



**Muscular Dystrophy Ireland**  
**National Survey 2009**  
**Report of Findings**

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## **Introduction and Summary of the Main Findings**

In September 2009, Muscular Dystrophy Ireland (MDI) ran a survey that was open to all people with muscular dystrophy and related neuromuscular conditions. This survey enabled people to highlight their experiences in relation to medical services, accessing equipment and adaptations, respite and personal assistance, and education, training and employment.

Neuromuscular conditions affect adults and children, males and females. Most of them are genetic. They are characterised by the progressive weakening and wasting of the muscles but the rate of this progression and severity of the condition varies according to the specific condition and between individuals. People with neuromuscular conditions require a multidisciplinary approach to their medical care, as well as various aids and adaptations, assistance and support to enable them to live an independent life of their own choosing.

This survey highlighted the following issues:

- Applying for entitlements, equipment and housing adaptations can be a long, slow process
- 56% of people with neuromuscular conditions are not registered on the National Physical and Sensory Disability Database
- Adults with neuromuscular conditions are less likely than children to attend specialist medical services for assessment and management of their condition
- People who do not attend a muscle clinic or neurologist are less likely to be referred to other specialist medical services which have the potential to improve their quality of life
- Overall medical care is generally rated above average but for some there is still a lot of improvement to be made
- 47% of people have experienced delays in accessing essential aids and appliances, with 18 people waiting for 6 months and 28 for one year and over
- Due to difficulty in accessing a Local Authority Grant for 34 people and the high cost of adapting a home, some are living in unsuitable housing
- 22 people need more Personal Assistant hours, a total need of 16,796 extra hours per year
- 115 people rely on family and friends for their care. 30% of adults report that this has had a negative impact on their family relationships
- 30% of people have had a respite break in the last 5 years, mainly at a break or camp organised by a voluntary organisation
- 7 parents report a reduction or removal of the Special Needs Assistant support in schools
- 42% of adults with neuromuscular conditions are unemployed
- 61% believe that living with their condition has negatively affected their ability to earn an income
- 65% believe that living with their condition has negatively affected their quality of life.

## Method

A questionnaire was developed by MDI to reflect some key issues:

- **Medical services:** access to muscle clinics, consultation with relevant specialists including neurologists, respiratory and cardiac physicians and access to community services such as physiotherapy and occupational therapy.
- **Equipment and adaptations:** access to aids and appliances, housing adaptations, waiting times.
- **Respite and Personal Assistance:** if someone requires assistance, do they have a PA service or if they have one, is it sufficient? Is any respite available to them?
- **Education, training and employment:** have people experienced any barriers to employment or further education? Has their condition had any effect on their quality of life?

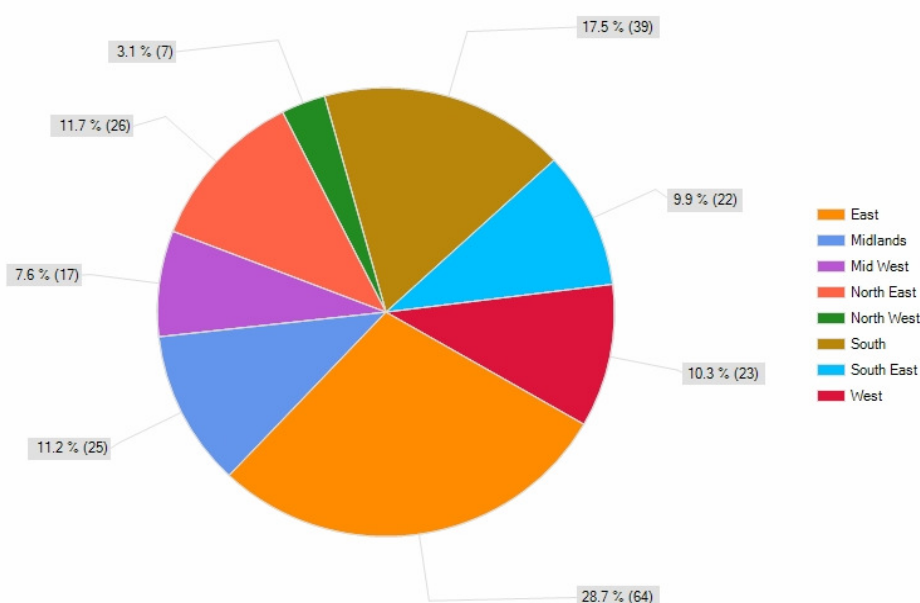
The questionnaire was composed mainly of questions that could be answered using tick boxes to minimise the amount of time people would have to spend completing it, but there was room for people to make further comments if they needed to. A copy of the questionnaire is included in the appendix on page 28.

The questionnaire was sent to all adults and parents of children with the condition who are registered with MDI as members. This was a total of 530 individuals. A stamped addressed envelope was included to assist people to return their completed questionnaire. The survey was also available online, to assist people who are unable to write or prefer to use a computer. The Myasthenia Gravis Association contacted their members to highlight the survey, and it was also available via a link on the MDI website to allow people who have neuromuscular conditions but are not members of MDI, to make their views heard as well.

## **SECTION 1: GENERAL INFORMATION**

A total of 227 people responded to the survey. 144 of those, or 63.7%, were adults who had a neuromuscular condition. 67, or 29.6% were parents of children with the condition and the remaining 15 or 6.6% were another family member or carer. One person did not respond to this question.

Respondents to the survey were representative of the broad age range that would be expected with a group of conditions that affect adults and children. The total under 18 years of age was 77, with 131 between 18 and 65 years and 19 over 65 years. Respondents also came from all regions of Ireland as outlined below:



There was quite an equal divide between those who classed themselves as living in an urban area (115 or 51.6%) and those who chose a rural area (108 or 48.4%).

People who responded represented the full spectrum of neuromuscular conditions. The condition that most respondents have is Duchenne muscular dystrophy, which is the most common type of MD (38 people), followed by myasthenia gravis (36 people), myotonic dystrophy (25 people) and Charcot-Marie-Tooth (23 people). People with rarer neuromuscular conditions were also represented, as demonstrated in the table in the appendix on page 27.

Respondents were asked if they were in receipt of a medical card, a long term illness card or a primary medical certificate. 70% of the 227 respondents (160 people) do have a medical card and 24% (54 people) have a long term illness card. Sixteen have applied for the medical card and been turned down, and nine have been turned down for the long term illness card. The main reasons

given were that the household income was too high, and that their condition (myasthenia gravis in four cases) is not included in the long term illness scheme. Some people were successful in appealing the decision not to grant a medical card but for one person this involved intervention by their local TD and for another it was a ten year process:

***“In 1998 the child was refused a personal medical card on the grounds of parental income. Appeal was refused also. Application was finally approved in November 2008.”***

Even after being granted the medical card, some people reported that they have to undergo extensive assessment every two years, so the card is never guaranteed. The person's condition meanwhile will not improve and is likely to progress further.

36% of respondents (82 people) have the primary medical certificate, which is necessary for claiming tax back on the cost of adapting a vehicle for a person with a disability. Nine people had applied for this but been refused. All of them stated that they had been told they were or their child was “too able”.

***“Primary medical cert originally refused prior to loss of muscle in legs – not disabled enough!”***

***“Child was not in a wheelchair and therefore did not qualify.”***

***“I applied for primary medical cert and was refused because my daughter didn't use a wheelchair at the time. She uses one now.”***

While there have to be rules and conditions in order to assess people for entitlements, it can be frustrating for people with a progressive condition who know that their mobility is decreasing and would like to plan ahead as it takes time to purchase accessible transport, yet they cannot do this.

### **The majority of people with neuromuscular conditions are not registered on the National Physical and Sensory Disability Database**

The last question in this section asked if the person with the neuromuscular condition was registered on the National Physical and Sensory Disability Database. 55.6% of respondents (124 people) are not on the database in comparison to 44.4% (99 people) who are. Four people do not know if they are on the database. This suggests that the NPPSD has insufficient participation to be utilised as a planning tool for service delivery, as over 50% of people with neuromuscular conditions in this survey are not registered on it.

