



Psychological support for families under the care of the kidney team



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Why is there a clinical psychologist in the children's kidney team?

Some children and young people may only need to come to the hospital once or twice a year, and take one or two medicines. For others with kidney failure, they may need to have more complex interventions, including dialysis or a new kidney through a transplant operation.

Some children and young people have lots of different medicines to take. They have to follow a special diet and may not be able to drink as much as they would like. There will also be blood tests, operations and other procedures. All of these things can have a significant impact on children, young people and their families, emotionally as well as physically. It can also make keeping up with school and friends difficult at times.

The clinical psychologist is there to work with the other members of the team to support children, young people and their families as they learn about living with their kidney condition and its treatment. They are able to use their training in psychology to identify what children, young people and families understand, believe and feel about their condition and its treatment and use this understanding to support them as they adapt. The psychologist will also share this understanding with the rest of the team, with the family's permission, to help the team provide information and support that is psychologically informed.

For some children, young people or their carers, the impact of the kidney condition or its treatment can become very distressing, leading to significant anxiety or depression. When this happens, the clinical psychologist will use their training in mental health to assess their needs. They may then offer individual therapy or refer patients on to specialist mental health services.

What are common concerns for young people with kidney conditions?

These include:

- coping with blood tests, dialysis and other medical procedures
- preparing for transplant
- managing lots of medicines, special diets and fluid restrictions
- understanding their condition and being expected to take increasing responsibility for managing it as they grow up and get ready to move to adult services
- managing their condition alongside trying to follow the same developmental pathways as other young people without kidney conditions.

What are common experiences for parents of young people with kidney conditions?

For many parents, adjusting to the news that their child has a kidney condition can take time, with repeated explanations and information giving. The condition may be very complex, requiring treatments at home. Some parents find this distressing as they feel they have become more like nurses than parents. Over time, as their child grows and develops, the challenges of managing their condition may change, with areas like eating, drinking and taking medicines becoming key issues.

Every child and family's experience is recognised as unique. The clinical psychologist has a key role in the team in relation to understanding this and supporting the team in developing partnership working with parents, carers and young people.

How can the clinical psychologist help me or my child?

This depends on your family's specific concerns or circumstances. We can offer:

- an initial discussion after a diagnosis to offer emotional counselling
- a developmental assessment with a pre-school child
- a pre-transplant discussion with an adolescent to assess how much they know, what their worries are and how they like information to be given
- help including talking, drawing, symbolic play, using the computer or DVDs for informational or emotional counselling
- assessments of mood or quality of life to help people think about areas that young patients or their parents might want further support with
- discussions and information relating to lifestyle choices, and how to independently manage a kidney condition to help prepare young people for adulthood.

What other roles does the clinical psychologist have within the kidney team?

The clinical psychologist also:

- provides psychological consultation for other team members when they discuss children and young people at the weekly ward round and 'complex care' meeting
- applies psychological knowledge to help the team look at how they work together, and how they can design services and pathways with service users
- teaches other staff about using psychology to support families
- does research, service evaluation and audit projects to improve psychological care.

What if I am not satisfied with the service that I receive?

If you have concerns about the service you receive from the psychologist, please discuss these first with the psychologist or another member of the kidney team. If this does not address your concerns, please contact the head of psychological health services, Sue Dolby. You can contact her by telephone on 0117 342 8168. Or you can call the patient support and complaints team, which can be reached on 0117 342 3604.

What happens to the information I share with the clinical psychologist?

The clinical psychologist works as a member of the multidisciplinary team and communicates regularly with them to provide the best care. If there is reason to think that there is a risk of harm to you or others, this information may need to be passed on to other people. The psychologist will talk to you about this first whenever possible. If there is something that you tell the psychologist that you do not want them to share with anyone other than their supervisor, please let them know. We will always try to make sure that that information is then kept private or confidential.

Please note that if for any reason you would value a second opinion concerning your diagnosis or treatment, you are entirely within your rights to request this.

The first step would usually be to discuss this with the doctor or other lead clinician who is responsible for your care.

Smoking is the primary cause of preventable illness and premature death. For support in stopping smoking contact **Smokefree Bristol** on **0117 922 2255**.

As well as providing clinical care, our Trust has an important role in research. This allows us to discover new and improved ways of treating patients.

While under our care, you may be invited to take part in research. To find out more please visit:
www.uhbristol.nhs.uk/research-innovation
or call the research and innovation team on
0117 342 0233.

For access to other patient leaflets and information please go to the following address:

www.uhbristol.nhs.uk/patients-and-visitors/information-for-patients/

Hospital Switchboard: 0117 923 0000



Minicom: 0117 934 9869



www.uhbristol.nhs.uk



For an Interpreter or Signer please contact the telephone number on your appointment letter.



For this leaflet in Large Print, Braille, Audio, or Email, please call the Patient Information Service:
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