



**Muscular Dystrophy Ireland
Volunteer Handbook**

MDI Mission Statement

Muscular Dystrophy Ireland aims to provide information, advice and support to people with neuromuscular conditions and their families through a range of support services. Our objective is to promote through practical empowerment, independent living for people with the condition muscular dystrophy. MDI supports advocating for services to enable people with neuromuscular conditions to fully participate in society and to live a life of their own choosing. MDI also aims to support and fund research into neuromuscular conditions.

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Introduction

Thank you very much for contacting MDI regarding volunteer work with the organisation. There's nothing more rewarding than volunteering your time for someone else and we at MDI appreciate the great work done by all our volunteers all over the country.

You can volunteer with Muscular Dystrophy Ireland (MDI) in a variety of ways including: Youth Clubs, Summer Camps, Fundraising, Respite, Transport Services and Administration. MDI welcomes volunteers from all sectors and backgrounds, including Nurses, Social Care Students, Care Workers, Administrators, Drivers, etc.

Please note: There are two distinct types of volunteering within the organisation;

- 1) Service Provision
(eg Youth Clubs, Summer Camps and Personal Assistant Services) and
- 2) Fundraising & Administration
(eg, Bag Packs, Collections, Sponsored Events (Mini Marathons, Cycles etc) and office based administration

To become a volunteer, the first step involves completing and returning the following forms, which you will find at the back of this handbook:

- MDI Application Form
- The MDI Declaration Form
- MDI Personal Details Form

Please submit the following information with the above forms and return them to MDI as soon as possible.

- A cover letter indicating which area you are interested in volunteering with.
- Current CV.
- Two signed passport photographs,
- A copy of your passport or drivers licence

Please return all of the above information to our head office at Muscular Dystrophy Ireland, 75 Lucan Road, Chapelizod, Dublin 20. When MDI receive this information and documents we will then continue with your application and make contact with you regarding volunteering opportunities available within the organisation.

If you have any questions or would like receive more information about any of the above, you can contact the Dublin office @ 01-6236414

About Muscular Dystrophy Ireland

Introduction to MDI

Muscular Dystrophy Ireland (MDI) is a voluntary organization, which was established in 1972 by a small group of people in the west of Ireland to support families who had a member with muscular dystrophy. Since then it has grown considerably and it now has a membership of over 603 members and a network of branches throughout Ireland.

There are now MDI offices in Donegal, Dublin, Galway, Tullamore and Kells, and MDI staff members are also based in the Mid-West and South East regions. MDI's primary objective is to provide support for people and their families who are living with muscular dystrophy and allied neuromuscular condition.

Mission and Aim

Muscular Dystrophy Ireland (MDI) aims to provide information and support to people with neuromuscular conditions and their families through a range of support services.

This includes:

- Promotion, through practical empowerment, of independent living for people with the condition muscular dystrophy.
- Lobbying for change in policy and services to enable people with neuromuscular conditions to fully participate in society and to live a life of their own choosing.
- Support and funding of research into neuromuscular conditions.

Primary Objective

Our primary objective is to provide support for persons and their families who are affected by muscular dystrophy and allied neuromuscular conditions. It does this through the provision of support services such as information, advice, respite breaks, home support, holidays, youth activities, provision of transport for members and publication of a newsletter.

History of MDI

The Muscular Dystrophy Society of Ireland (MDI) was founded in 1972 by a group of parents in Galway, whose children had muscular dystrophy. These parents met together in their homes to set up a support network for people with muscular dystrophy and their families.

In 1986, the first Dublin office was set up in Monkstown, Co Dublin. MDI then spent time in temporary accommodation for two years at Christchurch Place before acquiring space in the Carmichael Centre for Voluntary Groups, firstly in Carmichael House, North Brunswick Street, Dublin 7 in 1990, and then in Coleraine House, Coleraine Street, Dublin 7 in the year 2000.

In 2004, MDI felt it necessary to acquire an independent office space away from Carmichael Centre because of the growth and expansion of services and we moved to our previous offices in 71/72 North Brunswick Street, Dublin 7. Here we remained until April 2011 after which we moved in to our new, purpose built premises at 75 Lucan Road, Chapelizod, Dublin 20, which we were fortunate to be able to purchase one year earlier.

