

**MOST COMMON SYMPTOMS  
OBSERVED BEFORE DIAGNOSIS**



- ✓ muscle weakness
- ✓ fatigue
- ✓ gastrointestinal distress

**DIAGNOSTICS & PROGNOSIS**

**62%**

knew nothing about  
mito at diagnosis

**52%**

Described prognosis  
not being discussed

**18%**

Described poor  
prognosis

**COMMUNICATION &  
INFORMATION**



The main source of  
information came via  
the Mito Foundation

**86%**

Felt respectfully  
treated throughout  
their experience



**64%**

Did not have a conversation  
about clinical trials

**TREATMENTS EXPERIENCED**

**72%** Coenzyme Q10

**30%** Physical therapy

**64%** Vitamins & supplements

**QUALITY OF LIFE**



The most common impact  
on quality of life was poor  
mental health

**FUTURE EXPECTATIONS**



**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

**MESSAGES TO DECISION MAKERS**

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.