Muscular Dystrophy UK
Fighting muscle-wasting conditions

Volunteers’ handbook: everything you need to know about volunteering for MDUK
Working together to make every day count
Without the involvement of volunteers like you, MDUK wouldn’t be able to reach and improve the lives of the thousands of people living with muscle-wasting or associated neuromuscular conditions.

You – our volunteers – are our strength. You represent us, you raise funds for us, you campaign for us, you support and encourage others for us. By giving us your time, your experience and your expertise, you enable us to provide vital services to those who need them. You spread the word to those who need us but don’t know about us, you take us into your communities and help raise awareness of the positive difference our work makes.

So we’ve put together this handbook for you. It’s an invaluable guide to the finer points of volunteering with us, and a reinforcement of our commitment to you.

If you need more information about anything in this handbook, please do not hesitate to ask your MDUK contact. They’re here to make this work for you and for all of us.

Many thanks again for choosing to be an MDUK volunteer. You’re joining a wonderful community of like-minded people who are helping us to be here for everyone affected today, tomorrow and beyond. Together we will bring forward the day when we beat muscular dystrophy.

Thank you, and welcome to MDUK.

Catherine Woodhead, CEO
Who we are

Muscular Dystrophy UK (MDUK) is the only UK charity for the 70,000 people living with a range of muscle-wasting and weakening conditions.

With our head office in London and regional staff based throughout the UK, we operate across England, Scotland, Wales and Northern Ireland.

Every day counts when you’re living with a muscle-wasting condition. That’s why we’re urgently searching for treatments and cures to improve lives and benefit future generations. But we also provide many services to support people today. Together, we’re campaigning for faster access to potential treatments, and driving change to see better care and support to help people stay active, independent and connected.

We understand that muscular dystrophy can have a big impact of people’s lives. That’s why we’re here for anyone affected, right from the moment of diagnosis and beyond to support them to live life to the fullest. Working alongside people living with muscle-wasting conditions means we’re here with useful information and advice, together with emotional and practical support, a network of local groups and an online community.
Our valued volunteers

You are one of more than 500 amazing people who volunteer for MDUK.

Thank you for joining this great team of people and for offering your time, experience and expertise to our cause. Volunteers, such as yourself, make a huge difference by ensuring MDUK provides a high level of support, a high quality of information and proper rigour in the funding of research into treatments and potentially cures for muscle-wasting conditions.

No two volunteers are the same. But every one of you joins our cause for your own reasons: a compelling desire to make a difference, an ambition driven by someone close to you being diagnosed with a muscle-wasting condition, an opportunity to share your skills and expertise, or a new way to meet other people and have fun. Whatever your reason, we’re so glad you’ve chosen to volunteer for us!

“I think about all the new folk I’ve met through volunteering and of those who I’ve still to meet! And of all the opportunities the charity has given me and of those still to come!”
– Emily Bonner
How you add value to our work

There are many ways for you to be involved in what we do. Every way adds value, and our volunteering team at volunteering@musculardystrophyuk.org can tell you more. Here are just a few examples of what you can do:

- **support others living with muscle-wasting conditions** – by meeting and speaking to others online or through peer support groups, you can make a huge difference. You can be there for someone who wants help to understand their condition, who needs advice about how to get grants or benefits, or who just needs someone to talk to. Whatever your experience, you’ll help others not to feel alone.
• **help shape the charity’s work** – MDUK is committed to making sure people living with muscle-wasting conditions are involved in setting our priorities and the approach we take. You can use your experience and time to review our research grants, help shape the content of our print and digital materials, and use your experience to help the charity press for improvements through specialist neuromuscular centres.

• **raise funds** – you’ll be joining MDUK fundraisers across the country who are raising money towards research and MDUK services. Whether you are baking, running, skydiving or bucket collecting, there are loads of different ways to get involved. You’ll also meet enthusiastic local people along the way. Find out if there is a fundraising group in your area or find out how to set up a new one.

