# Advance care planning for people with cystic fibrosis

We want to provide the best possible care for people with cystic fibrosis (CF) their family and friends. One aspect of this care is to work with you to determine what your wishes would be in the event of a significant decline in your health, to ensure we know what is important to you if your illness became life-threatening.

As the course of cystic fibrosis can be unpredictable it may be difficult to know when people are reaching the end of their life. Advance care planning allows us to ‘hope for the best, but plan for the worst’. It is a process of discussion between you and your CF team and, if you want to, family members and/or friends. These discussions allow you to express your concerns, requests or wishes about your future care. By recording your wishes in this document it means that both your family and the CF team will know what you would prefer when you become more unwell and reach the end of your life. It is not always possible to follow all your wishes at the time but by recording them it means your CF team can do their best to follow these wherever possible.

## How to start planning

Advance care planning is **completely optional** and very flexible. You may feel that you are ready to start thinking about your options for treatment or identifying certain requests or options that you might prefer. However, if you are not ready please don’t worry, it is a personal choice, take your time and let your cystic fibrosis team know when you would like to talk about it. Your annual review is often a good time to talk to your cystic fibrosis team about your future and advance care planning, but you can ask your team at any time.

Most people choose to talk to a relative, friend or healthcare professional about their wishes and it can be helpful to write this down as a plan. You may want to go through this form all at once or complete it in stages. You may also prefer to do this with someone or on your own; there isn’t a right or wrong way. This **plan is not set in stone**; you are encouraged to update or change it whenever you want to. Your CF team will also prompt you to review it after six months.

A member of the CF team will come and talk to you about advance care planning within 24 hours of leaving the form with you; however you can take as much time as you need.

## Your details

|  |  |
| --- | --- |
| Your name: |  |
| Your date of birth: |  |
| Your address: |  |
| Your telephone number: |  |
| Your hospital number: |  |
| Date of first written plan: |  |
| Did you complete this form with anyone, if so who? |  |

## Important people

|  |  |
| --- | --- |
| Next of kin’s name: |  |
| Next of kin’s contact details: |  |
| Relationship to you: |  |

|  |
| --- |
| **If you were unable to communicate your wishes, who would you like your care and treatment to be discussed with first:** |
| Name and contact details: |
| **My care or treatment should not be discussed with the following people:** | |
| Name(s): | |

|  |
| --- |
| **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)?** |
| **Would you like any support with this?** |
| Yes  No |

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| --- |
| **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 will care for them in the future)?** |
|  |
| **Would you like any support with talking to and preparing your children?** |
| Yes  No |

## My Care

|  |
| --- |
| **Are you currently having any counselling or psychology support?** |
| Yes  No |
| If not, would you like this? Yes  No |
| Comments: |

|  |  |
| --- | --- |
| **Lung transplant (please tick)** | |
| I am on the active transplant waiting list |  |
| I am on the ‘watch and wait’ list |  |
| I am going through the referral process |  |
| I cannot have a lung transplant for medical reasons |  |
| I do not want a lung transplant |  |
| Lung transplant has not yet been mentioned by my CF team |  |

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| --- | --- |
| **Resuscitation**  Do not attempt cardio-pulmonary resuscitation (DNACPR) means that if your health severely deteriorates you will still be given all the standard treatments (antibiotics, physiotherapy, oxygen, non-invasive ventilation), but if you did not respond and were dying of lung failure we would not attempt CPR or pass the electrical current over your heart as it would not help with your lung failure. Your medical team will discuss whether a DNACPR form should be completed with you. This will not be done without discussion with you and your family. | |
| I have an active ‘Do not resuscitate’ form: | Yes  No  If yes, date DNACPR was signed: |
| Further comments (ie ceiling of treatments) |  |

|  |  |
| --- | --- |
| **Religious or spiritual beliefs** | |
| Faith/spiritual beliefs: |  |
| Name of religious leader: |  |
| Contact details: |  |

|  |  |
| --- | --- |
| I would like them to be contacted if I am in hospital | Yes  No |
| I would like them to be present when I am dying | Yes  No |
| Any other wishes relating to this: |  |

|  |  |  |
| --- | --- | --- |
| **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.** | | |
|  | **1st choice** | **2nd choice** |
| CF centre |  |  |
| Home |  |  |
| Hospice |  |  |
| Any other wishes relating to this: |  | |

