

Cystic **Fibrosis** helping you plan

**Advance care planning for
people with cystic fibrosis**

– guideline for healthcare professionals

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Introduction

How?

This advance care plan is for people with cystic fibrosis (CF) to complete and discuss with their CF team. Each individual may want to go about this in a different way; some people will want to read and complete it alone and then show their team, others will want to go through the whole process with a member of the CF team, some may want to do it with family and then show it to the team.

The CF team member leading the advance care planning with the patient needs to explain this is a flexible process and that it is also an entirely optional.

Who?

For the advance care plan to be completed it must be reviewed and signed by a member of the CF team. The team member can be of any profession but should have a good, already established therapeutic relationship with the patient. Ideally they will also have completed specific training on how to complete advance care planning.

When?

Establishing when a patient may be ready to talk about advance care planning is discussed by the CF team. Open-ended questions should be asked around what the patient understands about their disease and then offering advance care planning as a way of 'hoping for the best, but planning for the worst'. Advance care planning is completely optional. It should be explained and offered to patients but never pushed or forced upon individuals.

Triggers to start advance care planning include discussions with the consultants around prognosis, transplant or transplant referral. Patients may also be keen to start advance care planning earlier, especially those with children, those who are planning a family or those with unpredictable disease (history of haemoptysis or pneumothorax).



Preparing to complete the form

- A trained member of the CF team should initially discuss advance care planning with the patient. If the patient seems happy to continue with process then the healthcare professional should offer to show them the advance care planning document.
- Talk through the rough outline of what is covered in the document before leaving it with a patient.
- The patient may want to be left to read the form alone, or want to go through it with you but they should not be left for more than 24 hours without being reviewed by the same member of the team. This is to answer any questions and ask how they found reading/starting to complete the form. They should then be offered the opportunity to complete the form with the member of the CF team with them, or to plan a later date.
- Remember it is completely optional and individuals can complete part of the form, all of the form or decide they are not ready and need more time.
- If they request more time make sure you ask if they want you to re-visit it with them in a certain amount of time, or if they would rather be the one to ask for more support when they are ready. This will need documenting.
- Once the patient has agreed to complete the advance care plan you will need to arrange a time that suits them. You will need at least one hour and should ensure you have a quiet room where you will not be disturbed. Ask the patient if they would like a family member or friend present or would prefer to talk about it on their own.

Step-by-step guide to completing the advance care plan

This section will take you through each question and how to support the patient through them. Some patients will want to write on the form, others will want you to fill it in and some will have completed the form in advance. Ask the patient how they would like to work with you to go through the questions. It is completely normal for people to get upset when talking about dying and end of life; allow the patient time to talk and empathise. If they become upset, ask if they want to continue or would like a break or to come back to a certain question later.

Your details

1. Fill in the patient details, the date you are completing the form and your name (as a member of the CF team completing the form).

Important people

1. **Fill in the patient's next of kin.** Please ensure this is the same as the next of kin on your hospital system and if not confirm the details and update the hospital records if required.
2. **If you were unable to communicate your wishes who would you like your care and treatment to be discussed with first?** Patients will often want to know why they would not be able to communicate and what happens at end of life. Explain that the most common cause of death in CF is respiratory failure. As lungs fail there is a build-up of the waste gas, carbon dioxide, in your body and this can make you very sleepy. Also explain some of the medications used at end of life to control symptoms can make you drowsy.
3. **My care or treatment should not be discussed with the following people.** Any family or friends they would not want their care discussed with, list names and if they are family state the relationship to the patient.
4. **Do you have any specific wishes for plans regarding loved ones, including children, partners, family members or friends (for example: preparing memory boxes, writing letters)?** Start by asking how much they have talked to their loved ones about end of life. Explain some people write letters, leave cards or memory boxes for loved ones but it is a very personal choice. Document if they have started/done this, however they may say they will think about it/will do it soon, so document 'will consider this' or 'started memory box for sister' as appropriate. Ask if they would like any help and if so identify who within the team would be most appropriate.
5. **If you have children, are there any specific wishes that you have with regards to them (for example: visiting you in hospital, how you would like them to be told about what is happening, who would care for them in the future)?** If the patient does not have children move on to the next question. If they do have children ask how much they talk to their children about CF, what do their children understand? Do they want support with talking to the children and preparing them for the future?

My care

1. Are you currently having any counselling or psychology support? Are they receiving or would they like support. This could be specific to end of life or for any other issues. Document in comments if they are receiving psychological support, with whom and whether it is specific to end of life.

2. Lung transplant. As a member of the CF team you will know before your discussion about advance care planning what their transplant status is. If they are well and this has not been considered yet they may have lots of questions about lung transplant, contraindications, referral timing etc, which you will need to answer. If they are currently being referred for lung transplant or on the active list this may open up questions around survival and chances of receiving organs.

3. Resuscitation. You will already know if the patient has a DNACPR signed before speaking to them about advance care planning so this will guide you as to how to approach the conversation. Patients will know if a DNACPR has been signed for them but may want to discuss it again. You may need to explain that CPR for end stage lung disease would be futile but that all other treatment would be continued. Patients on the transplant list will often be for resuscitation and ECMO as a bridge to transplant and this may have been discussed by the CF consultants, but the patients may have further questions.

4. Religious or spiritual beliefs. Ask the patient if they have any specific religious or spiritual beliefs and then complete the other questions. They may not have specific beliefs but want prayers to be read for them or vice versa so explore their wishes around this topic.

