



Supporting people affected by Muscular Dystrophy in the West Midlands

GUIDELINES & CONDITIONS FOR GRANT APPLICANTS

About the Charity

Murray's Muscles (Hereafter known as "the Charity") is a grant giving charity providing funding for people with muscular dystrophy or a related neuromuscular condition in the West Midlands towards the cost of essential equipment such as wheelchairs, computers, and electric beds. Murray's Muscles officially became a charity in its own right in 2010. The Charity is headed up by the Field family and was originally started as a support group following their son's diagnosis of Duchenne muscular dystrophy in 2005.

Murray's Muscles Grant Criteria

1. Applications will only be accepted from, or on behalf of people with muscular dystrophy and related neuromuscular conditions. If you are unsure please call us to check. Alternatively you can download or view a list on the Muscular Dystrophy Campaign's website:
www.muscular-dystrophy.org/about_muscular_dystrophy
2. Applicants must have their diagnosis confirmed by a consultant.
3. The Charity does not fund grants outside the United Kingdom.
4. Grants are provided towards the cost of specialist equipment related to a need caused by the disability. The equipment must have a positive impact on the quality of life. In most instances the Charity does not provide the full cost of the equipment and the applicant will be required to raise the additional funding from other sources. (In some circumstances applicants can be referred to other trusts that may be able to provide additional funding.)
5. The Charity will not fund equipment provided by statutory services. However the Trust recognises regional differences in the access to certain NHS/Social Services equipment and differences in the quality and functionality of that equipment.
6. Under exceptional circumstances limited funding may be provided to families for 'Relief of Stress'.
7. Because of limited resources only one item of equipment will be considered at any one time. The Charity will also normally not consider funding the same item of equipment for the same individual within a 3-year period.
8. Funding is based on the needs of the individual and on family circumstances. It is recognised that the costs incurred on a family for adaptations, other equipment, transport and care over and above statutory provision are very high.
9. Funding will be provided only where the individual / family understand their personal liability, repair and maintenance responsibilities. Funding is provided on the basis that the equipment is the property and full responsibility of the individual / family. The Trust does not take responsibility for the repair, up-keep, liability (insurance) and disposal of such equipment. Adherence to this understanding will be required before funding is granted.
10. Grants will be held open for an 18-month period, after which they will lapse and a new application must be made to the Charity unless an extension is requested in writing. If the grant is no longer needed you are required to notify The Charity so that the funding can be distributed to others.

Murray's Muscles will not provide grants for certain categories of equipment, please refer to the document "What we will and will not fund"

Funding will be paid upon the receipt of an invoice or proof of purchase to the equipment supplier when all of the funding for the equipment is available and or to a social worker, other charity or organisation.

HOLDING FUNDS

Murray's Muscles can also help individuals / families by holding funds 'in trust' for the individual. For example, another charity may wish to make a contribution towards the cost of the equipment. The Charity can hold this funding, paying the full amount to the supplier once the balance is raised.

Opening the 'account'	In order to open 'an account' please complete the Murray's Muscles application form and send this back with a covering letter instructing us to open an account to 'hold funds' on behalf of the applicant, an account will be opened in the applicant's name.
Paying in cheques	All cheques to be paid into the account should be made payable to Murray's Muscles. Please ensure all cheques are accompanied by a letter with the applicant's name, this ensures the funds are registered against the correct applicant. When funds are to be paid in by other means please inform us beforehand with the names of the people raising the funds.
Claiming funds	All funds will be released upon the receipt of an invoice, cheques will be made payable to the supplier of the equipment for which the funds have been raised.
Interest	No interest is paid on any funds held.

HOW TO APPLY - FILLING IN THE APPLICATION FORM

If you need guidance to fill in this form or you want any more information please telephone the Murray's Muscles team on 01905 779907.

SECTION A - DETAILS OF THE PERSON REQUIRING ASSISTANCE

If you are filling out the form on behalf of someone with muscular dystrophy or a related condition, please fill it out in their name and with the details of the person affected. Please be as specific as possible about your neuromuscular condition.

SECTION B - WHAT DO YOU REQUIRE THE GRANT FOR?

1. Type of Equipment

It is expected that applicants will try to get the equipment they require from Statutory Services and come to the Trust only when this support is not available or when the equipment provided is not adequate or appropriate.

The Charity provides part funding for specific items (Please see the relevant list above). The Trust will however consider applications for other equipment, which meet the criteria detailed in the Guidelines for Grant Applications.

2. Equipment Details

Please give accurate details of the equipment you require. Also provide model details and other specifications. The application will not be processed without a quotation for the equipment, please make sure the quotation is enclosed.

