



# Muscular Dystrophy Ireland

STAFF INDUCTION

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Questions?

Will take approx. 1 hour

# Who is MDI?

Muscular Dystrophy Society of Ireland CLG (MDI) is a **voluntary, member organisation**, founded in **1972**.

## Our vision

- MDI envisages an Ireland that enables people with neuromuscular conditions to fully participate in society and reach their full potential.

**Our mission** is to support people with muscular dystrophy. We do this, using a **member-centred approach**, by:

- providing **information and support** to people with neuromuscular conditions and their families through a range of support services
- **advocating** for services and entitlements for members; educating and informing society about neuromuscular conditions
- supporting researchers and clinicians to carry out quality **research** into neuromuscular conditions.

# Who is MDI?

- We are a membership organisation.
- At the end of 2019, the organisation had 760 individuals with neuromuscular conditions registered as members.
- MDI also supports the families of people with neuromuscular conditions, including parents, carers and siblings, and provides support and information to healthcare and educational professionals. Our network of support extends to almost 4,500 people, delivered by our staff team nationwide.

# What is MD?

- Muscular dystrophy and neuromuscular conditions are characterised by the **progressive weakening and wasting of the muscles**.
- They can affect adults and children. Some forms arise at **birth or in childhood while others may not manifest themselves until later in life**.
- Each type of muscular dystrophy arises from a different **genetic mutation or deletion** which may be inherited from one or both parents, or be due to a spontaneous mutation. This means that some families may have more than one member with the condition.
- While currently there is **no cure** for muscular dystrophy, there have been huge advances in improving the quality of life for people with the condition and increased efforts are being made around the world to develop new treatments.

# What services do we provide?

## **1. Support Services**

- a) Respite Support Service
- b) Family Support Service
- c) Youth Support Service

## **2. Information and Advocacy**

## **3. Communications**

## **4. Transport**

## **5. MDI House Facilities**

- a) Home from Home Apartment
- b) b) Boardroom Hire and Training

## **6. Equipment**

# What services do we provide?

## **SUPPORT SERVICES**

There are three elements to the Support Services we offer members:

1. Respite Support Service
2. Family Support Service
3. Youth Support Service.

# Respite Service

- MDI's Respite Service is an essential support for people living with Muscular Dystrophy and their families.
- The main aim of our respite support service is to offer a personal assistant to members with muscular dystrophy in their homes and communities, facilitating their participation in the community, access to education, employment, and improved quality of life.
- Our respite service offers access to the following:
  1. Short-term emergency relief, providing a personal assistant
  2. Short-term counselling for adults and play therapy for children
  3. Adult overnight holiday breaks and youth camps.

# Respite Service

## Definition of MDI Respite Service

We define our Respite Service as mainly short-term emergency relief, providing **one-off personal assistance or personal assistance care for up to 12 weeks, depending on members' needs and resources available to MDI**, as well as offering access to short-term counselling and overnight breaks. The service may cover the following needs:

- Personal care
- Social inclusion: community participation
- Education: assistance attending school or college
- Employment: assistance attending work
- Mental well-being: access to counselling and play therapy.

Respite care can **occur in the family home and or in a variety of out-of-home settings in the community** depending on the needs of the family and resources available. MDI recognises that both the person with muscular dystrophy and family members need to avail of respite care services to maintain physical health and support emotional wellbeing. Respite can enable a family to take a break from their caring role and a person with muscular dystrophy to gain independence from their family.

# Respite Service

## Adult Overnight Breaks and Youth Camps Holiday Service

- During the summer, MDI normally holds six week-long camps and holiday breaks for children and adult members with Muscular Dystrophy at Kilcuan Respite Holiday Home, Clarinbridge, County Galway.
- Camps are broken down by age groups, have 12 members participating max and the ration of PA's and Nurses to members is vital. Below is a sample of 2019 camps.

Age Groups	Dates
Holiday 1 (26 years+)	10-15 June 2019
Holiday 2 (18-25 years)	24-29 June 2019
Holiday 3 (11-14 years)	08-13 July 2019
Holiday 4 (15-17 years)	22-27 July 2019
Holiday 5 (18-25 years)	26-31 Aug 2019
Holiday 6 (Over 50 years)	16-21 Sep 2019

# FAMILY SUPPORT SERVICE

- MDI Family Support Workers provide a wide range of information and support to our members with muscular dystrophy and their extended families and carers around the country.
- The Family Support Service provides an objective, non-judgmental, and supportive environment in which to discuss and explore issues of concern. All calls are held in strict confidence, but confidentiality may need to be waived in the event of a risk of harm to the person or another individual.
- We currently have **eight Family Support Workers** covering different regions in Ireland
- Our Family Support Workers offer information and support on a variety of areas such as emotional support and a listening ear, accessing counselling and play therapy services, Respite support services , advocacy on behalf of an individual member in relation to rights, entitlements and financial assistance, Education and employment, Equipment , Transport, Housing etc.

