The Loop | Your Neuromuscular Resource Hub

COVID-19 and its impact on people with neuromuscular conditions

MUSCULAR DYSTROPHY FOUNDATION • AUSTRALIA

in conjunction with survey partners:

Muscular Dystrophy WA

Muscular Dystrophy Tasmania
making a difference today

Muscular Dystrophy Queensland
We're stronger together

md capital region muscular dystrophy

MUSCULAR DYSTROPHY NSW
BUILDING STRENGTH REACHING POTENTIAL

MUSCULAR DYSTROPHY AUSTRALIA

Table of Contents

Executive Summary and Recommendations

In **July 2020**, a three-week survey was conducted to identify the impact of COVID-19 on people with neuromuscular conditions, their families and carers. There were **223** participants from across Australia with an unexpectedly high weighting from Victoria and an older age demographic. The results suggest people with neuromuscular conditions faced similar emotional and isolation challenges related to COVID-19 to the general public but faced a greater impact in relation to mental health. This included a general deterioration in mental health in broad terms due to a variety of COVID-19 factors with feelings of anxiousness, disappointment and rising frustration.

Participants generally indicated that a variety of communication tools ranging from a standard phone call through to remote meetings online and social media were all useful, and there was little issue in getting medication during the pandemic although some found getting groceries and personal protective equipment difficult.

Survey respondents suggested that organisations dedicated to the neuromuscular community could improve their COVID–19 communications , provide regular updates and plan activities within their communities. Respondents suggested that the organisations should approach government for specific consideration to be given to people with neuromuscular conditions, provide PPE support and work towards a more effective quarantine system.

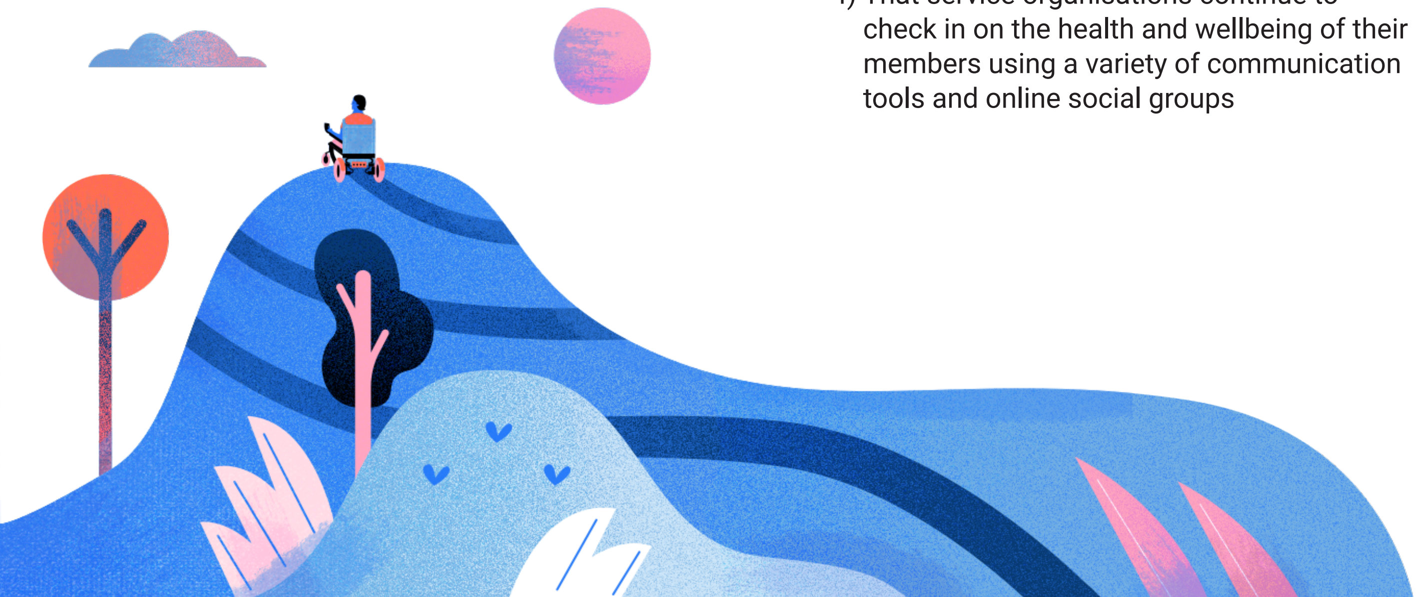
Recommendations based on the survey data and comments include:

1) That a mental health service is made available specifically to people with neuromuscular conditions and their families

2) That an awareness campaign is created to promote any existing services that can support the mental health of people with neuromuscular conditions

3) That service organisations which support people with neuromuscular conditions and their families organise the direct supply of personal protective equipment and help facilitate food delivery services

4) That service organisations continue to check in on the health and wellbeing of their members using a variety of communication tools and online social groups



1.0

Introduction and survey limitations

1.1 The need for a COVID-19 survey

In early 2020, Australia saw the arrival of the global COVID-19 pandemic.

A national approach to address the pandemic was formed and through February, March, and April, much of the country went into lockdown. This led to the virus being largely contained and controlled nationwide.

During May and June, as States & Territories began to reopen, the peak body neuromuscular organisations sought to identify how people with neuromuscular conditions, their families and carers were able to manage during the time and to identify any future issues should a second wave of COVID-19 occur.

As a result, an online survey was developed and conducted by Muscular Dystrophy Foundation Australia in partnership with Muscular Dystrophy Australia over a three-week period commencing 9 July and concluding 2 August.

The results highlight responses received by 223 participants, demonstrating how those living with neuromuscular conditions, their families and carers fared during the lockdown and the impact on their health and wellbeing.

The survey also contains both multiple choice and written responses. Supplementary to a better understanding of the needs of the neuromuscular community during the COVID-19 pandemic, the data may provide insight to improved service delivery to the neuromuscular communities during other socially isolated scenarios.

