

# LIVING WITH OR MINISTERING TO OTHERS WITH CHRONIC ILLNESS

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**Goal:** To provide practical and Biblical help for those enduring the pain and suffering of chronic illness, or those who wish to minister to others who are living with chronic illness.

## CLASS 3 -5 – Dealing with Difficult Medical Issues

### I. What to do When Doctors Won't Listen

#### 1. Understand why

What appears to be an unwillingness to listen or uncaring attitude may simply be the intense time pressure under which most clinicians function. The average time a clinician spends with a patient is only 18 minutes.

The sense that clinicians don't listen is as much of a problem with our healthcare system as it is a problem with clinicians themselves.

#### 2. Set reasonable expectations

- Time – recognize a clinician's time constraints (most visits ~15 min)

Think of how you operate when under time constraints. Do you tend to be laser focused on 'cutting to the chase' and getting to the point quickly?

- Their memory – they will not likely remember details about your health

How many people in your life do you remember key points of your last conversation with them?

- Content – avoid irrelevant topics

With limited time, it is best to avoid unnecessary conversation about trivial matters.

- Respect – show respect and rightly expect to be respected

Respect their expertise—which is presumably why you are seeing them. But you also have every reason to expect them to respect you as a person.

- They will listen – a key factor in a clinician's ability to help

If they do not give attention to your chief complaint, they are not fulfilling their role.

#### 3. Prepare for your visit

Recognizing the limited time, think through the most important things to communicate—and write them down rather than trusting your memory.

- Identify the most important matter(s) to be addressed
- Keep a health diary

This is especially important for symptoms that fluctuate over time.

- Prepare a summary of key symptoms
  - a. Onset: when did symptoms start?
  - b. Frequency: daily, weekly?
  - c. Severity: how do they impair your normal functioning?
  - d. Precipitating/alleviating factors: What makes symptoms worse? What brings relief?
- Write down important questions
- Drop off/send medical records in advance

#### 4. Advocate for yourself

- Redirect conversation when needed
- Ask pointed questions when your concerns seem to be ignored
- If your concerns are unaddressed, seek a new provider

A clinician who does not retain your confidence is not one you should continue to see.

## II. How to Deal with an Uncertain Diagnosis

1. Recognize medical uncertainty is common
2. Time is often a key ingredient to a diagnosis
3. Uncertainty is better than a misdiagnosis
4. Keys to getting the right diagnosis

### When to get a second opinion

- When diagnosed with a rare disease
- Your doctor is not a specialist in the disease
- When considering an intervention that could put your health at risk (surgery, drug)
- When symptoms are not responding to treatment

### Where to go for a second opinion

- A different institution, a different town, no relationship with current doctor
- An experienced specialist in the disease
- Look for external confirmation of their expertise (certified center, NIH grants for studying the disease)
- Most likely to be located in an academic medical center

### **III. How to Live with the Diagnosis of an Incurable Disease**

1. Give yourself time to absorb the new reality – avoiding life–altering decisions
2. Become a student of yourself – learn what exacerbate symptoms, what makes them better, how you respond when symptoms arise
3. Educate yourself about the disease

#### Why educate yourself about the disease?

- Patients who understand their disease have better outcomes
- The goal is to arm yourself with questions to ask
- Prepares you for engaging non-specialists with other needs

Questions to ask as you educate yourself:

- What is known about the natural course of the disease?
- Is there any evidence for effective treatment?
- Identify the most troubling symptoms
- Determine when getting a medical evaluation for new or worsening symptoms is needed

Be discerning about health information, much that is available is unsound and even harmful!

#### **Generally trustworthy sources:**

- WebMD
- Mayo Clinic
- National Institutes of Health
- National Organization for Rare Disorders

