

Empowering people with Cystic Fibrosis in Scotland



Butterfly
Trust

Cystic Fibrosis
support for Scotland

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Butterfly Trust

Cystic Fibrosis is a genetically inherited, life limiting condition with one in twenty five people carrying the faulty gene that causes the condition. People with Cystic Fibrosis experience repeated chest infections that cause chronic lung disease and malabsorption problems caused by an inefficient digestive system.

There is no cure for Cystic Fibrosis. Young people with the condition must endure an intensive daily treatment regime that is designed to slow the inevitable progression of the condition. This treatment is delivered at home by trained family carers. Providing this specialised care is physically and emotionally demanding as well as expensive and the impact is felt by the whole family.

The Butterfly Trust was founded in 2002 to provide support to the Cystic Fibrosis community of Scotland. Our aim is that people living with Cystic Fibrosis will have access to the support they need to ensure they can benefit from optimum home care and enjoy the best possible quality of life in the community. This means providing practical help and advocacy to promote their rights by giving them a voice in areas that include housing, finance, education, employment and independent living. We also offer emotional support and counselling to help relieve stress and grants to alleviate financial hardship.

All of our services are confidential and are provided free of charge to anyone affected by Cystic Fibrosis throughout Scotland. We are here to help so do not hesitate to contact us if there is support you need.

“Thank you for helping me through the stages of my successful claim for Employment and Support Allowance. Thanks too for my laptop, which allows me to keep in touch with my friends while I am in hospital.”

Adult with Cystic Fibrosis who is on the transplant list waiting for a lung transplant

Support Services

The majority of our services are offered by our volunteer outreach team who are trained to provide a professional service and have regular updates to ensure our clients receive the best possible outcome from any support we offer. More complex issues are dealt with by our team of professional staff based in our Edinburgh office.



Emotional support and counselling

- After diagnosis
- Dealing with difficult change
- Other times of stress

Benefits/DLA

- Help to complete application forms and navigate official systems
- Practical support through the application process
- Advocacy/representation at Disability Tribunals

Housing

- Support to make strong housing applications
- Representation at council and housing agency meetings
- Advocacy to negotiate property suitable for your requirements

Employment

- Advocacy and advice on employment issues
- Information and guidance for employers/potential employers
- Representation at employment related meetings



Access to financial support

- Grants to purchase essential household items
- Financial help with the cost of respite breaks and holidays
- Help to fund other expensive items that help improve quality of life

Befriending and mentoring

- An opportunity to share interests and social activities
- Regular contact with someone who can offer support and you can share your concerns with
- A person to help you develop life skills and build your self confidence

Massage therapy

- A therapeutic massage session can leave you feeling fresh, energised and relaxed as well as enhancing your sense of wellbeing
- Provided by professionally trained massage therapists who donate their time on a voluntary basis
- Free of charge and can be booked by simply asking a member of your CF team, ward staff or contacting us directly on 0131 445 5590

Transport

- Transport to and from hospital and clinic appointments

How you can help

To enable us to continue providing these services we need your help. There are lots of different ways in which you can do this including volunteering and raising funds.

Volunteering opportunities

Volunteering is a fantastic way to make a difference to the life of someone else. It can also be an incredible opportunity to enhance your own life and build new skills to help your personal and career development.

The Butterfly Trust has lots of volunteering roles available and we are more than happy to discuss these with you to find the ideal role to suit both your own needs and those of the organisation.

To find out more about how you can volunteer with the Butterfly Trust then visit our website www.butterflytrust.org.uk or email volunteer@butterflytrust.org.uk and request a volunteering application pack.

Fundraising

Join in one of our fundraising events that we organise throughout the year.

Organise one of your own events with our support and guidance if needed.

Nominate us to be charity of the year/charity for an event at your place of work, social club or anywhere you see that someone is looking to raise money for charity and needs an organisation to choose.

All you need to do is get in touch and request a fundraising pack from us, register your event and we will do everything we can to help you. Our very approachable fundraising team are available to answer your questions, provide information and advice, organise a visit and to talk through any ideas or concerns you may have.

“If it hadn’t been for the dedication of your organisation there is no way we could have provided this support to the family.”

Cystic Fibrosis Consultant

“I got the keys today for a brand new shiny 3 bedroom house! Thank you for all your help. You guys are amazing.”

Parent of child with Cystic Fibrosis

Standing order form



Your Personal Details

First Name: _____ Surname: _____
Address: _____
Postcode: _____ Tel Number: _____

Your Bank Details

Account No: _____ Sort Code: _____
Bank: _____ Branch: _____

Instructions for your Bank

Please pay to **The Butterfly Trust** the sum of: £ _____
Amount in words: _____ (pounds)

Every month with effect from ____ / ____ / ____ until further notice

Account Type: **Trustees Account**
Bankers Sort Code: **80-02-78**

Bankers: **Bank of Scotland**
Account No: **00584054**

Declaration

I pay UK income tax and would like THE BUTTERFLY TRUST to reclaim the tax on my gifts

Signature: _____ Date: _____

Please take this form to your bank and return a copy to:

Fundraising Team, The Butterfly Trust, Swanston Steading, 109/3 Swanston Road, Edinburgh EH10 7DS



Contact details

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www.justgiving.com/butterflytrust
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