

# Cystic Fibrosis *our focus*

**Financial help**

Factsheet – April 2013

Fighting for a  
Life Unlimited

# Financial help

## Introduction

This factsheet provides information about the financial help available from the Cystic Fibrosis Trust, and from other organisations, for people with cystic fibrosis and their families. For additional information contact the Cystic Fibrosis Trust helpline on 0300 373 1000 or visit our website [cysticfibrosis.org.uk](http://cysticfibrosis.org.uk).

Written by the Cystic Fibrosis Trust Support Service.

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## **Cystic Fibrosis Trust welfare grants**

### **General welfare fund**

This fund exists to help families of children with cystic fibrosis, and adults with cystic fibrosis, who are experiencing particular difficulty at a time of stress or crisis related to cystic fibrosis.

Many areas of need will be considered, however, because the financial help requested each year exceeds the resources available, the Fund limits itself to areas of urgent need where it can have an immediate effect.

For example:

- Help towards the cost of a household item directly relating to CF, particularly when setting up home for the first time.
- Help towards a first annual prescription charges prepayment certificate (PPC).
- A holiday / break following a particular event or an unusually stressful period, especially if the person concerned has not had a holiday for some time.
- Help with hospital costs, particularly in relation to transplant.
- Help with funeral costs.

The Fund is unable to consider grants to help meet debts / bills or for ongoing costs (for example the cost of driving lessons). It is also unable to help with house adaptations or renovations or the purchase of a car or computer.

Help may also be available from other charitable sources, for example your local Round Table / Rotary / Lions / Variety Clubs. The social worker or welfare rights adviser at your hospital or Citizens Advice Bureau should be able to provide you with more information and help you apply for grants / funding.

### **Edward W Joseph Home Care Fund**

This Fund is to facilitate increased care in the home, rather than hospital, for people with cystic fibrosis. It is recognised that people generally feel more comfortable and enjoy a greater sense of wellbeing when they are treated at home. The aim therefore is to enable people with CF to be cared for in their own home (if they wish) when there is a likelihood of them either being admitted to hospital unless additional temporary support can be provided for them in the home, or they could be discharged from hospital earlier.

The support must be provided by a suitably qualified person in agreement with their local specialist CF centre or CF clinic and is not intended to replace any help provided by statutory agencies such as health or social services.

## Further education grants

### The Joseph Levy Memorial Fund

This Fund was established following a bequest by the late Joseph Levy, a co-founder of the Cystic Fibrosis Trust. The aim is to assist young adults with cystic fibrosis to develop their careers by way of further or university education or in pursuing other professional qualifications.

Grants will be considered to cover the cost of tuition, living expenses, examination fees or other similar costs which are required to assist the applicant to progress their career.

Individuals who feel that they may fit the above criteria, and are aged 18 years or over, should write in confidence to:

**Mrs Elizabeth Neville**  
**1st floor, Pegasus House**  
**37/43 Sackville Street**  
**London W1X 2DL**

**T: 020 7333 8118**  
**E: [elizabeth.neville@shaftesbury.co.uk](mailto:elizabeth.neville@shaftesbury.co.uk)**

The deadline for applications is 31 March each year and awards are decided in mid-June.

### Family Action

Family Action (formerly the Family Welfare Association) offers educational grants and advice.

**T: 020 7254 6251**  
**[www.family-action.org.uk](http://www.family-action.org.uk)**

See also the CF Trust Higher Education factsheet.

## Holiday grants

### Cystic Fibrosis Holiday Fund

This charity was founded by the Levy family who were co-founders of the Cystic Fibrosis Trust. It provides grants for people with cystic fibrosis up to the age of 25, and their families, to have a break or holiday. Family holidays are encouraged although a range of different activities are considered.

Application forms can be obtained from:

**CF Holiday Fund**  
**1 Bell Street**  
**London NW1 5BY**

**T: 020 7616 1300**  
**[www.cf-holidayfund.org.uk](http://www.cf-holidayfund.org.uk)**

Applications are considered quarterly in February, April, July, and November.

