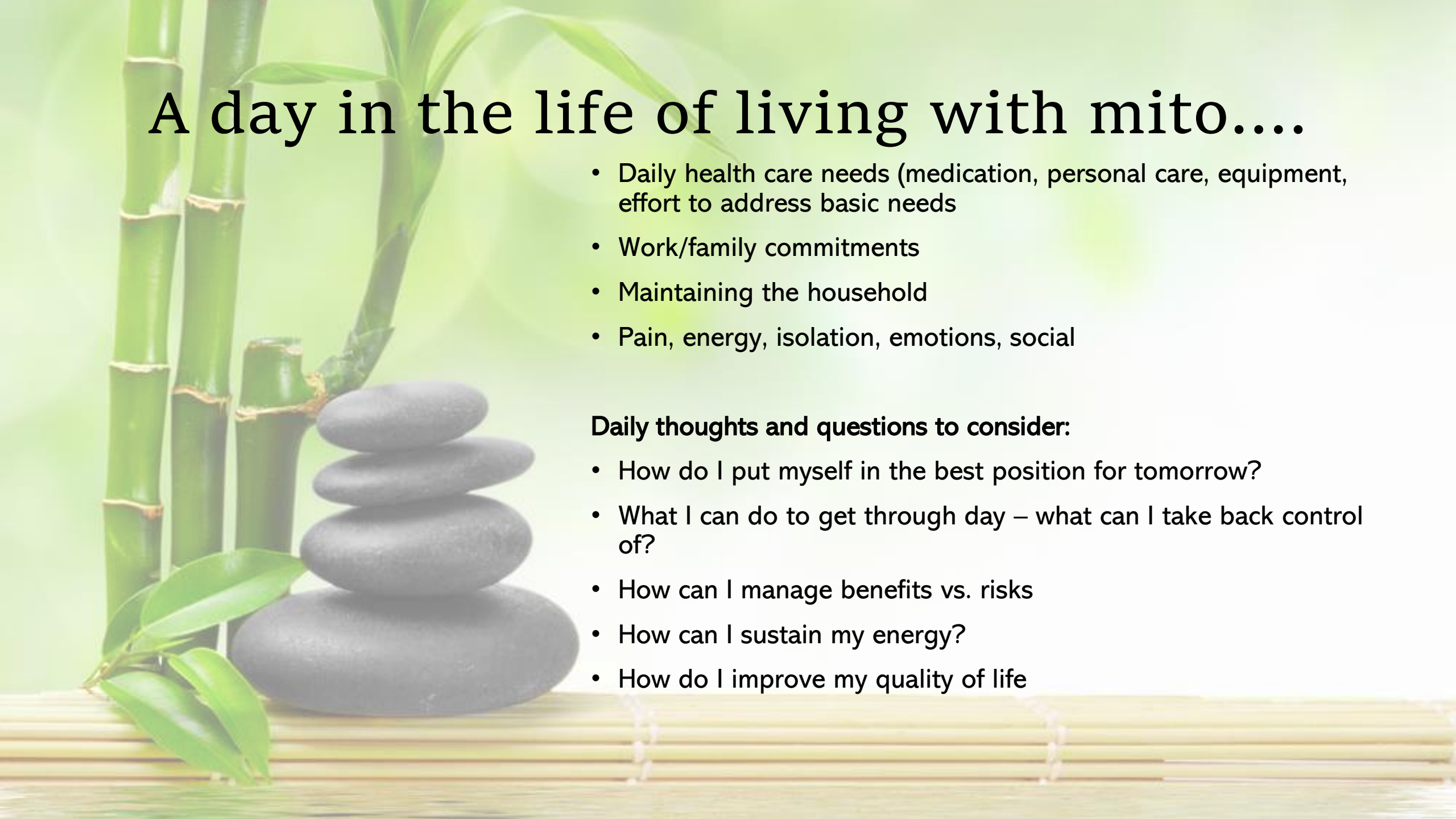


A day in the life of living with
mito...the importance of
quality of life'

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A day in the life of living with mito....

- Daily health care needs (medication, personal care, equipment, effort to address basic needs)
- Work/family commitments
- Maintaining the household
- Pain, energy, isolation, emotions, social

Daily thoughts and questions to consider:

- How do I put myself in the best position for tomorrow?
- What I can do to get through day – what can I take back control of?
- How can I manage benefits vs. risks
- How can I sustain my energy?
- How do I improve my quality of life



Sometimes its OK to...

- Do less
- Take time out
- Put yourself first
- Let less important/crucial things slip – prioritise your health so that you can be here tomorrow
- Prioritise the things we enjoy over the things we feel we ‘should do’
- Ask for help



Why we need to support our brain to improve quality of life

- The brain works constantly in the background, monitoring and controlling most of our bodily functions, using around 20% of the body's energy
- The brain is the most commonly affected organ. The high-energy requirement of the brain leaves it vulnerable to energy failure
- your brain never shuts off – even when you are sleeping, your brain consumes roughly as much energy as it does during the day (constant vigilance)
- The brain has no reserve energy stored
- If a task requires certain areas of the brain = energy needs increase
- Practices such as mindfulness can:
 - Reduce grey matter in the brain's amygdala (responds to stress)
 - Increases activity in the pre-frontal cortex (responsible for planning, problem solving and emotions)
 - Improve quality of life

Energy supply vs. energy demand

Stress Management Energy Accounting

Energy Withdrawal

- Socializing
- Change
- Making a mistake
- Sensory sensitivity
- Daily living skills
- Coping with anxiety
- Sensitivity to other people's moods
- Crowds
- Perceived injustice
- Certain people

Energy Deposit

- Solitude
- Special interest
- Physical activity
- Animals and nature
- Computer games
- Meditation
- Nutrition
- Sleep
- Being with pets
- Certain people

Psychological: how to care for your mind

- Share with someone –‘a problem shared is a problem halved’
- Use external methods to offload stress e.g. calendars; webster packs; bulk supplements; journals; notebooks, records of medical information, write down questions/thoughts as you think of them to take to specialist appointments
- Continue to learn and understand your condition and symptoms to reduce uncertainty
- Have someone you trust and know well to share and compare your ‘state of mind’ (reality checking)
- Reduce stressors where possible –work; toxic relationships; environmental changes
- Listen to your body and respond to it! Insight is a wonderful thing
- Engage in relaxing
- Mindfulness –being present in the moment –maintaining a moment-by-moment awareness of our thoughts, feelings, bodily sensations
- Always remember what you CAN control –let go of what you cant
- Remind yourself of what is attributed to your physical health –sometimes everything overwhelms us and becomes hard to differentiate
- Establish a strong clinical team to reduce pressure of managing symptoms yourself
- Most importantly –focus on recovery when you take a knock –everything else can and *has* to wait –use available resources!



Mind Full, or Mindful?