The survey questions were based on the following categories:

- **Demographics including age, gender, location, type of neuromuscular condition if applicable, Culturally and Linguistically Diverse (CALD), Aboriginal and Torres Strait Islander representation and employment status.**
- **Health and wellbeing before, during and reflecting on the pandemic**
- **Isolation during the pandemic**
- **Access to government and organisational services**
- **Access to mental health services**
- **Access to groceries, medicines and personal protective equipment**
- **Feedback on next steps that Muscular Dystrophy organisations can take to address key issues**

1.2 Limitations

While most of Australia has seen relatively low numbers of COVID-19 infections since the initial lockdown, Victoria has seen a second wave of COVID-19 with Melbourne returning to lockdown on 8 July and the borders between Victoria and other states closed.

As such, there was a significant difference between the experiences of Australians outside of Victoria which have seen a significant easing of restrictions and Victorians who had just re-entered lockdown during the survey period. As a result, some questions that focused on COVID-19 as being a past challenge may not be as applicable to Victorians, and likewise questions of health and wellbeing for Victorians should be taken in the context to a current pandemic lockdown rather than reflecting on a previous lockdown.

There is also a significantly larger number of participants from Victoria in the survey when compared with states of similar size. Although there is no specific data to confirm if this is a result of survey promotion or more interest in a COVID-19 survey, other responses anecdotally point to an increased awareness of how COVID-19 relates to their current situation and may therefore explain the increased participation rate.

Further examination of the data with advanced statistical tools may provide further guidance on how the Victorian experience differs from those in other parts of Australia.

A second limitation is the high number of participants who are retired or not in the workforce. As a result, it is difficult to draw any conclusions on aspects relating to the impact of employment by COVID-19 from this data. There is also a general weighting towards age demographics 45 years of age and older which may slant the responses accordingly.

A third limitation is the amount of information currently available in which to provide a basis of comparison. References to the general population are based on surveys and news media including:

- Fear of the coronavirus (COVID-19): Predictors in an online study conducted in March 2020: https://www.sciencedirect.com/science/article/pii/S0887618520300724
- Everyone Included: Social Impact of COVID-19 - United Nations: https://www.un.org/development/desa/dspd/everyone-included-covid-19.html
- COVID-19 cases by age group and sex– Australian Government Department of Health: https://www.health.gov.au/resources/covid-19-cases-by-age-group-and-sex

Further examination of the data may provide further guidance on how the Victorian experience differs from those in other parts of Australia

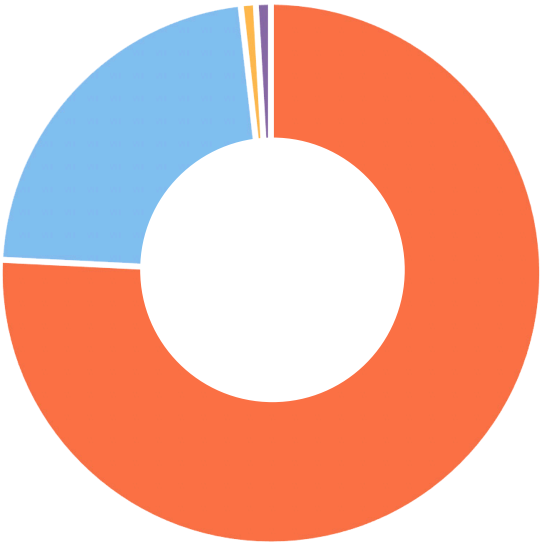
2.0

Demographics

2.1 Relationship between participant and neuromuscular condition

The response regarding the relationships of participants to a neuromuscular condition indicates that nearly all participants have direct experience to the topics discussed in the survey with three out of four participants living with a neuromuscular condition and most of the remainder consisting of family members of a person with a neuromuscular condition.

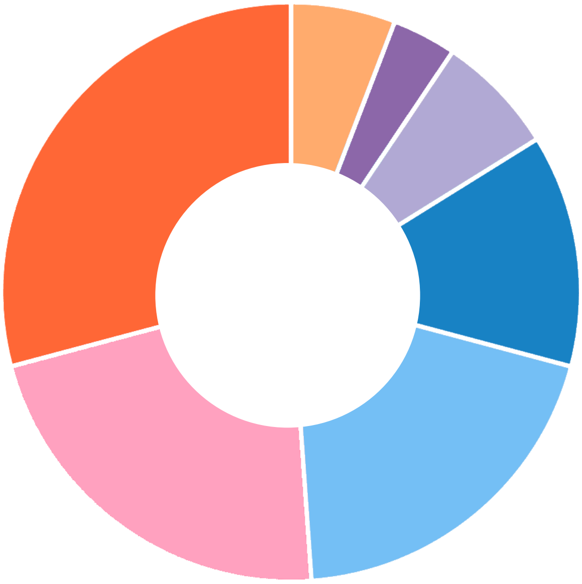
ABBREVIATION OF ANSWER	RESPONSES	
Living with NMC	75.78%	169
Family member	22.42%	50
Carer or support worker	0.90%	2
Question skipped	0.90%	2



2.2 Age demographic

The age of survey participants is heavily weighted towards older demographics with approximately 70% being aged 45 years or older and nearly 30% being over 64 years of age.

Although there is no specific evidence in this survey to suggest why this is the case, the weighting is broadly consistent with the ages of people that have been most affected by COVID-19. This may suggest why this older demographic participants may have greater interest in voicing their opinion on this topic.



AGE RANGE	RESPONSES	
0 - 17	5.83%	13
18-24	3.59%	8
25-34	6.37%	15
35-44	13%	29
45-54	19.73%	44
55-64	21.97%	49
65+	29.15%	65

2.3 Gender Demographic

The gender of participants has a slight weighting towards females, but the responses are close enough to suggest that both male and female viewpoints are well represented in the survey data.