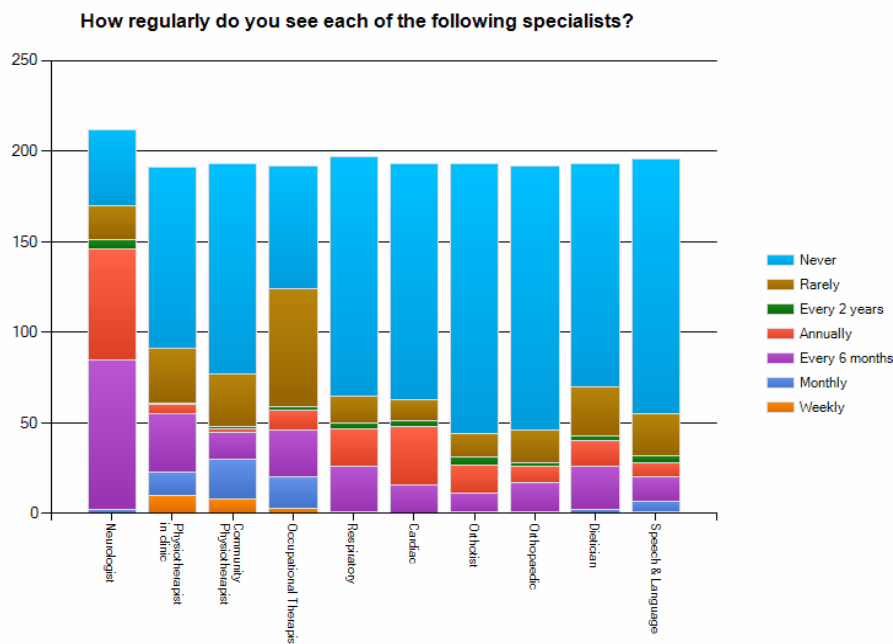
## **SECTION 2: MEDICAL SERVICES**

There is no cure for people with neuromuscular conditions and for most, no specific treatment available. However, management of the condition by a multidisciplinary team improves quality of life and can effect the progression of symptoms.

### **32% of adults never receive a neurology assessment**

There are two main muscle clinics in Ireland for people with muscular dystrophy and related neuromuscular conditions. The children's clinic is in the CRC and the adults' clinic is in Beaumont Hospital in Dublin. 65% of children whose parents responded to this survey (50 people) attend the CRC muscle clinic, while 13 children attend a muscle clinic in another location, such as Enable Ireland in Cork, Our Lady's Hospital in Crumlin, or Newcastle and London in the UK. Nine children do not attend a specialist muscle clinic but six do attend another neurologist for assessment. Only 3.8% of children (3 in total) do not receive any neurology care. It is a different situation for adults (those aged over 18). 31% of adults (46 people out of 150 who replied to this question) attend the muscle clinic in Beaumont Hospital, while 9% (14 people) attend another clinic. 55% of adults (82 people) do not attend a specialist muscle clinic but out of these 23% (35 people) do attend another neurologist. However, this leaves 32% of adults (47 people) who do not access any neurology care. When asked why they did not attend a neurologist, the answer that 56% of the respondents gave (33 out of 50 adults and children who do not attend one) was that they did not believe that the neurologist could help. 10% (6 people) cited long waiting lists as their reason for not attending, while 12% (7 people) mentioned the distance that they have to travel. Four people feel as if they get sufficient care from other specialists and do not need to attend a neurologist.

The diagram below shows how often respondents see a selection of specialists.



It is important to point out that not everyone with a neuromuscular condition will need to see all the specialists outlined in the above diagram. However, most people with muscular dystrophy or a related condition should benefit from physiotherapy, most need to access an Occupational Therapist at some stage, and as heart and respiratory issues can be common across many muscle conditions, it is important to have your condition monitored so you can get a referral to a respiratory or cardiac specialist if it is necessary.

**Adults less likely to receive specialist services such as physiotherapy**

Overall, 44% of respondents (100 people) never see a physiotherapist in the clinic and 51% (116 people) never see a physiotherapist in the community. When we look at these figures broken down into adults vs. children, adults with neuromuscular conditions are less likely to see a community physiotherapist. 67% of adults (84 out of 125 who answered this question) said that they never see one, as opposed to 48% of children (29 out of 61 whose parents answered this question). Likewise, 42% of adults never see an Occupational Therapist (53 people) as opposed to 21% of children (13 people). It may be the case that children are more likely to see the full range of specialists when they attend a multidisciplinary muscle clinic. The muscle clinic for adults however, is not multidisciplinary. It is also possible however, that there is a variation in the severity of the condition between adults and children. Some of the adults could have a less progressive form, which means they do not need to access as many services. However, when we just look at the people who use wheelchairs, both manual and powerchairs, which could be a measure of those who have a more severe type of condition, there are still 53% (58 out of 109 people who use wheelchairs) who never see a community physiotherapist, 57% (62 people) who never see a respiratory physician and 61% who never see a cardiologist (66 people).

**People who do not attend a muscle clinic or neurologist are less likely to be referred to other specialist medical services**

There is a higher number of people stating that they never see these specialists among those who do not attend a muscle clinic or a neurologist for assessment, as in the table below.

**Adults and Children who do not attend specialist medical services**

<b>Specialist</b>	<b>50 not attending muscle clinic or neurologist</b>		<b>164 who are attending muscle clinic or neurologist</b>	
Physiotherapist in the clinic	31	62%	69	42%
Community physiotherapist	30	60%	86	52%
Occupational Therapist	23	46%	45	27%
Respiratory physician	38	76%	94	57%
Cardiologist	35	70%	95	58%
Dietician	39	78%	84	51%

Some of the comments made in relation to this were:

***“My son is eight months old and seems to have fallen through every crack in the system. Having been diagnosed as a floppy baby at birth, no referral was made for him to an early intervention forum. I had to arrange all of this personally, and it is only now that he has been picked up by community services.”***

***“I think the lack of access to physiotherapy for people with muscular dystrophy is a joke.”***

***“I receive hydrotherapy weekly in a hydrotherapy pool. Physiotherapy rarely received since hydrotherapy began. It seems to be an either / or situation. No ‘hands on’ physio received for about ten months. No services during July and August. All services have to be constantly ‘chased up’ to ensure they stay available. The battle for services is a constant one.”***

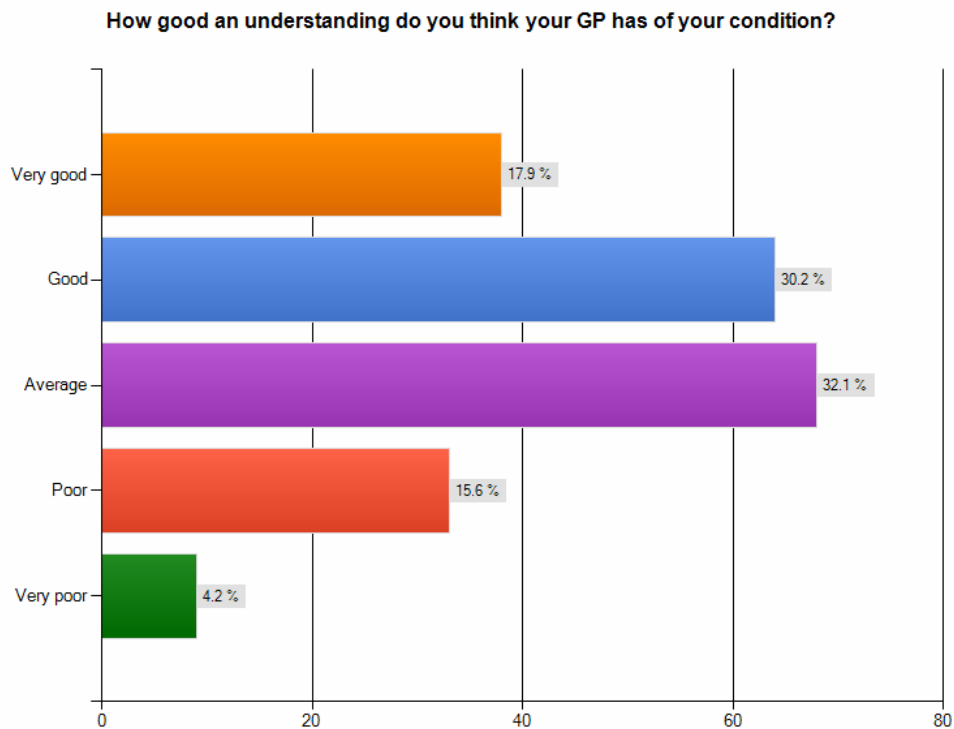
***“I benefited greatly from hydrotherapy while in rehabilitation, but have not been able to access hydrotherapy here and would really like to take up this form of exercise / physio again.”***