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| --- |
| **What are your thoughts around end of life and do you have any concerns regarding symptoms?** |
|  |

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| --- |
| **Is there anything else the CF 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?** |
|  |

|  |
| --- |
| **Do you have any specific goals or things you would like to do/achieve before you die?** |
|  |

|  |  |
| --- | --- |
| **Funeral arrangements** | |
| Have you thought about what you want at your funeral? | Yes  No |
| Have you written these plans down? | Yes  No |
| Where have you left the details? |  |
| Who with? |  |
| Have you made a decision about whether you would wish to be buried or cremated? (tick as appropriate) | Buried  Cremated  Don’t mind |
| Do you have any specific wishes for your funeral (for example music, reading, donations to charity, flowers)? |  |
| **The Cystic Fibrosis Trust offers funeral grants to help support the cost of a funeral. Search for ‘Cystic Fibrosis Trust Emergency Grants’ online.** | |

## Financial and legal matters

|  |  |
| --- | --- |
| **Putting your affairs in order** | |
| Do you have any other important documents? If so where are they kept? |  |
| Have you documented passwords/codes to your computer/tablet/phone/Facebook?  Does your next of kin know how to access your devices? |  |
| Do you have any specific financial concerns currently? | Yes  No |
| Is yes, would you like any further support with this? | Yes  No |

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| --- | --- |
| **Appointing attorneys under a Lasting Power of Attorney** (you do not have to do this, it is a legal document that lets you appoint a person to make decisions if you are not able to do so yourself). To do this you need to fill in the forms from www/gov.uk/power-of-attorney and then register it with the office of public guardian (it can take 10 weeks). | |
| **Lasting or enduring power of attorney for property and affairs**  Name and contact details: |  |
| **Lasting power of attorney for health and personal welfare**  Name and contact details: |  |

|  |  |
| --- | --- |
| **Do you have a Will? Further advice at** [www.gov.uk/make-will/overview](http://www.gov.uk/make-will/overview) | Yes  No |
| If yes, where is your will held? |  |
| For information about how to get started writing a Will contact the Cystic Fibrosis Trust helpline on [**helpline@cysticfibrosis.org.uk**](mailto:helpline@cysticfibrosis.org.uk?subject=Holiday%20Grant%20query). | |

## Organ donation

Depending on your medical history you may be able to donate some of your organs for transplantation. For more information, go to [www.organdonation.nhs.uk](http://www.organdonation.nhs.uk) or ring 0800 4320559.

|  |  |
| --- | --- |
| **I have registered for organ and /or tissue donation after my death:** | Yes  No |
| **If possible, I want to donate the following for transplantation after my death (tick your wishes):** | |
| Any of my organs or tissues |  |
| Skin |  |
| Eyes (Corneas) |  |
| Heart valves |  |
| Bone/cartilage |  |

Donating your body for medical science is a separate procedure and requires these forms to be completed before death.

Further information about body donation: <http://www.hta.gov.uk/bodyorganandtissuedination/howtodonateyourbody.cfm>

Make sure you keep a copy of the paper work and tell you relatives and healthcare professionals of your wishes.

**I would like to donate my body to medical research after my death?**

Yes  No

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| --- |
| **Is there anything else that you would like to add to this plan?** |
|  |
| **Do you need any further support or information in relation to any issues covered in this document?** |
|  |

**This document has been completed by:**

|  |  |
| --- | --- |
| Your name: |  |
| Your signature: |  |
| Date: |  |
| Suggested review date in six months: |  |
| Review date 1:  Suggested date for review 2: |  |
| Review date 2:  Suggested date for review 3: |  |
| Review date 3:  Suggested date for review 4: |  |

**Do you give permission for this form to be uploaded to our electronic records so the CF team and your GP/community teams could see it if they needed to?**

Yes  No

**This form has been discussed and reviewed with a member of the CF team.**

|  |  |
| --- | --- |
| CF team members name: |  |
| CF team members signature: |  |
| CF team members job role: |  |
| Date: |  |

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