



Muscular Dystrophy Ireland

Membership Support Survey - Covid 19

About MDI

Muscular Dystrophy Ireland (MDI) is a voluntary organisation that provides support to people with neuromuscular conditions and their families. Muscular Dystrophy Ireland envisages an Ireland that enables people with neuromuscular conditions to fully participate in society and reach their full potential.

Our Mission: 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 the conditions.
- Supporting researchers and clinicians to carry out quality research into neuromuscular conditions.

About Muscular Dystrophy: Muscular Dystrophy is a collective name for a range of neuromuscular conditions. It is characterised as a progressive weakening, wasting and loss of muscle mass over time. It can present at birth, childhood or manifest later in life.

Introduction and Aim of Survey

MDI invited members to take part in a survey between the 11th and 30th April 2020 and received 167 responses.

This survey was aimed at adults who are either individual or family members of MDI. The aim of the survey was to find out how MDI can best offer support to our members during the Covid 19 crisis. MDI will use this information gathered to help develop supports that best fit the needs expressed by our membership as a whole.

We want to thank members for taking the time to fill out this survey. It is MDI's main priority to support you and your family during this challenging time.

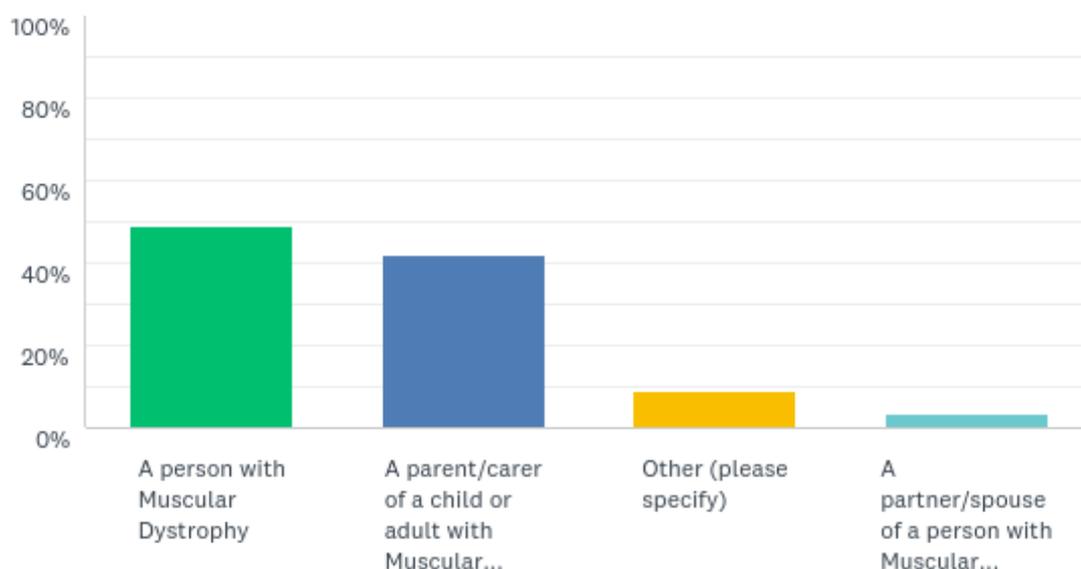
Methodology, Insights and Data Trends

- 167 MDI members completed the survey.
- 76 members answered by email.
- 91 members answered by a web link that was sent by text message and also posted on social media platforms. Trends show the text message had the most significant impact.
- We used the tool, Survey Monkey, to gather the data. There was a total of 8 questions and the estimated time to complete the survey was under 4 minutes.

Feedback Received

Q1: Which membership description fits you best?

