

# Caring for Yourself Before, During and After Your Next Doctor Visit

Remember: Everyone is different in how they get their needs met: Know yourself...Trust yourself!

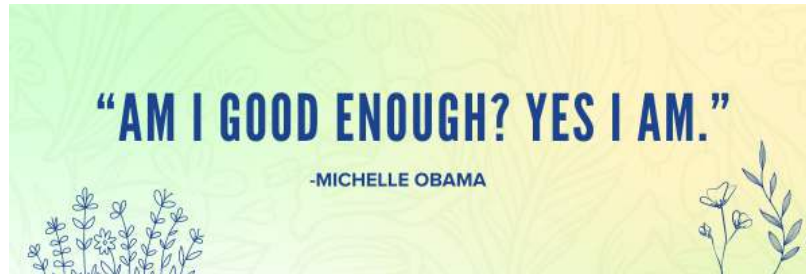
*\*\*Please note that this document is "For the Patients and By the Patients". This means that Mito Action cannot fully endorse any of the below recommendations or comments. These items were created by a close knit of people who are our MitoChampions. This document is to be used as a source of encouragement.*

## Mental and Emotional Preparation Before Your Doctor Visit

*\*\*Don't forget to check out "[How to Prepare for Your/Your Loved One's Next Doctor's Visit](#)" for more ways to physically prepare for your doctor visit!*

- 1. Affirm yourself in your mind ahead of time**
  - a. I know my body better than anyone in the world!
  - b. I am doing what I need to care for my body, the best way I know how: no matter the outcome of the appointment.
  - c. I am my best advocate. I am strong. I am able to do this.
  - d. I am doing my best to take care of myself.
- 2. Go into the visit with a positive attitude.** Remind yourself that each visit is a "new visit" and "new opportunity."
- 3. Affirm your diagnosis/symptoms**
  - a. Affirm with yourself what you already know to be true and remind yourself that a doctor's visit may not always be the best space to validate your symptoms, but support groups are!
  - b. Consider attending support groups before an appointment. Support groups create valuable sounding boards of emotional support, while helping you to prepare to advocate for yourself.
- 4. Create an exit plan and give yourself permission to exit in a way that feels most comfortable.** It is helpful to be simple and direct with your physician/ nurse about why you need to leave, but if you feel unsafe or triggered, trust yourself. You can leave without explaining yourself.
- 5. Recognize that things may not always go as planned, so try to prepare yourself to be patient with both yourself and your provider.** (i.e. appointments may take longer than expected, unforeseen testing can occur, etc.) For ideas of what to pack in your doctor visit bag click [here](#).
- 6. Consider who to reach out to for support on your way to your appointment, while you are waiting, and/or on the way home.** Remember some friends may be more skilled at supporting you at different times! Having spaces to process before, during and after appointments are very important. Reflecting ahead of time as to who are your best and safest people of support, is a vital part of emotional preparation.
- 7. Walk into the doctor's appointment with confidence.** Treat it like it is a "meeting" and use affirmations like "I am leading it!" or "I can do this!" Remember confidence is drawn out from within! "Am I good enough? Yes I am!"-Michelle Obama
- 8.**
- 9. Ask yourself: How can I flip the script?** For example, if the doctor is late, first validate your frustration, then instead of staying in that emotion, try to flip your understanding of the situation by thinking, "I love the way they spend time with their patients!"
- 10. Actively create an environment of calmness** a couple days before your appointment.

- a. Slow down; read a little longer/take a longer bath. Whatever is self care for you!
- b. Remove unnecessary distractions.
- c. Pray/meditate/seek out higher power.



### Emotional Self Care During Your Doctor Visit

1. **Make your accommodations/needs known to the office staff** and check in with yourself to see if you feel comfortable with their response.
2. **While you are waiting to see the doctor, take a giant deep breath in and breathe out slowly. As you breathe out, release any worry or anxiety. Use this time to focus on:**
  - a. 3 positive prepared affirmations
  - b. 3 moments of joy
  - c. 1 thing that you would like to better understand from this appointment
3. **Acknowledge that there are a variety of ways to accomplish what you need.** If you have a typical methodology for getting things accomplished, acknowledge this, but also try to be open to a doctor's new suggestions.
4. **Check in with the doctor to see if they had an opportunity to look over your records.** Give the doctor time and space to read what you have provided, if needed.
5. **Check in with yourself periodically during your visit.** Ask yourself:
  - a. How am I feeling right now? At this moment?
  - b. What is my doctor's personality/ "bedside manner"? Does it naturally fit with my personality? Am I ok with that?
6. **Use "mindfulness" skills to stay in the present.** A fidget ball, something tactile to touch, or rubbing your fingers together may help.
7. **Remind yourself that your doctors are human and they may not have all the answers.** Healthcare providers are an important part of the mito journey. If your doctor is unfamiliar with mitochondrial disease that is ok! This may be an opportunity to advocate and educate. If you feel like a clinician's lack of knowledge creates an unsupportive environment, it is also okay to consider an alternate provider.

### Now what?! After Your Doctor Visit

1. **Leave yourself time/space to process how the appointment went before you go home.** After the visit is completed, take a few minutes to reflect on the appointment. Go for a walk, get food or a drink, then jot down any follow up questions. Leave these with the receptionist or email them to your doctor directly.
2. **Be gracious with yourself.** You can "know" what to do during a doctor's appointment, yet we all have moments where we still feel unprepared. Remind yourself that you did your best and you are not alone in this process.
3. **Give yourself permission to feel!** All kinds of emotions can arise during and after a doctor visit for various reasons. Whatever emotions you are feeling are ok and give yourself permission to cry, if you need to!
4. **If you have a challenging doctor's visit...**

- a. Know how to use your voice! Talk with the patient advocacy department if an appointment goes really poorly (you can do this months later too! You don't have to decide immediately)
  - b. Give yourself permission to "let it be" if that will emotionally help you the best.
  - c. If you leave a review online, consider how you word the review. There is power in calm language. If you are angry, write out your review BUT DON'T send until you have put space between you and the event. Also, remember that not all clinicians read reviews. Is your purpose to share your thoughts with clinicians or "warn" other patients.
  - d. Work hard to not view all future appointments through a lens of pain created from a bad experience.
  - e. Phone a friend to process your experience/ role play.
  - f. Remember: There are tons of good doctors out there and you will find the right fit!
  - g. Put space between this visit and your next, if it is medically safe to do so. Space between visits may allow you to gather your thoughts, calm down, sort out your questions and hopes for the next visit.
  - h. Remember: You only have control over your own actions and you can choose to exit gracefully, but firmly, and be kind even if a doctor is not. It is not helpful to mistreat a doctor because you were mistreated.
- 5. Share your positive experiences when you have a good doctor visit and don't forget to refer this doctor to your other Mito friends!**