



Confident Caregiving: Strategies That Can Help You Along the Way

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Discussion Topics

1. How to prepare for medical appointments (Annette)
 1. Emergencies, MG crisis situations
 2. Neurology appointments early in disease
 3. Other non-MG provider appointments
2. Self-care (Suzanne)
 1. Healthy lifestyle
 2. Stress vs. worry



How to prepare for medical appointments

1. Emergencies, MG crisis situations
2. Neurology appointments early in disease
3. Other non-MG provider appointments



Emergencies, MG crisis situations

- Learn to anticipate, know triggers
 - Stress, lack of sleep, other health issues, etc...
- Explain what was done/not done in this situation and prior
- Learn body cues - recognize early signs of crisis
 - What early symptoms have you recognized that indicate an MG crisis?
- Prepare before hand so that information needed is ready
 - current medication list, Neurologist name and number

Emergencies add to anxiety and cause feelings of helplessness for both the MG patient and caregiver. Pre-planning will give control back!



Neurology appts early in disease

PACE

- **Present detailed information**
 - Practice being a good historian
- **Ask lots of questions**
 - Keep a tablet to with you to write down questions as you think of them
- **Check your understanding of information given to you**
 - Repeat back in your own words
- **Express any concerns about the recommended treatment**
 - Don't be afraid to advocate or disagree



Communicating With Your Doctor

The PACE Guide Sheet



APPOINTMENT DATE _____ TIME _____ DOCTOR _____

Reason(s) for the Appointment

Diagnosis and Prognosis

Describe your symptoms and concerns

Tests or Procedures

What do you hope can be done to help you?

Medications

Ask Questions and Express Concerns

Other Treatments

<https://wexnermedical.osu.edu/blog/take-pace-form-to-doctor>

CHECK YOUR UNDERSTANDING

- Ask the doctor to repeat or clarify information that is unclear
- Repeat aloud what the doctor said
- Summarize your understanding of what the doctor said

DON'T FORGET TO

- Bring all your medications or make a list of them and how they are taken
- Ask for a copy of test results or procedure reports



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Neurology appts early in disease (con't)

- Feel confident after you leave the appointment
 - Take a deep breath for a job well done
- Take action!
 - Discuss the plan
 - Follow through and do what is decided on for the plan
 - Take notes on how plan is working or what may need changed for next appointment.
 - Remember- this is a work in progress and the journey is different for each patient.



Other non-MG provider appointments

- How to communicate about MG
 - Don't assume other providers understand about MG
 - Ask if there is any information from the neurologist in the chart
 - Be a good historian regarding the patient's situation
 - Discuss what is relevant to this appointment
 - Share current medication list and treatment plan
 - bring literature from MGFA
 - state specifically that MG experts prepared the materials



Self-care for Caregivers

The good news

- Caregivers often feel pride, a sense of purpose, and other benefits from their caregiving activities.
- Population based studies show that many caregivers:
 - Cope successfully with caregiving
 - Report many psychological benefits from caregiving
 - may even experience improved health and reduced mortality because of their caregiving experience



Self-care for Caregivers

The Not So Good News

- Caregiving strain is associated with:
 - Stage, severity or newness of condition
 - Lack of adequate resources
 - Knowledge
 - Skills specific to the tasks required
 - Coping ability
 - Social support
 - Respite care – individual needs vary tremendously
 - Community services
 - Other demands of life



Stress and coping skills

- Are you worried or stressed
 - Worry is common and can lead us to think and problem solve about the things that concern us.
 - Stress adds a physical reaction to the challenges that we do not feel we have an immediate response to.
 - Heart racing
 - Queasy stomach
 - Cold hands
 - Headaches

If you do have physical symptoms along with your worries or concerns, it is important to include some type of relaxation technique that "resets" the sympathetic nervous system.



Healthy Lifestyle Factors

- When we are caregivers, it is important to also care for ourselves
- First, attend to physical needs
 - Sleep is perhaps one of the most important and often neglected parts of self-care
 - Healthy diet
 - Exercise
 - Fun activities!



Sleep

- Affects many aspects of mental (cognitive), emotional, physical performance
- Good sleep habits can improve sleep and are under your direct control
 - Behavioral factors
 - Environmental factors
 - Psychological factors
- *Any plan will have to be individualized*
- *Every plan will need time and persistence to take effect*



Sleep Hygiene

- Behavioral factors
 - Routine at bedtime
 - Ritual always helpful, more to some than others
 - Prepare for next day
 - Relaxation technique of choice
 - Wake at the same time – under your control (falling asleep is not)
 - Activity level – important, do not exercise before bedtime
 - Napping – avoid if possible, limit to 40 min or less
 - Avoid stimulants within six hours of bedtime
 - Restrict fluids within four hours of bedtime



Sleep Hygiene (con't)

- Environmental factors

- Light, especially blue light (electronic devices)
- Sound – white noise helpful
- Temperature – individuals vary