• **support one of our events** – with loads of people taking part in MDUK events throughout the year, we always need help on event
day. Whether you’re setting up and manning a water stand at our Town and Gown 10k series in Oxford, Cambridge or Leicester, or cheering on #TeamOrange runners at the London Marathon, or supporting any of our other events across the country, you’ll make the day one to remember for all participants.

- **help out at our London office** – our committed volunteers make a huge difference by working in the heart of our operation. In return, you’ll get invaluable work-related experience and skills.
- **campaign with us** – we’re pressing for better recognition of muscular dystrophy so that people get the care and support they need, and access to potential drugs much sooner. By sharing your story, speaking to your MP and by spreading the word to others, you’ll be adding your valuable voice to these campaigns.

**Tell us your ideas!**
The best ideas come from working together. If you have some fantastic suggestions or ways you want to volunteer, then speak to us to see if we are able to support them.

To find out about any of our volunteer roles, please get in touch with our team at volunteering@musculardystrophyuk.org or on 020 7803 4800.
Our commitment to you

We value your willingness to help, and appreciate the role you’re playing in making every day count for people with muscle-wasting conditions. In return for your commitment, we will:

- give you this *Volunteers’ handbook* as a summary of all the vital information you’ll need from our volunteer policy (you can also request the full policy document if you’d like to see it)
- agree with you an individual action plan that brings together your interests and the needs of the charity
- give you regular updates and latest news about the charity’s work
- put you in contact with other volunteers at MDUK
- offer you the support and training you need to fulfil your role
- reimburse you for pre-agreed reasonable expenses as per our expenses policy
- include you in MDUK’s public liability insurance when you’re volunteering for MDUK, as per our insurance policy
- deal with any complaints promptly and fairly.
What we need from you

You’ll expect the best from MDUK, and in return we expect the best from everyone who works for MDUK – staff and volunteers alike. To help you get the best out of your role with us, please:

- show enthusiasm and commitment to supporting the work of MDUK
- support our aims and objectives
- maintain and uphold the reputation and good name of the charity
- listen to and work co-operatively with staff members and other volunteers – treating everyone with courtesy and respect
- take reasonable care of your own health and safety and that of others who may be affected by anything you do or don’t do
- support the charity’s equal opportunities and diversity policy, helping to promote this to all our supporters
- give us feedback on how we can improve the volunteering experience with the charity
- tell us if, for any reason, you can no longer continue to commit to volunteering with MDUK.

If you have any questions or concerns, you can always discuss these with your MDUK contact.
With you every step of the way

Helping you to make a difference

Starting your role
When you join MDUK as a volunteer, your MDUK contact will arrange your induction and introduce you to your team and anyone else you’ll be working with. At your induction, you’ll also get information about your obligations around sharing data and information, and about health and safety requirements. If you have any questions, or feel you need further training and support in any areas of your role, now is an ideal time to ask.

If you plan to volunteer with us for some time, we suggest you start with a settling-in period. This will give you – and us – a chance to see how things are working out and how best to continue working together.
Training
To make the most of your role, it’s important you feel happy and confident in it. We’ll give you training or coaching to ensure you’re able to fulfil any role you take on. Your training may be formal, online, or ‘on the job’ where you gain hands-on experience in your role. In many cases, your training may be a mix of all these.

Reliability and commitment
To get the most out of your time with MDUK, it’s important we know we can depend on you. For example, we’d need you to stay for the duration of any arrangements you’ve made with us. If for any reason you find you can’t do this, please let your MDUK contact know as soon as possible. If you’re planning a holiday, please let us know which dates you’ll be unavailable and when you plan to return.

MDUK is committed to creating volunteering opportunities that are available to all. If your health affects the way you’re able to volunteer, please discuss alternative options with your MDUK contact.

Support
Your MDUK contact will give you ongoing support. As you become more involved with us, please keep a note of how things went, what you did and if any issues arose, what you enjoyed and what you would prefer not to do in the future. You’ll have the opportunity to talk about this with your MDUK contact, and see if you need further support or have any difficulties.
How it works

Like any organisation, MDUK has policies and procedures in place that all of our staff and volunteers need to be aware of. The important points are below. Please read through them all and familiarise yourself with them.

