



HANDOUT-ABLE- General Patient Guidelines For Advocating/Navigating Care, page 1

Navigating care to have medical needs met can be overwhelming. There are guidelines available as you manage needs in a complex system – with the goal of effectiveness in mind.

Tips:

- There is a benefit to advocating for yourself, with providers, caregivers, and other medical staff. Communicating the different layers of your medical needs can be complicated, and making a consistent, intentional decision to advocate for yourself is one of the most helpful tools you have in your arsenal in navigating relaying your medical needs.
 - If you need assistance with learning how to advocate, ask for help from family, friends, or your medical provider to see if an advocate could be arranged through your medical insurance payor to assist you. Just having someone to discuss results and ideas with is helpful. Brainstorm various possible solutions with your provider, all things considered.
 - You have choices in which care providers are on your team. Work at establishing relationships and learning the “ins and outs” of different clinics and levels of care.
- Providers who prescribe medications, treatments, and other interventions may employ the assumption that the prescribed course of action is working if they do not hear from you after the indicated time needed for the treatment to make its intended impact. Part of advocating with providers is that if the intended outcome does not come about, such as less pain, a decrease in the severity of symptoms, etc., then it is your role to inform the provider so that this can be reviewed, and a new course of action can be considered by your provider and yourself.
- When options for treatment arise, ask for all possible options so that you can communicate your preferences. Expanded options mean expanded opportunities for you to choose what you desire to address concerns.
- It is helpful to communicate the symptoms you are experiencing – even if you are not asked about them. Providers tend to think you are not experiencing a symptom unless you bring it up; it is indicated not to wait until your provider asks about an area of your system or how a bodily system is operating.
- Consider all available treatments (traditional and non-traditional) which are legal and healthy, for your symptoms as there may be available interventions that could assist in reducing symptoms in addition to other courses your provider is recommending. Communicate with your provider that you are considering alternative treatments to make sure that everyone is on the same page (to ensure you can avoid negative interactions of medications and substances, etc.)



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Tips (continued):

- If you desire to stop a particular pharmacological or other treatment, communicating in advance of initiating your decision with your provider allows for an orchestrated plan for tapering or other options. This will be helpful in your quest for coordinated care.
- Seeking a second opinion or third opinion to verify diagnoses is your right. Asking for that when you know that it is indicated is important.
- If you are given information that you do not understand from a medical professional, ask for it to be presented in a way that makes sense for you (pictures you can see, handouts you can read later, links to videos online, simplified language, etc., however manner you learn best).
- Finding access to specific providers who are specialists can sometimes be a challenge. Asking your insurance provider for a case manager or advocate to assist with referrals can be helpful.
- Asking for out-of-state referrals for specialty hospitals or other treatments can be asked about if providers in the area are not available to address queries in care.
- Sometimes, primary care providers rely on patients to provide updates on the results of testing and treatments after a specialist referral appointment is made, after the fact. If you do not feel like you have the skill set to be able to do this, you could:
 - Ask for a summary of visits from other providers and hospitals/clinics in writing, from specialists – to take to your primary care.
 - Notify your primary care office that you have undergone a visit with a specialist before your next primary care visit, and state you would prefer that they perform a records request rather than you notify the provider verbally of the visit. Some clinics may require your request in writing. This could be coordinated with enough time prior to your visit for records to be requested and delivered.
- Study and implement healthy lifestyle choices to maintain and improve your current health status.
- Most of all, know that you are the head of your medical team. Become educated at what ages different tests are recommended on a routine basis. Keep lists and records of your information so that you can be “in the know.” No matter what you are facing or the approach of care you are pursuing, take 100% responsibility for your health and work on positive and effective communication of all medical players, for the benefit of your care.



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