

CURRENT EXPERIENCE



muscle weakness
fatigue
gastrointestinal distress

Most common symptoms observed before diagnosis

62%

knew nothing about mito at diagnosis

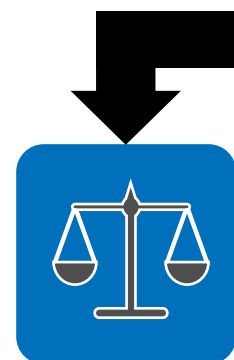
52%

described prognosis not being discussed

18%

described a poor prognosis

Diagnosis & prognosis



38% The most common impact on QoL was poor mental health

Quality of life

41% of participants had a preference for talking to someone over internet, written or information via phone apps



86%

FELT RESPECTFULLY TREATED THROUGHOUT THEIR EXPERIENCE

The main source of information came via

the Mito Foundation



Communication & Information

Treatments experienced

Conversations about treatment

Coenzyme Q10
72.0%

Vitamins & supplements
64.0%

Physical therapy
30.0%

64%

did NOT have a conversation about clinical trials

PATIENT

EXPERIENCE

EXPECTATIONS

KNOWLEDGE

PEEK

www.cc-dr.org

MITOCHONDRIAL DISEASE AUSTRALIAN STUDY 2018



INTERNATIONAL CENTRE FOR COMMUNITY-DRIVEN RESEARCH



Treatment

Cost is an important consideration in relation to future treatments... & effective treatments that reduce muscle fatigue & improve muscle strength are needed



Care & Support

Centralised & coordinated care across specialists and allied health professionals



Information

More information about specific types of mitochondrial disease & information that is accurate, comprehensive and honest



Health Professional Communication

More proactive communication & an understanding of the impact and implications of the condition

future expectations

Australia is behind in its approach to mitochondrial disease. The UK has legalised the first known preventative measure and yet we're still fighting for clinical trials, yet alone for the disease to be heard of.

Maybe raise awareness of it because I would say a good 90% of the people that I talked to have never heard about it before. Which makes sense because it is a fairly rare disease but it might make it easier on a lot of people if everyone knew even just a little bit about it.

Employing education programs for GPs and healthcare workers, and particularly implementing a full-time position for a counsellor as a wraparound service to help improve the emotional and physical needs of these people would be extremely economically beneficial.

There is absolutely nothing as far as treatment goes for my son and hundreds of other people in Australia for mitochondrial disease. All we have is vitamin supplements to treat a whole complicated area of health conditions associated with mitochondrial disease and that something needs to be done about it.

messages to decision-makers

mito+ FOUNDATION

ICDDR would like to thank each and every participant in this study We would also like to thank all of our study partner & sponsor the Mito Foundation