

Navigating Hospital Stays: A Guide for People Living with Neuromuscular Diseases

Hospital stays can be overwhelming, especially for people living with neuromuscular diseases, who may have unique medical needs and communication preferences. This guide is designed to help you and your loved ones feel more confident and prepared during your hospital experience. From understanding your care team's roles and learning to advocate effectively for your needs to managing medical records and billing, this resource offers practical tips and information to support you every step of the way.

Planning for Your Stay

What to bring to the hospital

You may not have time to think about what to bring to the hospital in the event of an unplanned emergency.

Essentials

Keep these items in a convenient place at home and carry them with you when you are out, so you'll have them in the event of an emergency:

- » Medical summary
- » Insurance information
- » Advanced directives
- » Extra change of clothes

Good to have

If there is time, gather these things to bring to the hospital:

- » Personal care items (eyeglasses, toothpaste, toiletries)
- » Comforting items (pillows, gaming system, headphones, fuzzy socks, chargers)

For caregivers

Any caregivers coming along should bring:

- » Wallet and identification
- » Phone charger
- » Change of clothes



Transportation options

If it is an emergency, always call 911 to have emergency medical services transport you in an ambulance. Do not try to drive yourself.

If possible, ask family or friends to provide transportation to the hospital. Discuss their availability for transportation when you are discharged.

Consider ride share or nonemergency medical transportation (NEMT) services. NEMT may be provided by public transportation agencies or private companies. Check with your health insurance provider to see if transportation costs are covered.

Household logistics

You may need to plan for these logistics — or designate someone to handle them — during a hospital stay.

- Plan care for dependent children or pets.
- If applicable, notify home health agencies that services should be put on hold.
- Consider having mail **forwarded** or **held**.
- Consider asking a family member or friend to keep a key to your house so they can check on things if needed.

Prepare your support system

Designate someone to come to the hospital with you to provide company, advocacy, and support. Here are more ways loved ones can help:

- Set up a visiting schedule with family and friends.
- Request loved ones send flowers or cards to brighten up your room.

Last-minute checklist

If you have time before you go to the hospital:

- Shower or bathe.
- Remove jewelry or other valuables.
- Make sure you have any needed paperwork.
- Pack comfortable clothing, blankets and/or pillows, a sound machine, or anything you need to feel comfortable.

Considerations for Unplanned Stays

People with neuromuscular diseases and their families should think ahead about unplanned hospital stays. These tips can help you prepare:

Create an emergency plan. Resources like the **MDA Emergency Room Summary** are invaluable to have on hand. This will save you a lot of time in the event of an emergency, as all your relevant information is accessible.

Alert first responders of your/your loved one's diagnosis. You can file a form with the local police, fire, and ambulance services so they know someone residing at your address has a neuromuscular disease and might need special transport.

Educate ER doctors and nurses about your neuromuscular disease. MDA and other organizations offer fact sheets about specific neuromuscular diseases that may be helpful to keep with you to share with healthcare providers who are not familiar with your diagnosis.

Building Hospital Know-How

Managing expectations

The hospital setting can be uncomfortable, even with planning and support. Think through how this change of environment and routine can make you feel. Here are a few ways to prepare:

- Consider meditation or therapeutic support to talk through your worries before admission.
- Make sure you understand the purpose of your stay. If it is a planned stay, ask your care team questions before admission.
- Familiarize yourself with the hospital “Bill of Rights.” This list of expectations for patients and providers is available in every hospital setting. It will give you a foundation for knowing your rights as a patient and advocating for yourself during your stay.

Understand hospital policies

If possible, find out the answers to these questions before you are admitted to the hospital:

- Are there visiting hours?
- Are children or pets allowed to visit?
- Can a loved one bring food from home?
- Do I need to bring my medications with me?
- How will my medications be administered?
- What is not permitted in the hospital?

Designate power of attorney

Experts recommend setting up a power of attorney (POA) before hospitalizations or serious medical procedures. POA is a legal document that allows you (the “principal”) to give another person (the “agent” or “attorney-in-fact”) the authority to make decisions on your behalf. This can include decisions about healthcare, finances, or both, depending on the type of POA you create.



Tips for Self-Advocacy in a Hospital Setting

Being in a hospital can be incredibly stressful, and needing to advocate for yourself may add to that stress. Do your best to remain calm and remember that healthcare providers want to help you. It's also important to know that there are other resources to help you, such as hospital ethics boards, patient advocates, lawyers, and facility staff.

Here's what you need to know about some common self-advocacy situations:

Requesting a transfer. Patients generally have the right to request a transfer under principles of patient autonomy and under the federal **Emergency Medical Treatment and Labor Act (EMTALA)**; however, both have limits. For example, the hospital or healthcare provider must have the capacity and necessary medical expertise to treat you. If you would like to appeal a hospital's decision not to accept your transfer, you could request a meeting with the hospital's ethics committee, speak with the chief medical officer, or appeal to the hospital's (or medical system's) patient

advocate. Health insurance can also pose issues with transfers. A private insurer may decline to cover the transfer or treatment, which you can dispute through the insurer's appeals process. Medicaid and Medicare often require you to follow an enrollment process for new treating providers, especially when traveling across state lines for care.