## **Other organisations providing holiday grants**

The Cystic Fibrosis Trust can help towards the cost of a break or holiday for young adults with cystic fibrosis. Contact the helpline on 0300 373 1000.

The following organisations can also help towards the cost of a family holiday:

**The Family Fund: 01904 621115 [www.familyfundtrust.org.uk](http://www.familyfundtrust.org.uk) (see below)**

**Family Holiday Association: 020 7436 3304 [www.fhaonline.org.uk](http://www.fhaonline.org.uk)**

**Pearson's Holiday Fund: 020 8657 3053 [www.pearsonsholidayfund.org](http://www.pearsonsholidayfund.org)**

## **Organisations providing general financial support**

### **The Family Fund**

The Family Fund is an independent organisation registered as a charity but funded by the Government. It helps families who are caring at home for a severely disabled or ill child under 16 years of age. There is no means test but social and economic circumstances will be taken into account and the Family Fund will not replace help available from your Health or Local Authority.

It can help with driving lessons, hospital visiting costs, domestic appliances, furniture and furnishings, moving home and decorating costs, and holidays and computers.

Application forms are available from:

**Family Fund  
4 Alpha Court  
Monks Cross Drive  
York YO32 9WN**

**T: 01904 621115  
[www.familyfundtrust.org.uk](http://www.familyfundtrust.org.uk)**

### **Family Action**

Family Action (formerly the Family Welfare Association) is another organisation that can be helpful in finding funds, although it is unable to help with anything already provided by the statutory authorities. It provides a wide variety of grants for families on low incomes and / or benefits, and can help with clothing, fuel bills, beds / bedding and household needs such as cookers and other appliances.

Family Action also offers an Educational Grants Advisory Service that offers guidance and advice on funding for education and training but will not consider private fees.

Applications must be made through a social worker.  
For further information contact:

**Family Action  
501-505 Kingsland Road  
London E8 4AU**

**T: 020 7254 6251  
[www.family-action.org.uk](http://www.family-action.org.uk)**

## React

React (Rapid Effective Assistance for Children with potentially Terminal Illness) is a charity that aims to help families of children with a life-limiting illness in a practical way by providing essential needs. These include help towards travelling expenses, home nursing, clothing and bedding, domestic appliances and funeral expenses. React is unique in its speedy response, sometimes within hours.

For an application form, contact React using one of the methods below:

**St Luke's House**  
**270 Sandycombe Road**  
**Kew, Richmond,**  
**Surrey TW9 3NP**

**T 020 8940 2575**  
**[www.reactcharity.org](http://www.reactcharity.org)**

## Housing adaptations and improvements

The following help may be available from your Local Housing Authority. All grants are means-tested.

- Renovation grants – for the improvement or repair of a dwelling, or for the provision of dwellings by the conversion of a house or other building.
- Disabled facilities grant – for the provision of facilities for a disabled person in a dwelling, or in the common parts of a building containing one or more flats.
- Minor works grant – for improvements or repairs to the home. These are discretionary with a maximum payment payable per application.
- Warm Front Grant – these are grants given by the Government in partnership with Eaga to low-income households for energy-efficient measures in the home, such as draught proofing and insulation, or for heating systems. You must be in receipt of certain benefits to qualify for a grant – to find out more call 0800 072 9007 or visit [www.eaga.co.uk](http://www.eaga.co.uk).

The Cystic Fibrosis Trust also produces a housing factsheet which can be obtained by contacting us or downloaded from the website [cysticfibrosis.org.uk](http://cysticfibrosis.org.uk).

## Mobility

### Road tax exemption

If you receive the enhanced rate mobility component of Personal Independence Payment (PIP), you, or someone you choose to nominate in your place, may apply for exemption from paying road tax. Those in receipt of the standard rate mobility component of the Personal Independence Payment will qualify for a 50% reduction in the cost of their road tax.