3. Equipment Assessment

Every application must be supported by an assessment carried out by a professional. This assessment should confirm that the piece of equipment is the most suitable for your needs. It should also detail (if appropriate) why this equipment is unavailable from the NHS or Social Services.

The letter must be on headed paper and needs to detail the following:

1. Needs of the individual
2. Needs for this specific model / equipment specification
3. Health and safety - the ability of the person to use the equipment safely (e.g. if a wheelchair, road safety awareness, visual perception)
4. Reason the equipment cannot be provided by a statutory authority
5. Contribution (if any) being made towards the cost by a statutory authority (e.g. voucher)
6. Qualification / Occupation / Employer of professional with contact details (in case we need to get in touch)

The assessment could be carried out by a range of professionals if appropriately qualified, for example – a physiotherapist, occupational therapist, specialist dealer, Muscular Dystrophy Campaign Regional care advisor, social worker or nurse. You are responsible for ensuring that an adequate assessment has been carried out and issues such as health and safety have been thoroughly considered.

If your assessment has been carried out by a specialist dealer, you will also need to provide a letter of support from another professional confirming the applicant's name, address and the type of muscular dystrophy. This letter can be written by a physiotherapist, occupational therapist, Muscular Dystrophy Campaign Regional Care Advisor, GP,

social worker, nurse, teacher/school support worker or other professional who knows the applicant. Please fill in details of the assessor, their name, occupation, qualification and employer (if appropriate).

PLEASE NOTE THAT APPLICATIONS WILL NOT BE PROCESSED WITHOUT THE ASSESSMENT LETTER AND QUOTATION. FORMS RECEIVED WITHOUT THESE DOCUMENTS WILL BE RETURNED.

4. Seeking other Funding

In most instances the Charity does not provide the full cost of the equipment and the applicant will be required to raise the additional funding from other sources. We need to know that you are making efforts to identify the remainder. If fundraising is already underway, please let us know your fundraising activities. If you require help please see below.

You can download a publication from the Muscular Dystrophy Campaign's website called "Raising Funds for Individuals with Muscular Dystrophy". This will give you a list of other organisations you may also wish to apply to for funding. This is located in the publications section here: http://www.muscular-dystrophy.org/how_we_help_you/publications/1934_raising_funds_for_individuals_with_muscular_dystrophy.

SECTION C - APPLYING FOR A WHEELCHAIR

The information requested is for campaigning purposes and to understand what is happening in the NHS Wheelchair Service. It is not used to determine whether or not to provide funding towards a wheelchair. Please complete as much as you can as this will help us with our work to improve the provision.

Murray's Muscles, Joseph Patrick Trust and Muscular Dystrophy Campaign actively campaign to improve health and social services for people with neuromuscular conditions, to tackle the discrimination they may face and to convince the Government and others to provide more money for research. We actively seek to raise awareness of the issues faced by people with neuromuscular conditions.

Getting involved in campaigning could mean writing to your MP or local health providers, speaking to your local newspaper about an issue, which you feel strongly about, or attending campaigning events.

Grants may be made towards the cost of an Electric Powered Indoor/Outdoor wheelchair (EPIOC) or a light weight manual wheelchair. It is expected that you will have already sought funding / a wheelchair from the NHS Wheelchair service. The Charity however recognises that there is a postcode lottery in relation to wheelchair and equipment provision. This means that waiting times for NHS assessments and equipment, assessment criteria and the quality of NHS equipment vary. Some people will have no EPIOC, some will have a heavy manual chair or a very basic EPIOC from the NHS, others will have a NHS voucher and require additional resources for a better quality private chair. The circumstances vary from region to region. If you have an inadequate NHS wheelchair you can still apply for consideration for Charity funding.

We are sure you will have thought very carefully before deciding to seek funding for a wheelchair. There are of course advantages and disadvantages in seeking part funding through Murray's Muscles. Before you seek funding for a 'private wheelchair' you may wish to consider the following:

- ▶ You will need to ensure the wheelchair is suitable and any seating requirements and health and safety issues are addressed. These are considered in detail by a NHS wheelchair assessment, but may not be if you receive your wheelchair privately.
- ▶ How you will pay for repair and maintenance and any additional needs including seating systems. This can be very expensive and additionally you could be without a wheelchair for a considerable period while it is repaired. Having a NHS supplied wheelchair means that the costs of repairs, maintenance and replacement are covered.