Answered: 167 Skipped: 0

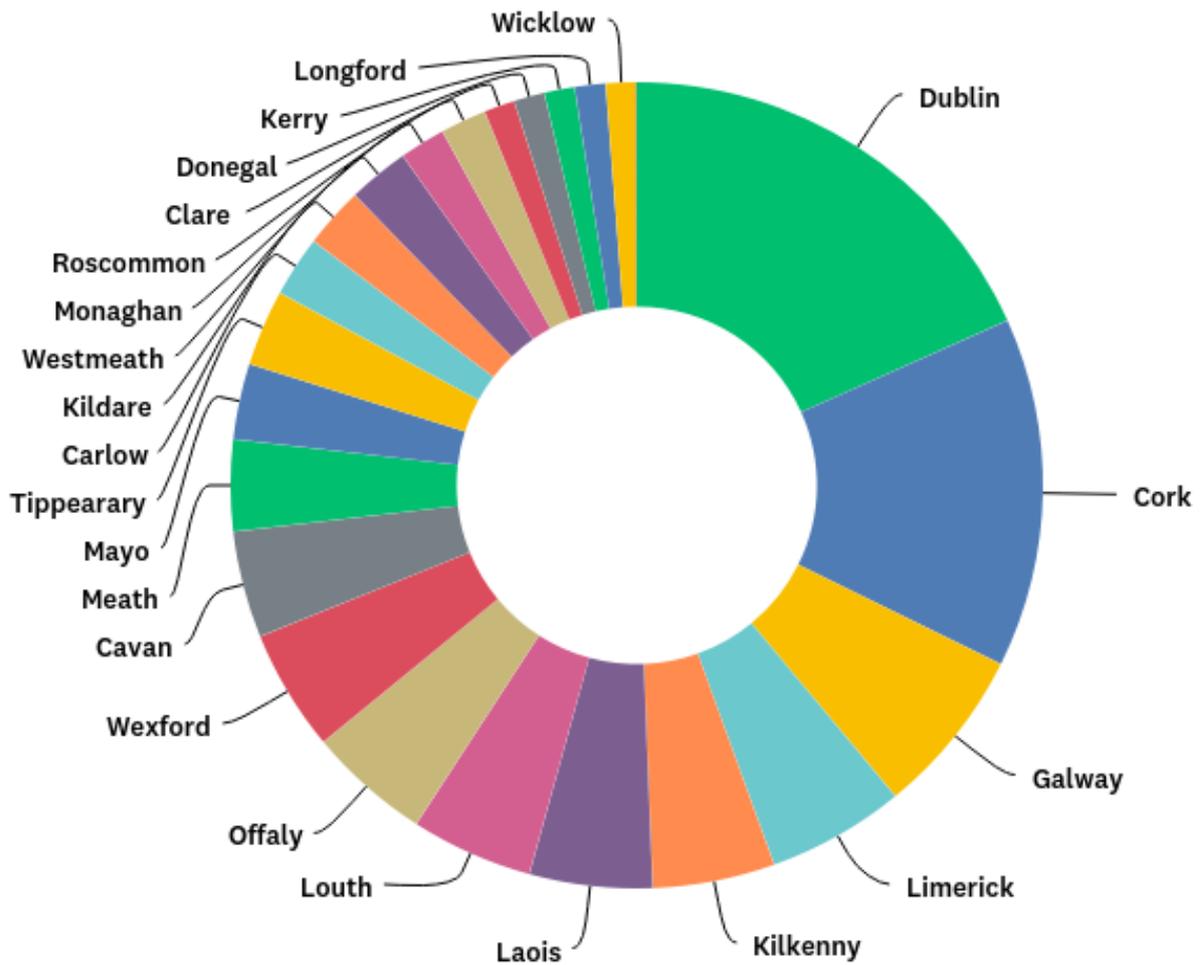


ANSWER CHOICES	RESPONSES	
A person with Muscular Dystrophy	49.10%	82
A parent/carer of a child or adult with Muscular Dystrophy	41.92%	70
Other (please specify)	8.98%	15
A partner/spouse of a person with Muscular Dystrophy	3.59%	6
Total Respondents: 167		

8.98% Other: The 'Other' category was mainly adults with long term illnesses that are not classified under the umbrella of Muscular Dystrophy.