**Need for education and training of GPs in managing neuromuscular conditions**

In relation to GPs, respondents were asked how good an understanding they thought their GP had of their condition. It is encouraging that the majority of people felt that their GP had a good or very good understanding (102 people out of 212 who replied to this question, or 48%), with another 32% (68 people) saying average. However, 20% of respondents (42 people) rated their GP as having a poor or very poor understanding of their condition. We cannot expect

GPs to be experts on all conditions, but some understanding of the person's needs is very important. One mother of a child with muscular dystrophy said:

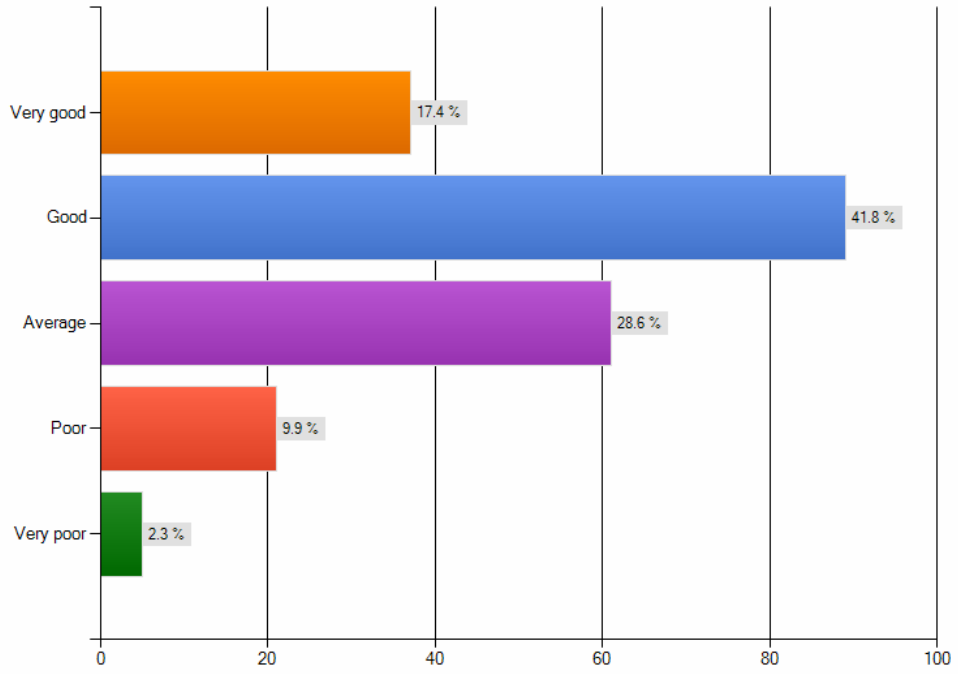
***“GP has very little knowledge of the condition but is very considerate to our needs.”***



**Overall medical care rated above average but there is still improvement to be made for some**

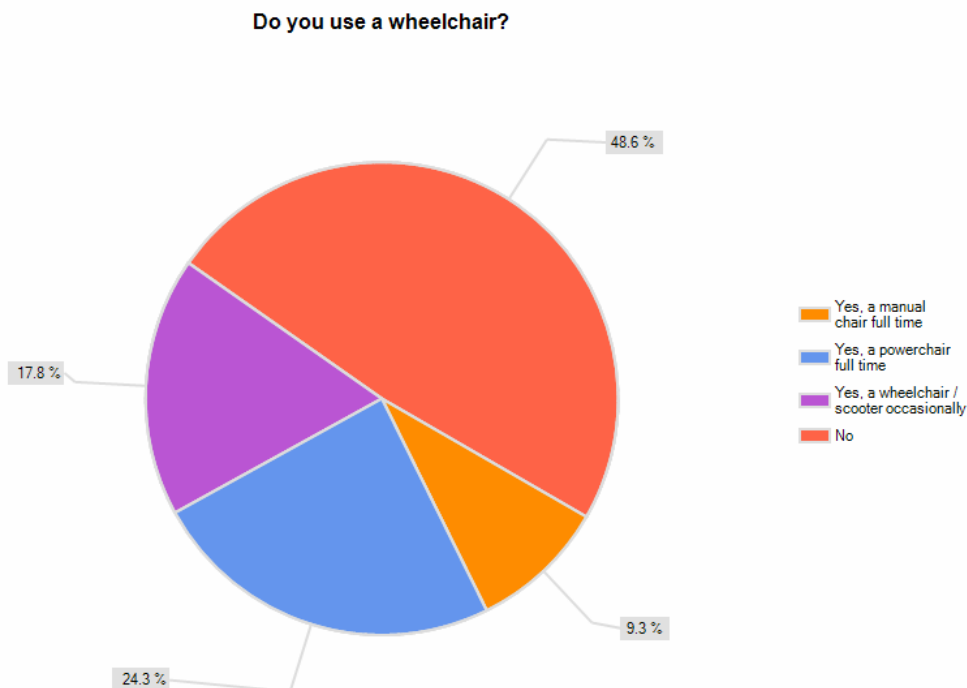
Respondents were also asked how they rated the overall medical care that they receive. Again, it is very encouraging that an even higher majority, 126 people out of 213 who replied to this question, or 59% rated their overall medical care as being good or very good, with only 12% (26 people) rating it as poor or very poor. Even though this is encouraging however, the fact that even as many people as 26 rate their care so poorly shows that there is still work to do to increase the quality and availability of services to all.

How would you rate the overall medical care that you receive?



### **SECTION 3: EQUIPMENT AND ADAPTATIONS**

Over half of the respondents stated that they currently use a wheelchair or scooter, and of these, 65% (72 people) use a manual or powerchair full time, as in the diagram below.



Some of the people who said that they do not currently use a wheelchair pointed out that as their condition progresses they or their child will or might need to use one. This also applies to questions relating to equipment needs and housing adaptations – those who do not need them now will in the future.

#### **Access to assisted ventilation: 3 people need a BiPAP but are still waiting to receive one**

The majority of people do not need to use assisted ventilation such as a BiPAP machine at this time, but 17% (36 out of the 216 who answered this question) do need to use one. This is fully funded for all but one person who has to pay for the machine under the Drugs Payment Scheme. However, three people stated that they have been informed that they need to use a BiPAP but they have not received one yet. They said:

***“I don’t have a breathing machine but was told I need one and never received one as I could not afford it.”***

***“Need BiPAP but have not received it.”***

***“Still waiting for BiPAP – 10 months so far.”***

Waiting for over ten months for assisted ventilation is concerning, due to the progressive nature of neuromuscular conditions. If someone needs to use

equipment such as a BiPAP, they need to start using it as soon as possible in order to get the maximum benefit. When their respiratory function is affected, they are at greater risk of developing infections and in some cases this can lead to prolonged hospitalisation. This has a negative effect on the health of the person but is also a greater cost to the state.

