University Hospitals Bristol NHS
NHS Foundation Trust

Patient Information Service
Psychological health services

Psychological support for families living with cystic fibrosis

Respecting everyone
Embracing change
Recognising success
Working together
Our hospitals.

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For Patients. For Health. For Bristol.

Why are there clinical psychologists in the cystic fibrosis team?

It is well recognised that living with cystic fibrosis (CF) can have an emotional and psychological impact, and it is important that patients and families have access to appropriate support in managing this. The clinical psychologist has an important role within the team to help manage distress, from diagnosis onwards.

What are common concerns for patients with CF and their families?

- Adjustment to living with CF
- Making difficult decisions and coming to terms with change
- Motivation to engage in activities
- Anxiety when preparing for medical procedures
- Relationship issues
- Mood difficulties.

What are common experiences for parents of young people with CF?

Each parent will react differently to their child's diagnosis and to living with CF. Parents often report feelings of sadness, loss, anger and worry, especially given uncertainties about the future. Parents might try to cope by avoiding thinking or talking about CF, or by making it a very important part of life, for themselves and their families. Different ways of coping within families can be helpful, or unhelpful, depending on the unique situations. Sometimes it can be helpful to talk to people who know about CF, who are not a part of the family.

How can the clinical psychologist help me?

If you decide that you would like to meet with a psychologist, please let any member of the CF team know. The psychologist will then make contact with you to plan an initial meeting. We can see parents, children, adults and other family members together or individually, depending on what you prefer. We are likely to meet with you in a room near outpatient clinics, in the psychological health services department, or in cubicles on the ward during a hospital admission.

The first meeting is an opportunity for you to discuss with us what might be helpful for you in managing any emotional or personal difficulties you may be experiencing as a result of CF. Sometimes more than one appointment is necessary for us to get a full picture of your situation and agree with you a way forward to help you to manage or resolve the problem. It might be that meeting with a psychologist provides a space for you to reflect on your feelings about difficult experiences, and accept that these feelings are understandable. It might also help in developing some practical strategies for making difficult feelings easier to cope with. We could also help you to consider ways of managing difficult decisions or changes to health management.

We might also support parents by liaising with medical professionals to ensure that parents and carers have all the information they need in a way that is understandable to them.

Sometimes, it may be enough to meet with one of us once or twice for you to feel you can take things forward with your usual level of support. We may be able to give you information, or point you in the direction of other resources, and you may not feel you need ongoing support from us. However, you may feel it would be beneficial to meet regularly, say once a week, with a clinical psychologist over a longer period of time. This will be negotiated with you when we meet and reviewed regularly as we go along.

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

The clinical psychologists also:

- provide consultation, education, and training on the psychological aspects of CF care to healthcare professionals

- engage in research and developing services in relation to psychological health and wellbeing for patients, families, and staff

- work in close collaboration with other psychologists working in CF in the geographical area, as well as nationally.

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 CF 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, 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:
0117 342 3728 / 3725

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