Q2: Please select the county that you live in from the list below

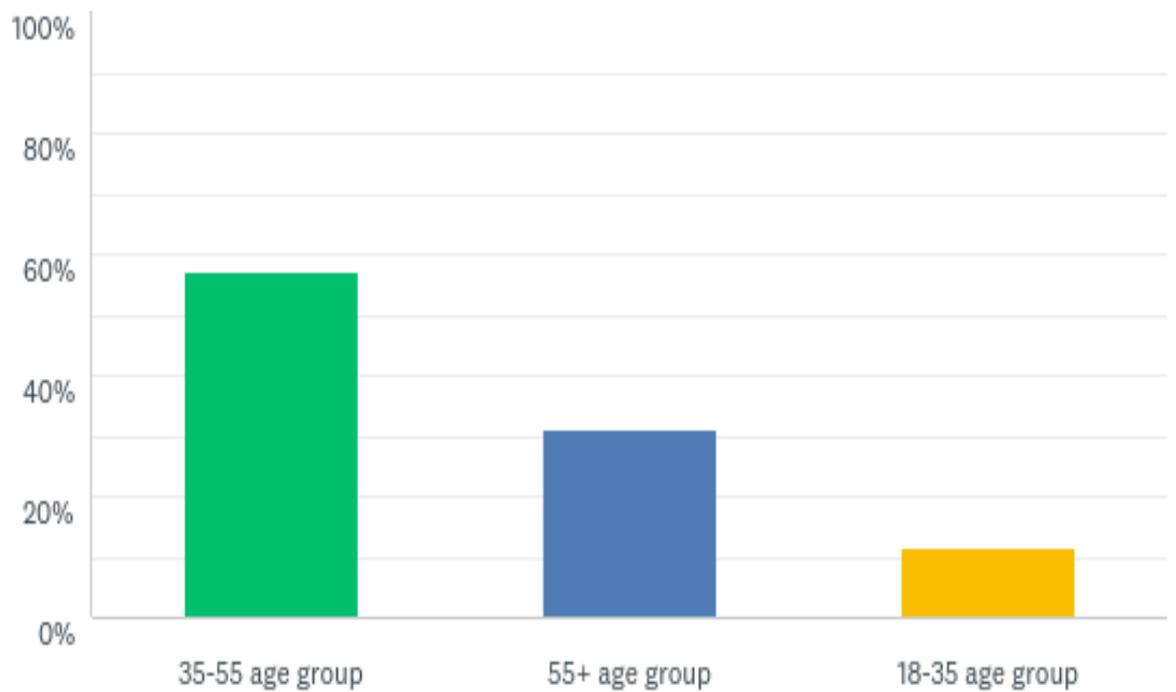
Answered: 164 Skipped: 3



ANSWER CHOICES	RESPONSES	
Dublin	18.29%	30
Cork	14.02%	23
Galway	6.71%	11
Limerick	5.49%	9
Kilkenny	4.88%	8
Laois	4.88%	8
Louth	4.88%	8
Offaly	4.88%	8
Wexford	4.88%	8
Cavan	4.27%	7
Meath	3.66%	6
Mayo	3.05%	5
Tipperary	3.05%	5
Carlow	2.44%	4
Kildare	2.44%	4
Westmeath	2.44%	4
Monaghan	1.83%	3
Roscommon	1.83%	3
Clare	1.22%	2
Donegal	1.22%	2
Kerry	1.22%	2
Longford	1.22%	2
Wicklow	1.22%	2
Leitrim	0.00%	0
Sligo	0.00%	0
Waterford	0.00%	0
TOTAL		164

