

Clinical psychology in UK cystic fibrosis services: Information for people with cystic fibrosis and their families/carers

In 2024, Cystic Fibrosis Trust **published clinical guidelines** on cystic fibrosis (CF) clinical psychology care. These are for CF clinical psychologists, to help make sure that everyone with CF in the UK can see a clinical psychologist and get a similar service.

This is a summary of those guidelines. It has been written by CF clinical psychologists and is for people with CF and their families, partners and carers. It answers common questions about CF clinical psychology services.

What is a clinical psychologist?

A clinical psychologist works with people of any age to provide psychological assessment and help with lots of issues. These could include emotional wellbeing, mental health issues, and managing long-term health conditions, such as CF. A psychologist is different from a psychiatrist. Clinical psychologists are not medically trained and usually do not prescribe medications. If mental health-related medication is needed, your GP, your CF team, or local mental health services can address this with you. Your CF centre may have a leaflet about the CF psychology service, which will list the issues a CF psychologist may be able to help you with.

A clinical psychologist will use non-medical ways to help people with emotional or physical health challenges. This is usually through 'talking therapy'.

With young children, psychologists will more often work through their parents or carers. They will help them to support their child with CF and to manage CF treatments and care. They will do this using talking therapies, behavioural and other approaches.

Clinical psychologists work with people to build on strengths they already have, to find new ways of coping and to understand any psychological or health management issues they may have. The support offered is tailored to the needs of the person with CF. Sometimes they will need just a few sessions, and at other times the psychologist may offer some weekly/fortnightly therapeutic sessions.

A clinical psychologist has a doctorate in clinical psychology (or a master's degree in clinical psychology if they qualified before 1994), and must be registered with **the Health and Care Professions Council (HCPC)**, and follow the standards set out by the HCPC.

Everyone with CF in the UK should have access to a CF clinical psychologist through their CF centre, (see the UK Standards of Care for CF services). If your centre does not have a psychologist, you could speak to a CF consultant at your centre to see if there is a plan to make this service available. If you have queries about access to psychology services within your CF team you could contact the Cystic Fibrosis Trust Helpline.

Why do we have CF clinical psychologists and what do they do?

Getting used to having CF, and living well with it, can have emotional as well as physical effects. Having a CF clinical psychologist in the CF team helps to make sure that we think about emotional health and wellbeing alongside physical health, from diagnosis and throughout life. CF can bring extra stresses to what can already be challenging modern lives and circumstances. Rates of some emotional health issues such as depression and anxiety are higher in people with CF compared to general rates.

Emotional health can affect physical health, and both may be affected by life events (such as trauma or discrimination), and by wider factors, such as financial struggles and other social inequalities. However, people with CF and their families can also show great strength and resilience. CF services have clinical psychologists in place to help all people with CF (and parents or carers of children with CF) develop the best coping skills.

The clinical psychologist is a key part of the CF team and will meet many patients and families within the CF service (sometimes all of them, in smaller services). Psychologists also carry out annual screening or assessment for any issues, usually as part of the CF annual review. This might be a face-to-face meeting. Or, in larger centres, you may fill in questionnaires, which will also invite you to ask to see the psychologist if you would like to. Psychologists prefer to prevent any difficulties with emotional health or issues in managing CF from getting worse. They want to help people develop ways of coping before problems become more serious or start to affect self-care and CF care.

The psychologist can also advise the CF team on many psychological issues, so even if they do not meet everyone who goes to a CF centre they can contribute to the psychological care given by the CF unit. They can also talk to others, for example other health services, education settings and employers, about your care as needed. The psychologist may be able to give you and/or your child better continuity of care than in some other psychological therapy services. This is because you usually get to know the psychologist or a small CF clinical psychology team over time in your CF centre.

