



Fundraising for your equipment or care needs: a guide

When you live with a progressive muscle-wasting condition, you may need many different pieces of equipment or increased access to care throughout your life. This factsheet aims to outline ways you can get support, and give you some guidance on how to go about raising funds for things you need but cannot get through statutory services.

Statutory funding that may already be available

Before deciding to raise funds, find out what the statutory services have a duty to provide, and in what circumstances they can provide funds. You should only fundraise for things that statutory services don't provide. The list below should help clarify the situation for you:

▶ **wheelchairs and mobility equipment**

Your local wheelchair services, which is part of the NHS, should provide wheelchairs. Your GP can give you a referral to wheelchair services, acting on recommendations from your neuromuscular consultant. The NHS should also provide walking aids, after assessment by a physiotherapist or occupational therapist (OT). If you want an assessment, ask your GP for a referral.

▶ **adapted vehicles**

If you're on the enhanced rate of the mobility component of Personal Independence Payments (PIP), or the higher rate of the mobility component of Disability Living Allowance (DLA), you can get a specially adapted vehicle via the Motability scheme. This is a non-statutory provision, which involves exchanging your PIP or DLA mobility payments for a lease on car, scooter or powered wheelchair. See our [Motability](#) factsheet for more information about the scheme.

▶ **equipment to assist independence at home**

This can be provided free of charge by Social Services, following an assessment by an OT.

▶ **medical equipment**

This is provided free of charge by the NHS.

▶ **medical treatment**

This is provided free of charge by the NHS. Always speak to your consultant first before investigating treatment options abroad or alternative therapies).

▶ **home adaptations**

These can be funded through a Disabled Facilities Grant (DFG), which is free (up to a certain amount) for children under 18, but means-tested for adults. Your local Social Services or OT can help you access this grant. See our [Grants for housing adaptations factsheet](#) for more information.



▶ **computers**

The education authority can fund computers for use in school and the employment authorities for use at work. Speak to the Disability Employment Adviser at the Job Centre Plus for further information.

▶ **education**

The state has a duty to provide appropriate education for all children. If necessary, they can fund education in a private or charitably run establishment.

▶ **care packages**

Get in touch with your local Social Services. 'Social care' (such as washing, dressing and meal preparation) may be means-tested, while 'medical care' (which needs to be given by a nurse or doctor) is not. See our [Care package](#) factsheet for more information.

▶ **respite care**

Funding for respite care may be available via the NHS or Social Services.

Things to remember when raising funds

When fundraising for yourself or someone else:

- ▶ never raise funds without the knowledge and agreement of the person needing the equipment or care
- ▶ never raise funds for equipment that the individual has not had a professional assessment for
- ▶ know how much you need to raise and only start fundraising if you are confident it is achievable
- ▶ be clear with donor charities or individuals that the fundraising is for an individual and not for a registered charity
- ▶ keep clear accounts, including all paperwork and receipts
- ▶ return any funds that cannot be used for the agreed purpose

Criteria for funding applications

Every organisation will have their own criteria. You can usually find this information on their website or by phoning the office.

Here is a guideline of things organisations generally look at when deciding whether or not to award a grant:

- ▶ diagnosis
- ▶ what the request is for
- ▶ where the person lives
- ▶ the age of the person
- ▶ the financial status of the person or family applying
- ▶ the applicant's employment background (including periods of military service)
- ▶ support of a relevant professional
- ▶ the amount of funding required



Charities that may be able to help

The following charities offer support on a national level. For information about any local charities that could provide financial assistance, we recommend speaking your GP, neuromuscular care advisor or local Citizens Advice Bureau.

► For both children and adults:

Joseph Patrick Trust

Helps towards the cost of equipment for people of all ages who are living with muscle-wasting conditions. The Trust requires a completed application form and professional assessment report.

Tel: **020 7803 4811**

Email: JPTGrants@musculardystrophyuk.org

Web: www.musculardystrophyuk.org/jpt-grants

Family Action

Gives grants for equipment to people of all ages, throughout the UK, who are on low incomes.

Tel: **020 7254 6251**

Web: www.family-action.org.uk

Independence at Home

Provides small grants to people with long-term illnesses or disabilities, and who are in financial need.

Tel: **020 8427 7929**

Email: iah@independenceathome.org.uk

Web: www.independenceathome.org.uk

The ACT Foundation

Helps fund equipment and adaptations for disabled people of all ages.

Tel: **01753 753900**

Email: info@theactfoundation.co.uk

Web: www.theactfoundation.co.uk

Aidis Trust

Advises on the use of, and helps fund, assistive technology (including communication aids and computers). For disabled people of all ages.

Tel: **0808 800 0009**

Web: www.aidis.org

Turn2us

Gives financial help, information and support to disabled people of all ages.

Tel: **0808 802 2000**

Email: admin@turn2us.org.uk

Web: www.turn2us.org.uk



Disability Aid Trust

Helps with the cost of helpers to enable those aged 17 and above to travel on a holiday.

Tel: **0800 028 0647**

Email: secretary@disabilityaidtrust.org.uk

Web: www.disabilityaidtrust.org.uk

The Ogilvie Charities

Provides grants towards equipment or household items for those in need and unable to provide funding themselves. The charity also gives grants for respite holidays for carers.

Tel: **01394 388746**

Email: ogilviecharities@btconnect.com

Web: www.ogilviecharities.org.uk

The Respite Association

Provides funding for short-term respite care for carers of people who have disabilities or are terminally ill.

Tel: **01775 820176**

Email: help@respiteassociation.org

Web: www.respiteassociation.org

► For children only:

The Family Fund

Assists families of disabled children under 16. Help is means-tested and goes towards the cost of days out, holidays and equipment.

Tel: **01904 550055**

Email: info@familyfund.org.uk

Web: www.familyfund.org.uk

React

Assists families of children living with life-limiting conditions with the cost of equipment, travel expenses and respite breaks.

Tel: **020 8940 2575**

Web: www.reactcharity.org

Newlife

Helps families of children under 18 who are seriously ill or disabled. The charity will consider applications for equipment grants, and also has a provision for loans of emergency equipment, including hoists, wheelchairs and specialist beds. They also provide loans, free of charge, of specialist toys.

Tel: **01543 462777**

Web: www.newlifecharity.co.uk

Email: info@newlifecharity.co.uk

Caudwell Children

Funds equipment for seriously ill or disabled children.

Tel: **0345 300 1348**

Email: charity@caudwellchildren.com



Sullivan's Heroes

Offers fundraising support and financial assistance for families funding vital home adaptations for a disabled child.

Web: www.sullivansheroes.org

Whizz-Kidz

Helps fund mobility aids, including wheelchairs, for children under 18.

Tel: **020 7233 6600**

Web: www.whizz-kidz.org.uk

Email: info@whizz-kidz.org.uk

Useful websites

Disability Grants: lists charities and trusts that provide funding towards disability equipment, holidays, housing and days out.

www.disability-grants.org

Scope: you can search for grants locally and nationally.

www.scope.org.uk/support/disabled-people/search-grants

Turn2us: you can search for organisations that give grants and other types of help.

www.turn2us.org.uk/Find-Benefits-Grants

Disclaimer

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Here for you

The friendly staff in the care and support team at the Muscular Dystrophy UK's London office are available on **0800 652 6352** or **info@muscular dystrophyuk.org** from 8.30am to 6pm Monday to Friday to offer free information and emotional support.

If they can't help you, they are more than happy to signpost you to specialist services close to you, or to other people who can help.

www.muscular dystrophyuk.org