GENDER	RESPONSES	
Male	46.19%	103
Female	53.81%	120

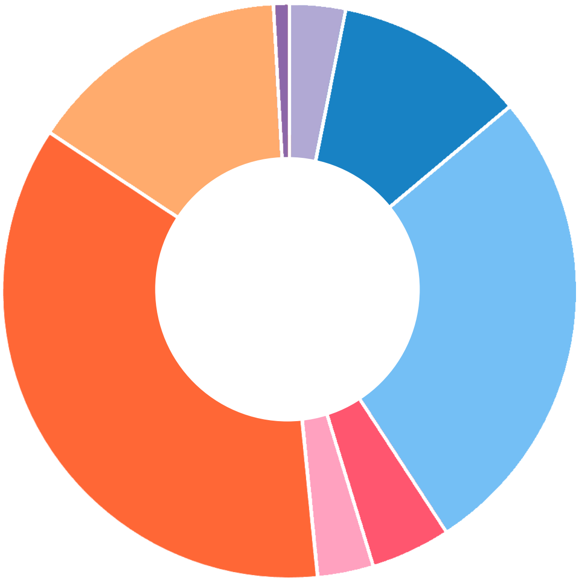
2.4 State location of survey participants

The location of participants is one of the more surprising results with nearly 36% of participants coming from Victoria.

This is particularly notable given that a similar population size of New South Wales was only approximately 11% of responses.

Some of this data is likely to be reflective of the promotion of the survey as indicated by South Australia which has a large population but does not have a specific muscular dystrophy organisation to promote the survey, but promotion alone is unlikely to explain all of the significant number of Victorians.

Anecdotally responses to other survey questions suggest that the recommencement of COVID-19 lockdown during the survey period may have generated increased interest in participation given the difference in COVID-19 infections during this time when compared with the rest of Australia.

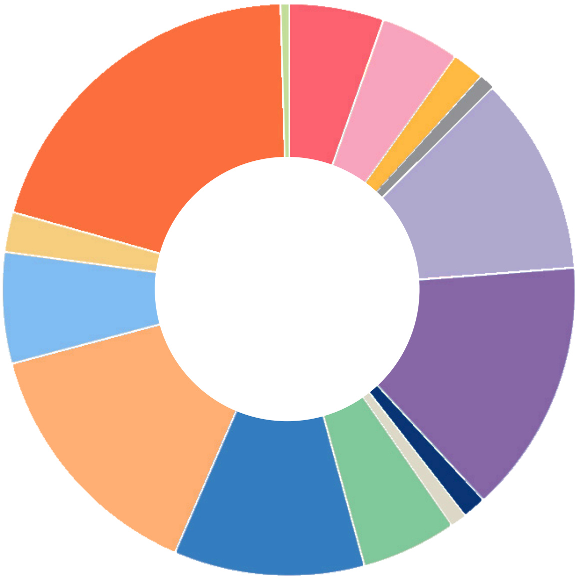


STATE	RESPONSES	
ACT	3.14%	7
New South Wales	10.76%	24
Queensland	26.91%	60
South Australia	4.48%	10
Tasmania	3.14%	7
Victoria	35.87%	80
Western Australia	14.80%	33
Question Skipped	0.90%	2

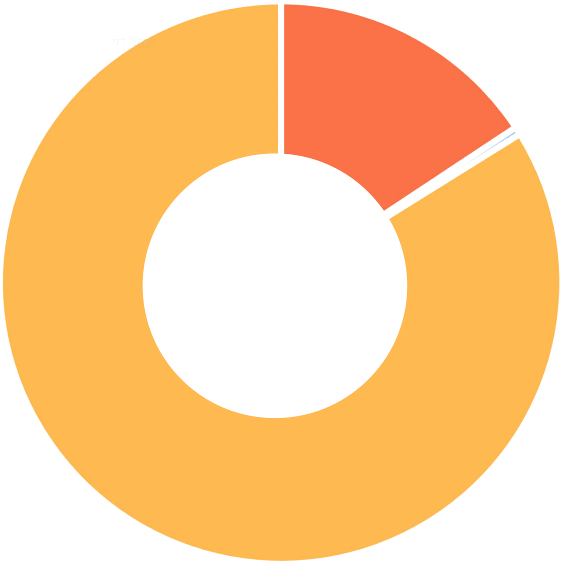
2.5 Type of NMC associated with participants

NEUROMUSCULAR CONDITION	RESPONSES	
Becker MD	5.38%	12
Charcot Marie-Tooth Disease	4.48%	10
Congenital MD	1.79%	4
Congenital Myopathies	0.90%	2
Duchenne MD	11.21%	25
Facioscapulohumeral MD	14.35%	32
Friedreich Ataxia	1.35%	3
Idiopathic Inflammatory Myopathies	0.90%	2
Inclusion Body Myositis	5.38%	12
Limb Girdle MDs	10.76%	24
Myotonic MD	14.35%	32
Spinal Muscular Atrophy Type 2, 3, & 4	6.28%	14
Undiagnosed/Awaiting Diagnosis	2.24%	5
Other	20.18%	45
Question Skipped	0.45%	1

The responses regarding the type of neuromuscular conditions were quite varied. Interestingly while 14 specific conditions were listed, the highest response is in the 'other' category highlighting the large number of neuromuscular conditions.