**Accidents and incidents**: all MDUK-led events should have a first aider present to deal with any accidents or incidents. However, when you’re at another organisation’s event or you’re the appointed first aider at an MDUK event, please report all accidents and incidents to your MDUK contact promptly. You may also be given an incident form to complete. If you believe it’s a real emergency, please contact the emergency services ASAP!

**Boundaries**: it’s important for all staff, volunteers and supporters to have clear boundaries. This will help us provide a service according to agreed expectations, making sure everyone gets the same quality of service. We understand that staff and volunteers may sometimes have contact with MDUK supporters in a personal capacity – as friends, family member or colleagues. In this situation, please be sure to avoid any apparent conflict of interest, such as if a family members works for an organisation you are working with as part of your volunteering role. If you are unsure of what may constitute a conflict of interest, please speak to your MDUK contact.

**Cars and driving**: if you’re involved in an activity or role for MDUK that requires you to use your car, you must inform your own vehicle insurers of this; not for journeys made to and from volunteering, but for those you make as part of your volunteer role. Many insurance companies agree to cover these car journeys at no extra charge, but it’s important to check this with your own insurance company. MDUK insurance, as described on page 21, will not cover your car. Your MDUK contact can give you a template letter to use to let...
your insurance company know you intend to drive as part of your volunteer role.

Confidentiality: as a volunteer, you are expected to maintain complete confidentiality during your time with MDUK. When you complete and sign the acceptance agreement form (your MDUK contact will share this with you), you are also signing a confidentiality declaration. You will need to keep confidential all information about people we support, our volunteers, our employees and our work unless sharing this information is required by law.

Disclosure and Barring Service (DBS) checks: MDUK is involved in working with or supporting children, young people and vulnerable adults in many ways. If your volunteer role involves working with these groups, you will need to undergo a DBS check – this is part of our policy on safeguarding. Your MDUK contact will be able to tell you more, and if you need such a check for your role. You may also need to complete a DBS check if your role involves personal influence over financial transactions, or if you’re handling money.

Data protection: we are required by law to have an individual’s consent before we can collect, retain or use any data about them.
We obtain this consent by using data protection statements that comply with the Data Protection Act. This is a law that protects an individual’s personal information.

During your work with us, you may have access to and handle the personal information of the people you’re helping. If you do, it’s very important that you’re aware of our data protection policy. Your MDUK contact will share it with you, but if you’re unsure, please ask them if it’s required for your role. You may also be required to complete a short training module on General Data Protection Regulations (GDPR) as part of the training for your role.

Diversity: it’s our policy to provide equal opportunities in employment or volunteering regardless of age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race (including colour, nationality and ethnic or national origins), religion or religious or philosophical belief, sex or sexual orientation. Our policy is to treat all volunteers and volunteer applicants with respect and dignity, and to ensure no-one is victimised or subjected to harassment or discrimination on the above grounds.

Expenses: we will reimburse you for any reasonable out-of-pocket expenses you incur while carrying out your volunteering role. However, please note that we will only reimburse you up to an agreed maximum amount. Please retain and provide tickets and receipts to reclaim those costs.

Gifts: giving or receiving gifts may be a nice gesture, but can also suggest favouritism, or raise expectations of the level of support you can provide in your role. Because of this, we ask our volunteers not to give or receive personal gifts from staff or anyone receiving help from MDUK.
**Health and safety:** MDUK is committed to looking after the health, safety and wellbeing of everyone who works for us, is on our premises or uses our services. This applies equally to our volunteers and staff members.

All of your volunteer activities are covered by the same health and safety regulations that cover tasks carried out by MDUK staff. So it’s important you understand and accept your personal responsibility to promote and maintain health and safety standards so we can provide a safe working environment for everyone. If you have specific responsibilities for health and safety, you’ll the relevant training and guidance.

