

The emotional challenges of physical symptoms

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Please note that the information contained in this presentation is not to be used for medical decision making but rather as a guide to support the abovementioned topic

General feelings linked to physical symptoms

- ▶ Continued accumulation of symptoms and the need for adaptation on a regular basis
- ▶ Changes in daily living, finances, relationships etc
- ▶ Increase in need for support/loss of independence
- ▶ Attached emotions e.g. anger; paranoia; fear; sadness
- ▶ Yet 'another' part of your body letting you down
- ▶ Fears become a reality (fears of the future)
- ▶ We have to be the 'experts' in our care - we may research our symptoms, which can be devastating and inaccurate (create fear)
- ▶ Mentally draining to manage things every day
- ▶ We feel we cant be perfect all the time and that we are letting others down - feel like giving up at times or struggle to cope
- ▶ physically and emotionally tired - sometimes you just have enough - ongoing doctors appointments, tests etc.
- ▶ ongoing frustrations (no answers, doctors don't know, not being able to do things that you could once do)
- ▶ feeling like you are alone/isolated (even with a support network)
- ▶ guilt - want to do things but cant (self-blame)
- ▶ overreactions and hypersensitivity
- ▶ Diagnosis of mental health issues such as depression or anxiety can often neglect to consider the pure difficulties of managing a devastating chronic illness such as Mito, along with the physical aspects one needs to manage.
- ▶ Differentiating mental health concerns from primary to secondary (comorbidity) - We should attempt to differentiate between what is an emotional response to physical symptoms vs. what mental health concerns are caused directly by mitochondrial dysfunction (physiological)
- ▶ when does mental health become its own symptom of mito? E.g. MELAS may cause changes in the brain such as the occipital lobe which controls vision; hippocampus controlling memory and orientation

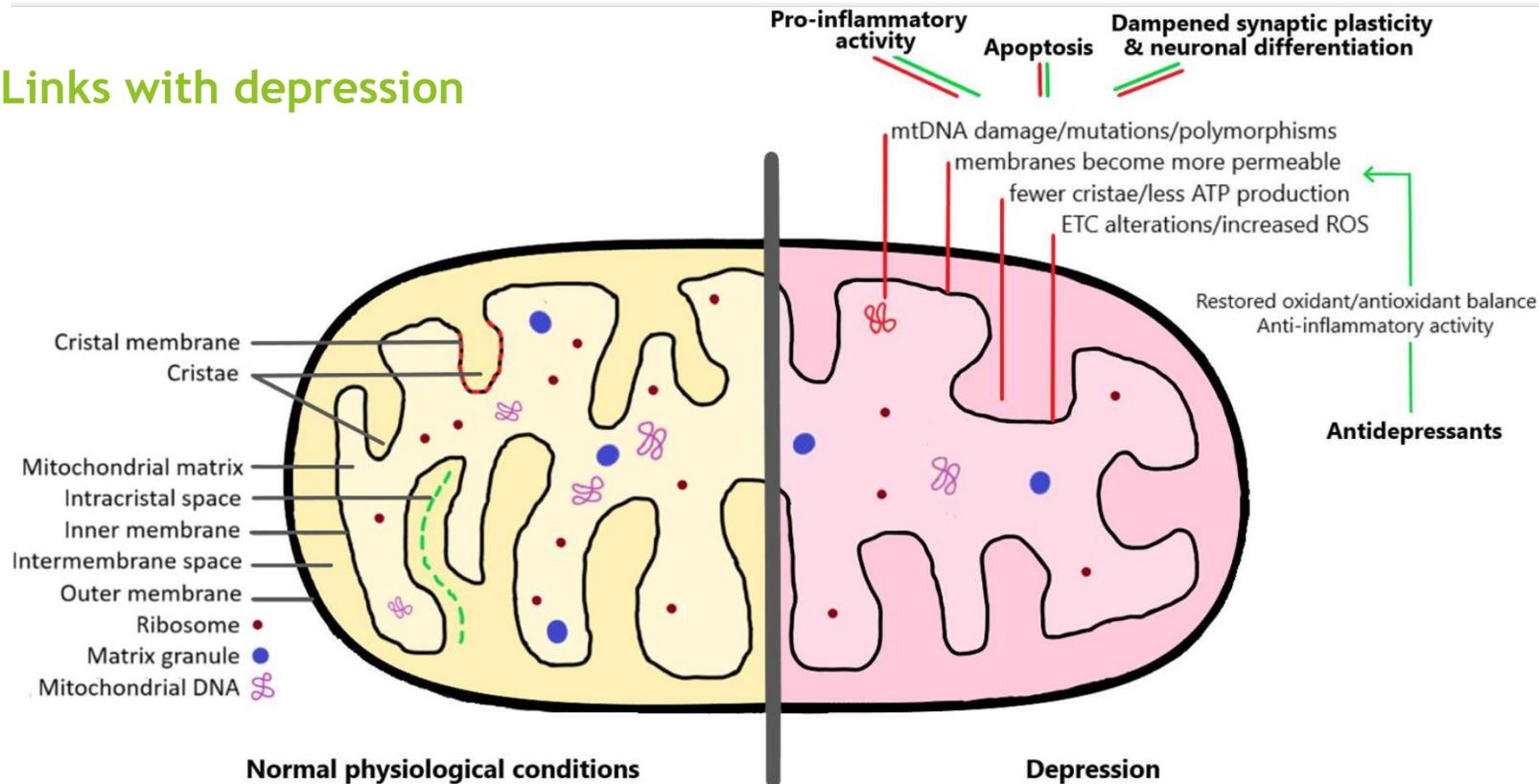
It is only natural to become worried and fearful about the future or sad and anxious about the changes we have to face physically. The fear of losing our ability to function both physically and mentally cannot be underestimated.