2.6 Culturally and Linguistically Diverse/Aboriginal and Torres Strait Islanders Responses



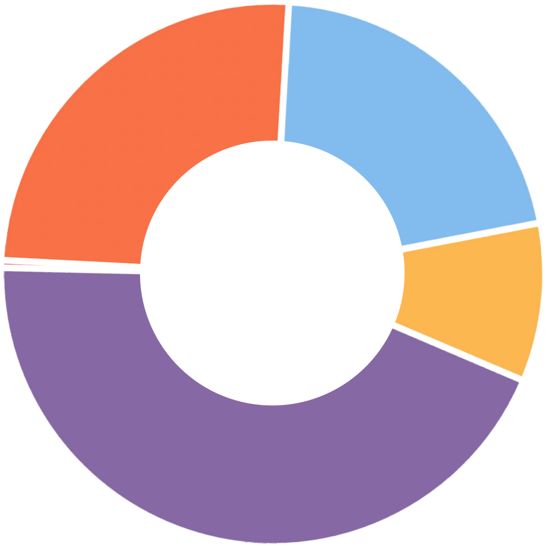
The question regarding CALD and ATSI audiences did not give an option for response "neither of the above". As such 83.86% of the respondents skipped this question. It is our assumption that those who skipped the question were neither of these classifications.

ETHNICITY	RESPONSES	
CALD	15.70%	35
ATSI	0.45%	1
Other	83.86%	187

2.7 Employment status before COVID-19 Pandemic

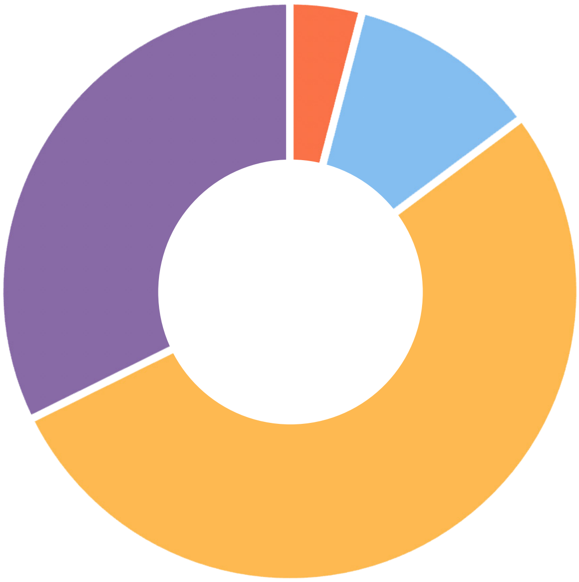
The age demographics are also reflected in the employment demographics with the largest response from people who are retired and only 25% being employed.

While employment and support for employment has featured heavily as a topic of conversation throughout the COVID-19 pandemic, the response suggests it will be hard to draw any definitive conclusions on this topic through this survey.



EMPLOYMENT STATUS	RESPONSES	
Employed	25.11%	56
Unemployed	21.08%	47
Student	9.42%	21
Retired	43.95%	98
Question skipped	0.45%	1

2.8 Change of employment at the start of COVID-19



In relation to changes to employment, there is a larger decrease than increase indicated in the data.

However, it is difficult to draw any conclusions from this given the low response rate relating to employment and the 5% increase indicated which contradicts general employment data.

EMPLOYMENT CHANGES	RESPONSES	
Increase	4.04%	9
Decrease	10.76%	24
Remain the same	52.91%	118
Question skipped	32.29%	72

3.0

Survey Analysis

In general terms, the survey results are similar to what would be expected by the general public with a few notable exceptions.

At the start of the pandemic, people with neuromuscular conditions and their families primarily felt anxious as well as disappointed and frustrated. Comments suggest that this is largely due to a fear of the virus and the unknown impact of COVID-19 at that time. As the pandemic became more familiar, the neuromuscular community shifted its focus.

While disappointment remained, anxiousness decreased and frustration became the dominant feeling. According to comments, this related primarily to a loss of routine, loss of independence, loss of access to regular services and basic freedoms due to needing to stay indoors.

While frustration, disappointment and anxiousness were the dominant emotional responses, feelings of loneliness, calmness, relief and anger were all represented but to a lesser extent.

The more positive emotions relating to calmness and relief were generally associated with people that felt their environment was a safe space and had found new ways to interact with others. These individuals reported creating a new routine within the 'new normal' of lockdown, largely happy with the activities being undertaken and the support being received.

An interesting finding from the data relates to the separation between loneliness and isolation.

Loneliness was not a dominant emotion for most people with neuromuscular conditions surveyed.

However, there was an acknowledgement that isolation was an issue: with few people indicating they were isolated before COVID-19, but over half confirmed that their isolation had increased compared with 35% that felt it stayed about the same.

Comments suggested that that while isolation did not directly contribute to a change in loneliness, it did contribute to other frustrations for example; a loss of independence and access to routines and services.

In relation to support during COVID-19, the question was asked as to which type of communication was most useful to people with neuromuscular conditions.

The overwhelming answer was basically 'all of them'. Keeping connected with others was a high priority during COVID-19 with live video catchups (e.g. Zoom, House Party or Facetime), social media (e.g. Messenger, Snapchat or Instagram), emails or a simple phone call all being popular choices for keeping in touch during the COVID-19 pandemic.

However, government and NFP agency support was more limited with 29% of respondents skipping the question, suggesting that more work may need to be done to ensure that people with neuromuscular conditions are aware of the services available to them.

The number that skipped question 18 is even more concerning given most other non-written questions had a relatively low rate for being skipped and that most people likely came across the survey via promotion from a muscular dystrophy agency, meaning the number of people not engaged may be much larger.

Of the participants that did respond to the question, responses were generally positive with advice from the NDIS, state disability agency, Federal government, state government and muscular dystrophy organisations all ranging from average to excellent.

In relation to accessing key items during the COVID-19 pandemic, a majority of respondents confirmed that they were able to get groceries although there was still a considerable number that could not.

Comments suggest that people with access to the NDIS were provided a code that allowed for groceries to be delivered online at times when the general population were unable to use the service.

Nearly all participants confirmed that they were able to continue receiving medication which is encouraging news. By contrast, access to COVID-19 specific personal protective equipment and hand sanitisers was relatively even between people that could access it and people that could not, reflecting the documented shortages of these equipment by the general population at the time.