Q3: Please select the age bracket you belong to from the list below

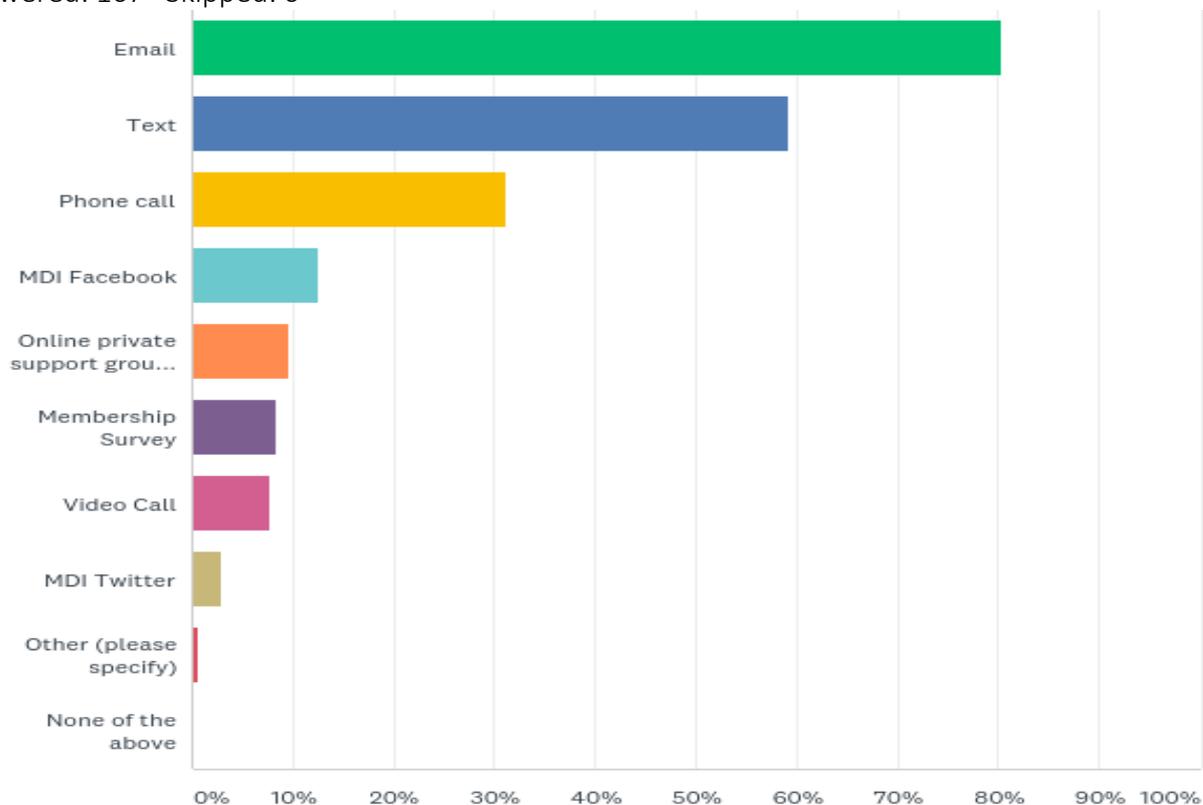
Answered: 161 Skipped: 6



ANSWER CHOICES	RESPONSES
35-55 age group	57.14% 92
55+ age group	31.06% 50
18-35 age group	11.80% 19
TOTAL	161

Q4: What is your preferred method to communicate with MDI and for MDI to share information with you during the Covid 19 crisis? (Please select as many as you wish)