Requesting a second opinion. You should always feel free to request a second opinion, and most healthcare providers and hospitals will provide recommendations for other healthcare providers who can provide second opinions when asked. Dartmouth Health has a helpful resource about **requesting a second opinion**.

Changing providers. Many healthcare providers have portals that can facilitate the transfer of medical records, and you can use a hospital's patient advocates to facilitate these transfers and learn about transportation options to your new healthcare provider.

Your Care Team

Your care team includes a range of professionals, from doctors and nurses to therapists, social workers, and case managers. Understanding each person's role — and knowing who to go to for what — can help you communicate effectively and ensure your needs are met promptly. Don't hesitate to ask for introductions or clarification about who is providing your care.

In many cases, you will have a regular care team familiar with your neuromuscular condition, but during emergency or unplanned hospital visits, you may be treated by different medical professionals.

It's important to keep accurate, up-to-date medical records and advocate for communication between all your providers to ensure consistent, informed care across settings.

Your care team may include these health professionals:

Neurologist: A doctor who specializes in the nervous system and muscles. They often direct care for neuromuscular diseases, focusing on diagnosis, monitoring progression, and prescribing medications. They may coordinate with other specialists for treatments outside their scope of practice.

Cardiologist: A doctor who specializes in treating heart issues, which are common in some neuromuscular diseases. They often work closely with your neurologist to manage any changes in heart function.

Endocrinologist: A doctor who specializes in managing metabolic and hormonal issues, which may affect muscle function and overall health in neuromuscular conditions.

Respiratory therapist: A clinician who helps manage breathing challenges by monitoring lung function and providing supportive devices that aid in coughing, airway clearance, and ventilation.

Physical therapist: A clinician who evaluates mobility needs and teaches exercises to maintain function, prevent contractures, and support range of motion. They may assist with equipment recommendations and wheelchair evaluations.

Occupational therapist: A clinician who helps individuals maintain independence in daily tasks using adaptive tools and techniques. They can offer guidance on home/work modifications and aids, such as grab bars or communication devices.



Speech therapist/speech language pathologist: A clinician who addresses issues with speech and swallowing caused by muscle weakness. They can provide assessments, therapeutic techniques, and assistive devices to support communication and safe eating.

Social worker: A healthcare team member who supports patients and families with discharge planning, emotional support, resource connections, and navigating insurance or benefits.

Chaplain/spiritual advisor: A healthcare team member who provides emotional and spiritual support during hospitalization, regardless of faith or belief system.

Patient advocate: A hospital staff member who supports patients by ensuring their rights are respected and concerns are addressed. They may also be called a care coordinator, patient relations representative, or ombudsman. In smaller hospitals, this role may be filled by a social worker, case manager, or nurse.

Discharge planner: A hospital staff member who coordinates a safe, smooth transition from hospital to home or another care setting. This is especially important for those with complex care needs.

Dietitian: A nutrition expert who helps manage dietary needs to support energy, muscle function, and overall health. They can offer guidance on swallowing issues, weight changes, and feeding strategies.

Child life specialist: A hospital staff member who supports children and families by reducing stress around medical care through play, education, and emotional support tailored to the child's age and needs.

Recreation therapy: A therapist who uses adapted activities to support emotional well-being, movement, and social connection, helping patients stay engaged and maintain a sense of normalcy during hospitalization.

Resident: A doctor who has graduated from medical school and is now undergoing specialized training in a specific area of medicine, such as neurology, internal medicine, or rehabilitation. In a hospital setting, you may be examined by a doctor who identifies themselves as a resident.

Attending physician: A fully licensed, senior doctor who has completed all medical training, including medical school and residency, and is responsible for overseeing a patient's overall care during a hospital stay.



Nurse: Nurses are the backbone of the healthcare system and work directly with patients to provide physical and emotional care. They have varying levels of education depending on their title:

- **Patient techs/certified nursing assistants** assist with personal care tasks like bathing, dressing, and eating. They help maintain comfort and dignity while reporting changes to the nursing team.
- **Licensed practical nurses (LPN)/ licensed vocational nurses (LVN)** provide basic nursing care under the supervision of RNs or doctors. They are licensed after completing a one-year program and passing a state exam.
- **Registered nurses (RN)** deliver direct patient care, manage medications, and coordinate treatment. RNs are licensed professionals with an associate or bachelor's degree in nursing.
- **Nurse practitioners (NP)** are advanced practice nurses with a master's or doctoral degree who can diagnose or treat diseases and prescribe medications. Many NPs specialize in areas like neurology or primary care.

Medical Records and Billing

Keeping track of your medical records and understanding your hospital bills can be challenging, but it's crucial. Knowing what's in your records, requesting copies when needed, and understanding what your insurance does and doesn't cover can help you avoid confusion and unexpected costs. Don't hesitate to ask for help from hospital billing departments or patient advocates.



Requesting medical records

Health Information Management (HIM)

This hospital department is responsible for organizing and maintaining your medical records. This includes ensuring that your information is accurate, complete, and secure. HIM professionals do not provide direct care, but they play a key role in making sure your health records are available to the right people at the right time.