### **Delays in receiving essential aids and appliances**

47% (98 people out of 209 who answered the question) said that they have experienced problems accessing equipment and for 32% of those, there was difficulty in accessing an Occupational Therapist, which was generally perceived as being due to cutbacks and a problem with OTs leaving but their position not being replaced. Eight people were waiting for six months to one year to see an Occupational Therapist, two were waiting over two years and one person said that they had never seen one:

***“I have never seen an OT. None available (cutbacks) since I was diagnosed (about six years).”***

While ten people said that they waited for under three months to get the equipment that they need, eighteen waited for six months, twenty for one year and eight over one year. Additional comments that were made include:

***“Ordering of equipment at HSE level very poor. From time of processing orders to awaiting approval to delivery of same.”***

***“I believe that more support could be given by OTs, particularly around equipment. However, there may be an alternative to this if direct payments become available and individuals were allowed to purchase the necessary equipment which is needed.”***

***“I was in touch with the Community OT after a hospital stay. Visits ceased after some time and I later needed contact again but had to start as a new patient and wait a very long time.”***

The situation varies from region to region however, and some people have had very good experiences:

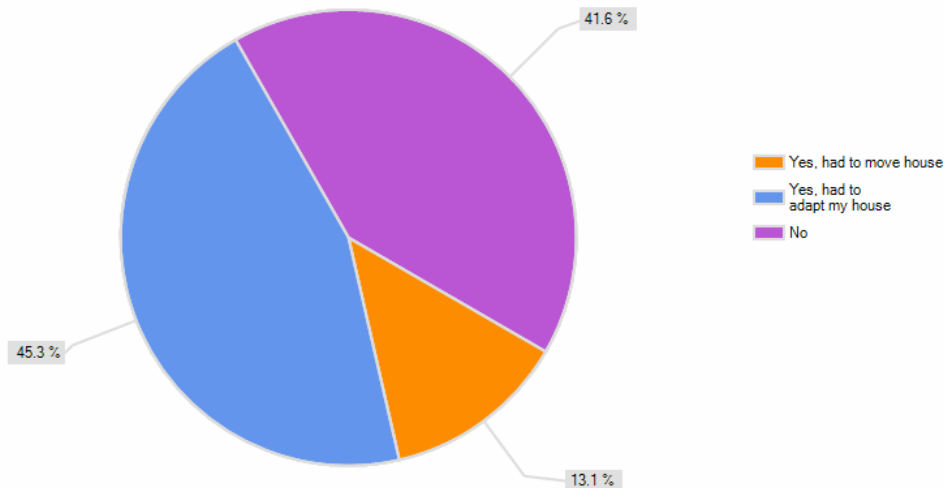
***“Can phone OT when anything is needed.”***

***“Occupational Therapists move very quickly through jobs, however, when you get a good one they are worth their weight in gold.”***

### **The majority of people need to move house or adapt their home to make it suitable for their needs**

58% (125 people out of 214 who replied to the question) said that they have had to move house or adapt their home because of their condition, as in the diagram below. It should be pointed out however, that some of those people who have not yet had to adapt their house, will need to do so in future because of the progressive nature of neuromuscular conditions.

Have you had to move house or adapt your home because of your condition?



### **High cost of adapting a home**

64% (74 out of 115 people who have carried out adaptations on a new or existing house) received a grant from the Local Authority towards the cost of the work. However, for 60% who received the grant, it was not sufficient to cover the cost of the actual work that they needed. For one person at least, this came to an additional €20,000 that they had to pay themselves. One person said that they could not afford to carry out the necessary adaptations due to the difference between the grant awarded and the quotations they were getting for the work to be done:

***“Work has not been done. Need to build disabled person’s bedroom / bathroom as existing rooms unsuitable. Grant €20,000 approved in 2006 but because of difficulty getting quotations and those that we did get were in the region of €70,000 to €100,000, we could not afford to go ahead with the work and it remains undone.”***

### **Difficulty accessing Local Authority grant to adapt the home**

34 people stated that they had applied for a grant but were turned down, either because the grant was now means tested and their income was higher than the limit or due to cutbacks in the Local Authorities. Others are still waiting on a decision. Comments included:

***“Applied for a grant but was refused as there was no funding available.”***

***“Four year waiting list. Did not apply because of the waiting time.”***

***“Applied and have been waiting two years for a decision.”***

***“Grant not sufficient to meet cost of work especially as years go by and more adaptations need to be done but can only get one grant.”***

***“The grant system for house adaptations seems to be a farce as the council can just say they have no money but you are restricted to time if your child is about to go into a wheelchair and so cannot wait for funding.”***

5% (11 people out of 212 who answered this question) said that they are currently on the waiting list for council accommodation. Four have been waiting for 6 months to 1 year, four for 2-3 years, two for 5-6 years and one for 12 years. It is difficult waiting for housing for a number of years with a progressive condition and therefore changing needs. One mother of two daughters who both have a neuromuscular condition and use wheelchairs has a council apartment but it is no longer suitable for their needs. She said:

***“Waiting list for housing is the big issue. I am caring for two daughters with MD. I live in a ground floor two bed apartment and there is no space for them. The city council said that there is no bungalow and no grant if you decide to move to a house with bedrooms upstairs. No grant until 2010, you have to live there for 6 months before you can apply for the grant and it is not guaranteed. It’s not fair for all the family. I don’t have a lot of money to buy a house. I am caring for my two children, my husband helps only he works part time.”***

## **SECTION 4: RESPITE AND PERSONAL ASSISTANCE**

### **22 people require additional PA hours averaging 15 hours each per week**

38% (87 people out of 227) currently have a paid assistant or carer. 55% of those (48 people) have a Personal Assistant, 22% (19 people) have home help and 23% (20 people) have another carer, such as an assistant in school. The number of hours people get varies between 1-5 hours per week (14 people) to over 100 hours per week (7 people). The majority however, have less than 20 hours per week (34 people, with 17 getting over 20 hours and the remaining 6 who answered this question only having assistance in school). 53% (31 people) reported that these hours were sufficient but 47% (27 people) said that they needed more hours. 22 of the people who needed more hours estimated how many extra hours would be sufficient. The estimates varied between an additional 5 hours per week up to 90 extra hours per week, but the average was 15 extra hours per week per person. This would equate to 323 hours per week or 16,796 additional Personal Assistant (PA) hours per year for 22 people. Over time with the condition progressing, people will require an increase in PA hours, and more people will need to access the service as many of the children represented in this survey will need a PA as they get older. One person also reported that it is difficult to estimate the number of hours that would be required, as for them, 18 hours would be sufficient if they were living with their parents, but to live independently they would need a lot more support.

### **The benefits of a PA service**

The importance of a PA cannot be understated. When a person requires assistance because of their disability, not getting the support that they need means that they have difficulty accessing further education, work and the ability to earn their own income, social opportunities, living independently and travelling outside the home. Comments relating to the benefit of PAs included:

***“I moved into an apartment provided by a Voluntary Housing Association and having the personal assistance allowed me to do this.”***

***“When I was first ill MDI provided support in the form of a PA as my wife worked full time. This was invaluable and we could not have managed without it.”***

***“My husband couldn’t accept work when my son was little as I was pregnant and unable to lift my son up or in and out of the car, so he needed to be there to do the lifting. He feels it did affect our ability to earn which in turn affects the standard of living. We could not access extra personal assistance hours so that was a very difficult time for us as a family.”***