Answered: 167 Skipped: 0

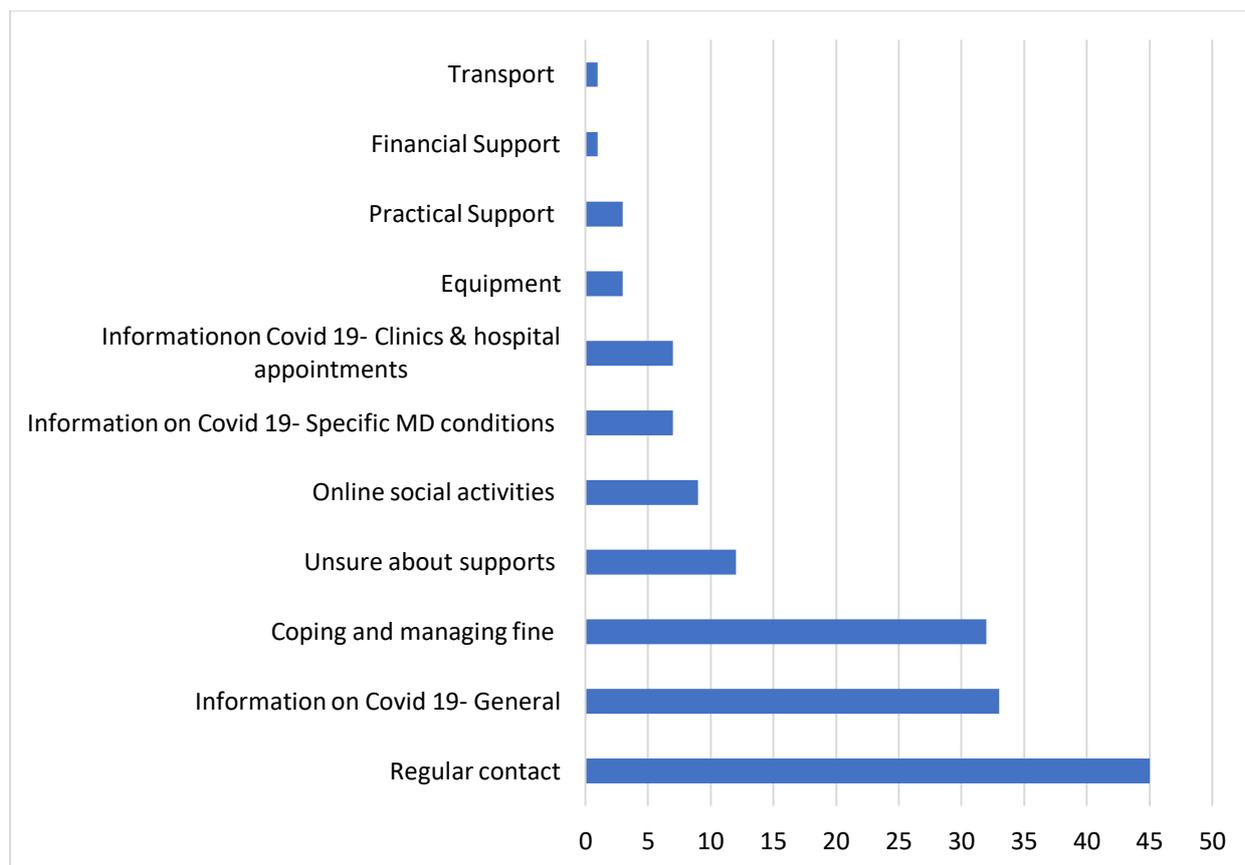


ANSWER CHOICES	RESPONSES
Email	80.24% 134
Text	59.28% 99
Phone call	31.14% 52
MDI Facebook	12.57% 21
Online private support group for MDI adult members facilitated by support worker	9.58% 16
Membership Survey	8.38% 14
Video Call	7.78% 13
MDI Twitter	2.99% 5
Other (please specify)	0.60% 1
None of the above	0.00% 0
Total Respondents: 167	

0.60% Other: The 'Other' category suggested the facilitation of group consultations / information sessions with Duchenne Muscular Dystrophy (DMD) consultants in place of clinics which have been cancelled.

Q5: How can MDI best support you and your family during the Covid 19 crisis?

Answered: 141 Skipped: 26



ANSWER CHOICES	RESPONSES
Regular contact	45 29%
Information on Covid 19 - General	33 21%
Coping and managing fine	32 21%
Unsure about supports	12 8%
Online social activities	9 6%
Information on Covid 19 - Specific MD conditions	7 5%
Information on Covid 19 - Clinics & hospital appointments	7 4%
Equipment	3 2%
Practical Support	3 2%
Financial Support	1 1%
Transport	1 1%

