

Patient information factsheet

Advance care planning

We have written this factsheet to give you information about planning your future care. We hope it will answer some of the questions you may have, but if there is anything you don't understand, a member of your healthcare team will be happy to explain further.

What is advance care planning?

Advance care planning is an opportunity for you to collect your thoughts and wishes about your future care. It can include planning your care for the coming months and years, and for the end of your life. This process can help you to think about what is important to you and explore any concerns you may have regarding your future care. This may include telling others how you would like to be cared for if you become very unwell and are unable to tell them yourself.

As with any type of plan, your views and wishes may change or evolve over time. Advance care planning is a flexible process, so the details can be reviewed on a regular basis and any changes made when necessary.

Advance care planning is open to all, but it's up to you to decide who to talk to. This could include your family, friends, the cystic fibrosis (CF) team and the palliative care team. It is your individual plan, so you can choose when to talk and what aspects of care you wish to discuss.

Why might I want to do it?

Advance care planning allows you to 'hope for the best but plan for the worst'. Doing this may help you to cope with the uncertainty that can occur due to the unpredictability of your condition. You may use this opportunity to help you to open up conversations with friends and family. This can be done at your own pace. Often this process leads to a plan that can be kept with your medical records and will allow the whole medical team to be clear about your wishes.

Contact us

If you would like to know more about advance care planning, you can speak to:

- our cystic fibrosis team
- our hospital palliative care team
- the transplant team
- your GP

Useful links

- NHS website: www.nhs.uk/conditions/end-of-life-care
- National Council for Palliative Care (NCPC) website: www.ncpc.org.uk/publication/planning-your-future-care
- Cystic Fibrosis Trust website: www.cysticfibrosis.org.uk/advancecare
- Cystic Fibrosis Trust helpline: 0300 373 1000

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.