### **IV. Thinking About Unproven Therapies**

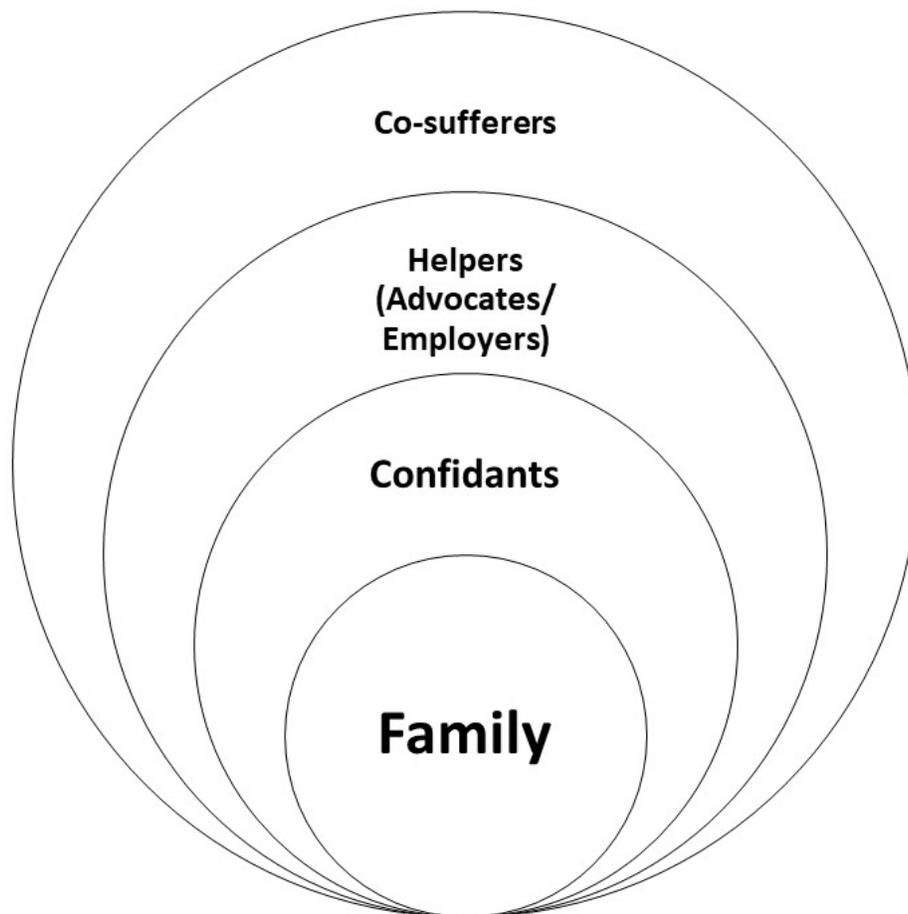
1. Recognize there are three types of potential medical interventions
  - Interventions that have been proven to be safe and effective for your condition
  - Interventions proven to be unsafe and/or ineffective for your condition
  - Interventions whose safety or effectiveness is uncertain
2. Determine which category an option fits within
3. Questions for uncertain therapies
  - Is there a plausible reason to expect the treatment will work for my ailment?
  - What is the expertise of the person making the recommendation? Do they have a financial interest in the product?
  - What harm could the therapy produce?
  - Can I be sure of the quality of the product?

4. Identify specific objective for therapy
5. After time on therapy, assess safety and effectiveness

#### **V. Thinking Through Who to Tell**

1. Requires careful thought
  - Do they need to know?
  - Maintain confidentiality? Tell them to do so.
  - Will their knowing help me?
2. Varies over time
3. Influenced by the impact of your disease
4. Consider keeping a list
5. Plan for disclosure

#### **Circle of Disclosure**



## **VI. Helpful Resources**

Agency for Healthcare Research and Quality, *Questions to Ask Your Doctor*. [ahrq.gov/patients-consumers/patient-involvement/ask-your-doctor/index.html](http://ahrq.gov/patients-consumers/patient-involvement/ask-your-doctor/index.html). This site provides helpful guidance on gaining the most from your office visit with a clinician. The site contains sample questions and informative videos.

Office of Disease Prevention and Health Promotion, HHS, *Choosing a Doctor: Quick Tips*. [healthfinder.gov/HealthTopics/Category/doctor-visits/regular-check-ups/choosing-a-doctor-quick-tips](http://healthfinder.gov/HealthTopics/Category/doctor-visits/regular-check-ups/choosing-a-doctor-quick-tips). This site provides some guidance on how to find the right provider.

Genetic and Rare Diseases Information Center, NIH, *How to Find a Disease Specialist*. [rarediseases.info.nih.gov/guides/pages/25/how-to-find-a-disease-specialist](http://rarediseases.info.nih.gov/guides/pages/25/how-to-find-a-disease-specialist). This site provides resources to help patients find specialists with expertise in rare disorders.

Access to Credible Genetic Research Network: Tool for Evaluating Health Information, <http://www.trustortrash.org/#> This website will walk you through three key questions to ask to help you determine whether or not you should trust health information you find on the internet, books, or other sources.

American Chronic Pain Association, <https://www.theacpa.org/>, This organization has a wealth of resources on their website for patients living with chronic pain.

Groopman J, Hartzband P. *Your Medical Mind: How to Decide What Is Right for You*. Penguin Books, 2011. This is a helpful book that provides an accessible guide for readers on making difficult medical decisions, including those where there is uncertainty surrounding the choice.