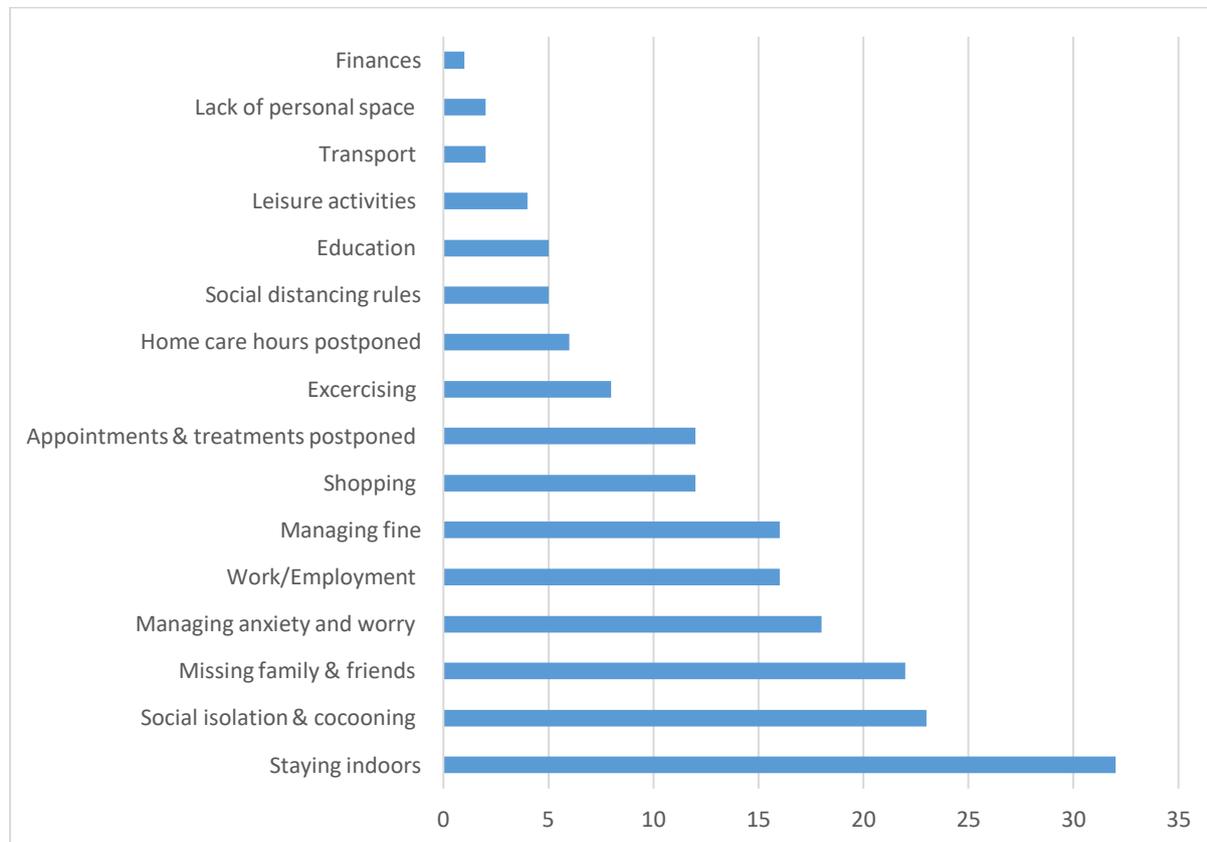
Overall, 29 per cent of respondents stated it was extremely “comforting” to know MDI Support Service was there if they need or had an “emergency” and were very happy with “regular” “occasional” contact and “reminders that MDI are there”. Some further quotes included “just knowing there’s support available is great”, “having a backup if things go wrong”, “keep doing what MDI have been doing” and “MDI are fantastic” and “doing a great job”.

In relation to information, 21 per cent of respondents stated they would like to receive regular communication, updates, and advice from the HSE and medical professionals that are relevant to Muscular Dystrophy as a whole. 5 per cent of respondents stated they would like to receive regular updates relating to the status of hospital and clinic appointments, and treatments, as well as receiving regular information on drug trails, and help improving communication with consultants and doctors. 4 per cent of respondents would like to receive regular information and updates from medical professionals that are specific to their MD condition during Covid 19.

For the 21 per cent of respondents who stated they were managing and coping fine, the main factor mentioned was that they had a good family and friendship support system available to them. In relation to online social activities, for adults, suggestions included coffee mornings and interactive packs with crosswords, puzzle sheets, garden seeds, card games and so on. For our younger members, online children’s activities and virtual youth clubs were stated. Further comments included that MDI “online children’s Easter Egg treasure riddles were a good idea” and that the virtual youth clubs happening weekly “are being enjoyed and looked forward to by my children”.

Q6: What issues are you and your family finding the most challenging during the Covid 19 crisis?

