

Cystic Fibrosis Trust

Your guide to leaving
a gift in your Will





"My Will is made out to the Cystic Fibrosis Trust, as CF denied me an older brother and caused years of upset to my mother. I like to think it will help with research to find the cure and save others from enduring that pain. Cystic fibrosis will always be in my DNA." – Mark, a legacy pledger

Now more than ever, we need your support

Cystic fibrosis (CF) is a devastating condition that affects over 10,600 people in the UK. While babies born with the condition today are expected to live much longer thanks to the advances in treatments, care and understanding, the average age at death is currently still only 31 years.* This is still far too young and there is so much work to be done before everyone with CF can live a life unlimited by the condition.

The Cystic Fibrosis Trust is dedicated to creating a world where being born with CF no longer means a lifelong burden of care and an early death. We work towards a brighter future for everyone affected by the condition by investing in world-leading research, campaigning for equal access to life-changing treatments, promoting the highest standards of clinical care, and providing vital day-to-day support for those who need us most. Legacies play a critical role in supporting this work.

With a record number of people living with CF in the UK, a gift in your Will could help bring hope to thousands of people with CF and their families. Anything you can leave will make a huge difference to our work. A gift of just 1% of your estate will help us to continue to be there for generations to come.



*Figures according to the 2019 UK CF Registry Annual Data Report

When we formed in 1964, the outlook for children with CF was very bleak, with 90% dying before the age of 10. There was little information for parents and very few doctors working in the field. However, thanks to the support of our amazing community, today there are more adults living with CF than children, and every day we are moving closer to a world where everyone with CF can look forward to a longer and healthier life.

1964 – A decade of firsts, from the Trust itself to the first adult UK CF clinic



1985 – Professor Bob Williamson and his team discover a marker very close to the CF gene



2007 – Following campaigning by the Trust, all babies born in the UK are now tested for CF at birth using the heel-prick test



1983 – The Trust begins funding the first specialist doctors and CF nurses in the UK



1992 – The first UK patient database is set up at the University of Dundee, paid for by the Trust



However, Kaftrio is simply a new chapter to our work. There's still more we need to know about the impacts and effects of these new medicines. Above all, they're not the right treatment for everyone. There are also so many other research areas that are crying out for breakthroughs. Together, we need to accelerate research to find life-changing treatments for every single person with cystic fibrosis.

2013 – Public funding is secured for Kalydeco, the first precision medicine for people with cystic fibrosis



2019 – After a hard-fought four-year battle, led by the CF community and the Trust, Orkambi and Symkevi are finally made available on the NHS



2016 – The world's first CF Registry-based clinical trials launches



2020 – Deals are struck across the UK for the latest CFTR modulator Kaftrio, the first triple-combination drug to treat the root cause of cystic fibrosis





"Mary dedicated her life to helping improve the lives of those affected by CF, through the work she carried out during her clinical and research career as a doctor. Leaving a gift in her Will was Mary's way of continuing to support the Trust's research after her death."

– David, whose Godmother left a gift in her Will

Your questions answered

Making a Will can help ensure your wishes will be respected and those you love are looked after when you die, but it doesn't need to be time consuming. Here are some commonly asked questions you might find useful:

Do I need a solicitor to write or amend my Will?

We would always recommend you consult a solicitor when writing your Will, as their expertise will give you the peace of mind that your wishes are respected and the Will is legally correct. For help on finding a local solicitor, you can contact the Law Society in England and Wales (020 7242 1222), Scotland (013 1226 7411) or Northern Ireland (028 9023 1614).

I want to take care of my loved ones; can I still leave a gift to the Cystic Fibrosis Trust?

Yes you can. Most people want to look after their friends and family first. Whatever you decide to leave us will make a huge difference; just 1% of your estate can help us shape a better future for so many people affected by this life-limiting condition.



What type of gift can I leave?

There are two main ways of leaving a gift in your Will. A **pecuniary** legacy (also known as a cash gift) is a fixed amount of money, while a **residuary** legacy (also known as a share in your estate) is a percentage or share of the balance of your estate, once all other payments and gifts have been made. Many supporters choose to leave a residual gift as it keeps in line with inflation and doesn't lose value over time.

Can the Trust help me write my Will?

If you're over the age of 18, you can use our free Will-writing service, where you can write a new Will or update an existing one for free. There is no obligation to leave a gift to the Trust but we hope that, after thinking of loved ones, you may wish to consider us as well. Any gift, large or small, will help us to continue our vital work for generations to come. Contact us on giftsinwills@cysticfibrosis.org.uk or call **020 3795 2132** for more details.

Are there any tax benefits if I leave a charitable gift in my Will?

Most charitable gifts are exempt from Inheritance Tax, and they can even reduce the amount of tax your estate has to pay. To find out more, visit HMRC.gov.uk/inheritance-tax or ask your solicitor.



If your question hasn't been answered, please contact our Gifts in Wills team at giftsinwills@cysticfibrosis.org.uk or call **020 3795 2132**.

Wording for your Will

If you would like to leave a gift in your Will to the Cystic Fibrosis Trust, here is some suggested wording that you may want to use to ensure your wishes are carried out:

To leave a share of your estate

“I give to Cystic Fibrosis Trust of One Aldgate, London, EC3N 1RE, registered charity numbers 1079049 and SC040196, [all/_% of the residue] of my estate absolutely for its general purposes and I declare that the receipt of the Legacy Administration Officer or other proper officer at Cystic Fibrosis Trust for the time being shall be a sufficient discharge to my executor(s).”

To leave a cash gift

“I give to Cystic Fibrosis Trust of One Aldgate, London, EC3N 1RE, registered charity numbers 1079049 and SC040196, the sum of [specify words and figures] free of tax for its general purposes and I declare that the receipt of the Legacy Administration Officer or other proper officer at Cystic Fibrosis Trust for the time being shall be a sufficient discharge to my executor(s).”



Our promise to you

- **We will be transparent about our work.** We value every gift we receive and spend donations so they have the most impact for people affected by cystic fibrosis.
- **We will be respectful.** We know that this is a big decision so please decide in your own time. We respect that loved ones come first and we won't try to change this.
- **We will listen and respond.** We will answer any questions as honestly and quickly as we can and will communicate with you in a way that suits you.
- **We are committed to high standards.** We comply with the law, including those that apply to data protection and health, and ensure all those working with us comply with legal requirements and best practice.
- **We are fair and responsible.** We take care not to cause unreasonable nuisance or disruption and to not use any images or words that cause unjustifiable distress or offence.



Thank you

If you would like any more information or have any further questions, please do get in touch. We aren't solicitors ourselves but we can answer any general questions you may have about leaving a gift in your Will to the Cystic Fibrosis Trust, and we are always happy to help.

If you have already chosen to leave a gift in your Will, we'd love to hear from you. We will never ask about the details of the gift, as this is private to you, but it helps us to plan for our future and it is wonderful to know people have supported us in this way.

Call us on **020 3795 2132** or email **giftsinwills@cysticfibrosis.org.uk**



Cystic Fibrosis Trust

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