- Psychological factors

When daytime distractions recede, psychological factors may become more pressing

- Anxiety most common

- Medical concerns
- Family concerns
- Financial concerns

- Relaxation routine

- Calms the body as well as the mind
- Your mind will not remain blank (don't think of a white bear analogy)

- Gratitude journal



Types of coping skills

Alter, adapt to, accept or avoid challenge

- Task-oriented
 - Anticipatory
 - Prioritizing
 - Organizing
 - Problem solving
 - Changing the situation
 - Changing your behavior
 - Changing your thinking
- Emotion focused
 - Social support
 - Learning to control your reactions, emotions
- Avoidance or distraction
 - Positive in certain circumstances



Task-oriented Coping

- Anticipatory
 - Prioritizing
 - See next slide
 - Organizing
 - Time management
 - Routines
 - Learning what resources are available

Value Grid

	Important or Valued	Not important or valued
Urgent		
Not urgent	*****	



Task-oriented Coping

- Problem solving
 - Identify the stressor
 - What resources do you have?
 - What resources do you need?
 - Can you change your behavior?
 - For instance, with the current coronavirus –
 - Learn to correctly wash your hands
 - Order groceries online
 - Can you change your thinking?
 - Fact check your thoughts
 - How realistic are they?
 - What can you control?



Emotion-focused Coping

- Social support
 - This is one of the greatest buffers against stress
 - “Social distancing” does not mean ***emotional distancing***
 - Learn who is supportive and in what way
 - Someone to talk to
 - For information
 - For fun
 - Someone with practical skills
 - Help with chores
 - Transportation
 - Someone who values you
- Learning to control your emotions



Avoidance-focused Coping

- When you do not have control
 - This is not a defeat
 - Saves your energy for solvable problems
- Distraction
 - Adaptive at times as a mental respite
 - Games, puzzles, shows
 - Set limits



Stress

- Stress involves a physiological response in your body
- The sympathetic nervous system engages when you perceive a threat – and it cannot differentiate between a sabertooth tiger or a bill you can't pay or any other stressor
- It prepares you for “Fight or Flight”
- Think about what you need to either fight an enemy or run away
 - Increased heart rate
 - Increased breathing rate
 - More energy – liver breaks down stores
 - Large muscle groups activated



Immediate Stress Relievers

- Sometimes we need a way to immediately relieve stress
- These are examples:
 - Take deep breaths
 - Inhale to a count of 4, hold for 4, exhale for 7
 - Use your abdominal muscles
 - Relax your muscles
 - Use a “body scan” – head to toes
 - Move – go for a walk, gently exercise
 - Ground yourself in the present
 - Do a “sensory scan” – name 3 things you can see, hear, smell, touch
 - Distract yourself – but set a time limit
 - Listen to favorite music, play an engaging game, call a friend



Relaxation Strategies

- All relaxation practices involve deep, slow breathing
 - This is under your direct control
 - Learn through an app or a video correct technique
- There are many different practices – find one that you like and practice daily to “reset” your system
 - Meditation
 - Progressive muscle relaxation
 - Chi Gong, others
 - Yoga
 - Guided imagery
 - Repetitive prayer



Relaxation Apps

- Breathe2relax
- Virtualhopebox
- Headspace
- Calm
- There are many, many others
- Please find one that suits you



Resilience

- Resilience is the capacity to recover quickly from difficulties; toughness; grit. **Psychological resilience** is the ability to mentally or emotionally cope with a crisis and to return to pre-crisis status quickly
- Resilience is a key part of thriving as a caregiver – and this is a skill that can be developed and increased with practice
- Positive psychology has contributed many practices that contribute to resilience



Resilience Practices

- Build your connections
 - Social connections are key
 - Prioritize relationships
 - Join groups
- Foster wellness
 - Physical, emotional, mental, spiritual
 - Healthy habits
 - Practice mindfulness
 - Avoid negative outlets
 - Find purpose
- Set goals and anticipate, plan, move forward
- Seek help when needed



Cultivate Gratitude

- Gratitude is also a crucial element in living your best life
- Positive experiences are, unfortunately, not given as much weight as negative ones – the ratio is 2:1
 - For every negative experience, you need two positive ones to balance out
 - We are “wired” to pay more attention to negative ones
- Gratitude is associated with better outcomes
 - Physical, emotional, mental
- Practices
 - Keep a gratitude journal - record 3 unique experiences each day
 - Savor positive experiences
 - Dwell on each detail
 - With others – and ask them about their positive experiences
 - Start an email chain about gratitude
 - Write a letter to recognize someone



Practice self-compassion

- **Keep things in perspective.** How you think can play a significant part in how you feel — and how resilient you are when faced with obstacles.
 - If you feel overwhelmed by a challenge, remind yourself that what happened to you isn't an indicator of how your future will go, and that you're not helpless. You may not be able to change a highly stressful event, but you can change how you interpret and respond to it.
- Be proud of your accomplishments



Thank You!



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