Answered: 149 Skipped: 18



Answer Choices	Responses
Staying indoors	32 17%
Social isolation & cocooning	23 13%
Missing family & friends	22 12%
Managing anxiety and worry	18 10%
Work/Employment	16 9%
Managing fine	16 9%
Shopping	12 7%
Appointments & treatments postponed	12 7%
Exercising	8 4%
Home care hours postponed	6 3%
Social distancing rules	5 3%
Education	5 3%
Leisure activities	4 2%
Transport	2 1%
Lack of personal space	2 1%
Finances	1 1%

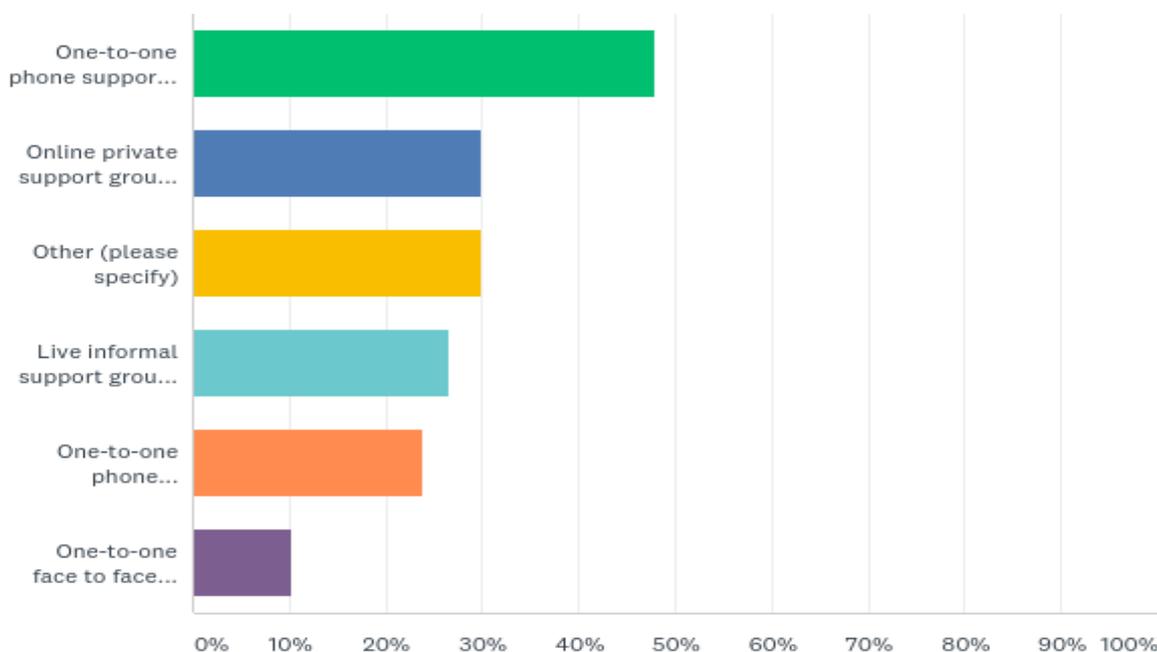
Overall, 17 per cent of respondents mentioned staying indoors was the most challenging, with 13 per cent stating the concept of cocooning in general and the feeling of social isolation were particularly difficult. 10 per cent of respondents mentioned trying to manage their anxiety and worry was hard, with the fear of becoming infected with the virus being the main underlining concern for the majority.

In relation to work/employment, nine per cent of respondents who were parents stated trying to maintain a work-life balance, doing homework and keeping children entertained was particularly difficult; others mentioned that missing their job and having a no “routine” was hard. Respondents’ overall concern in relation to shopping was the worry regarding other people observing social-distancing rules and, for others, the concern was in relation to missing doing it themselves or finding online delivery slot times.

For 7 per cent of respondents, the cancellation of hospitals, clinics and doctors’ appointments was a concern, and having no access to Occupational Therapists, Physiotherapists and no contact from consultants was particularly difficult. Others mentioned the postponement of treatments such as Spinraza and the worry about the long-term funding of such treatments after the crisis was over. And lastly, in relation to exercising, 3 per cent of respondents mentioned that having no access to swimming pools was a significant challenge.