MDI has grown considerably and now has a membership of nearly 603 individuals and families and a network of branches and offices throughout Ireland. Branches are represented on the National Council of MDI, which determines policy. MDI now employs staff nationwide and offers national support services such as Family Support, Information, Respite and Home Support, Transport and Youth Services (i.e. Camps and Youth Clubs) and counselling services. All of these services are run and coordinated from MDI's Dublin administration office at Chapelizod, Dublin 20, which also encompasses a fully wheelchair accessible three bed-roomed "Home from Home" apartment for short term respite breaks for members.

Structure of MDI

MDI has a National Council which meets four times per year and its role is to determine policy. The members of the National Council are elected at the AGM. The Chairperson of each local branch is automatically a member of the National Council. The National Executive Members of MDI are elected at the AGM and sit on the National Council.

The Executive comprises a Chairperson, Vice Chairperson, Treasurer, Secretary and there is allocation for a further three members. This committee meets once a month to determine the management of MDI. The CEO is responsible for the day-to-day management and operation of the organisation.

Muscular Dystrophy

What is Muscular Dystrophy?

Muscular dystrophy is the collective name for a range of neuromuscular conditions, which are characterized by the progressive weakening and wasting of the muscles. It can affect adults and children. Some forms arise at birth or in childhood, others may not manifest themselves until later in life. Each type of muscular dystrophy arises from a different genetic mutation or deletion which is inherited from one or both parents, or is due to a spontaneous mutation. This means that there are many families who have more than one member with the condition. There is no cure for muscular dystrophy but there have been huge advances in increasing the quality of life for people with the condition and scientists around the world are working hard to develop new treatments.

Types of Muscular Dystrophy

The conditions listed below are covered by MDI. Further information about each condition can be found on our website, www.mdi.ie

1. Muscular Dystrophies

- Becker muscular dystrophy
- Congenital muscular dystrophy - General
 - MDC1A (merosin-deficient congenital muscular dystrophy)
 - Rigid spine syndrome (RSS)
 - Ullrich congenital muscular dystrophies
- Duchenne muscular dystrophy
- Emry-Dreifuss muscular dystrophy
- Facioscapulohumeral muscular dystrophy
- Limb-girdle types of muscular dystrophy (LGMD) - General
 - LGMD 1B (also known as Liminopathy)
 - LGMD 1C (also known as Caveolinopathy)
 - LGMD 2A (also known as Calpainopathy)
 - LGMD 2B (also known as Dysferlinopathy)
 - LGMD 2I
 - LGMD 2C 2D 2E & 2F
- Ocular myopathies including ocularopharangeal muscular dystrophy

2. Myotonic Disorders

- Congenital Myotonic Dystrophy
- Myotonia
- Myotonic Dystrophy

3. Congenital Myopathies

- Central Core Myopathy
- Congenital fibre-type disproportion myopathy
- Minicore (Multicore) myopathy
- Myotubular or Centronuclear myopathy
- Nemaline myopathy

4. Mitochondrial Myopathies

5. Metabolic Disorders

- McArdles Disease
- Metabolic Conditions

6. Periodic Paralyzes

7. Autoimmune Myositides

- Polymyositis, Dermatomyositis and Sarcoid myopathy
- Juvenile dermatomyositis
- Inclusion body myositis

8. Spinal Muscular Atrophies

- Severe (Type I)
- Intermediate (Type II)
- Mild (Type III)
- Adult spinal muscular atrophy

9. Hereditary Motor and Sensory Neuropathies

(Also known as Charcot-Marie-Tooth or Peroneal muscular atrophy)

10. Disorders of the Neuromuscular Junction

- Myasthenia Gravis

MDI Services

Information Service

Information Library at MDI Office

Very often the Information Service is the first source of assistance for people affected by a neuromuscular condition. It provides information about neuromuscular conditions and other subjects such as benefits, holidays, transport, support groups, genetics etc. Enquiries are received by letter, email or over the telephone from people who have neuromuscular conditions, their family and friends, professionals such as occupational therapists, public health nurses, general practitioners and from members of other organisations.

The Information Officer gathers and disseminates information on the neuromuscular conditions. They would also keep abreast of all developments in research throughout Europe and America. At the time of diagnosis of a neuromuscular condition, the person with muscular dystrophy and their family will receive basic information about the symptoms and progression of the condition from their medical consultant. Families often find it difficult to absorb all the information they receive at this time and it is recognised by our service that families should have access to information whenever they require it.