### Motability

This is a voluntary organisation set up on the initiative of the Government and intended to help people on the enhanced rate mobility component of Personal Independence Payment (PIP) to buy or lease a car. For full details write to **Motability, Goodman House, Station Approach, Harlow, Essex CM20 2ET.**

**T: 01279 635666**  
**[www.motability.co.uk](http://www.motability.co.uk)**

## Young Drivers Scholarship

If you are aged 16–24 and on the enhanced rate mobility component of Personal Independence Payment (PIP), you can apply for help with the cost of driving lessons. Contact the **Charitable Grants Department at the Motability address above or call 01279 635999**.

The Family Fund can also sometimes help towards the cost of driving lessons. Contact the Fund on **01904 621115 or visit [www.familyfundtrust.org.uk](http://www.familyfundtrust.org.uk)** (see page 5).

## Blue Badge Scheme

This scheme is designed to help people with severe mobility problems by allowing them to park close to shops and public buildings.

In England, if you have been awarded eight points or more in the ‘moving around’ activity of Personal Independence Payment (PIP) you can get a Blue Badge.

In Scotland and Wales you can get the badge if you have been awarded eight points or more in the ‘moving around’ activity or 12 points in the ‘planning and following journeys’ activity. As at 1 April 2013, eligibility for the scheme in Northern Ireland has not yet been decided.

Blue Badges can also be applied for through your local authority, if you fall outside of this criterion. Visit **[www.direct.gov.uk](http://www.direct.gov.uk) for details or call the Blue Badge Helpline on 020 7944 2914**.

## NHS benefits

NHS benefits include free prescriptions, dental treatment, eye tests and vouchers to help with the cost of glasses and travel to hospital. You may qualify for some or all of these if you are receiving Income Support, income-based Jobseeker’s Allowance or other means-tested benefits. There is also an NHS Low Income Scheme (LIS) – to find out more about this either contact the Health Benefits Division on **0191 203 5555 or pick up leaflet HC11 ‘Help with Health Costs’ from a Jobcentre Plus, Post Office, NHS hospital, dentist or optician, or visit <http://www.nhsbsa.nhs.uk/1125.aspx>**.

## Prescription charges

You may also be eligible for free prescriptions if you have another specified medical condition apart from cystic fibrosis which is included in the Department of Health’s exemption list, for example, diabetes or a permanent fistula. If you are not eligible for free prescriptions you can purchase a pre-payment certificate (PPC) for either three months or a year.

You can either pick up an application form from your pharmacist or doctor or call the **NHS Business Services Authority on 0845 850 0030**. You can also apply online at **<http://www.nhsbsa.nhs.uk/1127.aspx>**.

The Cystic Fibrosis Trust may be able to help you with the cost of purchasing your first annual PPC. Contact the **helpline on 0300 373 1000**.

## Hospital travel costs

Patients, and people accompanying or visiting them, may be entitled to help with fares or other travel expenses to a hospital where they receive treatment, if they are receiving either Income Support or income-based Jobseeker’s Allowance. You may be able to obtain a refund from the

hospital if you produce proof of these benefits or you can apply for a grant from the Social Fund. (see page 8)

If you are not in receipt of these benefits but on a low income you may still be able to get help. Contact your local Benefit Office for a form. Some hospitals have their own endowment funds.

The following organisations may also be able to help:

The Family Fund (see page 5)

React (see page 6)

## **Transplants**

The Cystic Fibrosis Trust can help with costs incurred during transplant assessment and transplant. Contact our helpline on **0300 373 1000**.

The Transplant Patients' Trust of Great Britain may also be able to help. Write to:

**Transplant Patients' Trust**  
**PO Box 44**  
**Hexham NE47 0YX**

**T: 01420 82817**

**[www.orpheusweb.co.uk/body/rmrt/tptgb.html](http://www.orpheusweb.co.uk/body/rmrt/tptgb.html)**

Applications should be made through a social worker at the transplant unit you attend.