5. It can be hard to predict end of life in cystic fibrosis and often people need hospital care. Depending on your situation it is worth considering where you would most like to be cared for when you are dying, if possible. This question will also be led by transplant status, if patients are on the active transplant list it is very likely they would be considered for ECMO as a bridge to transplant and therefore may die in hospital. Explain this but take the opportunity to explore their thoughts around place of death. If your patient is not for transplant there are more options around place of death but you still need to explain it can be complex in CF due to the high burden of treatments. However, with correct planning and linking with a community team death at home or in a hospice (you may need to explain what a hospice is) is possible and can be explored.

6. What are your thoughts around end of life and do you have any concerns regarding symptoms? Try and establish if patients have any specific concerns/anxieties around symptoms. These are often linked to previous experiences, for example haemoptysis or things they may have heard from other patients. They may want you to explain how patients with CF usually die and medications for symptom control, which you will have learnt about in your training.

7. Is there anything else the cystic fibrosis team need to know about how you would like to be cared for at the end of life, if you couldn't communicate with us? Give the patient an opportunity to raise any other thoughts or concerns with you. Allow them time to consider and think.



8. Do you have any specific goals or things you would like to do/achieve before you die? This could be a bucket list, birthday, wedding or for more well patients life goals for the next few years. Again, as the person completing this form has a good relationship with the patient it makes it easier to guide this conversation as you will be aware of their home and family situation. Patients may ask about various charities that sponsor wishes.

9. Funeral arrangements. Patients will often have thought a lot about their funeral but not documented it, so this is a chance to empower them to document their wishes. Others may not have strong options, but again you can encourage them to document this, as otherwise funeral plans fall to loved ones who may not be aware of the person's wishes. Advise the patient about the Cystic Fibrosis Trust emergency grants for funerals, which are up to £750 and can be easily applied for via the website.

Financial and legal matters

1. Putting your affairs in order. Prompt the patient to think about other important documentation loved ones may need to know about (ie: mortgage, bank statement, loans). Passwords should not be documented on the form but encourage the patient to share them with loved ones if they want to. Financial concerns cause a lot of worries at end of life so give the patient an opportunity to highlight any concerns and offer support.

2. Appointing attorneys under a Lasting Power of Attorney. A lasting power of attorney (LPA) is a legal document that lets you (the ‘donor’) appoint one or more people (known as ‘attorneys’) to help you make decisions or to make decisions on your behalf. This gives you more control over what happens to you if, for example, you can’t make decisions at the time they need to be made (you ‘lack mental capacity’). There are two types of LPA: health and welfare, and property and financial affairs. Health and welfare LPA is designed to document decisions about things like: your daily routine, eg washing, dressing, eating, medical care and life-sustaining treatment. It can only be used when you’re unable to make your own decisions. The financial and property affairs LPA is to document decisions about money and property for example, managing a bank or building society account, paying bills and collecting benefits or a pension. This can be used as soon as it’s registered with your permission. You will have learnt more about LPA in your training to help you support patients and answer their questions.

3. Will. Discuss if the patient has a Will and where it is kept. If they do not have a Will, explore their thoughts about this and encourage them to complete one. The Cystic Fibrosis Trust offers free support with writing a Will and can be contacted on behalf of the patient (with the patient’s consent) via email or patients can do this independently.

Organ donation

1. Organ donation. Patients are often surprised to hear they can donate some of their organs, so educate them around this and record their preferences. If they do wish to donate, encourage them to register formally for organ donation and discuss it with their loved ones.

2. Donating your body for medical research. If patients wish to donate their whole body for medical research it is essential they make their wishes known in writing before they die and that this is witnessed. Also encourage them to inform their next of kin and the executor of their Will if this is not the same person. Remember to tell patients that this will mean there will not be a body for burial.

3. Is there anything else that you would like to add to this plan? Often at this point it is worth revisiting any questions the patient may have struggled with or wanted a little more time to think about. There may be other things they want on their plan, so add these to this section.

4. Do you need any further support or information in relation to any issues covered in this document? This could be financial advice, psychological support, further discussions with the medical team, spiritual support or further discussions around advance care planning.

Signing the form

1. Get the patient to sign the form and fill in their details.
2. Ask if they are happy for their information to be shared with the GP and community teams (and transplant centre if appropriate). Explain why shared information is useful and will result in a more co-ordinated approach to their care.
3. You then need to sign off the form; you are agreeing that everything documented is appropriate and realistic for their care.

Documentation and sharing of information

- If you have electronic records, upload the advance care plan under an advance care plan tab or code to allow for easy identification.
- If you do not have electronic records, place a paper copy at the front on the patient’s medical notes.
- Patients should be offered their own copy of the advance care plan to keep if they wish. It may be useful to encourage patients to keep a copy on their person in case they are admitted to local hospitals/A&E departments.
- A copy of the advance care plan should be attached to the discharge summary and sent to the GP.
- If the patient is referred to community palliative care services they should also receive a copy of the advance care plan.
- If the patient is being referred for transplant or under the care of a transplant centre please ensure they receive a copy of the advance care plan.
- For patients in the pan-London area a Co-ordinate My Care (CMC) record can be set up. This is an online urgent care plan that GPs, London ambulance service and acute hospitals all have access to. The key elements of the advance care plan can be uploaded to their CMC record with contact details for the CF team.

Cystic Fibrosis Trust

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