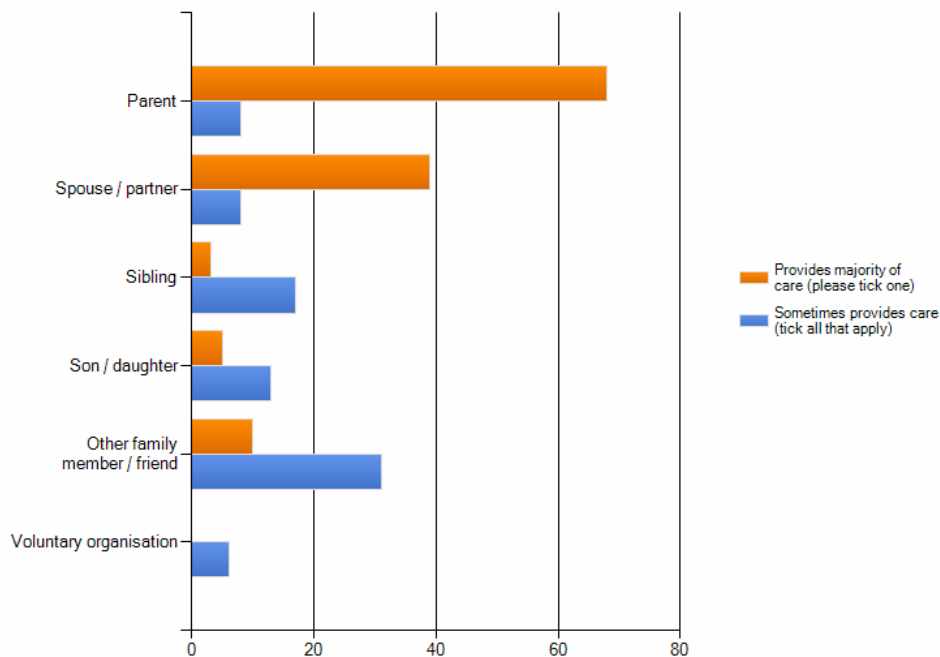
It does have to be said however, that there is an additional cost to the person when they have a PA. As one person said:

***“If you are lucky enough to have a personal assistant service, this may afford you the opportunity to work, socialise, travel etc, but you then***

***have to pay for two people for everything (e.g. admission tickets to cinema, concerts, travel tickets, accommodation, meals etc.). Therefore you now have a service, but you pay highly for the privileges!”***

115 people said that they have to rely on family and friends because they need assistance but do not have any PA hours or because the hours they have are not sufficient. The diagram below shows who provides the majority of care or assistance.

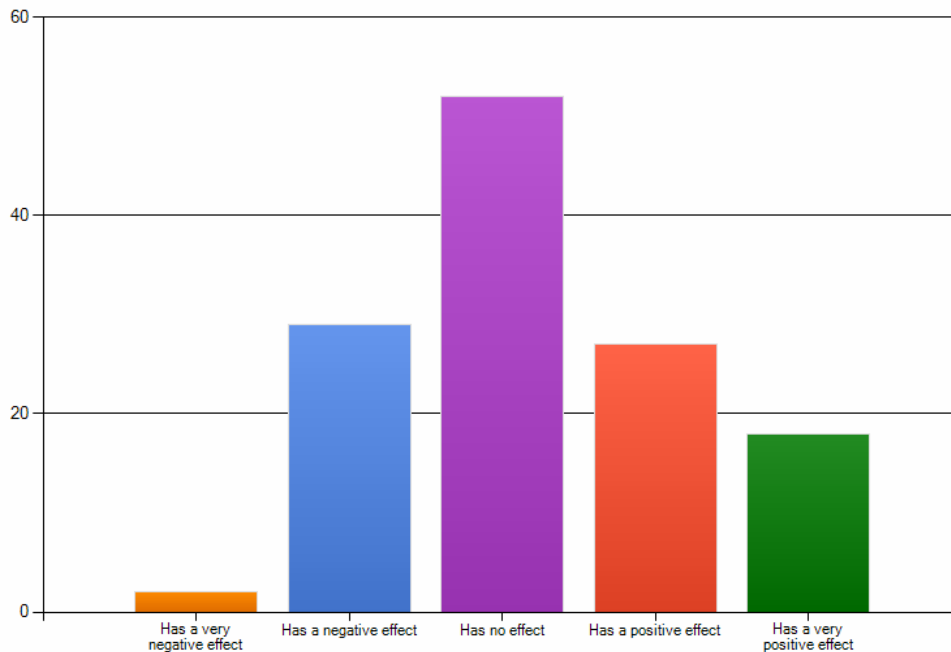
**If you need a Personal Assistant but do not have one or do not have sufficient hours, who provides the care or assistance that you need?**



**Effects on relationships when a family member is the primary carer**

When this is broken down into adults and children, the parent is the primary carer for 91% of those under 18 as would be expected. However, while 56% of those over 18 state that a spouse or partner provides the majority of care, 29.5% say that it is a parent who fulfils this role. When asked if this affects their relationship with the family member, most believed that it had no effect (40.6%) although 35% believed it had a positive or very positive effect and 24% stated that it had a negative or very negative effect.

If the person providing the majority of care that you need is a family member, do you think this affects your relationship with them?



There is a difference in how adults with neuromuscular conditions rated the relationship with the family member however and how parents rated the relationship with their child. Adults were more likely to rate it as being negative or very negative (30% or 23 people) while only 14% of parents (6 people) believed that it was negative. 30% of adults (23 people) believed that it was positive or very positive compared to 42% of parents (18 people). This could be because the relationship between a parent and a child is a caring relationship even when the child does not have a disability, and as one parent said:

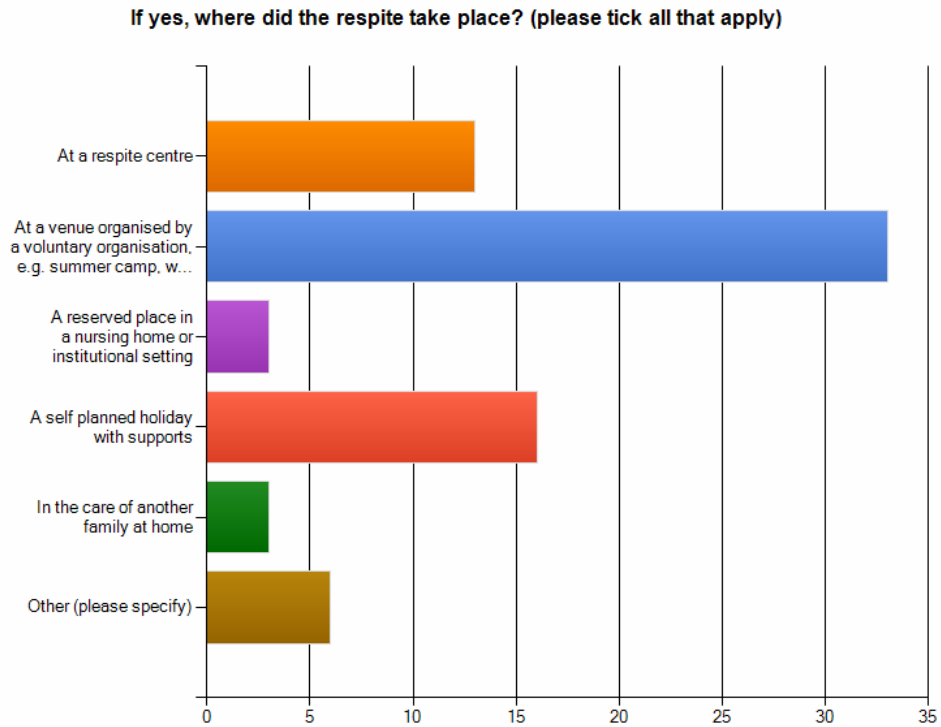
***“Have no other choice but to care for the child so you just get on with it.”***

Even if there are other family members or friends who would be available to help with care, other factors can intervene:

