

Patient information factsheet

Palliative care for people with cystic fibrosis (CF)

We've written this factsheet to explain how the palliative care team can help and support you. We hope it will answer some of the questions you may have.

What does the palliative care team do?

Over the last few years, our palliative care team has transformed the way we work with people with cystic fibrosis (CF) and the CF team, and what sort of service we offer.

The palliative care team provides specialist care for people who have complex symptoms caused by their CF. Our aim is to support you and your family, and improve your quality of life through an individualised approach.

The team is made up of specialist doctors and nurses who provide an advisory service and work alongside the CF team looking after you. The advice and support we offer will be complementary to the rest of your treatment. The palliative care aspects may be particularly important to you at times and less so at other times.

How can we help you?

We can:

- advise you about pain and other symptoms you may have, such as breathlessness, feeling sick and irregular sleeping patterns
- support you emotionally and psychologically
- provide support, advice and information for your family
- assist with decisions about your care and planning for the future
- help you to deal with the uncertainties that your illness brings, which may involve 'hoping for the best whilst planning for the worst'
- support you with making decisions around end of life care, if needed

What happens next?

After we have met you and discussed your needs, we will agree a plan with you and your CF team. This could involve just a one-off meeting or regular meetings with our team while you are in hospital. Your family can be involved in these meetings if you wish. If you have ongoing palliative care needs when you leave hospital, we can discuss with you how best to address these. We often review people with CF when they come back into hospital, but this would be your decision.

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Contact us

Palliative care team

Telephone: **023 8120 4126** (8.30am to 4.30pm, Monday to Sunday)

If you require the palliative care team outside the above hours, please leave a message on the answering machine.

CF team

Telephone: **023 8120 6801** (9am to 5pm, Monday to Friday)

For emergencies outside of these hours, please contact C5 ward on **023 8120 6777**.

Useful links

www.cysticfibrosis.org.uk/life-with-cystic-fibrosis/planning-for-end-of-life

If you need a translation of this document, an interpreter or a version in large print, Braille or on audio tape, please telephone **023 8120 4688** for help.