At the time of this survey, COVID-19 restrictions were lifted in most parts of Australia. It is interesting to note that the level of anxiousness was relatively even between people who felt an increase in anxiousness and people who felt a decrease. This could be down to the fact that the future impact of COVID-19 remains unclear. Some parts of Australia have seen life return to relative normality while Victoria experienced a return to lockdown.

Arguably the largest concern raised by people with neuromuscular conditions when reflecting on the impact of COVID-19 was regarding their mental health. Over 70% did not, or could not, access mental health during COVID-19. In a related question focused on the health and wellbeing of people in the neuromuscular conditions, approximately 36% of people indicated that their health and wellbeing deteriorated during this time, while over half confirmed that their health and wellbeing did not change.

While it is encouraging that over half of respondents did not face significant changes to their health and wellbeing, it is of concern that over one-third of respondents raised this issue. One comment for example stating that mental health support often felt "…out of reach."

The relatively short lockdown faced by people with neuromuscular conditions in most parts of Australia may account for the few differences between the general population and people with neuromuscular conditions in handling the pandemic. However, the lack of mental health supports, with over a third of respondents indicating a deterioration of health and well-being is a clear sign that prolonged isolation, further lockdowns or a tightening of restrictions could have significant consequences if government and support organisations don't consider improving access to mental health resources during this time.

In addition to the primary survey questions, there were also a number of written questions asking what neuromuscular support ororganisations can to do provide support over the next 12 months and what are the top three things that muscular dystrophy organisations should take to government. In each case, more than half of the respondents did not respond to the written questions, but of those that did respond, the following lists indicate the type of comments in approximate order of their popularity.

Suggestions for support by neuromuscular organisations:

1. Need more information from neuromuscular organisation about COVID-19 impact (disability-specific, groceries, government advice)
2. Improvements in communication: more phone calls, more zoom
3. Organise more activities
4. More help: home support and mental health support

Top suggestions to take to government:

1. Support specifically for people with neuromuscular conditions
2. Mental health support
3. Improvements in the provision of PPE
4. Stop quarantine breaches

Specific details on each question can be found in Appendix A.

NB: We have only included responses that offered actions or suggestions for change.

4.0

Conclusion & Calls to Action

4.1 Conclusion

The COVID-19 survey for people with neuromuscular conditions revealed many results consistent with the mainstream population during the pandemic including feelings of anxiousness, disappointment and rising frustration.

The survey revealed a reliance on a variety of communication methods and an increase in isolation.

However, there has been several issues that particularly relate to people with neuromuscular conditions including a deterioration of health and wellbeing, the availability of mental health services, awareness of general organisational and government services and some people finding it difficult to get food and personal protective equipment.

The survey revealed a reliance on a variety of communication methods and an increase in isolation.

Importantly, the need for mental health services is not easily attributable to one factor such as isolation, suggesting that it is a combination of factors and feelings associated with COVID-19 restrictions that contribute to mental health challenges rather than one standout issue.

Based on the survey responses the following are important factors to the neuromuscular community:

1. That a mental health service is made available specifically to people with neuromuscular conditions and their families
2. That an awareness campaign is created to promote any existing services that can support the mental health of people with neuromuscular conditions
3. That service organisations which support people with neuromuscular conditions and their families organise the direct supply of personal protective equipment and help facilitate food delivery services
4. That service organisations continue to check in on the health and wellbeing of their members using a variety of communication tools and online social groups

4.2 Calls to Action

Three calls to action stand out and will be prioritised:

Mental Health and social connection/inclusion

> Mental Health support for communities that are compromised.

> The pandemic has amplified the pre-existing mental health issues in the neuromuscular space. Understanding that this is the standard environment that our community live in and as such, is something that the muscular dystrophy entities will work to address.

> Advocate at local, state, national government level.

> Advocate at the Mental Health Commission.

> Acknowledging disability specific mental health challenges is important.

> Seek funding through ILC for mental health services.

> Ensure that there is an evidence-based structure around formalised help – eg. group, individual, telehealth.

Contingency planning

> Assisting the neuromuscular community to plan for the unexpected.

> Asking the question "what is next and what plans can be put in place now to assist with decreasing anxiety about the unknown?"

Facilitated access to health services

> Maintain and strengthen tele/digital health for both medical and mental health.

> Advocating that tele/digital health should not just be a response to COVID-19 but strengthened to ensure that it is able to be easily accessed by those that require tele/digital services over the long term.

As a collective of muscular dystrophy entities, an action plan for the three call to action points listed above will be developed through the:

> Utilisation of a working party established by the collective muscular dystrophy entities listed in this report;

> Consultation with the neuromuscular community, NDIS and health services;

> Notify government of the neuromuscular community priorities; and

> Work with government to tap into existing programs.

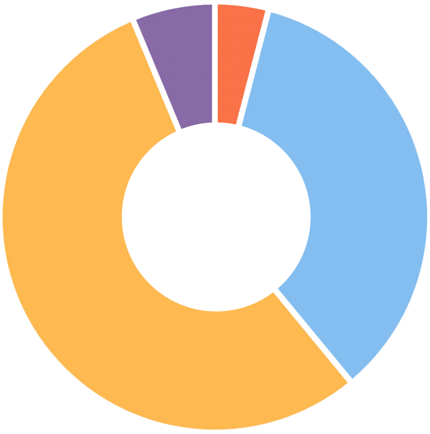
The issues raised impact more than just the neuromuscular community. As such, facilitating further conversations with other sector service providers to learn what others are doing in the health and disability space to address the identified issues will be essential. Seeking opportunity for the neuromuscular community to be involved in the conversation will be key to determining the road map in implementing solutions that will make a positive impact on the mental health of the neuromuscular community.

APPENDIX A: Survey Results

Q10

Did your health and wellbeing change during the COVID-19 pandemic?