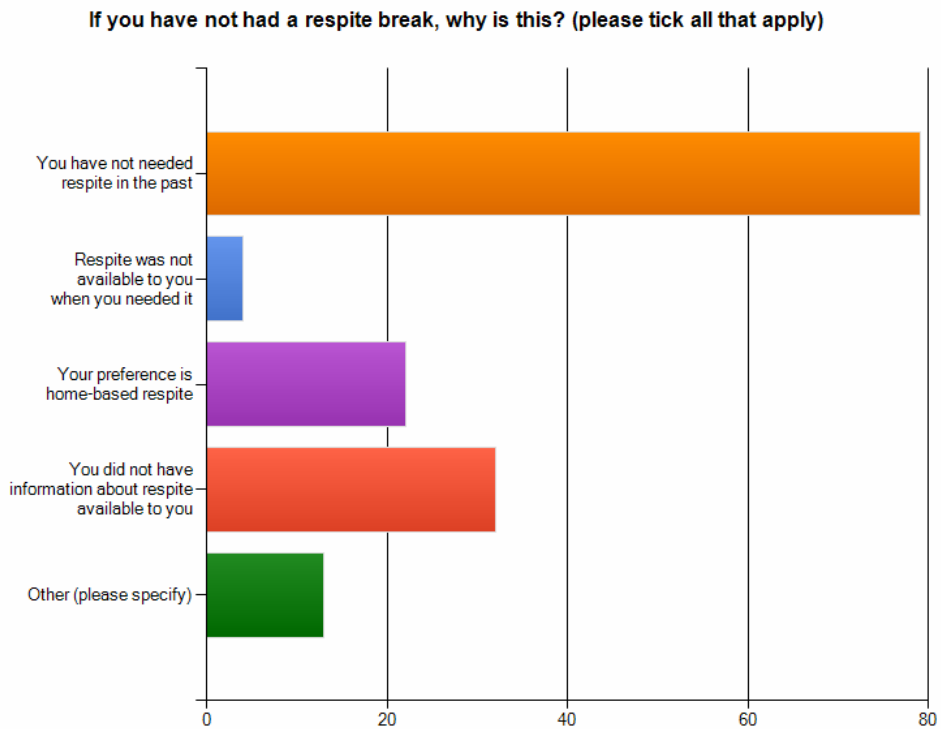
***“As a parent you feel guilty leaving. My son has epilepsy and family are afraid he will have a seizure even though they want to help.”***

There is a suggestion that some people may feel guilty for acknowledging that being a primary carer or being a person with a disability who has to rely on a partner or parent for their care can be difficult. It does not mean that you love your family member any less, or that you do not have extremely happy and positive times with them, but being a carer can involve personal and financial strain, and so a respite service is a very important support. Only 30% of people (59 out of 198 who responded to this question) have had a respite break within the last 5 years. For the majority of people, this was a summer

camp or weekend break organised by a voluntary organisation. The chart below shows the different types of respite that people have accessed.



The chart below shows the reasons why 139 people have not had a respite break.

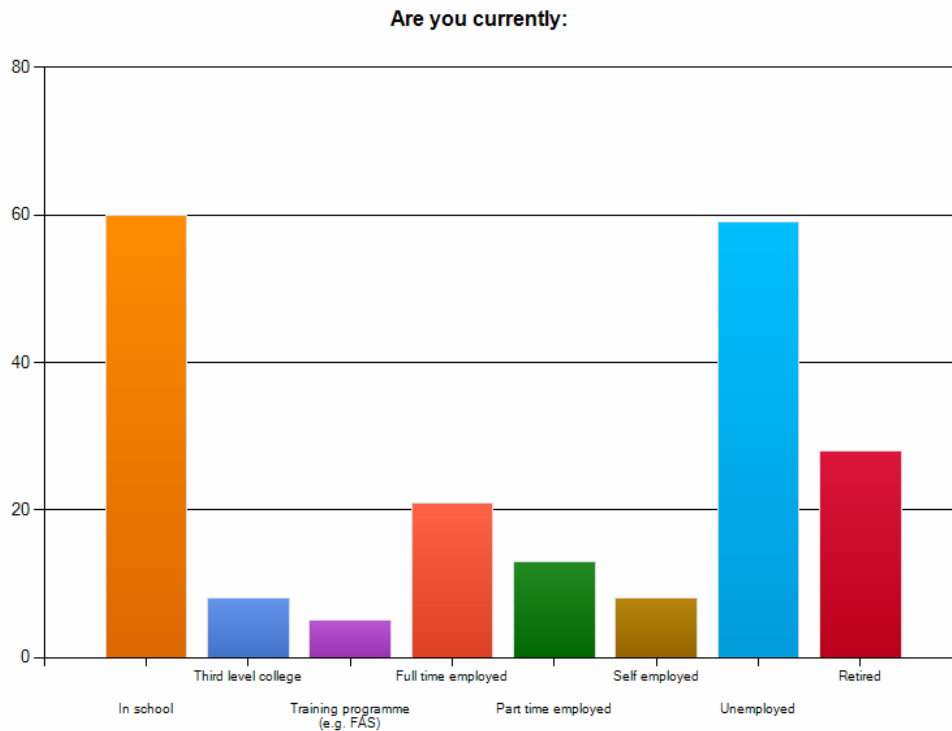


**People with neuromuscular conditions prefer respite in the home**

The majority of people who have not had a respite break have not felt that they needed one. However, the fact that 32 people said that they did not have information about respite available to them shows that there is work to do in publicising the respite services that people might be able to apply for. It is also apparent that the majority of people prefer to receive respite in the home or as a break away. Only 3 people reported that they have received respite in a nursing home or institutional setting and 22 said that they have not received respite as their preference is for home based respite. This should be taken into consideration by the Health Service Executive when allocating respite funding.

## **SECTION 5: EDUCATION, TRAINING AND EMPLOYMENT**

The chart below shows that the majority of people represented in this survey are either in school (30% or 60 people) or unemployed (29% or 59 people).



Parents of children who are currently in school were asked if their child has a Special Needs Assistant (SNA). The majority do (72% or 44 children) and 16% (9 children) do not need an SNA. Two people reported that their child had an SNA but the position has been removed due to cutbacks and 5 people reported that their child shares an SNA with other children in the school due to reduced funding.

### **42% of adults with neuromuscular conditions are unemployed**

When examining the statistics only from adults with neuromuscular conditions, 42.5% (57 people) are unemployed. This is much higher than the national average, which had risen to 12.6% unemployment in September 2009 when this survey was issued. 9% (12 people) are part time employed and 16% (21 people) are full time employed. A further 7% are in third level college or on a training programme (9 people). Some of these people who are unemployed reported that they would be able to work and would like to work, but that full time employment is unsuitable.

***“I was in full time employment but had to stop due to ill health.”***

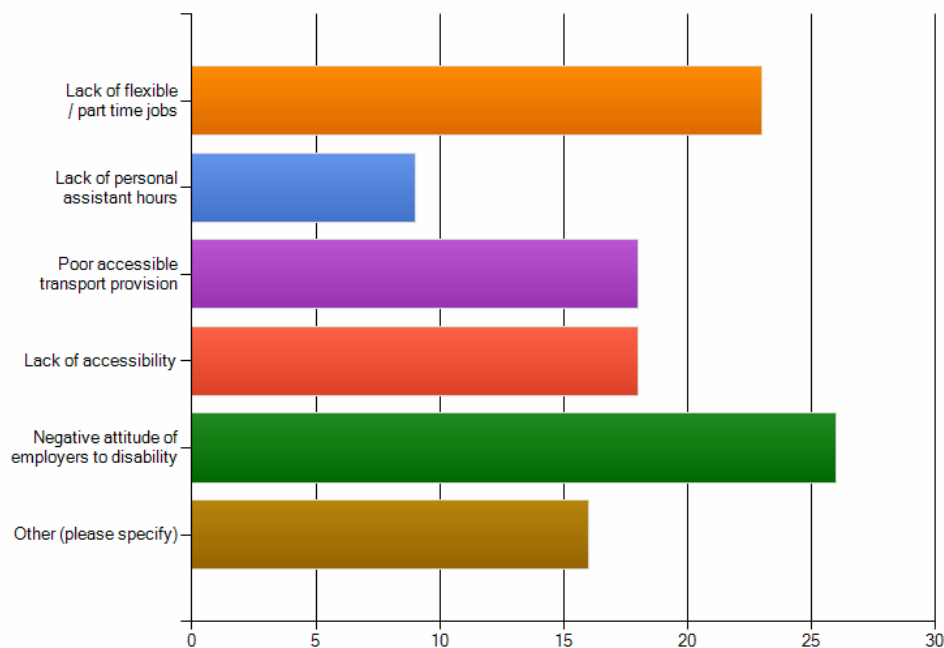
***“The illness has left me needing a lot of surgery since I was 18 and I am in a lot of pain daily and feel tired and drained all the time. I can just about walk and I am limited to how far I can walk and I get sick regularly. It has left me feeling very frustrated, annoyed and cranky as it has held me back in life. I am educated and would be able to work if I had***

***employment that was suitable and not a full 40 hours, if the employer understood that I suffer from MD and do get sick sometimes.”***

Adults with neuromuscular conditions were asked if they have ever completed a training course (e.g. through FÁS) to assist them to access employment. 24% (46 people) have completed a course but out of these, only 48% (22 people) were successful in gaining employment.