# Youth Support Services

- MDI Youth Workers work directly with children and young people with muscular dystrophy and their families around the country. MDI's youth work is purposeful, needs-led and outcomes-focused to support, encourage and enable our young members to grow, develop and achieve their full potential.
- Our young members have an opportunity to get together with their peers but also with friends in the wider community, form friendships, share experiences, have fun, and build confidence and self-esteem.
- We have **six Youth Workers** covering the country

# Youth Support Services

- Our youth work activities include a mixture of day trips/outings, youth clubs, workshops, and home visits. Social outings include trips to the cinema, shopping, going to the circus, zoo or theatre, bowling, or any activity the young member is interested in.
- Youth club activities and workshops include a variety of topics such as art and crafts, cooking, creative writing, teddy bear making, science, film making, computers, drama, sport, Christmas and Halloween parties, as well as events specifically for siblings.
- **PA's are an essential component of the Youth Services.**
- Each Youth Worker receives GLUAIS minibus driver training and is equipped with a fully wheelchair-accessible van which can transport up to five people.
- **PA's are allowed to drive our vans if they have received GLUAIS training.**

# Other Services

- **Information & Advocacy:** Info Officer provides accurate and relevant information to people with muscular dystrophy and associated neuromuscular conditions, their families, healthcare and education professionals and the general public
- **Communication's:** Newsletters, Website, Social Media etc.
- **Transport:**
  - MDI has one minibus based in Dublin that serves mainly to transfer members who arrive in Dublin from all over the country to attend hospitals and clinical appointments
  - This part of our service operates in a hub of Dublin and surrounding counties
  - The MDI fleet is available to members for loan subject to terms and conditions
- **Equipment:** MDI has a range of equipment that is loaned to members for short to medium terms.
- **Home from Home Apt:** The MDI 'Home from Home' Self Catering Apartment is located at MDI House. It is a self-contained fully wheelchair accessible apartment which is available for short-term stays for people with a physical or sensory disability

# Organisational Structure



Line Managed by CEO –National Office Staff:

1. Transport Co-Ordinator
2. Information Officer
3. Facilities Co-ordinator
4. Database Officer
5. Communication & Fundraising Officer

# Organisational Structure



Line managed by Head of Services:

1. 6 x Family Support Workers
2. 4 x Youth Workers
3. 1 x Respite Admin- Line manages all PA's

# PA's Roles & Responsibilities

- Report to Respite Admin under the supervision of the Head of Services regarding everything to do **with your role**. This means you report on everything to do with role i.e. annual leave, sick leave, supervision etc.
- The purpose of this role is to enable our members to achieve maximum independence in all aspects of daily living by providing assistance in one or more of the following areas: personal care, domestic assistance, social and community participation and educational assistance.
- Provide in-home and out of home respite care to members
- Assist with personal care needs **as identified by MDI** e.g. mealtimes, personal hygiene, toileting, transferring, turning, dressing, hoisting etc

# PA's Roles & Responsibilities

- Assist with assistive interventions **as identified by MDI**; such as medication administration, peg feeding, administering cough assist, BiPaP, suctioning etc. Training provided.
- Assist with domestic chores **as identified by MDI**
- Assist with social and emotional wellbeing needs **as identified by MDI** e.g. social and community participation, educational and employment assistance etc.
- If working with youth service, assist with supporting youth engagement i.e. social outings, youth clubs and workshops etc. **MDI Youth Workers are in charge of all activities/events and PA's are responsible for taking direction at all times from Youth Workers.**
- **Maintain confidentiality and discretion around all Personal Assistant work**
- Develop and **build professional relationships** with MDI members and family members applying a family centred approach

# PA's Roles & Responsibilities

- Participate in internal supervision with line manager
- Work as part of a multidisciplinary team with all MDI staff e.g. Family Support Worker, Youth Worker etc.
- Adhere to all MDI policies and procedures; **employment handbook**, vulnerable adults safeguarding policy, children first policy, PA guidelines, social-media policy, confidentiality policy etc.
- Submit timesheets monthly- **25<sup>th</sup> of every month- If timesheets are late you salary will not go through on time**
- Attend staff training as required

# PA's Roles & Responsibilities

## PA Pathway



# Essential Training

## Essential Training

- ✓ MDI Induction Staff Training- **Virtual**
- ✓ First Aid Training- 3 Day course
- ✓ Manual Handling and **People Moving** Training
- ✓ Children's First Training- **Online**
- ✓ Safeguarding Vulnerable Adults Training- **Online**
- ✓ **COVID 19**- Hand hygiene for HSE clinical staff /Hand hygiene for HSE Non-clinical staff - **Online**
- ✓ **COVID 19**- . Putting on and taking off PPE in community healthcare settings -**Online**
- ✓ **COVID 19**- . Introduction to Infection Prevention and Control - **Online**

## Additional Training : If relevant to respite role

- ✓ SAM: Safe Administration of Medication
- ✓ Assistive Intervention Training: MDI Training- **Virtual**
- ✓ Epilepsy Training

**ALL TRAINING IS PAID FOR AND YOU ARE PAID FOR ATTENDING TRAINING**

# PA Terms & Conditions

- INSERT THINGS IN CONTRACT SICK LEAVE ANNUAL LEAVE ENTITLEMENTS , TYPE OF CONTRACT ETC

# PA Guidelines: Additional Information Specific to role

## **Frequently asked questions:**

Respite cancelled 24 hours before PA is due

- You receive full payment for the exact hours you were scheduled for.

