

Becoming Your Own Advocate

Narcolepsy is a life-long neurological disorder that often affects quality of life. Social, career, and other choices often are compromised. Especially for young people, the condition can cause embarrassment, anxiety, and depression, particularly if peers and loved ones are not supportive.

There is no cure for narcolepsy, but there are treatments and lifestyle changes that can significantly relieve symptoms. Being your own advocate plays a crucial role in managing narcolepsy.

Self-Advocacy

An effective self-advocate is someone who's good at letting other people know what he or she is thinking, feeling, and needing. Sometimes self-advocacy means asking lots of questions and asking them until you really understand the answers. Sometimes it means helping other people understand what's important to you and sometimes it means asking for help when you really need it. Self-advocacy doesn't mean you'll always get just what you want in the way you want it, but having the skills and confidence to communicate your wants and needs is an important first step in reaching your goals.

Self-advocacy encompasses deciding what you need, developing a plan, carrying out that plan, and then evaluating the efficacy of your efforts. This will include learning new skills and asking people to help you. To be an effective self-advocate you will need to listen, negotiate, problem solve, and be assertive. Improving your self-advocacy skills will enable you to speak for yourself and actively participate in decisions affecting your life.

There are four basic steps to self-advocacy - define the problem, develop an action plan, carry out the action plan, and evaluate how you did.

There should be certain non-negotiables when it comes to your medical care. Communication is crucial to quality healthcare. When people take an active role in their care, research shows they fare better – in satisfaction and in how well treatments work. Don't be afraid to ask questions. It is important to educate yourself and take control of your narcolepsy.

Managing narcolepsy means eliminating as much stress and negativity as possible, being self-aware of your needs and personal limits, knowing your legal rights, and communicating them in an assertive, effective manner.



Define the problem



Develop an action plan



Carry out the action plan



Evaluate how you did

Develop Self-Understanding

Individuals who understand, recognize, and acknowledge their abilities and physical limitations will be able to more effectively advocate for themselves. This is a very difficult process and will likely change over time. However, self-understanding of abilities and physical limitations will enable individuals to set realistic goals for themselves and have a better chance of enjoying their social, educational, and professional experiences despite having narcolepsy.

Characteristics of Self-Advocacy

In order to self-advocate, individuals first need to recognize, accept, and understand their condition. To be an effective self-advocate, it is important to voice your opinion, address ongoing concerns, and develop learning strategies for setting goals, time management, and problem solving.

Below is a chart outlining steps to be an effective self-advocate.

1 Self-Awareness

- Interests, strengths, and preferences
- Goals and dreams
- Support needs
- Physical, mental, and emotional limitations
- Understanding that narcolepsy is life-long
- Ability to recognize symptoms necessitating need to self-advocate

2 Know Your Legal Rights

- Personal rights
- Educational rights
- Professional rights
- Knowledge of resources

3 Communication

- Assertiveness
- Negotiation
- Body language
- Compromise

4 Leadership

- Knowledge of resources and support
- Advocating for others with narcolepsy
- Organizational participation

Becoming an Empowered Patient

Being an empowered patient means taking an equal and active role in the care of yourself, managing healthcare information, proactively researching and learning the most about the disease or condition, and seeking needed

answers. Being equipped in this way can improve the chances of doctors listening and providing better care.

Having a rare or undiagnosed condition can be difficult. It is common to feel isolated, alone, afraid, anxious, sad, and misunderstood. But when you seek help for the symptoms, and instead, leave the physician's office feeling dismissed and patronized, those feelings can turn to hopelessness. The best protection against developing these feelings are well-kept medical records, patience, being organized, and the confidence to seek another opinion when you feel it's required.

One of the best and most important resources is support from other patients, their families, and friends. Additionally, when you are experiencing a specific symptom, feel lost or confused with the journey of finding a diagnosis, or want additional advice on best practices, patient advocates can provide a myriad of benefits and are another important resource for support.

Getting Multiple Opinions

Sometimes it is valuable to gain a second, third, or even fourth opinion when seeking a diagnosis. Getting additional opinions not only provides an opportunity for you to learn more about your condition, it also offers peace of mind that you are approaching your new diagnosis with the best chances for a favorable outcome. It is important to consider consulting medical professionals who are active in research. Professionals who work in academic medical centers may be good sources for identifying difficult-to-diagnose diseases because of their interests, resources, and professional expertise.

Obtaining Your Own Medical Records

There are multiple steps to becoming an empowered patient. One of these is becoming knowledgeable about your own health information by requesting, reviewing, and organizing your medical records. Having copies of your medical records will establish your standing as a strong and active member of your healthcare team.

Understanding Your Rights as a Patient to Obtain Your Medical Records

The federal Health Information Portability and Accountability Act (HIPAA, pronounced hip-a) gives patients the right to obtain a copy of their medical records from any medical provider, with a few exceptions. Patients may inspect, review, and receive a copy of their entire medical and billing records.