Stress on the body

- ▶ Mitochondria regulate brain function through oxidative stress and apoptosis
- ▶ Alterations in mitochondrial function may precede the development of depressive symptoms
- ▶ Stress related to Mito can not only impact mood, but can also increase physiological symptoms. Stress is commonly linked to common health problems such as high BP, heart disease and diabetes

On your body	On your mood
Headaches	Anxiety
Muscle tension and/or pain	Restlessness
Chest pain	Lack of motivation
Fatigue	Feeling overwhelmed
Stomach	Irritability
Sleep	Sadness/depression

Links with depression



- The brain has high aerobic activity, requiring about 20 times more energy than the rest of the body by weight, making it highly vulnerable to conditions stemming from impaired energy production. A resting cortical neuron consumes 4.7 billion ATP molecules every second ([Zhu et al., 2012](#)).
- ATP levels in the brain are generally lower in depressed patients compared to control subjects - possibly related to the dampened neuronal plasticity and impaired hippocampal neurogenesis thought to be operative in depression, as neurogenesis is a metabolically demanding process.
- Dysfunctional mitochondria decrease the available ATP, which would ultimately increase oxidative stress, inflammatory responses, and pro-apoptotic events, some of which are known to be involved in the pathogenesis of depression.

Mitochondria and Mood: Mitochondrial Dysfunction as a Key Player in the Manifestation of Depression 2018

Evidence-based findings

- ▶ chronic stress induced through a form of psychosocial stressor decreases mitochondrial energy production capacity and alters mitochondrial morphology

Psychological Stress and Mitochondria: A Systematic Review 2018

- ▶ “Mitochondrial functions modulate (adjust) neuroendocrine, metabolic inflammatory and transcriptional responses to acute psychological stress”
- ▶ “...mitochondria impact the nature and magnitude of physiological and molecular responses to a controlled psychological stressor.”
- ▶ “Stressful experiences, on their own, do not cause damage or disease, rather, it is the organism’s responses to stress that have the potential to result in physiological dysregulation and dysfunction, culminating in allostatic load and disease. Our study demonstrates how mitochondria can shape the major stress-response pathways, thereby recalibrating the multisystemic response to psychological stress.”