## **Driving:**

- MDI Mini Bus: PA's are insured to drive if they receive Gluais Training
- PA's are not insured to drive members cars or their own cars in course of their work
- If respite, is more than 30mins from PA's home PA's receive 1 hours pay for travel

## **Training:**

- MDI pay for all PA's training and hours for PA to complete

## **Social Respite:**

- Member is not responsible for paying for food etc. but if there is an entry fee required members are required to pay. A lot of venues will let carer(s) go free

QUESTIONS?

# Additional Training

## MDI Assistive Interventions Introduction Training

### Aim of the Training:

- The virtual training covers an introduction to different assistive equipment that supports our members with MD

### Main Equipment:

- ✓ Bi pap
- ✓ Ci pap
- ✓ Suctioning
- ✓ Peg Feeding
- ✓ Cough Assist

Additional Training  
MDI Assistive Interventions Introduction Training

**Staff Training Pathway**



MDI Assistive Interventions Introduction Training Complete



MDI Assistive Interventions Policy and Guideline Reviewed



Member/Company trains staff in specific equipment

# Additional Training

BiPAP



# Additional Training

## BiPAP

- Bilevel positive airway pressure (**BiPAP**) therapy is used in the treatment of respiratory diseases that make breathing difficult.
- BiPAP machines are tabletop devices fitted with tubing and a mask. You simply put the mask over your nose and/or mouth to receive two levels of pressurized air. One pressure level is delivered when you inhale, and a lower pressure is delivered when you exhale. BiPAP machines often feature a “smart” breath timer that adapts to your respiratory patterns. It automatically resets the level of pressurized air when needed to help keep your breathing level on target.
- This therapy is a type of noninvasive ventilation (NIV). That’s because BiPAP therapy doesn’t require a surgical procedure, such as intubation or tracheotomy. BiPAP therapy targets dysfunctional breathing patterns. By having a custom air pressure for when you inhale and a second custom air pressure when you exhale, the machine is able to provide relief to overworked lungs and chest wall muscles.
- Depending on individual needs, BiPAP therapy can take place when you’re awake or asleep. Daytime use can limit social interactions, among other things, but may be necessary in certain situations. Typically, a BiPAP machine is used at night to help keep your airways open while you’re sleeping. This aids the exchange of oxygen with carbon dioxide, making it easier for you to breathe.

# Additional Training

## Cough Assist



# Additional Training

## Cough Assist

- The cough assist helps to clear secretions by applying a positive pressure to fill the lungs, then quickly switching to a negative pressure to produce a high expiratory flow rate and simulate a cough. It is known as 'manual insufflation-exsufflation' and can be applied via a mask, mouthpiece, endotracheal or tracheostomy tube.
- It is most useful in patients with an ineffective cough due to muscle weakness, in conditions such as [muscular dystrophies](#), [myasthenia gravis](#), SMA, Spinal cord lesions, MND etc. In conditions such as [spinal cord injury](#) or neuromuscular disease, an individual may require assistance to cough using manual techniques or a medical device.
- Manual assisted cough is the compression of the diaphragm by another person to replace the work of abdominal muscles in order to facilitate a cough. A medical device can be used to assist coughing effort by a positive pressure breath followed by a rapid change to negative pressure.

# Additional Training

## Peg Feeding



# Additional Training

## PEG Feeding

- A **percutaneous endoscopic gastronomy (PEG)** tube is used to deliver nutrition, hydration and medicines into the individual's stomach.
- The PEG tube is inserted directly through the abdominal wall into the stomach. They are suitable for long term use. A Flange, Dome, or inflated balloon anchors the tube in place on the inside and prevent the leakage of gastric juices or food.
- Individuals will require a tube if they are unable to swallow safely, putting them at risk of aspiration of food, and drink and medicines into their lungs.

# Additional Training

## Suctioning



# Additional Training

## Suctioning

- Suctioning is a procedure that removes excess secretions from the mouth and throat (oropharynx), from the nose and throat (nasopharynx), and from the windpipe (trachea) using a mechanical aspiration device (Suction machine).
- The primary indication for suctioning the patient at home is the patient's inability to adequately clear the airway by coughing

# Additional Training

INSERT ALL LINKS YOU RESEARCHED, UTUBE, COMPANIES ETC. HERE

THANK YOU FOR ATTENDING