Family Support Service

Family Support Worker Team

MDI has Family Support Workers (FSW's) based in the different regions of the country, and their role is to provide support to people with muscular dystrophy and their families. This could be in the form of home visits, telephone contact or group meetings, depending on what each person requires and wants.

At the time of diagnosis, there is a need for support from the local Family Support Worker (FSW). The FSW provides personal contact and support to people with neuromuscular conditions and their families. This includes visits to members in their own homes to give information about neuromuscular conditions, aids and appliances, welfare issues, etc. In many cases, the FSW is the sole point of contact for members so this support service is invaluable. The FSW can also liaise with health care professionals, teachers, social welfare etc. when required, to assist members to access services. They also organise support meetings, to enable members to come together and share their experiences.

As the condition progresses, members may find that they need increased access to aids and equipment; they may also be looking at a change of career if they were involved in a more physical area of work. The FSW can provide support at such times of change. Unfortunately, some types of muscular dystrophy can reduce lifespan and the FSW is there to provide support for the family before, during and after the bereavement. When an individual or family requires counselling, support is available, and the member can then find a counsellor that they are comfortable with.

Youth Support Service

There are currently five Youth / Respite Workers (YRWs) based in the east, south, midlands, west and north-east regions, who work directly with young people who have muscular dystrophy and their families. The support offered by the youth service is beneficial to the young person with MD as well as their parents / carers.

The support offered by the youth service can be divided into 5 main areas:

1. Home Visit

YRWs work on a one to one basis with members in their own homes, engaging in activities such as arts & crafts, playing board games, doing homework, watching TV, listening to music, playing computer games, or just having a friendly chat. This interaction is vital for the member to build up a trusting relationship with the YRW. It also gives their parents / carers some free time to do whatever they wish, knowing that their child is comfortable and well looked after.

2. Social Outings

Each YRW is fully trained in MiDAS (mini-bus driver awareness scheme) and is equipped with a fully wheelchair accessible van which can transport up to 5 people. This gives the YRW the freedom to collect members from home / school and go on trips, encouraging independence. Social outings include trips to the cinema, shopping, going to the circus, bowling, or any activity the member would like to take part in.

3. Summer / Easter Camps

MDI camps are an integral part of the YRW calendar. They have been described as a "working holiday" by the YRWs, giving them the opportunity to get to know the members in a relaxed, holiday atmosphere. These camps are open to members from 11 years of age, and there are many different activities on offer. Some of these include water based activities, such as swimming and canoeing, nights to the dog track, sight-seeing, shopping and a wide range of other group activities.

4. Youth Clubs

YRWs also organise youth clubs / outings, allowing young people with muscular dystrophy to meet up with other members with similar conditions. This type of social interaction can boost the member's self-esteem and confidence, while also allowing young people to make new friendships and interact socially. Some examples of youth clubs include power soccer, drama workshops, group outings to the cinema / bowling and computer workshops. YRWs also liaise with mainstream youth organisations, and encourage members to get involved where possible.

5. Hospital Respite

It is a difficult time when anybody is in hospital, but it can be particularly difficult when a child is hospitalised. YRWs offer to visit young members when they are in hospital and stay with them, allowing their parents / carers to go home or have a break for a few hours. This has proven to be a crucial support over the years, with some parents saying it was a life-line to them during such a difficult time.

Respite Service

Respite care is short-term care that helps a family take a break from the daily routine and stress. Respite care can occur in the person's / family home or in a variety of out-of-home settings, and can occur for any length of time depending on the needs of the family and available resources. MDI recognises that the person / child with muscular dystrophy and family members both need to avail of respite care services in order to maintain physical health and emotional wellbeing.

The respite service is an essential support for people living with muscular dystrophy and their families. Support is coordinated by the Respite Coordinator, in conjunction with the Family Support & Clinic Coordinator and the CEO. MDI Respite Services are categorized as follows:

1. MDI Youth Respite
2. MDI Emergency Respite
3. MDI PA Respite
4. MDI Financial Contribution

Transport

Over the years MDI has built up a transport fleet that covers all of the country. The transport service is co-ordinated from Dublin. There are now twelve mini buses in the fleet. This consists of two full time buses dedicated to transporting members to and from clinics, hospital appointments, transport links, social outings and also dropping MDI loan equipment such as hoists or wheelchairs to hotels or members' residences. These buses are based in Cork and Dublin. On average the Dublin bus will service sixteen transport requests per week, the Cork average is fourteen.

