

Cystic Fibrosis helping you plan

End-of-life planning:
things to think about



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Introduction

It's a good idea for everyone, regardless of age or the state of their health, to think about planning for their final days and the people they leave behind. Writing a will is a great start, particularly if you have children, but there may be other things that are important to you that you can discuss in advance of your death; for example your thoughts on end-of-life care, making memories for your family or funeral arrangements.

The information in this leaflet is intended to help you with some of these practical decisions and arrangements. For emotional and psychological support please speak to your CF team or contact our helpline on **0300 373 1000** (Monday–Friday, 9am–5pm).



Talking about dying

“Death is a destination we all share, no one has ever escaped it.” (Steve Jobs, founder of Apple)

Of course we all know we will die. Yet, despite its inevitability, death is understandably often a very hard thing for people to talk about. There can be lots of reasons for this; maybe it's too upsetting, too frightening or it's just not the right time. For people with cystic fibrosis (CF), it's likely that there's always been a heightened awareness of death, but that doesn't necessarily mean it's any easier to talk about.

Beliefs and feelings about death are deeply personal and everyone will have their own way of thinking or talking about it. Some people won't want to talk about death at all, others might but only with their medical team, and some people may feel comfortable with conversations about death but hold back for fear of upsetting others. It's not possible to give information or guidance to suit your individual beliefs or feelings. However, it's worth bearing a few things in mind.

- Talking about dying with those closest to you is likely to be very hard. But these conversations might strengthen your relationships and enable you to better support each other.
- Starting these conversations might flag up fears or concerns, which could be allayed.
- Some people say that getting the conversation out of the way helps them focus on living.
- Talking about and planning for end-of-life can help some people feel more in control of their care.
- Having a conversation about dying early on can be easier than when someone is very poorly.



Talking about care at the end of life

Cystic fibrosis is an unpredictable condition and knowing when someone is at the end of their life isn't always straightforward. Sometimes people appear to be very unwell and clinical teams may feel they are approaching death, only for the person to make a good recovery. Unfortunately, this unpredictability can work the other way around, too. Your CF team would be happy to spend time talking with you about your feelings about end-of-life care; they can help you think this through and plan, especially if the topic is hard to discuss with loved ones. Having these conversations when you are well gives you an opportunity to talk about your wishes and fears and to ask questions at a time when you aren't stressed with poor health.

Symptom management and palliative care

Palliative care is about holistic support (care of the whole person) and managing difficult symptoms; being referred to a palliative care team does not mean your death is imminent and palliative care is not the same as end of life care. These teams have very specific expertise in dealing with symptom management (pain, insomnia or anxiety for example) as well as psychological and social support. They can work alongside CF teams to ensure that you are as comfortable as possible at a time of declining health. Family and partners can also benefit from the holistic support that palliative care teams can offer.

Palliative care can be provided in different settings including at home, in hospital or in a hospice. Hospices provide support and care to people at all stages of terminal illness and patients can visit for the day or longer period to benefit from their services, which can include symptom management, practical and financial advice, complementary therapies and psychological support.

The unpredictability of CF means that the condition is managed differently to other conditions at the end of life. Often active treatment is stopped for patients with terminal conditions (for example cancers) because the treatment has no benefit to their health or quality of life. Instead, palliative care and symptom management become the focus. However, for a person with CF who is thought to be approaching the end of their life, active treatment will usually continue alongside palliative care.

This is for a number of reasons:

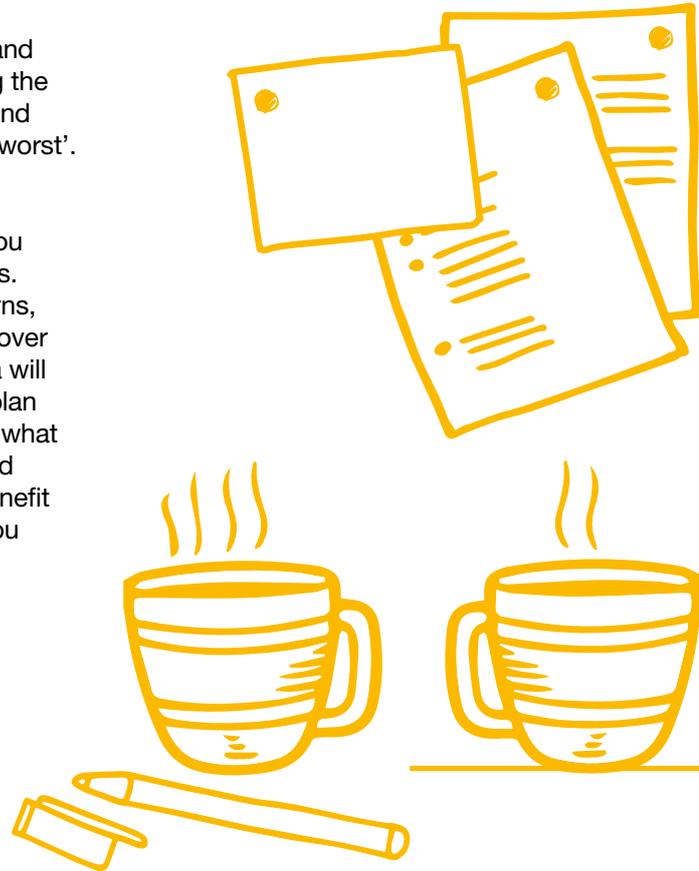
- Active treatment can also ease difficult symptoms, which is unlikely to be the case for other terminal conditions.
- Active treatment is needed if a patient is still being considered for lung transplant.