How to put this into action:

If you need a copy of your medical records, the HIM department is usually your first point of contact. You can reach out to them through your hospital's main number or patient portal to ask about their process for requesting records.

Release of Information

This refers to the official process of sharing your medical records with you or someone else you authorize, such as another doctor, family member, or legal representative. This process ensures that your private health information is shared safely and only with your permission, in compliance with privacy laws like the Health Insurance Portability and Accountability Act (HIPAA).

How to put this into action:

To request your records, you'll usually need to complete a Release of Information form. This form will ask for details like which records you need, where to send them, and who is allowed to access them. Some hospitals let you submit this online, while others may require you to mail or fax the form to the HIM department.

Billing basics

These terms and concepts will help you understand your insurance coverage and hospital bills.

Insurance coverage:

- **A copay, or copayment,** is a fixed amount you pay out-of-pocket for a covered health care service, like a doctor's visit or prescription. It's essentially a flat fee you pay at the time of service, regardless of the actual cost of the service.
- **An insurance deductible** is the amount of money you are required to pay out-of-pocket before the insurance coverage begins to pay for covered expenses.
- **Coinsurance** is a cost-sharing arrangement where you and your insurance company share the cost of covered medical expenses after you've met your deductible. You pay a percentage of the bill, while the insurance company covers the rest.
- **An insurance denial** occurs when an insurance company refuses to pay for a medical service or treatment, whether it's a claim for services already received or a request for services yet to be delivered. This means the insurance company won't cover the costs associated with the specific medical care, and the patient may be responsible for those expenses.
- **An insurance appeal** is a formal request you or your healthcare provider makes for the insurance company to reconsider a decision to deny coverage for a medical service or treatment. Essentially, it's a way to ask the insurance company to review its original decision and potentially change it in your favor.



Billing errors and disputes:

- **You can ask your hospital to provide an itemized bill** that breaks down all the charges from your visit or stay, listing each service, supply, or medication separately. This can help you better understand your medical expenses, check for errors, or prepare for insurance questions or financial assistance applications. To request an itemized bill, contact your hospital's billing department and ask for a detailed breakdown of all charges. If you are working with a case manager, patient advocate, or social worker, they may be able to assist you in requesting and understanding your itemized bill.
- **The federal No Surprises Act** protects patients from surprise medical bills, particularly for emergency services, nonemergency services at in-network facilities by out-of-network providers, and air ambulance services. It went into effect on Jan. 1, 2022, and aims to clarify patient responsibilities and minimize unexpected costs.

Resources within the hospital

Ask your hospital how you can access these financial resources:

Financial assistance:

- Hospital financial assistance, sometimes referred to as “charity care,” is a program that provides free or discounted health services to patients who can’t afford them. These programs are often required by law for nonprofit hospitals and may also be offered by for-profit hospitals.
- Eligibility varies by hospital, but generally, a patient must be uninsured or have difficulty affording their co-pays or deductibles.

Emergency Medicaid:

- Emergency Medicaid is temporary health coverage for individuals with immediate, life-threatening medical conditions who are ineligible for regular Medicaid. It ensures access to emergency medical care, including hospital visits, without financial barriers.
- Emergency Medicaid covers services necessary to diagnose and treat a medical emergency, not ongoing or routine healthcare.



- Emergency Medicaid coverage varies by state.

Patient advocate/social worker:

- A hospital’s patient advocate or social worker may be able to help you obtain insurance coverage or financial assistance.
- Social workers may also connect you with local charities that help with costs not covered through insurance.

Resources From MDA

Explore these resources for more tips and tools to prepare for hospital stays:

- > [MDA Access Workshop: Access to Medical Care](#)
- > [MDA Access Workshop: Access to Coverage: Insurance](#)
- > [Preparing for Emergencies: A Checklist for People with Neuromuscular Diseases](#)
- > [MDA Quest Media: Smart Steps to Take in a Medical Emergency](#)
- > [MDA Quest Media: How to Speak Up for Your Healthcare Needs in Hospitals and Doctors’ Offices](#)

MDA is here to support you. If you have questions, are looking for additional resources, or would like to connect with others in the neuromuscular community, please contact the MDA Resource Center at **833-ASK-MDA1 (833-275-6321)** or **ResourceCenter@mdausa.org**.

This resource was developed with the expertise and knowledge of Julianne Meiser, MSS, LCSW, from Children's Hospital of Philadelphia.

About Muscular Dystrophy Association

Muscular Dystrophy Association (MDA) is the #1 voluntary health organization in the United States for people living with muscular dystrophy, ALS, and over 300 other neuromuscular conditions. For 75 years, MDA has led the way in accelerating research, advancing care, and advocating for support and inclusion of families living with neuromuscular diseases.


MDA's mission is to empower the people we serve to live longer, more independent lives.

DISCLAIMER: This document is meant to inform and educate the community. The information presented is not intended to replace discussions with medical, legal, or financial specialists, and it should not be considered financial, medical, or legal advice. Please consult with your healthcare provider, legal advisor, or financial specialist for information specific to you.

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