## **The Social Fund**

When you are living on a tight budget you may sometimes need extra help which you may be able to get from the Social Fund for important costs. Listed below are some of the payments, grants and loans available from this Fund, which is administered by the Department for Work and Pensions.

Information, advice and claim forms can be obtained from your social worker or welfare rights officer at the hospital / clinic you attend or from your local Citizens Advice Bureau or Benefits Office.

## **Sure Start Maternity Grant**

You may be entitled to help with costs of items for a new baby if you are in receipt of either Income Support, income-based Jobseeker's Allowance, Working Families' Tax Credit or Disabled Persons Tax Credit.

## Funeral expenses

You may be eligible for a payment from the Social Fund to cover the cost of essential funeral expenses if you are in receipt of Income Support, income-based Jobseeker's Allowance, Housing or Council Tax Benefit, Working Families' Tax Credit or Disabled Persons Tax Credit. The claim should be made between the date of death and no later than three months after the date of the funeral.

Additional help may be available from other charities such as React. Call **020 8940 2575** or visit **[www.reactcharity.org](http://www.reactcharity.org)**.

The Cystic Fibrosis Trust also offers grants to help with funeral expenses. Application forms are obtainable from our helpline on **0300 373 1000** or **from our website [cysticfibrosis.org.uk](http://cysticfibrosis.org.uk)**.

## Community Care Grants

These are payments to help people in receipt of Income Support or Income-based Jobseekers Allowance with home items, clothing and travel costs. The Grants are paid to help people avoid going into institutional care or to move out of institutions into the community. They are also to help families under pressure to either stay in their own home or move because of a disaster or serious situation.

## Loans

### Budgeting Loans

These are interest-free and available only to people who have been receiving Income Support or income-based Jobseeker's Allowance for 26 weeks. They help spread the cost of buying items needed other than regular expenses.

### Crisis Loans

Crisis Loans can be given to help meet short-term needs in an emergency or after a disaster. You do not have to be in receipt of any statutory benefits to qualify but you must have no savings and no access to any funds to meet your needs. The loan must be the only means to prevent serious risk to the health or safety of any member of your family. The rate and period of repayment are based on your income and circumstances.

Visit **[www.jobcentreplus.gov.uk](http://www.jobcentreplus.gov.uk)** or contact your local Jobcentre Plus for more information on grants available from the Social Fund.

## Further information

The Cystic Fibrosis Trust provides information about cystic fibrosis through our factsheets, leaflets and other publications.

Most of our publications are available through our helpline and can be downloaded from our website or ordered using our online publications order form. Visit [cysticfibrosis.org.uk/publications](http://cysticfibrosis.org.uk/publications).

The Cystic Fibrosis Trust helpline can help you with a range of issues, no matter how big or small. Our trained staff can provide a listening ear, practical advice, welfare/benefits information or direct you to other sources of support. The helpline can be contacted on 0300 373 1000 or [helpline@cysticfibrosis.org.uk](mailto:helpline@cysticfibrosis.org.uk) and is open Monday to Friday, 9am – 5pm.

Calls to 0300 numbers cost no more than 5p per minute from a standard BT residential landline. Charges from other landlines and mobile networks may vary, but will be no more than a standard geographic call and are included in all inclusive minutes and discount schemes. If you are worried about the cost of the call please let us know and we'll call you back.

You can also find more information at our website [cysticfibrosis.org.uk](http://cysticfibrosis.org.uk).

**Cystic Fibrosis Trust**  
**2nd Floor One Aldgate**  
**London**  
**EC3N 1RE**  
**020 3795 1555**

[cysticfibrosis.org.uk](http://cysticfibrosis.org.uk)



More factsheets available at:  
[cysticfibrosis.org.uk/publications](http://cysticfibrosis.org.uk/publications)

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The information included in this publication is not intended to replace any advice you may receive from your doctor or CF multidisciplinary team and it is important that you seek medical advice whenever considering a change of treatment.

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