In paediatric care, the CF clinical psychologist will often be in CF clinics with other members of the CF team. They can help parents, carers, other family members and children and adolescents with CF to manage CF and to look after themselves emotionally too. In adult CF centres, the psychologist is less likely to be in CF clinics routinely, especially in larger centres. They will usually offer separate psychology appointments on the CF ward, or in CF outpatients. Appointments may be face-to-face, or by video or telephone. The psychologist will try to fit these around your other CF appointments, family life, education, and work. Some psychology services may have waiting lists for non-urgent issues.

If you are referred to the CF clinical psychologist, they will arrange to meet you to talk about your needs. After this assessment you can then discuss what could be tried. Or if you or the psychologist feel your needs will be better met by another service, they can help you arrange this.

The CF clinical psychologist can work with parents of babies and children with CF, and people with CF at any age, on lots of issues including:

- getting used to the diagnosis of CF
- managing CF in childhood, including parenting a child with CF, and the effect of CF on family life
- managing CF treatment and CF care at any age – for example, difficulties taking CF treatments, fear of medical procedures, or dealing with hospital appointments and stays
- decision-making and 'living well' with CF alongside ordinary life, including school and work
- coping with CF at any age, from birth through to older adulthood
- supporting the move to adult CF care (transition)
- adjustment to changes in physical health, issues to do with new CF treatments (including modulator treatments), or difficulties in managing effects of CF upon life in general
- mental health and emotional wellbeing, including issues such as stress, anxiety, depression, other difficult emotions, trauma, self-esteem and confidence, body image or eating pattern concerns, managing change and issues in relationships
- managing more severe CF, and issues such as referral for lung transplantation or end-of-life care.

What about confidentiality if you see a CF clinical psychologist?

The CF clinical psychologist will want to make sure that you agree or 'consent' to their input, as with all other healthcare. They will also discuss confidentiality, including any questions or concerns you may have about this when they meet you. The psychologist is part of the CF team and will go to their meetings. They will only pass on information from you if you have agreed to this and if it helps other CF team members understand your view. Psychologists may make their own notes, or they may keep notes in your main CF record. They can talk to you about what information it would be helpful to share with the CF team, and talk about whether there is anything more personal that you would prefer not to be shared. Any records will be kept securely and in line with strict NHS guidance about access.

Like all health professionals, CF clinical psychologists occasionally need to share information without consent. This could be if they feel that someone is a very high risk to themselves or other people, or think that a child or vulnerable adult may be at risk.

How do I get to see the CF clinical psychologist?

The CF clinical psychologist at your CF centre may be introduced to you, for example in the CF clinic or ward, whether you are a parent or a person with CF. Or you may meet them at your CF annual review. You might be given a leaflet at your CF centre, explaining what the CF clinical psychologist does and how to ask to see them.

If not, ask any member of your CF team about how you can see the CF clinical psychologist. In some services you can self-refer to the psychologist, while in others you may need to ask for this through the CF team or CF consultant.

Other psychological services that might be helpful

If you would like help with psychological issues that are connected to CF, or if you have a problem that affects your CF, then the CF clinical psychologist may be the best person to help you. At other times, you may want help with issues that are less connected to CF. Or you may just prefer to have psychological support from outside the CF service

If you or your child wish to access local psychological or mental health services, your GP can tell you what is available. You can also find information from the NHS about locally based [NHS talking therapy services in England](#), and many useful self-help resources on [mental health/emotional wellbeing](#).

Other members of the CF team can also offer emotional support and advice (rather than psychological therapy), especially the CF social worker and CF specialist nurses. CF clinical psychologists will work closely with them, but they all have different roles as they have different training and skills. If you are not clear whose support you need, ask your CF team.

If you have any questions about the clinical psychology service in your centre, or any concerns about accessing a CF clinical psychologist, speak to your CF team.

Cystic Fibrosis Trust is the charity uniting people to stop cystic fibrosis. Our community will improve care, speak out, support each other and fund vital research as we race towards effective treatments for all.

We won't stop until everyone can live without the limits of cystic fibrosis.

Cystic Fibrosis Trust

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We welcome your feedback on our resources. You can also ask for this resource in large print or as a text file.

Email **infoteam@cysticfibrosis.org.uk**

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