



THE PSYCHOLOGICAL IMPACTS OF MITOCHONDRIAL DISEASE

A diagnosis of mitochondrial disease (mito) for you or a loved one can be very stressful and may leave you experiencing a rollercoaster of emotions. The stress of living with mito and learning to manage the multiple aspects of the condition can affect the mental wellbeing of everyone affected.

Psychological distress in patients with mito and other chronic illnesses tends to be under-diagnosed and under-treated in the community. The recent Patient Experience, Expectations and Knowledge (PEEK) study, commissioned by the Mito Foundation and carried out by the International Centre for Community Driven Research found that 42% of respondents reported experiencing depression and/or anxiety. This is three times higher than the national average. The PEEK study found there were multiple factors that influenced feelings of anxiety and depression in individuals with mito including:

- Experiencing fatigue, chronic pain and sleep disturbance
- Feelings of social isolation and the loss of relationships with family and friends
- Withdrawing from usual activities due to physical limitations
- Feeling a lack of support from the medical community with diagnosis and treatment
- A lack of understanding of mito by doctors, family, friends and the community
- Financial stress due to an inability to work or limited work options
- Concern of burdening others with caring responsibilities
- Reproductive challenges
- Lack of treatment options

The psychological impacts of mito can affect both the person with mito and their loved ones, regardless of the severity or progression of the disease.

There are many factors which influence the mental health of those with mito including:

- Changes in physical appearance, energy, weight, mobility, function
- Cognitive changes such as confusion
- Dependence upon others for personal care or management of affairs
- Loss or alteration of social roles within the family or community
- Loss of a loved one with mito
- Fear of the unknown and the future
- Sense of life being controlled by others and lack of support and understanding within the medical system

GRIEF

Living with mito can have a profound impact on the way you live and may create feelings of grief in response to the changes and subsequent losses that happen in your life.

You may experience multiple losses such as feeling a loss of control, personal power, independence, identity, financial security and lifestyle. In addition, you may also be confronted with having to modify your hopes, dreams and visions for the future.

Grief is a natural response to loss. Grief is expressed in many ways and it can affect every part of your life; your emotions, thoughts and behaviour, beliefs, physical health, your sense of self and identity, and your relationships with others.

Stages and types of grief

- Anticipatory grief - loss experienced while you or your loved one is alive and managing the impact of chronic illness
- Chronic grief – prolonged periods of grief that limit your daily life
- Multiple losses – those experiencing the loss of loved ones through the disease

Grief is experienced differently for each individual. For some, attempts to cope with grief may result in personality changes from day to day due to the impact of living with uncertainty and unpredictability.

You and your loved ones are likely to experience mixed emotions during various stages of diagnosis, the journey of having mito and death. Emotions can arise that can be unpredictable and varying and may include denial, anger, frustration, confusion, fear, depression and hopelessness.

There is no time limit or 'correct' way of working through emotions and feelings. Each person and their situation is different. Allow time to work through emotions and feelings in your own way.

RECOMMENDATIONS FOR DEALING WITH YOUR EMOTIONS AND FEELINGS

- Speak to your doctor and/or health professionals about how you are feeling. Your feelings are valid
- Speak to your GP about visiting a psychologist or counsellor
- Learn to be aware, listen to your body and know your limits
- Minimise unnecessary stressors in your life
- Be aware that chronic stress has an effect on both your physical and mental health, it lowers your immune system and increases your risk of heart disease and diabetes

HEALTHY COPING SKILLS

- Practise mindfulness – pay attention to your experiences and reactions in the present moment, try mindful meditation or mindful breathing
- Engage in regular exercise (refer to mito exercise fact sheet)
- Eat a healthy and balanced diet
- Connect with your spirituality/religion
- Engage in hobbies, social activities and enjoyable activities for example, drawing, knitting, cooking, spending time in nature.

A strengths based approach is a useful way to view your situation – consider what resources you have in your life that can assist you in better managing the challenges you face.

SUPPORT NETWORKS

- Counselling
- Family and friends
- Supportive medical team
- Mito Foundation Helpline
- Mito Foundation support groups, information days and events
- Mito Connect Calls
- Mito Foundation Facebook Group

FINDING A GOOD DOCTOR

An important part of your journey will be to find a supportive doctor, including your local GP. Your GP does not need to be a specialist in mito. They have an important role in helping you develop a strong supportive network of health professionals and support services in your area.

The Mito Foundation can assist in finding a mito specialist in your area. Please call our Helpline on 1300 977 180 or [complete this form](#).

It may also be beneficial to have a 'coordinator' of support services that is aware of your personal situation. The National Disability Insurance Scheme (NDIS) can provide such coordinators if you are eligible. Otherwise, a good GP can assist you in coordinating your care.

EDUCATION AND KNOWLEDGE ABOUT MITO

Learning about the disease is a personal choice. Some may find more information confronting and perhaps overwhelming and scary, which may negatively impact your lifestyle. Others may find comfort in knowing as much as they can in order to make informed decisions about care and take a proactive approach. Whatever you decide, remember to take care of yourself and your wellbeing.

Each mito patient has different symptoms of different severity. If you read or hear about someone else's condition, it does not mean it will necessarily happen to you or your loved one.

The following organisations can provide free over the phone counselling services:

Australian Centre for Grief and Bereavement – 1800 642 066 grief.org.au

Beyond Blue – 1300 224 636 (available 24 hours a day) beyondblue.org.au

Lifeline – 13 11 14 (available 24 hours a day) lifeline.org.au

MensLine Australia – 1300 789 978 (available 24 hours a day) mensline.org.au

Kids Help Line: 1800 55 1800 kidshelpline.com.au

REFERENCES

Dr Debbie Kralik, RN, Phd, Ms Kerry Telford BASW, Transitions in Chronic Illness, Grief and Loss, University of South Australia, 2005

Content sourced from Lifeline, 'Living with a chronic condition', Beyond Blue, 'Grief and Loss', Reach out, 'How to practise mindfulness'.

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