There are three mini buses that are loaned out to various members for short term loan periods to help in difficult situations.

MDI also has a minibus based in Limerick and one in Donegal which are loaned out to members with the kind help of local members.

The remainder of the fleet is driven by our Youth/Respite Workers. These five buses are located throughout the country and can be loaned to members when not in use by the YRWs. This is a first come first served agreement and is subject to terms and conditions that are aimed at members' safety and the integrity of the vehicles. The MDI fleet is a crucial part of the respite camps as it allows transport for members to and from same. Days out and group activities are made possible and a standard of comfort and safety is guaranteed.

MDI sometimes use the services of third party transport providers when our two full time buses are booked out. The standard of service and safety provided by these companies is of the highest order and is constantly monitored by management at MDI.

Equipment Loan Service

MDI has a number of pieces of equipment that members can borrow on a short or long term loan basis. These pieces of equipment include:-

Air mattresses	Electric wheelchairs	Shower Chairs
Beds	Electric Beds	Slings
Commodes	Hoists	Manual Wheelchairs
Computers	Ramps	

All of the above listed pieces of equipment are held in various parts of the country and can be transported where required. There is a limited amount of equipment available and MDI will try to accommodate members who need a piece of equipment, but it will depend on availability.

MDI also has details of where members can purchase these pieces of equipment if they wish to do so.

Volunteering with MDI

MDI welcomes all those who wish to volunteer with the organisation. Volunteers are not required to have any previous experience in volunteering, however all volunteers must be over the age of 18.

Volunteer Role Description

MDI endeavours to ensure that every volunteer is involved in meaningful activity while giving their time to the organisation. In order to achieve this, it is vital that all volunteers are clear about their role and what is expected of them. Every volunteer will be given a role description when they begin with MDI, as part of their induction and training. This will describe the activities the volunteer will be involved in and the specific requirements of the role. MDI aims to ensure that the volunteer's specific skills, expertise and interests are utilised and matched to the work of the organisation and that all volunteers have a meaningful and enjoyable experience while volunteering with us. Any changes in the role of a volunteer will be discussed and agreed by both the volunteer and their supporting member of staff.

Volunteer Expectations

Volunteers can expect the following while working with MDI;

- To be treated with respect and as a member of the team
- To be provided with induction training to get the most out of your volunteering
- To be provided with ongoing supervision and support
- To access team training sessions

Volunteer Responsibilities

Volunteers are expected to uphold the following responsibilities while they are working with MDI;

- To perform their volunteering role to the best of their ability

- To follow Muscular Dystrophy Ireland's procedures and standards, including those relating to health and safety, equal opportunities and confidentiality, in relation to its staff, volunteers and members
- To meet time commitments and standards agreed to, and to give reasonable notice so that other arrangements can be made.
- To be committed to human rights and equality
- To treat staff members, MDI members and visitors with respect
- To respect the privacy and confidentiality of all those who use MDI services

Volunteer Support, Training and Development

Volunteering with MDI is not a paid role, however MDI is dedicated to offering support and development opportunities to all our volunteers

Muscular Dystrophy Ireland commits to the following:

1. Induction and Training

- To provide you with a thorough induction of the work of Muscular Dystrophy Ireland and your volunteering role and any reasonable training you need to meet the requirements of this role.

2. Supervision, support and flexibility

- To explain the standards we expect for our staff and volunteers and to encourage and support you to achieve and maintain them
- To provide a named person who will meet with you as necessary to discuss your role and any successes and challenges
- To do our best to help you to develop your volunteering role with us.

3. Health and Safety

- To provide adequate training and feedback in relation to our health and safety policy.

4. Insurance

- To provide adequate insurance cover for volunteers whilst undertaking voluntary work approved and authorised by us.

5. Equal Opportunities

- To ensure that all volunteers are dealt with in accordance with our equal opportunities policy

5. Expenses

- To reimburse reasonable travel and lunch expenses once an Expenses Sheet is completed and receipts have been submitted.

