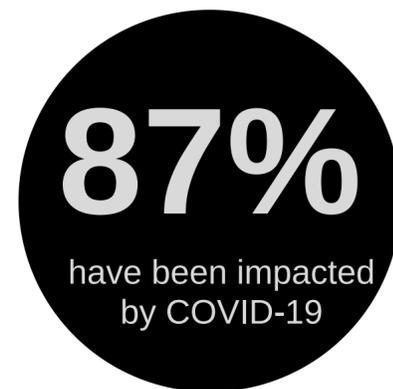


genetic conditions **vulnerable** **Worried**
great risk **Respiratory weakness**
complications **increased risk of dying**
Compromised immune system
immune deficiencies **breathing issues**
sick **Low immune system**
infections risk of seizures with any fever



Medical Supplies



Challenges getting medication included:

- 59% Pharmacy unable to fill prescription due to a shortage
- 30% Unable to or are afraid to travel to the pharmacy
- 12% Not able to get a medical appointment with doctor for prescription



There were challenges getting:

- 40% Personal protective equipment
- 7% Medical foods, supplements
- 5% Medication infusion services
- 5% Feeding tube supplies
- 5% Durable medical equipment



GP and specialists



Have been contacted by their GP or specialist about COVID 19 and their genetic, rare or undiagnosed condition



80% have been offered a phone or video call as an alternative to an in-office appointment with a doctor



Would continue with telehealth appointments whenever possible in the future



Have had a medical appointment cancelled due to COVID-19



Would continue with telehealth for some appointments



40% have experienced challenges with accessing medical care or treatment



42% have had to limit or stop support workers coming to their home due to COVID 19



67% of allied health appointments are being offered through telehealth and 70% found the telehealth experience adequate or very good



22% have accessed mental health services as a result of distress related to COVID 19



16% needed to seek urgent care or visit the emergency department during the COVID-19 outbreak, but 9% didn't seek treatment due to the COVID risk



37% of households have been impacted by a loss of income due to coronavirus, resulting in 5% losing health insurance



47% are overwhelmed by the information they are receiving

COVID-19 concerns and experiences

Experience has been awful **enormous strain emotionally and physically**
really overwhelming!!! abandoned by the system **PPE hard to find** **constant struggle**
Lack of communication **stress and anxiety** Lack of funding **deterioration of condition**
Cancelled appointments trial treatment cancelled **Increased cost of living** **SO HARD**
felt invisible **mental breakdown** **treatment delayed** inability to access essential therapies