Adults were asked if they had experienced barriers that have stopped them from gaining employment. The diagram below shows that people have experienced problems due to a lack of part time or flexible hours (23 people), poor accessible transport provision (18 people) and lack of accessibility (18 people). 26 people reported a perceived negative attitude of employers to disability, which shows that there is still a need for disability awareness training.

**If you are of working age, have you experienced any of the following barriers to accessing employment?**



While some have had positive experiences with their employers, as one person stated:

***“It is not black and white but MD definitely makes it more of a challenge to secure employment.”***

**The majority of people with neuromuscular conditions believe that it has negatively affected their ability to earn an income and their quality of life**

61% of respondents (95 out of 155 who answered this question) feel that living with a neuromuscular condition has affected their ability to earn an income. Some of the comments in relation to this were:

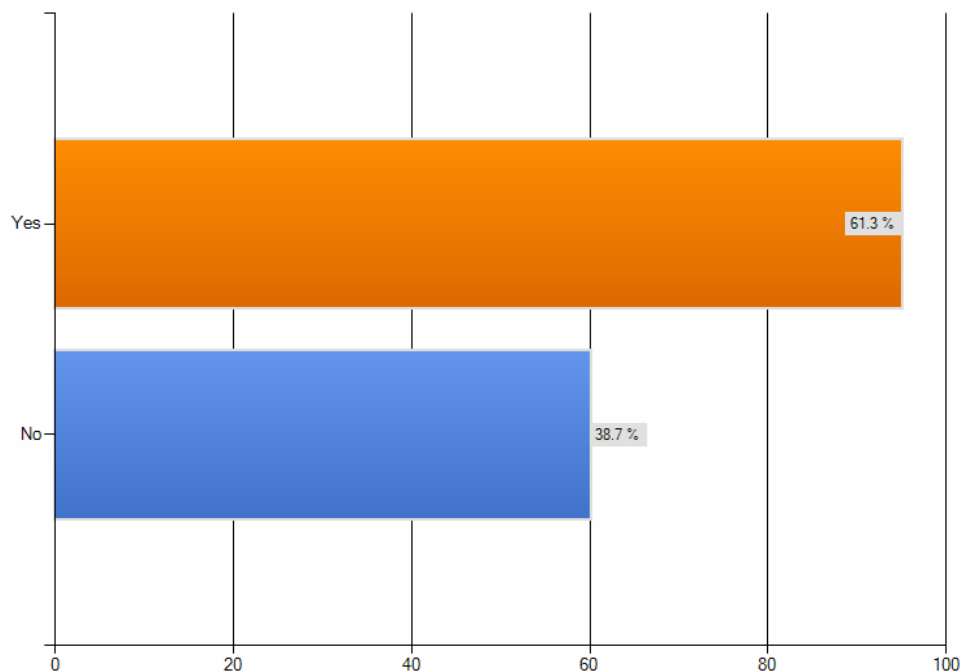
***“I have been in hospital such a lot that I am deemed unemployable.”***

***“I was once refused a computer job because of MD.”***

***“I would only be able to work for one hour, which is no good to anyone.”***

***“Unable to work because of MD but not insurably qualified to receive allowances. No income whatsoever!”***

Do you believe that living with MD has negatively affected your ability to earn an income?

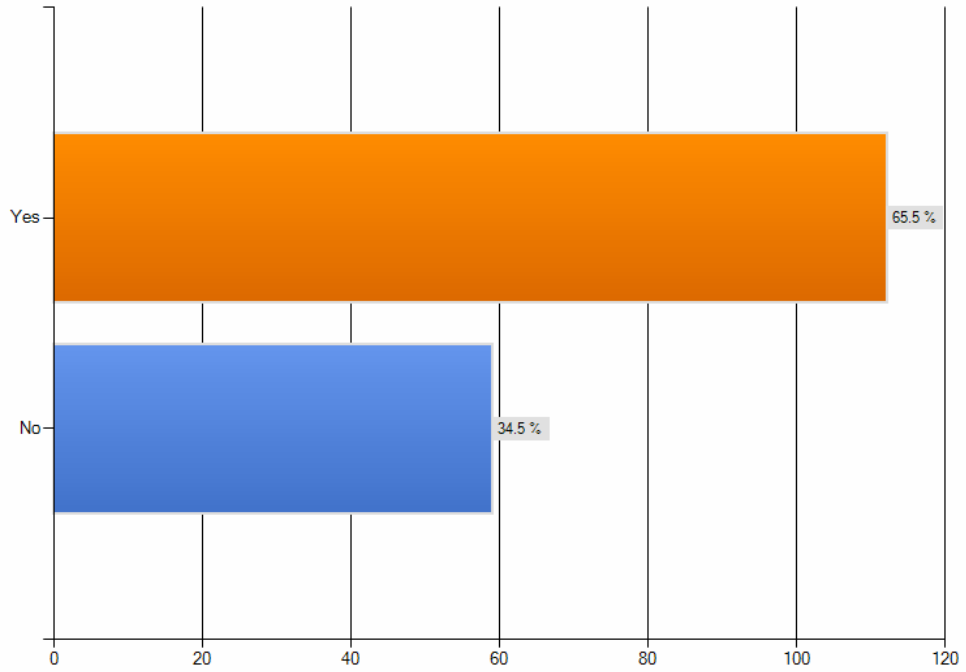


When asked if they believed that living with their condition had negatively affected their standard of living, 65% of respondents (112 out of 171 people who answered this question) stated that it had. One person said:

***“Living with MD has affected the quality of life both for myself and my family.”***

While it is difficult for parents to anticipate if their child’s condition will affect their ability to earn an income or their standard of living in the future, some reported that there are difficulties for the whole family when a child is diagnosed with a disability due to negative attitudes of employers or clients when they have to take time off if their child is sick or has hospital appointments, and if they have to stop work to care for their child or children. Support for carers is extremely important.

Do you believe that living with MD has negatively affected your standard of living?



## Conclusion

People living with neuromuscular conditions have to negotiate their way around a wide variety of medical specialists, various procedures to access entitlements, aids, appliances and adaptations, a struggle to get the assistance that they need and difficulty accessing employment. As one person said:

***“You need to have a strong voice to get things done.”***

There is still work to be done to ensure equal access to care and entitlements for all people with neuromuscular conditions, without them having to push and struggle for everything.

Adults with neuromuscular conditions require access to a multidisciplinary muscle clinic to ensure that they are able to access all the necessary specialists to manage their condition. The process for applying for aids and adaptations must be looked at, as people with a progressive condition cannot wait for over a year to receive the necessary equipment.

There is a great need for Personal Assistance – without PA hours, many people are relying on family and friends for their care and in the case of adults especially, this can have a negative impact on their family relationships.

The high levels of unemployment among adults with neuromuscular conditions must be addressed. There are a number of people who want to work and gain more independence but are unable to work full time hours, or require access to personal assistants and accessible transport.

With better access to medical and social services and promotion of support to assist people with neuromuscular conditions to live independent lives of their own choosing, we can reduce the 65% of people who believe that living with their condition has had a negative impact on their quality of life.