6. Problems/Difficulties

- To try to resolve fairly any problems, grievances or difficulties you may have while you volunteer with us.
- In the event of an unresolved problem, to offer an opportunity to discuss the issues in accordance with the procedures set out in the staff handbook

Health and Safety

Health, Safety and Welfare of Volunteers

It is the duty of Muscular Dystrophy Ireland to ensure, in so far as is reasonably practicable, the health, safety and welfare while at work of all staff, volunteers, members and visitors to the premises. Volunteers will be required to familiarise themselves with the MDI Health and Safety Statement and specific safety requirements which apply to their area of work. All volunteers have a duty to take care of themselves and others who may be affected by their acts or omissions. Volunteers also have the following health and safety duties;

- To take care of their own safety, health and welfare as well as that of others by their actions and omissions.
- To co-operate with the employer to comply with their legal duties.
- To use all Personal Protective Equipment (PPE) as issued (as applicable).
- To report any potential risks to their employer or supervisor without delay.
- To report any accidents to their employer or supervisor without delay.
- Not to interfere with anything or anybody in a way that might lead to injury or risk.
- Not to attend for work or during the working time consume or abuse any intoxicant.
- Smoking is not permitted anywhere on MDI premises.

Fire Safety Policy and Procedures

Fire safety is a critical ingredient in MDI's Safety Statement. We must protect our employees, volunteers, members and others from the potential threat of fire. The policy of MDI is to ensure as far as is reasonably practicable, all action is taken to minimise the risk of fire on premises we work at. Every employee is responsible for maintaining fire safety by avoiding creating fire hazards with either flammable materials or sources of ignition.

Personal Safety and Protection

All staff and volunteers are responsible for their personal security and safety, and that of their colleagues at all times. If staff or volunteers identify potential risks to their safety on the premises they should make this known to management.

Muscular Dystrophy Ireland
75 Lucan Road
Chapelizod
Dublin 20
Tel: (01) 6236414b or 6236415
Fax: (01) 6208663
Email: info@mdi.ie
Website: www.mdi.ie



Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

Kate Power / Barry Buckley/ Joe Mooney
Muscular Dystrophy Ireland
75 Lucan Road, Chapelizod, D 20.

SURNAME:		PREVIOUS NAME (if any):			
FORENAME:		ALIAS (if any):		P.P.S. NO:	
DATE OF BIRTH: (dd/mm/yy)			PLACE OF BIRTH:		
HAVE YOU EVER CHANGED YOUR NAME?				YES	NO
IF YES PLEASE STATE FORMER NAME:					

PLEASE STATE <u>ALL</u> ADDRESSES FROM YEAR OF BIRTH TO PRESENT DATE (incl all addresses outside the Republic of Ireland):							
HOUSE NO.	STREET	TOWN	COUNTY	POST CODE	COUNTRY	YEAR FROM (YYYY)	YEAR TO (YYYY)

Have you ever been convicted of an offence in the Republic of Ireland or elsewhere?

No Yes If yes, please provide details below & also details of all prosecutions, successful or not, pending or completed, in the State or elsewhere

DATE	COURT	OFFENCE	COURT OUTCOME

DECLARATION

To Commissioner, An Garda Síochána, Central Vetting Unit

I, the undersigned who have applied to work as /employed as _____ hereby authorise An Garda Síochána to furnish the Health Service Executive (HSE), a statement that there are no convictions recorded against me in the Republic of Ireland or elsewhere, or a statement of all prosecutions, successful or not, pending or completed, in the State or elsewhere as the case may be.

I am aware that any information resulting from this inquiry may be shared for recruitment, selection and appointment purposes within the HSE and other HSE-funded organisations in the event that I apply for employment / positions within any area of the HSE or any HSE-funded organisation.

Signature of Applicant : _____ Date : _____

Please print name: _____

FOR HSE OFFICE USE ONLY

Line Manager: _____ Location: _____

Authorised Signatory : _____ Reg. No.: _____ Date : _____

Please print name: _____

FOR CVU OFFICE USE ONLY

According to Garda Records there are no previous convictions recorded against the above named applicant:

OR the following convictions appear on Garda Records: OR the following convictions are pending:

NOTE: Checks were carried out by this office based on the information supplied. The convictions supplied may apply to the subject of your enquiry. Please verify before use.

Signed: _____ Member I/C

C.V.U

Expiry of clearance: _____