Advance care planning

As we've said, cystic fibrosis can be unpredictable and it may be difficult to know when people are reaching the end of their life. Advance care planning allows you and your CF team to 'hope for the best, but plan for the worst'.

Developing an advance care plan is a process of discussion between you and your CF team and, if you want to include them, family members and/or friends. These discussions allow you to express your concerns, requests or wishes about your future care and will cover a range of topics including end-of-life care, writing a will and organ donation. Recording your wishes in this plan means that both your family and CF team will know what you would prefer when you become more unwell and reach the end of your life. Family and friends can benefit from this too as it helps them to understand what you want when you are nearing the end of life.

A template advance care plan is available at cysticfibrosis.org.uk/advancecare



Making a will

Going through the process of making a will is often the trigger for conversations around death and dying; writing a will prompts you to think about important issues that may not otherwise come up in day-to-day life. Preparing a will is usually a fairly straightforward process and is so important in making sure that your wishes are noted, particularly regarding guardianship of any children, funeral arrangements and who should benefit from your estate (your money and any property you own). Having a will in place can help to ensure that your family/friends are not left unsure or in dispute after your death.

If you don't make a will, the law will dictate what happens to your estate – who gets what and how much – and this may not be what you would have wanted or expected. This can be particularly important when couples are not married or not in a civil partnership. In such cases and with no will, your partner would not automatically be entitled to any of your estate, even if you have children.

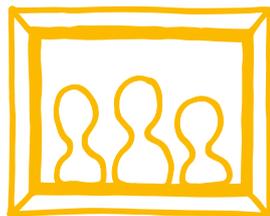
It's important that you let those close to you know where they can find a copy of your will when the time comes. Your will is an important document and as such you might consider storing it in a fireproof and waterproof safe at home, with your solicitor or accountant or register it with the probate office.

It's very important that a will is prepared in a way that ensures it's legally valid and properly reflects your wishes. Although there is no need for a will to be drawn up or witnessed by a solicitor, it is generally advisable to use a solicitor either to fully prepare or check your will to make sure it will have the effect you want. This is because it is easy to make mistakes and, if there are errors in the will, this can cause problems after your death. Sorting out misunderstandings and disputes after your death may result in considerable legal costs, which will reduce the amount of money in the estate.



If you wish to make a will yourself, you can of course do so. However, you should only consider this option if the will is straightforward and will be executed in the correct way for the will to be valid.

The Money Advice Service (a government initiative), offers a useful overview about your will writing options. Have a look here: www.moneyadviceservice.org.uk/en/articles/writing-a-will-your-options



The following links may also be useful in planning your will.

The Law Society (England and Wales) has a useful overview of wills at www.useaprofessional.co.uk/wills

For specific information for wills in Scotland, please look at the **Law Society of Scotland**: www.lawscot.org.uk and click on the 'for the public' tab then 'what solicitors can do for you'. For Northern Ireland look at www.nidirect.gov.uk/articles/making-will

Citizens Advice have a useful page on death and wills at www.citizensadvice.org.uk/family/death-and-wills/

Willaid is a charity venture offering wills drawn up by participating solicitors in exchange for a donation to various charities. The offer is available in November. Find out more at www.willaid.org.uk