Another option is to discuss with your local NHS Wheelchair service a 'partnership' in funding your wheelchair. You could try and negotiate for a voucher from the NHS towards the cost of your wheelchair. You may also be able to agree free maintenance or funding for seating requirements from the NHS. It may also be possible for the Charity to fund additional functions for your NHS Wheelchair, for example a new / different joystick or a new NHS Wheelchair part funded by the Charity.

SECTION D - TERMS & CONDITIONS

The equipment that you are seeking to purchase is expensive and it is essential that it stays in good working order. The best option is to get an extended warranty but you will also need to purchase insurance for repair as well as damage and theft. Electrical equipment such as electric beds should be insured. It is your choice what insurance company you use. For equipment that is used only at home, the cheapest way may be to include the equipment as

part of your home insurance policy. It may be possible to agree an arrangement with the NHS Wheelchair Service to maintain and repair an electric wheelchair.

Murray's Muscles is unable to collect the equipment when you no longer have use for it. You need to make your own arrangements for equipment disposal and recycling. Murray's Muscles is often in touch with other families in your area and may know someone looking for equipment / you can also advertise it in the Muscular Dystrophy Campaign's magazine Target MD.

Equipment that is in good condition could be reconditioned for someone else to use and you may wish to get in contact with a local dealer who might be able to help with this. If the equipment is old and worn, we recommend you scrap it safely, particularly if there are electrical components, batteries etc.

APPLYING FOR POWERED MOBILITY EQUIPMENT (including scooters and electric wheelchairs)

Applicants are required to insure powered mobility equipment – an electric wheelchair or scooter, for accidental damage and personal (public) liability under a recognised specialist insurance policy. You are required to provide us with the name of the company on the application.

The following insurance companies may provide you with competitive quotations and are experienced in insuring equipment for people with disabilities.

(This is in no way an endorsement of their policies.)

- ▶ **Fish Insurance Services** - Freephone: 0500 432 141, 01772 724442, Fax 01772 733773,
Freepost, 3-4 Riversway Business Village, Navigation Way, Ashton-on-Ribble, Preston PR2 2YP
Website: www.fishinsurance.co.uk e-mail address: info@fishinsurance.co.uk - Specialist disability insurers
- ▶ **Chartwell Insurance and disabled Drivers Bureau** - Phone: 020 8958 0900
Website www.chartwellinsurance.co.uk - specialist disability driving and wheelchair insurance

Given the cost of the equipment we also require you to have considered the maintenance costs. You need to do this by ensuring you; have a warranty of at least two years and if possible three years; agree with the NHS Wheelchair service that they will provide free maintenance and another wheelchair if needed; or take out maintenance insurance. Maintenance insurance can cost over £100 per year (depending on the cost of the wheelchair).

The Charity is happy to partnership fund your Wheelchair with a NHS Wheelchair Service (see below) and this might mean they will 'own' the chair but they will cover maintenance costs.

SECTION E - DECLARATION

Please make sure you sign the form and include the required documents.

ADDITIONAL SUPPORT, INFORMATION AND PERMISSION FORM

The information that you provide on these pages will help us provide you with more help if you wish. These pages are optional and none of the information on these pages will be used when considering your Murray's Muscles grant application.

1. Funding from other Sources

Saying yes to these questions will enable us to send on your details to others with funds. It will also enable us to offer you additional funds, should they become available. (Murray's Muscles has additional funds on occasions.)

2. Telling your story

The Murray's Muscles, the Joseph Patrick Trust and the Muscular Dystrophy Campaign actively campaign to improve health and social services for people with neuromuscular conditions, to tackle the discrimination they may face and to convince the Government and others to provide more money for research and equipment etc. We actively seek to raise awareness of issues they face and this is where you can help. Personal stories always make magazine features, fundraising packs or news articles much more compelling and show very powerfully the impact muscular dystrophy has on people's lives. To tell your story and become a 'media volunteer', please complete the media volunteer form and return to us.

3. More Advice and Support

One of the services funded by Muscular Dystrophy Campaign is a network of Muscular Dystrophy Campaign Regional care advisors. They are a nationwide team of care workers, working alongside medical and health and social care staff who can offer specialist advice and support to children, families and adults with neuromuscular

conditions. There may be a Regional care advisor who covers your local area. We are happy to put them in touch with you if you wish.

WHEN WILL YOU HEAR FROM US?

Every application is considered individually at a meeting of the Grants Panel. We will notify you of the outcome within 14 days of the meeting. Meetings are held at regular intervals and we will also confirm the date of the meeting when we acknowledge receipt of your application.

Help is available on how to fill in the application form and on putting the background information and supporting material together. If you need help or want more information please telephone 01905 779 907.