## **Acknowledgements**

Thank you to everyone who took the time to complete this survey.

Thanks as well to Karen Clancy, National Coordinator of the Myasthenia Gravis Association (Ireland) for bringing this survey to the attention of members of that organisation to ensure that we captured the views of people with a wide range of neuromuscular conditions.

## Appendix

### The Neuromuscular Conditions Represented in this Survey

Neuromuscular Condition	Number of People
Duchenne muscular dystrophy	38
Myasthenia gravis	36
Myotonic dystrophy	25
Charcot-Marie-Tooth	23
Spinal muscular atrophy	15
Limb girdle muscular dystrophy	15
Facioscapulohumeral muscular dystrophy	13
Congenital muscular dystrophy	7
Becker muscular dystrophy	6
Mitochondrial myopathy	5
Periodic paralysis	3
Oculopharyngeal muscular dystrophy	3
Scapuloperoneal muscular dystrophy	2
Friedreich's Ataxia	2
Bethlem myopathy	1
Nemaline myopathy	1
Central core myopathy	1
Dermatomyositis	1
Inclusion body myositis	1
Unspecified / unknown MD	26
Unspecified myopathy	3

**Total: 227**



## Muscular Dystrophy Ireland National Survey 2009

*Please tick the box or circle your preferred answer. There is room at the end of the questionnaire if you would like to make any additional comments.*

### **SECTION 1: General Information**

• **Are you:**

- A person with MD
- A parent of a child with MD
- Another family member / carer of a person with MD

• **Age of person with MD:** \_\_\_\_\_

• **What region do you live in?**

- East
- Midlands
- Mid West
- North East
- North West
- South
- South East
- West

• **How would you describe the area that you live in?**

Rural            /            Urban

• **What type of MD do you / the person with MD have?**

\_\_\_\_\_

• **Do you / the person with MD have any of the following:**

	Have this	Applied and was refused	Applied and waiting for decision
Medical card			
Long term illness card			
Primary medical cert.			

- If you applied for any of the above and were refused, what reason was given? Did you appeal the decision?

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- Are you / the person with MD registered on the National Physical and Sensory Disability Database?  
Yes / No

## **SECTION 2: Medical Services**

- Do you / the person with MD attend a specialist muscle clinic?  
 Yes, the CRC  
 Yes, in Beaumont Hospital  
 Yes, in another location (*please specify*) \_\_\_\_\_  
 No
- If no, do you attend a neurologist in another location?  
Yes / No
- How regularly do you see any of the following specialists?

	Weekly	Monthly	Every 6 months	Annually	Every 2 years	Rarely	Never
Neurologist							
Physiotherapist in clinic							
Community physiotherapist							
Occupational Therapist							
Respiratory							
Cardiac							
Orthotist							
Orthopaedic							
Dietician							
Speech & Language							

- If you do not attend a neurologist for assessment, why is this?  
 Long waiting lists  
 Distance to travel to neurologist  
 Belief that they cannot help  
 Other (*please specify*) \_\_\_\_\_
- How good an understanding do you think your GP has of your condition?

Very good                  Good                  Average                  Poor                  Very poor

• **How would you rate the overall medical care that you receive?**

Very good                  Good                  Average                  Poor                  Very poor

**SECTION 3: Equipment and Adaptations**

• **Do you use a wheelchair?**

- Yes, a manual chair full time
- Yes, an electric wheelchair full time
- Yes, a wheelchair occasionally
- No

• **Do you need to use a breathing machine, e.g. BiPAP?**

Yes / No

If yes, do you have to pay for this machine?

- No, it is fully funded
- Yes, I have to pay under the Drugs Payment Scheme

• **Have you ever experienced any problems assessing equipment?**

- Yes, difficulty accessing Occupational Therapist  
How long have you been / were you waiting? \_\_\_\_\_
- Yes, waiting time to get equipment  
How long have you been / were you waiting? \_\_\_\_\_
- Yes, other reason (please specify) \_\_\_\_\_
- No

• **Have you had to move house or adapt your home because of MD?**

- Yes, had to move house
- Yes, had to adapt home
- No

• **If you adapted your home, did you receive a grant from the local authority towards the cost?**

Yes / No

If yes, was this sufficient to meet the cost of the work?

Yes / No

If you applied for a grant but were refused, what reason was given?

\_\_\_\_\_

If you have applied for a grant but have not yet had a decision, how long have you been waiting? \_\_\_\_\_

• **Are you on the waiting list for council accommodation?**

Yes / No

If yes, how long have you been waiting? \_\_\_\_\_

**SECTION 4: Personal Assistant and Respite Services**

- **Do you have access to any of the following services?**

- Personal Assistant
- Home Help
- Other paid carer

- **If you have a Personal Assistant, how many hours per week do you receive?** \_\_\_\_\_

Are these hours sufficient?

Yes / No

If no, how many extra hours per week do you think you would need to provide a sufficient service? \_\_\_\_\_

- **If you do not have a Personal Assistant but need one, are you on a waiting list to access this service?**

Yes / No

How long have you been on the waiting list? \_\_\_\_\_

- **If you need a Personal Assistant but do not have one or do not have sufficient hours to meet your needs, who provides the care that you need?**

	<b>Provides majority of care (tick one)</b>	<b>Sometimes provides care (tick all that apply)</b>
Parent		
Spouse / partner		
Sibling		
Son / daughter		
Other family member / friend		
Voluntary organisation		

- **If the person providing the majority of the care that you need is a family member, do you think this affects your relationship with them?**

Has a very negative effect

Has a negative effect

Has no effect

Has a positive effect

Has a very positive effect

- **Have you or your family had a respite break in the last 5 years?**

Yes / No

**If yes, where did the respite take place? (please tick all that apply)**

- At a Respite Centre (please specify where) \_\_\_\_\_
- A venue organised by a voluntary organisation, e.g. summer camp, weekend break
- A reserved place in a Nursing Home or institutional setting
- A self planned holiday with supports
- In the care of another family at home
- Other (please specify) \_\_\_\_\_

**If no, is this because:**

- You have not needed respite in the past
- Respite was not available to you when you needed it
- Your preference is home-based respite
- You did not have information about respite available to you
- Other reasons (*please specify*) \_\_\_\_\_

**SECTION 5: Education, Training and Employment**

• **Are you currently:**

- In school
- Third level college
- Training programme (e.g. FÁS)
- Full time employed
- Part time employed
- Self employed
- Unemployed
  
- Retired

• **If you are completing this for a child who is currently in school, do they have a Special Needs Assistant (SNA)?**

- Yes
  - No, applied but was refused
  - No, had one but the position was removed due to cutbacks
  - No, do not need an SNA
- If you applied for an SNA but were refused, what reason was given?
- \_\_\_\_\_
- \_\_\_\_\_

• **What has been your highest level of education to date?**

- Primary
- Secondary
- Leaving cert (or equivalent)
- Third level
- Postgraduate

• **Have you ever completed a training course to help you find work, e.g. through FÁS?**

Yes / No

**If yes, did this assist you in finding work?**

Yes / No

• **If you are of working age, have you experienced any of the following barriers to accessing employment? (*please tick all that apply*)**

- Lack of flexible / part time jobs
- Lack of Personal Assistant hours
- Poor accessible transport provision

- Lack of accessibility
- Negative attitude of employers to disability
- Other (please specify) \_\_\_\_\_

• **Do you believe that living with MD has negatively affected your:**

Ability to earn an income	Yes	/	No
Standard of living	Yes	/	No

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**Do you have any additional comments that you would like to make regarding any of the issues raised in this questionnaire?**

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***Thank you for taking the time to complete this survey. Your support is very much appreciated.***

Please return the questionnaire to:  
Karen Pickering  
Information Officer  
Muscular Dystrophy Ireland  
71/72 North Brunswick Street  
Dublin 7  
Email: [karen@mdi.ie](mailto:karen@mdi.ie)