Thinking about organ donation

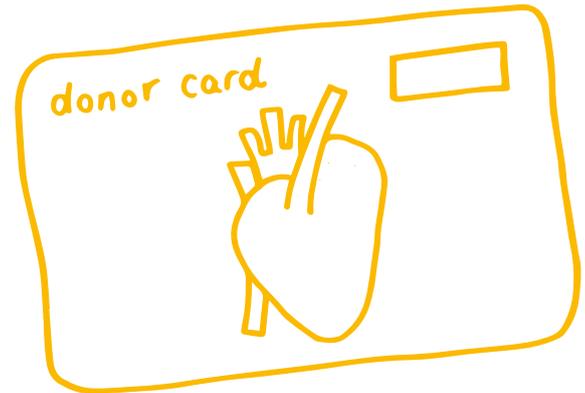
It is possible for people with CF to donate organs after death. Organ donation is obviously a very important topic for people with CF, but usually relating to being the recipient of a donated organ. While a person with CF couldn't donate their lungs, other organs can be donated.

If you do wish to donate your organs, it's really important that you let your family know. When families are aware of their loved ones wishing to be a donor, they are twice as likely to say 'yes' to donation. If they aren't aware of your wishes, it can be surprising and potentially upsetting for them to deal with this whilst coping with their loss.

You can find out more at the website for your respective country:

- **England:** www.organdonation.nhs.uk
- **Northern Ireland:** www.organdonationni.info
- **Scotland:** www.organdonationscotland.org
- **Wales:** www.organdonationwales.org

Some people may want to donate their entire body for medical science and information about this can be found here: www.hta.gov.uk/faqs/body-donation-faqs. If this is something you want to do, you will need to put your wishes in writing – it is not a decision your family can make for you after your death.



Planning your funeral

Some people have no preferences about their funeral but others may have strong feelings for religious or personal reasons, and these need to be talked about or written down. If it's important to you then let someone know, and if you decide to make a written plan, make sure someone knows where to find it.

Decisions about your funeral will include whether you wish to be cremated or buried, for example. If cremated, do you want your ashes to be scattered somewhere special? Would you prefer a religious ceremony at your funeral, or something different? What about personal touches: do you want certain music played, or a particular reading at the ceremony? Are there special people that you would like to be involved in your funeral?

Dying Matters produces a 'My Funeral Wishes' document that you might find helpful. You can see it, and other information about funeral planning, here: www.dyingmatters.org/page/my-funeral-wishes.

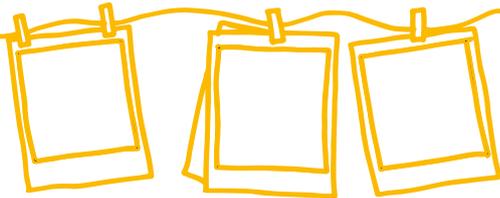
The Cystic Fibrosis Trust provides a funeral grant of up to £750 when someone with CF dies. The application process is very straightforward – just one simple form – and our helpline team will be on hand to help fill this in. You might want to let your family know in advance that this grant will be available for them, and all they will need to do is contact our helpline on 0300 373 1000 (Monday–Friday, 9am–5pm) or helpline@cysticfibrosis.org.uk. The grant can be paid to the person organising your funeral, or directly to the funeral directors.

If you want to, you could keep a copy of the form ready to be filled in, perhaps stored with your will or funeral plans. You can download the form from our website or contact the helpline team and they will post a copy out to you.



Making memories

Some people choose to create a physical record of moments and memories to leave behind for family and friends, particularly for children. Memory boxes, for example, can contain photographs, cards, personal items and notes that have a special meaning or hold special memories. Some people choose to do video recordings for their family to watch after their death, or perhaps specific notes or videos for specific occasions (for example a child's special birthday or a wedding).



Your digital life after death

Nowadays many of us have an online presence and it may be useful to think about how you want that handled after death. Would you want it to be closed down? Or would you be happy for friends to remain in touch via your social pages? If this is important to you, make sure you tell someone.

Most social media platforms provide information on what happens to accounts after death, which can usually be found on their help pages.

You may want to think about retrieving your digital information (for example photographs and videos) from your devices (laptop, tablet and phone). Information left on your device after death would not be accessible to anyone because devices are usually password protected.

Support

The Cystic Fibrosis Trust helpline can offer a listening ear if you want someone to talk to. Please phone **0300 373 1000** (Monday–Friday, 9am–5pm) or email helpline@cysticfibrosis.org.uk.

Additionally, the following web pages might be helpful.

- **Dying Matters: planning ahead**
www.dyingmatters.org/page/planning-ahead
- **Dying Matters: information and support**
www.dyingmatters.org/overview/need-support

Cystic Fibrosis Trust

cysticfibrosis.org.uk

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