You may request your own records. Please consult the government website for HIPAA to learn more about this important statute and your rights. (www.hhs.gov/ocr/privacy/index.html).

If a provider denies a request for medical records, they must provide a denial letter. But in some cases, denials can be appealed. If you need help with the appeal process, the Patient Advocate Foundation (www.patientadvocate.org/resources.php?p=36) has a step-by-step guide on how to appeal a denial and sample appeal letters.

Recording Ongoing Health History

A personal care notebook serves as an organizing tool to help patients keep track of important information about their healthcare history. A care notebook can help you maintain an ongoing record of care, services, providers, and notes, thereby empowering you to become an expert of your own or a loved one's care. Be sure to update the medical records included within the notebook regularly, especially after medical procedures, vaccinations, major illnesses or diagnoses, health test results, or other relevant events. The care notebook can also be brought to medical appointments, conferences, and travel, and can be an invaluable resource for patients that see new physicians.

Another option for tracking and maintaining a patient's medical history is the use of personal electronic health records. There are applications that allow patients to manage and access their health information in an environment that is confidential, private, secure, and organized.

Creating a Care Notebook

As narcolepsy is a chronic condition that impacts all areas of life, you will be involved with a number of healthcare professionals, educators, other groups, and insurance companies at various stages in this journey.

You may be asked for past records, tests, educational plans, etc., as well as names and contact numbers.

A care notebook will help you better communicate your needs. It is an organizational tool designed to keep needed information at the ready for meetings with doctors, health insurers, school officials, and others. It allows patients to keep, in one place, all of the relevant information, documents, and data needed to track and manage a disease, in this case, narcolepsy. Many healthcare providers have recognized the value of care notebooks and may provide assistance to patients with setting one up. The creation of a care notebook is an individualized process. What works for one person may not work for another.

Getting Started

Building a care notebook is about getting organized. A good first step is to gather all of the relevant information about the medical history, doctors' reports, test results (including results from the sleep study evaluation(s), neuropsychological, education, vision tests, etc.), list of medications, contact information for all of their healthcare

providers, as well as patient contact information. In addition, the care notebook will provide a place to track data such as vital statistics, diet, behavior, and sleep.

Care Notebook Checklist Sample

Materials to purchase

- 1 1/2 inch or larger binder
- Dividers with pockets
- Calendar
- Business card pages
- CD holder sleeves
- Loose leaf paper
- Plastic folder sleeves
- Sticky note tabs
- Pens

Sections to Organize

Cover Page – Lists your contact information in case it gets lost, who to contact in case of an emergency.

Questions/Notes – This is where you can keep your list of questions to ask at your next appointment and paper to take notes on during your visit. Once you write down the answers to your questions you can move that documentation to the specific specialty section.

Care Log – Track your vital signs, diet, sleep patterns, or any daily activities you feel you need to share with your provider.

Medication List – Keep a list of all of your medications you take and have taken in the past. Be sure to include dose (how much) and frequency (how often).

Calendar – Keep track of appointments you have and remind yourself when to schedule your next appointments.

Medical History – Write down your personal and family medical history, also list your allergies and immunizations here.

Hospitalizations – Keep a list of all the times you have been admitted and your discharge summaries here.

Medical Contact List – Obtain business cards from every physician, specialist, testing facility, lab, and therapist you visit. Place them all in business card holders. Even if you stop visiting any of the medical specialists, hold onto their cards so you can refer to them if you need copies of previous medical records. You can also place your appointment reminder cards in here so you don't lose them.

Medical Specialists – Keep a separate section for each specialist you see. You can place your after visit summaries here.

Medical Test Results and Labs – Keep a list of all of your test results and labs. You can also store your medical imaging CDs in the CD holder sleeves in this section.

Education Specialists/Teachers – Keep a section for each school or each teacher, specialist.

Psychologist – Keep a section for each psychologist or whomever performs testing or counseling.

Accommodation Letters/Requests/School Individual Plans – Keep a section for school education plans, IEP, 504, ACT/SAT accommodation request letters and accommodations received.

Insurance – Keep copies of your insurance cards, track how much you have been billed, how much insurance has covered, what you have paid and when. If you need to contact the insurance company, keep a log of who you spoke with, what you spoke about and when you spoke.

Research Articles – Keep the latest research articles and abstracts of articles to share with your providers.

Update Notebook Periodically

If your notebook becomes too large, create a second binder with the same sections and place anything 5 years or older in it. Put a note in each section in the current binder that there are archived notes. Keep a copy of the most recent sleep study in the current binder.

Remember

Keep your care notebook in a consistent location. When you take a document out to make a copy, remember to put the original back immediately so that the notebook stays accurate and complete.



narcolepsynetwork.org

learnaboutnarcolepsy.org



wakeupnarcolepsy.org