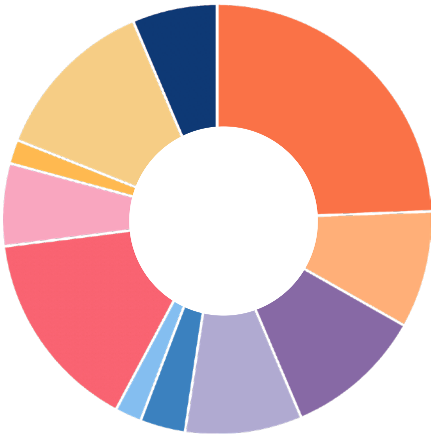
HEALTH & WELLBEING CHANGES	RESPONSES	
Improved	4.04%	9
Deteriorated	34.98%	78
Stayed the Same	54.71%	122
Question Skipped	6.28%	14



Q11

Select which of the feelings you experienced at the start of COVID-19?

There were 206 responses (92.38%) and 17 skipped the question (7.62%)



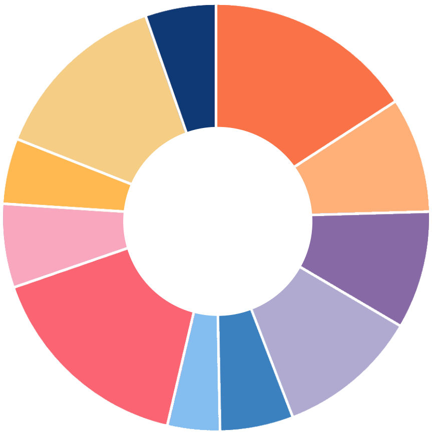
FEELINGS EXPERIENCED	RESPONSES	
Anxiousness	59.22%	122
Loneliness	21.36%	44
Sadness	25.42%	52
Calmness	21.36%	44
Confident	8.25%	17
Happiness	4.85%	10
Frustration	36.89%	76
Anger	15.05%	31
Relief	4.37%	9
Disappointment	30.58%	63
Other	15.53%	32

Q12

Feelings now that COVID-19 has been with us for the past few months

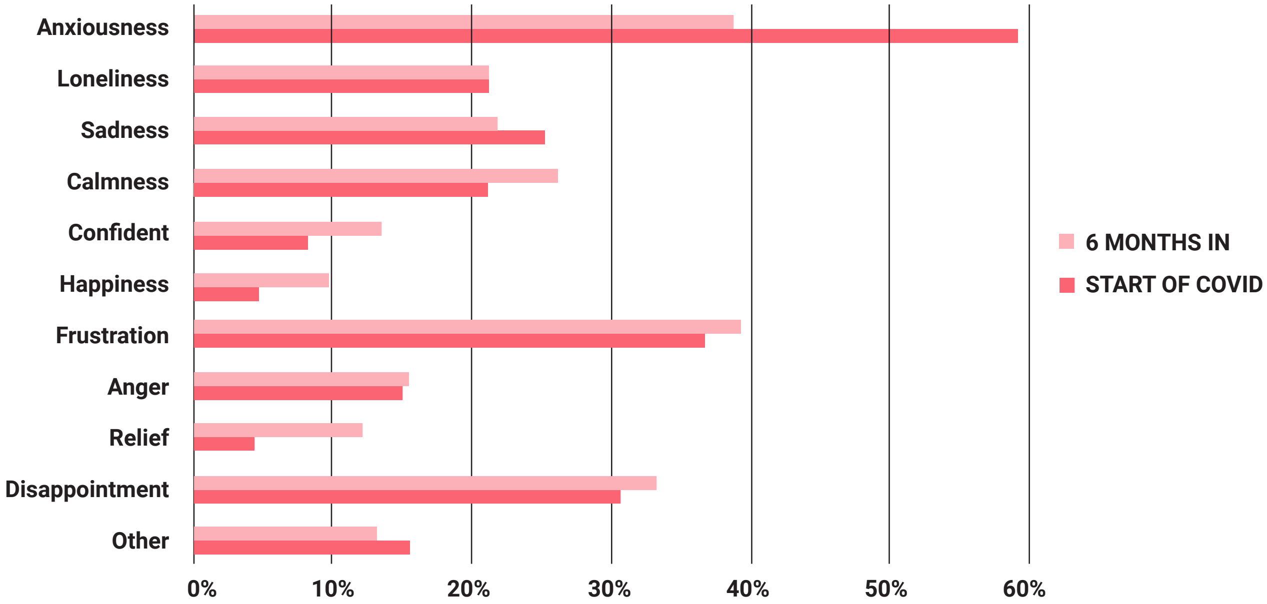
Multiple answers per respondent

FEELINGS EXPERIENCED	RESPONSES	
Anxiousness	38.83%	80
Loneliness	21.36%	44
Sadness	21.84%	45
Calmness	26.21%	54
Confident	13.59%	28
Happiness	9.71%	20
Frustration	39.32%	81
Anger	15.53%	32
Relief	12.14%	25
Disappointment	33.50%	69
Other	13.11%	27



Q 11&12

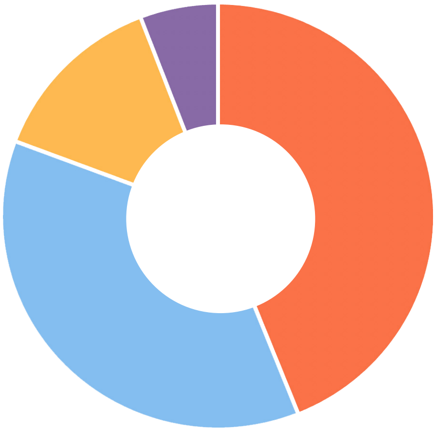
Consolidated data on feelings at beginning and then 6 months in of COVID-19 pandemic



Q 13

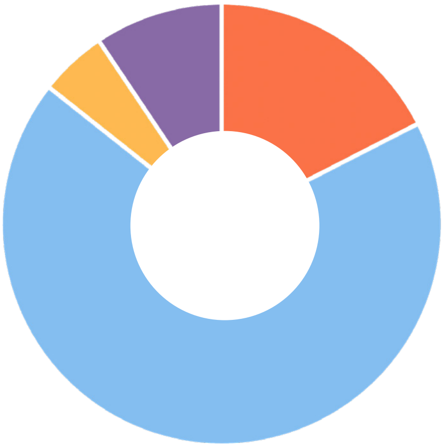
Do you have anxiety around restrictions being lifted in your state/territory?