Risk assessments must be prepared in advance for all activities taking place in the name of MDUK. This is a review of the potential hazards of an event and the considerations that have been made to reduce or remove these. You can get a risk assessment template from your MDUK contact.
Please:
- fulfil your role with MDUK without endangering either your own or anyone else's health and safety
- follow all relevant instructions and procedures relating to safety and follow MDUK’s guidance
- tell your MDUK contact about any personal health and safety requirements you may have.

If you have any concerns, please speak to your MDUK contact as soon as possible.

**Insurance**: MDUK has employers’ liability insurance, which provides insurance against liability for injury and illness experienced by volunteers or staff as a direct result of their involvement with MDUK activities.

As a registered volunteer, you’re also covered by our public liability insurance when carrying out any volunteer duties on our behalf. (You and your MDUK contact will have agreed these activities beforehand.) This covers our legal liability to pay compensation for injuries or illness to a third party, or damage to the property of third parties as a result of MDUK’s negligence at fundraising or other events. It does not cover pure accidents (for example, if a spectator at an event trips over their shoelaces) or malicious damage (for example, deliberate damage to equipment).

**No smoking policy**: smoking is not permitted anywhere on MDUK property or at any MDUK events.

**Emergency contact**: when you applied to become a volunteer, you will have provided us with an emergency contact that we can reach in the unlikely event of an emergency. If this information needs updating, please let us know immediately.
**Social media:** we encourage all our volunteers to be active on social media. It’s an excellent way of developing networks and reaching out to other people who could benefit from our help, or who may want to support the charity. We would encourage you to highlight in your Twitter bio that you’re a MDUK volunteer. It’s important however that you adhere to our social media guidelines when representing the charity so that the content you post on your social media channels reflects the values of the charity. Your main MDUK contact can share these guidelines with you.

And please follow the MDUK social media accounts below too:
- **Twitter:** @MDUK_News
- **Facebook:** www.facebook.com/musculardystrophyUK
- **Instagram:** @musculardystrophyuk
- **LinkedIn:** www.linkedin.com/company/musculardystrophyuk

**What to wear:** as a volunteer for MDUK, you’re an ambassador for the organisation. The positive image you present to visitors, clients and the community reflects positively on us.

Please use your judgment to dress appropriately for any role or activity you’re undertaking. We can usually give you an official MDUK-branded T-shirt or polo shirt to wear while carrying out your duties. If you’re not sure what to wear, please ask your MDUK contact.

**“I enjoy being able to help others who are going through difficult times in their lives. In one afternoon we can help 40 to 50 families or individuals in raising funds for equipment that will make their lives easier.”**
– Patricia Lock on being a member of the Joseph Patrick Trust panel
The value you add

Volunteers are our greatest asset and we value every single one of you. We simply couldn’t do what we do without you, and we’re so glad you chose to join us!

**President’s Awards:** these are a fantastic way to recognise your achievements and say a huge thank you. Every year at our National Conference, we acknowledge the contribution of our passionate campaigners, committed volunteers or simply brilliant fundraisers with our President’s Awards. You can nominate someone you feel has made a remarkable difference. Ask your MDUK contact or check our website for further details.

**Keeping you involved:** the more you know about MDUK and everything we’re doing, the better you’ll be able to perform your role. So we’ll keep you up-to-date on whatever is going on by sending you our regular news emails and our lifestyle magazine, *Target MD*, which comes out twice a year and is bursting with the latest news, stories, anecdotes and key information. You will be asked if you want to sign up to these free of charge when you begin your volunteering but do speak to your main MDUK contact if you change your mind at any point.

The other way you can stay up-to-date is by visiting our website at www.musculardystrophyuk.org. You’ll be informed of latest news and developments, know about events and activities, and you can shop online for MDUK merchandise!
We want your time with us to be as exciting and rewarding as possible, but we also realise there may be moments when things aren’t going as well as you’d like. If this is the case, here’s what you can do.

