's kidney symptoms and medications and discuss the different types of treatments suitable for your child.
- Kidney clinical nurse specialist (CNS) team The kidney CNS team will work with your child, your family, your child's school and other agencies to provide information, education and support. The team can also signpost you to external organisations if you would like more information on disability allowance, counselling and financial assistance.
- **Kidney dietitians** The kidney dietitians will provide specialist kidney dietary advice to support your child's treatment plan to help aid growth. Advice may include restricting certain food groups, increasing certain foods and adding calories through supplements. Your child's dietitian will provide you with more specific information about this.
- **Kidney pharmacist** The kidney pharmacist will provide specialist advice on your child's medications and can support you with medication supply issues, including medications prescribed by your child's general practitioner (GP).
- **Play specialist team** The play specialist team can help support your child through their kidney journey by providing distraction during blood tests and by teaching them about their condition through the use of play.
- Kidney youth worker The kidney youth worker can support young people aged 11 years
  old and above. They offer a range of services including emotional support, transition into adult
  services planning, advocacy (helping your child express their views and wishes relating to their
  health), and access to resources.



Our clinic uses the Ready Steady Go programme to help support young people gain the knowledge and skills to manage their condition and to take ownership of their health needs. As part of this programme, we will invite children from the age of 11 years to attend part of their clinic appointments alone without their parent or guardian. The kidney youth worker can support with this transition process.



For more information about the Ready Steady Go programme, scan the QR code or visit: <a href="https://www.readysteadygo.net">www.readysteadygo.net</a>

## How long will the appointments be?

Each appointment will be approximately 45 minutes, but please allow extra time for any additional tests your child may need, such as a blood test.

## Will my child need any follow-up care?

We will arrange to see your child in our low clearance clinic every four to six weeks.

## **Further information**

Parking permits are available from your child's kidney CNS team to enable you to get reduced parking costs when you come into hospital for your child's clinic appointments.

#### Contact us

If you have any questions or concerns, please contact a member of your child's kidney MDT using the relevant details outlined in the 'Children's kidney service contacts: open access' section on the next page.

## **Useful links**

## **Kidney Care UK**

A charity who works to improve the quality of life for people with kidney disease by aiding support, information and granting aids.

Website: www.kidneycareuk.org

#### NHS

Website: www.nhs.uk/conditions/kidney-disease

If you are a patient at one of our hospitals and need this document translated, or in another format such as easy read, large print, Braille or audio, please telephone 0800 484 0135 or email patientsupporthub@uhs.nhs.uk

For help preparing for your visit, arranging an interpreter or accessing the hospital, please visit www.uhs.nhs.uk/additionalsupport

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## Children's kidney service contacts: open access

# If your child is unwell and you need urgent advice

Call the clinical nurse specialist (CNS) team.

Telephone: 07467 338675

(Monday to Friday, 8.30am to 7.30pm)

Outside of these hours, call G4 SUN ward. Telephone: **023 8120 8620** or **023 8120 4251** 

Ask to speak to the nurse-in-charge who will offer advice **or** contact your child's consultant. If you have not heard back within one hour, please call the ward again.

Haemodialysis unit (for HD patients only) Telephone: **023 8120 4147** (Monday, Wednesday and Friday, 7.30am to 7.30pm)

Alternatively, visit your nearest open access ward or emergency department. Call **999** where appropriate.

## **Medical or nursing issues**

Children's kidney team

Email: childrensrenalteam@uhs.nhs.uk

Telephone: 023 8120 3202

Alternatively, you can contact us via the My Medical Record messaging tool. Please make it clear in the subject line what your message is about and who it is for.

We will aim to respond within five working days. If the matter becomes urgent, please follow the 'urgent' pathway above.

## Dietetic, dietary, feed or milk matters

#### For non-urgent queries

Children's kidney dietetic team

Email: childrensrenaldietitian@uhs.nhs.uk

Telephone: **07557 316516** 

We will check emails and answerphone messages regularly during our working hours.

#### For urgent queries

Contact the CNS team using the details above, your GP or call **111** for advice.

## Clinic appointment changes

Admin team

Telephone: **023 8120 6254** or **023 8120 5222** Email: **paediatricnephrology@uhs.nhs.uk** 

#### **Medications**

If your child needs a medication that their GP cannot prescribe, please use the following link or QR code: <a href="https://forms.office.">https://forms.office.</a>

com/e/e3hkVJmL4k to request it

two weeks before the medication is needed.

We aim to confirm receipt of requests within five working days. Once confirmed, please call the outpatient pharmacy to check when it will be ready to collect. You may be able to tie this in with your child's clinic appointments.

#### **Outpatient pharmacy**

Telephone: **023 8120 5789** (Monday to Friday, 9am to 6pm and Saturday, 9am to 1pm)

## Non-urgent queries

Kidney pharmacist

Email: <a href="mailto:childhealthpharmacy@uhs.nhs.uk">childhealthpharmacy@uhs.nhs.uk</a>
Please mark your email for the attention of the

kidney pharmacist.

Working days: Monday to Thursday

#### **Urgent queries**

Kidney pharmacist

Telephone: 07825 048740 (calls only, texts will

not be checked)

If you are unable to reach the kidney pharmacist, follow the 'urgent' pathway above.

Unless otherwise stated, the telephone numbers included in this factsheet are Monday to Friday, 8am to 5pm. Please note that emails sent or received from outside the Trust may not be secure.