INCREASED ANXIETY	RESPONSES	
Yes	43.95%	98
No	36.77%	82
Unsure	13.45%	30
Question skipped	5.83%	13



Q 14

Prior to COVID-19 did you feel isolated at all?

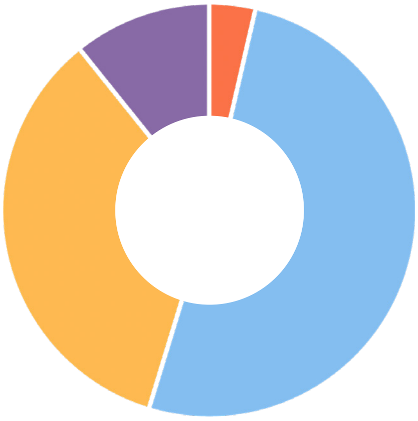


ISOLATION FELT	RESPONSES	
Yes	17.49%	39
No	68.16%	152
Unsure	4.93%	11
Question skipped	9.42%	21

Q 15

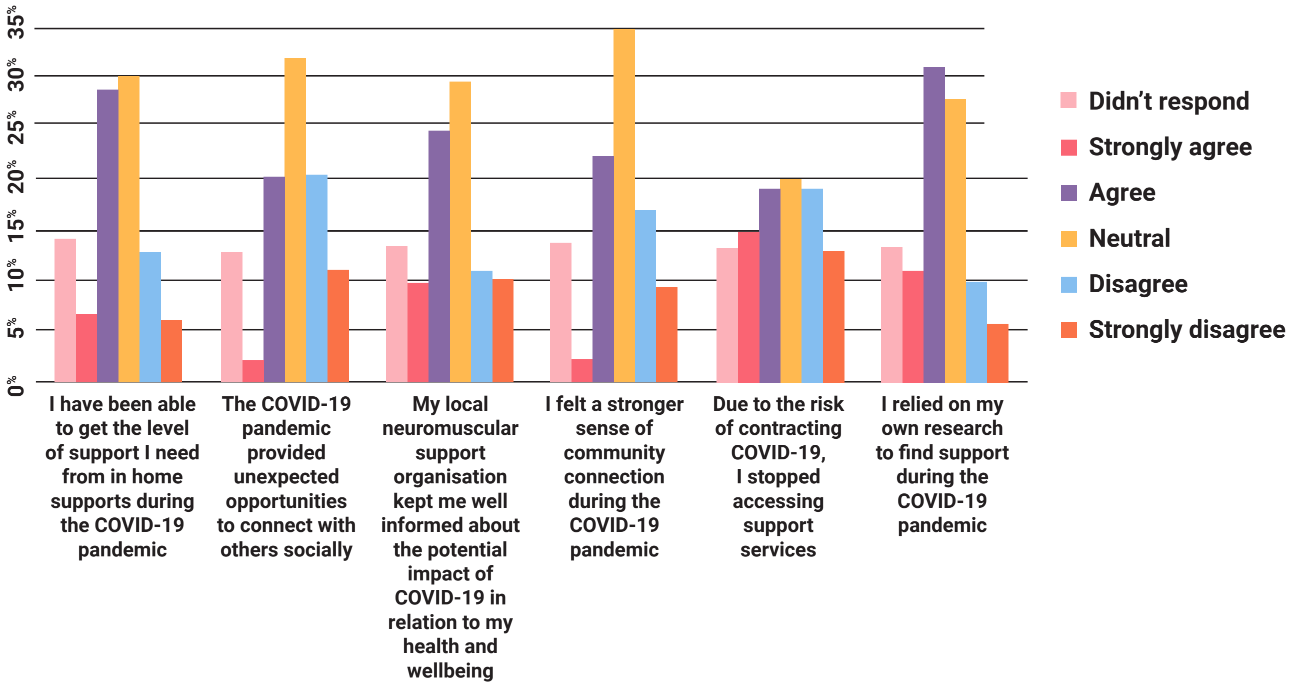
What impact do you feel COVID-19 had on your level of isolation?

IMPACT ON ISOLATION	RESPONSES	
Decreased	3.59%	8
Increased	51.12%	114
Stayed the same	34.53%	77
Question skipped	10.76%	24



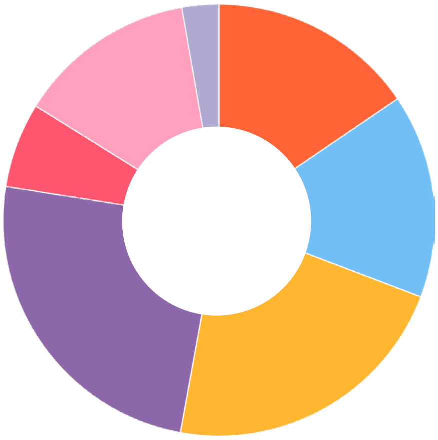
Q 16

Responses to the following statements:



Q 17

With respect to the last statement, if you agreed or strongly agreed to this please indicate all the ways you connected socially:



WAYS PEOPLE KEPT CONNECTED SOCIALLY	RESPONSES	
Live video catchups	45.91%	73
Social media	45.28%	72
Emails	65.41%	104
Phone calls	72.96%	116
Attending online events	18.87%	30
Face-to-face with social distancing	39.62%	63
Other	8.18%	13

