

MDA COMMUNITY SURVEY

ON COVID-19

This survey to the neuromuscular disease community was created to better understand information and support needs and gaps related to COVID-19.

1,922 community members completed the survey



of respondents are living with a diagnosis served by MDA



of respondents are a caregiver for an individual living with a diagnosis served by MDA

Five Biggest Concerns Around COVID-19



Additional Concerns Shared

Loss of additional muscle due to lack of physical activity

I'm concerned about anxiety and depression this may cause in some of my children

I'm concerned that my loved ones won't be able to be with me to advocate, explain my numerous diagnosis, to make decisions if I'm not capable, and won't be kept updated efficiently.

Three Largest Needs Impacted by COVID-19



Access to daily needs (groceries, medications, mail, etc.)

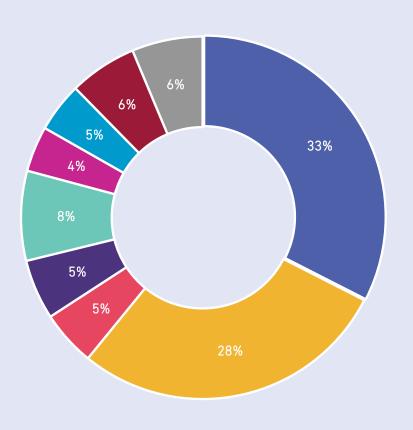


Information on creating a plan if I, or my caregiver, get the virus



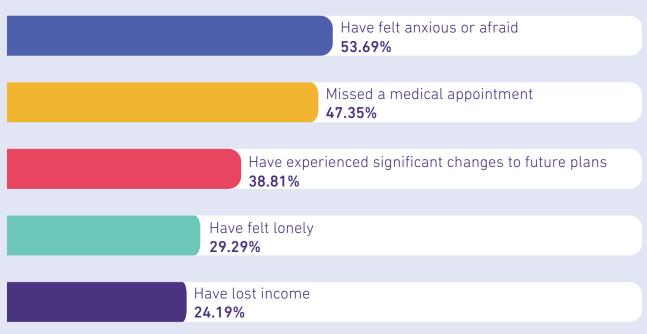
Financial assistance to pay bills

Survey Participants Biggest Fear Related to the Virus



- That I, or my loved one, may contract the virus
- That I, or my loved one, will end up hospitalized due to the virus
- My area hospital will not have enough supplies to treat all patients
- I live alone and if I get sick I won't be able to care for myself
- What will I do if my caregiver contracts the virus
- If needed, that me, or my loved one, wouldn't be able to obtain a test
- Financial loss
- My, or my loved one's, overall mental health and well-being
- Other

In the Last Three Weeks Due to COVID-19 and/or Social Distancing Requirements I Have/My Loved One Has:



^{*}Multiple answers allowed. Top five answers shown here.

Information Survey Participants felt would be Most Helpful During this Time



- More information on how the virus may impact someone with my, or my loved one's, diagnosis
- Information on how to accept items to your home (packages, grocery, mail, etc.)
- Information on how to be tested
- Resources available to help individuals struggling with the impact of COVID-19
- Information on telemedicine