Q7: For Over 18's: Would any of the activities listed below be of interest to you during the Covid 19 crisis? (Please select as many as you wish)

Answered: 117 Skipped: 50

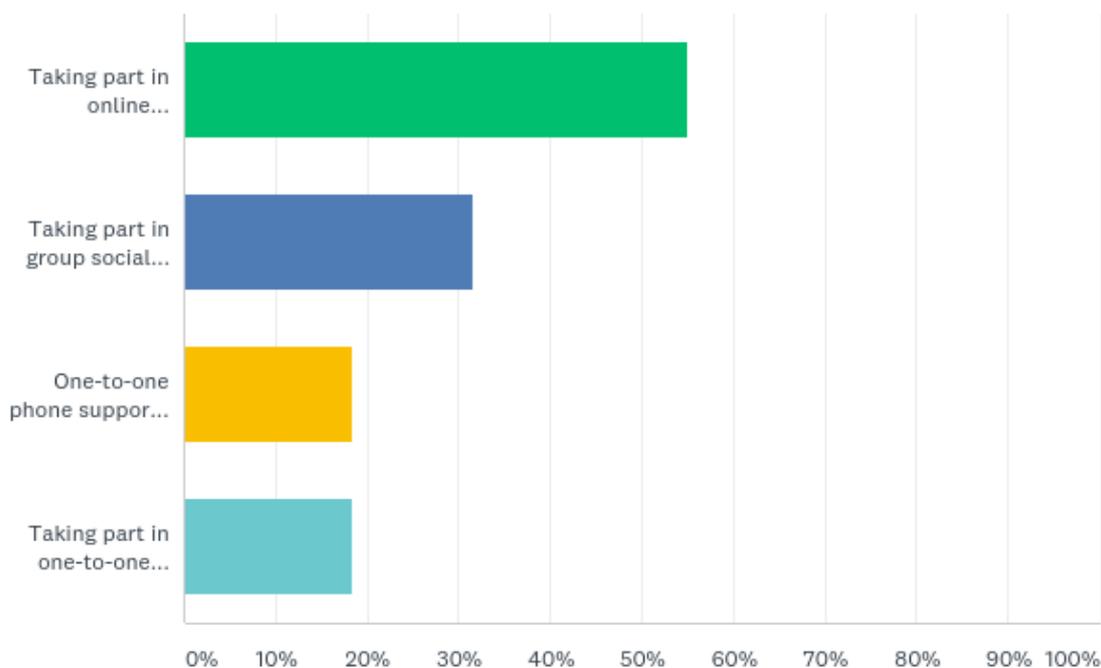


ANSWER CHOICES	RESPONSES	
One-to-one phone support with MDI support worker?	47.86%	56
Online private support group for MDI adult members using a Facebook platform facilitated by MDI support worker? This would be a private space for all MDI adult members – both people who have Muscular Dystrophy and their families – to connect, discuss issues, offer support to each other and share resources.	29.91%	35
Other (please specify)	29.91%	35
Live informal support groups with other members using an online group video tool facilitated by MDI support worker? (i.e Tea rooms/coffee mornings etc?)	26.50%	31
One-to-one phone counselling facilitated by a trained and accredited counsellor of your choice?	23.93%	28
One-to-one face to face video support with MDI support worker?	10.26%	12
Total Respondents: 117		

29.91% Other: Overall in this category, most respondents stated they have good support and contact and are not in need of any of the above at present.

Q8: For Under 18’s in your Family: Would any of the activities listed below be of interest to you and your family during the Covid 19 crisis? (Please select as many as you wish)

Answered: 60 Skipped: 107



ANSWER CHOICES	RESPONSES
Taking part in online competition activities and prizes facilitated by MDI Support Worker?	55.00% 33
Taking part in group social and fun activities using a safe and private live online video tool with other MDI members of your age group facilitated by MDI youth worker?	31.67% 19
One-to-one phone support with MDI youth worker?	18.33% 11
Taking part in one-to-one social and learning activities with MDI youth worker using a safe and private live online video tool?	18.33% 11
Total Respondents: 60	

Thank you for reading.

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