Q 18

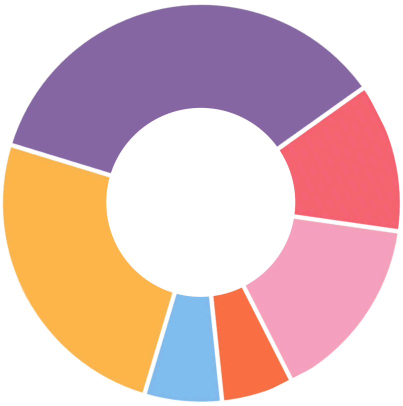
How would you rate the advice you received from the following agencies during the COVID-19 pandemic:

🟥 Didn't respond
🟥 Excellent
🟪 Good
🟧 Average
🟦 Poor
🟧 Very poor

NDIS or state disability agency:

Department of Health (Federal Govt):

State Government:



Local Government:

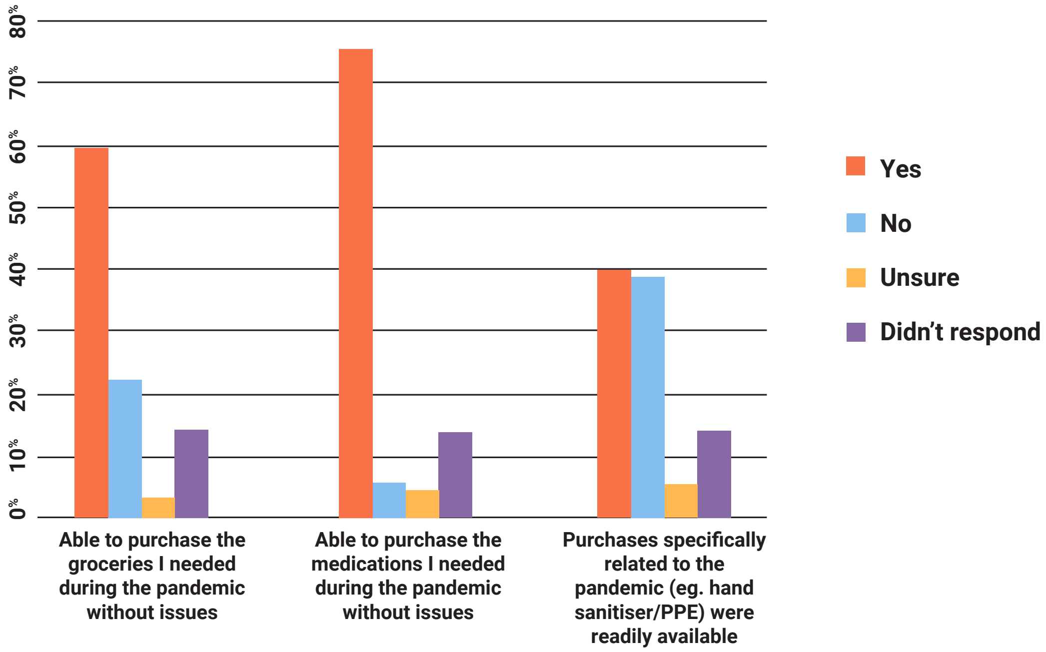
Local Hospital:

Neuromuscular Organisation:

AGENCY	VERY POOR	POOR	AVERAGE	GOOD	EXCELLENT	DID NOT RESPOND
NDIS or state disability service agency	10%	13%	34%	18%	4%	21%
Department of Health (Federal)	7%	9%	28%	30%	10%	16%
State Government	6%	6%	25%	35%	12%	15%
Local Goverment	12%	19%	29%	19%	4%	17%
Local Hospital	12%	13%	28%	17%	8%	22%
Neuromuscular organisation	9%	13%	22%	29%	9%	19%

Q 19

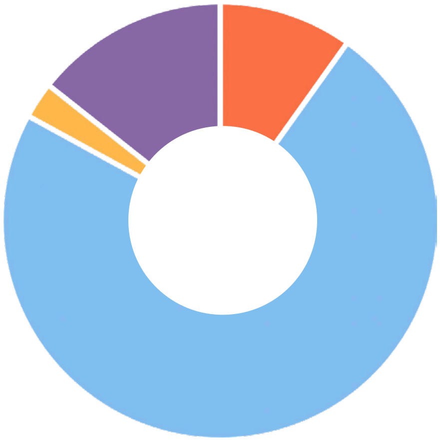
Response to the statements below:



RESPONSE	YES	NO	UNSURE	DID NOT RESPOND
Able to purchase the groceries needed without issues	60%	22%	4%	14%
Able to purchase the medications needed without issues	76%	6%	4%	14%
Purchases specifically related to the pandemic (eg. hand sanitiser/PPE) were readily available	40%	39%	6%	14%

Q 21

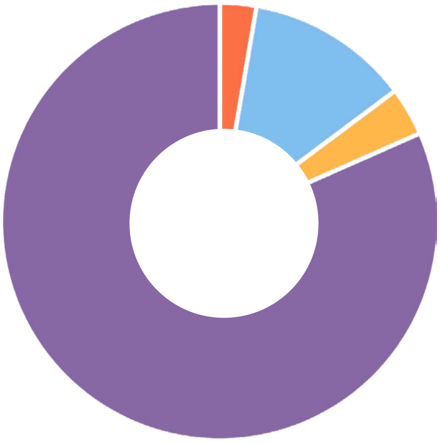
Did you access mental health services during COVID-19?



ACCESS TO MENTAL HEALTH SERVICES	RESPONSES	
Yes	9.87%	22
No	73.09%	163
Rather not say	2.69%	6
Question skipped	14.35%	32

Q 22

If you answered yes to Q21, did you have any difficulties accessing these services?



DIFFICULTIES WITH ACCESSING	RESPONSES	
Yes	2.69%	6
No	12.11%	27
Rather not say	3.59%	8
Question skipped	81.61%	182