**Role issues**: if you’re having difficulties with any aspect of your role, please talk to your MDUK contact as soon as possible. They will be able to offer guidance and support.

If the issue is more deep-seated and your role isn’t working out as you’d hoped it would, please let your MDUK contact know. Between the two of you, it may be possible to work out any difficulties. If it isn’t, and it’s agreed that your current role just won’t work, please don’t give up. Speak to your contact about finding a more appropriate role, or check at the volunteer area of our website to see what other opportunities are available.

MDUK also has a grievance policy for volunteers, which is contained within the full-length volunteer policy.

**Complaints**: MDUK strives to create the best possible atmosphere for volunteers but if there is an issue you can’t resolve through the grievance policy, or the issue is more serious, you have the right to make a complaint. This can give us a positive opportunity to improve the way we do things and provide a better service for the people we serve.

MDUK takes all complaints seriously, whether they are given formally or informally. Please discuss with your main contact or another member of MDUK staff. The formal complaint policy is within the full-length volunteer policy.
You can direct any complaints to the HR Manager, Muscular Dystrophy UK, 61a Great Suffolk Street, London, SE1 0BU. You can also call 020 7803 4800 or email volunteering@musculardystrophyuk.org.

If you have any questions, speak to your MDUK contact or get in touch with us on 020 7803 4800 or info@musculardystrophyuk.org

Sometimes you may have challenging moments as a volunteer, but MDUK is here to support you to manage these situations.

MDUK has strict safeguarding policies for all individuals we support. Some volunteers will be given specific training on these policies and processes, but if you have any concerns, please speak to your MDUK contact immediately. If you’re concerned for the immediate safety of any individual, please get in touch with emergency services.

As a representative of MDUK, you may find people want to make a complaint. Please refer them to a member of staff who will ensure the correct procedure for complaints is followed.
We want to ensure all volunteers are trained to deal with difficult situations and MDUK staff are always available to help. Do speak to your MDUK contact if you have any concerns or require any assistance.

It’s helpful to know who can help you with different queries. Here are some contact details for the teams you may need to get in touch with. If you are unsure who best to approach, please speak to your main MDUK contact.

Important contact details for you

- **Your main MDUK contact:**
  - Name ______________________________________________________
  - Telephone __________________________________________________
  - Email ______________________________________________________

- **Volunteering:**
  - volunteering@musculardystrophyuk.org

- **HR Manager:**
  - 020 7803 4849
  - jobs@musculardystrophyuk.org

- **MDUK Information line:**
  - 0800 652 6352 / info@musculardystrophyuk.org

- **Fundraising hotline:**
  - 0300 012 0172 / volunteerfundraising@musculardystrophyuk.org

- **Research Line:**
  - 020 7803 4813 / research@musculardystrophyuk.org

- **Joseph Patrick Trust equipment grants:**
  - 020 7803 4811 / jptgrants@musculardystrophyuk.org

- **MDUK main office:**
  - 61a Great Suffolk Street, London, SE1 0BU
  - 020 7803 4800 / info@musculardystrophyuk.org
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With over 70,000 people in the UK living with these conditions, MDUK is urgently searching for treatments and cures to improve lives today and transform those of future generations. Together, we're pressing for faster access to potential drugs and we're driving change to see better care and support to help people stay active, independent and connected.

We understand that muscular dystrophy and muscle-wasting conditions can change everything. That's why we're here for anyone who is affected, right from the moment of diagnosis and beyond. We're here to help people take back some control of their lives and to live well with the condition. We understand the everyday challenges of muscular dystrophy and muscle-wasting conditions, so we're here with information and advice, together with emotional and practical support, a network of local groups and an online community.

www.musculardystrophyuk.org

To find out more go to:

Helpline: 0800 652 6352
Research Line: 020 7803 4813
info@musculardystrophyuk.org

Muscular Dystrophy UK, 61A Great Suffolk Street, London SE1 0BU
Registered Charity No. 205395 and Registered Scottish Charity No. SC039445