



# How to Be a Successful Patient and Self-Advocate

## **MEDICAL MANAGEMENT**

### **Create a Face Sheet**

It's a page (or more) of bullet points to get doctors up to speed quickly so you have more time to ask more meaningful questions and discuss a course of action. Bring two printed copies to doctor visits; one for the doctor, the other for your own reference.

[\(Please download the Face Sheet template under Patient Advocacy\)](#)

- Include the following information and keep it updated:
  - Past Medical History
  - Past Surgical History
  - Current Medications
  - Past Medications
  - History of Present Illness

### **Find a Superstar Primary Care Doctor**

This doctor takes an overview and connects all the dots.

- Get referrals from health-care providers you trust, rather than a friend or online review.
- Listen to your gut and don't feel pressured. If it doesn't feel right, move on to a physician who does. Interview several doctors, hire new doctors when you're not getting what you need. You are the boss.
- As you evaluate primary care doctors, ask yourself the following questions:
  - Do they promptly return calls?
  - Do they seem truly interested in your well-being?
  - Will they be assertive on your behalf?
  - Do they listen to your concerns and address them?
  - Do they communicate well with other doctors?

### **Find the Doctors Who Know the Most About Your Illness**

If you can travel to the best hospitals and doctors, do it. Get the best or at least consult with the best and bring it home to your local team. This is especially important if you have a rare disease.



## **Be an Active Member of Your Medical Team**

- Do your own research: be empowered by learning all you can about your disease and taking an active role in your health.
- Print information from the internet and ask your doctor to confirm accuracy.
- Look for support groups through hospitals and social media like Facebook. If you can't find a support group, consider starting one.

## **Organize Medical Records**

- Keep all of your medical records in a binder and arrange in chronological order.
- Store all your MRI's and other disks in the binder pockets.
- If the binder gets too thick, start a second binder. I keep one for Johns Hopkins, another for Mayo Clinic, and a third for my blood work.
- Always bring the binder containing your blood work, so you can track the values over time and have the numbers readily available for any doctor.

## **Ensure Clear Communication**

- Ask how your doctor prefers to communicate. Many are most responsive through patient portals.
- Some practices will dedicate a nurse or coordinator to you personally.
- Learn how your doctors handle emergencies before you are in crisis.
- Ask for an interpreter in advance when there might be language barriers.

## **Ask Questions**

- Prepare for appointments by making a list of questions to discuss with your doctor.
- Ask about the benefits, side effects, and disadvantages of a recommended procedure or medication. Take notes!
- Speak up if something doesn't sound right. Doctors make mistakes just like the rest of us... They may forget about medication allergies, previous advice or a different specialist's recommendations.
- Consider asking permission to record the entire appointment or at least the question-answer part of a visit. It can be very helpful to hear and process it later.

### **Avoid Unnecessary Hospitalizations**

Hospitals are full of sick people and bacteria. At last count 1.7 million Americans a year contract hospital-acquired infections.

- The good news: many treatments are available via home care.
- It's okay to ask healthcare providers to wash their hands before they examine you. Say "I'm sure you washed up before I walked in, but would you mind doing it now too?"

### **MONEY MATTERS**

#### **Seek Financial Help**

- Apply to Social Security for disability status and disability payments.
- Contact Medicare to determine eligibility for future insurance benefits.
- Call local, county, and state agencies; they may be able to provide support for mental health needs, personal care, food etc.
- If you have health insurance, call the company and ask for a go-to person contact to help with their processes.
- If health insurance coverage and government assistance are not enough - a real struggle for so many people - consider getting help through platforms like GoFundMe and Fundly to raise money.

#### **Insurance Coverage**

- Recruit a family member to help track insurance information, submit claims and follow up.
- When insurance companies stall or refuse to reimburse, you can hire an expert advocate to assert your claims. This is an added expense but may pay off if the advocate secures larger reimbursements or more coverage than you would have on your own. And always review your medical bills; errors are a common occurrence. If you don't have the time or energy to go through every itemized bill, ask for help or hire a professional.

#### **Know Your Rights at Work**

According to the ADA (Americans with Disabilities Act), employers with 15 or more employees must make reasonable accommodations, which can include duty changes, rest breaks, rearrangements of the workstation, or even the ability to work from home.

- Make sure expectations are clear on both ends.
- Write up the promised accommodations and get signatures.



## **PERSONAL STUFF**

### **Ask for help**

It's hard for some of us to ask for help. Do it. People want to help, they just don't know what to do.

- Make a list of where you need help.
- Ask people to take you to appointments, especially ones where you'll hear a lot of information.
- Maybe you need help paying bills, balancing checkbooks, grocery shopping, managing mail, organizing insurance bills, house cleaning, childcare, property care etc.

### **The Dreaded "How are you?" Conversation**

People will ask and it shows they care. But the answer is often hard to hear and tiring to say. I've learned that some people feel uncomfortable with the most honest responses. And I don't want to be a downer all the time – or a burden. Here's my trick: I answer with what I've been doing instead of how. Save the tough health stuff for a therapist, support group, or the friends who have shown they are willing and able to listen.

### **Get Involved**

Connect with people having similar experiences. Knowing you are not alone is invaluable.