Mitochondria Linked to Psychological Stress Response in Study 2015

EMOTIONAL IMPACTS OF SYMPTOMS

Physical symptoms	Emotional responses	Coping strategies
Hearing loss	Difficulties in restaurants, phones, TV, background noise, misunderstanding, communication. Embarrassment, isolation, loss of friendships	<ul style="list-style-type: none"> - Ensure you access services available to you - Access available equipment to enhance hearing aids/implants - Explain to others when you are struggling (develop confidence) - Make necessary arrangements beforehand e.g. book ahead for meals out to ensure a quiet spot; use Bluetooth devices when out with others; use the NRS to make calls for important information recording
Vision loss	Loss of independence in driving, daily activities. Feeling detached from the world; missing out on everyday sights	<ul style="list-style-type: none"> - Manage diabetes well to avoid deterioration of eyesight - Explore available supports/equipment e.g. visual aids; signage; sign language on hands - Ask questions about your environment - don't be afraid to have someone explain your environment - Seek immediate medical treatment if you notice sudden changes
Gastrointestinal issues	Fear of infections with tubes; swallowing difficulties; anxiety about meals; embarrassment eating with others; feeling of loss of what once was (anger, sadness); missing the taste/texture; feeling a loss of dignity	<ul style="list-style-type: none"> - Remain up to date with available supports and access them - Listen to your body when your voice is hoarse - Be aware of how you eat/swallow and inform specialists as soon as issues arise - Take control of your management and advise doctors of what you need to make things easier
Diabetes	Injections daily; embarrassment; pain; frustration; BSL testing regularly; consequences of poor management	<ul style="list-style-type: none"> - Remind yourself of the importance of your health and push through the challenges - Educate yourself on what options are out there e.g. insulin pump; sensor readings; subsidies available - Ensure that you test your BSL's regularly and 'know your fingers'
Muscle weakness	Fear of falling; feeling of loss of previous abilities; wishing you could do things more regularly; pain; frustration with own body; difficulty keeping up	<ul style="list-style-type: none"> - Listen to your body and take a break if you feel you need to - you will do more harm than good if you try to push too hard - Do what you can on days you feel good - stretch gently and pace yourself
Fatigue	Constant tiredness; guilt/anger/frustration of not being able to 'keep up'	<ul style="list-style-type: none"> - Remind yourself that you did not choose Mito - be kind to you and allow yourself to recover - Know that the small things are not worth the health implications from the stress you carry over them

General Coping strategies

- ▶ Share with someone - ‘a problem shared is a problem halved’ - make sure they are good listeners!
- ▶ Compartmentalise - separate/distance Mito from you
- ▶ Use external methods e.g. calendars; journals; notebooks
- ▶ Keep records of medical information
- ▶ Write down questions/thoughts as you think of them to take to specialist appointments
- ▶ Mindfulness - remind yourself of what you CAN control (reduce the ‘mess’ in your head)
- ▶ Ask questions and understand your medication including possible side effects
- ▶ Have someone you trust and see often - to share and compare your ‘state of mind’ - often useful when you feel that things are changing
- ▶ Physiologically, avoidance of alcohol, tobacco and other chemicals is recommended, along with general health management of diet, temperature control and sleep
- ▶ Reduce stressors where possible - work; toxic relationships; NDIS support; environmental changes
- ▶ Listen to your body and follow it! Insight is a wonderful thing (e.g. croaky voice; sore legs)

List of potentially harmful medications

Please note that this information should be discussed with your doctor and is not to be used to make medical decisions

Category	Toxin	Brand name *	Action and Symptoms
NSAIDs	diclofenac, indomethacin, naproxen	Voltaren, Indocin, Aleve, ibuprofen,	Hepatotoxicity
Antipsychotic neuroleptic drugs	Chlorpromazine	Thorazine	Inhibits oxidative-phosphorylation
	Fluphenazine	Permitil, Prolixin	
	Haloperidol	Haldol, Decanoate	
	Risperidone	Risperdal	
	Clozapine	Clozaril, Clopine	
Barbituates	Phenobarbital		Reduces mito protein synthesis; decreases number and size of mitochondria
	Secobarbital	Seconal	Inhibits NADH dehydrogenase (complex I)
	Butalbital	Fiorinal	
	Amobarbital	Amytal	
	Pentobarbital	Nembutal	
Antidepressants	Fluoxetine	Prozac	
	Amitriptyline	Elavil	Causes autonomic dysfunction
	Clomipramine		memory impairment
	Amoxapine		
	Sertraline	Zoloft	hepatotoxicity
	Citalopram	Cipramil	
Anxiety meds	Alprazolam	Xanax	
	Diazepam	Valium, diastat	