

10 THINGS TO CONSIDER

When a Loved One is Hospitalized

■ NAVIGATING THE HEALTHCARE PROCESS



A heart attack, stroke, or a bad fall can put a loved one in the hospital without warning. If you are the person taking on the leadership role in navigating the healthcare process, here are ten things you should know.

Locate your loved one's **Important Papers**

In times of crisis, it's important to be able to quickly locate and share your loved one's important documents, such as the Health Care Proxy and Durable Power of Attorney. These documents indicate the people your loved one has selected to "step into their shoes" and make important life decisions on their behalf. Ideally this won't come as a surprise so that the proxies will be aware of and understand the responsibilities involved. Be sure to look thoroughly for any specific directives that might be in place such as "Do-Not-Resuscitate (DNR)" orders or a standing MOLST form.

Remember, to be an integral player or decision maker in your loved one's healthcare process, there needs to be a Health Care Proxy in place naming you as the proxy as HIPAA regulations prevent hospital staff from sharing medical information with a broad range of people.



Document Descriptions:

A Health Care Proxy (also referred to as Advanced Directives in some jurisdictions) informs physicians and family members about who your loved one has chosen to represent them regarding their health care decisions in the event they are unable to speak or advocate for themselves. This can include decisions around "Do-Not-Resuscitate (DNR)" orders and end-of-life.

MOLST forms are specific to Massachusetts and, along with the individual's physician, give an opportunity for a person with advanced illness to have their decisions regarding life-sustaining treatments known, communicated and honored across all health care settings in Massachusetts.

A Durable Power of Attorney is a legal document that allows your loved one to name an individual to step into their shoes to handle all other decisions but healthcare. This document is often used to handle the financial affairs of a loved one who cannot do so for themselves.

Be prepared to share your loved one's **Health History**

At the hospital you will likely be asked for information such as any medications, allergies, dates of any diagnoses, surgeries or procedures, or contact information for physicians, specialty professionals and consultants who have been caring for your loved one. Hopefully electronic medical records will help to solve this problem over time. Until then, this is a lot of information to remember with accuracy, so it's a best practice to keep a written list and to review it with some regularity ensure it is up-to-date. If you're already at the hospital, ask if someone can visit your loved one's home to take photos of the medication bottles and email or text them to you.

Be prepared to speak up if needed to keep your loved one honest. Often times patients don't tell their doctors everything because they are embarrassed or they "don't want to bother the doctor". Many of us live in a state of denial about the possible decline in our health or ability to function. Remember, you may know things that the professionals don't know.



Speak Up

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Best Practice

Keep an up to date written list of medications, allergies, dates of any diagnoses, surgeries or procedures, or contact information for physicians, specialty professionals and consultants.

Understand which medical professional is **Responsible For Your Loved One's Care**

In many teaching hospitals in particular, the person in charge may be called a “hospitalist” or a “criticalist”. Additionally, there may be a slew of providers who are caring for or being consulted on your loved one's needs – such as neurologist, cardiologist and other specialty physicians.

Ask for the business card of any professional that is providing care to your loved one. This includes specialists, physicians, physician's assistants, social workers, dieticians, nurse practitioners, etc. You can use the card to note the date and time that the visit was made, this will help you keep track of who is caring for your loved one and when. You will also be able to contact the appropriate person should you have questions or concerns during or after the hospitalization.

Think of yourself as **Part of the Health Care Team**

Learn about what is going on with your loved one on a daily basis. Ask the Nurse who is caring for your loved one about the care schedule. Ask what tests will be conducted and when they will occur. Find out if your loved one be receiving ancillary services such as physical or occupational therapy and how often.



The nursing staff is often your best source of information and comfort and is often viewed as the lifeline for both the patient and family. Nurses are with their patients on a consistent basis and they are often in the best position to provide you with information.

Keep information that you have gathered about your loved one's diagnosis and other health care changes in needs in a notebook. This will allow you to stay organized regarding their schedule for medications and services, important information for specialties involved and discharge instructions.



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Don't be afraid to ask for the hospital staff to explain something to you "in plain English".

If you don't understand the terms used, **Ask For Clarification**

Don't be afraid to ask for the hospital staff to explain something to you "in plain English". Medical professionals use their own terms and often speak to you so quickly, they forget that you may not understand what they are discussing. Don't be afraid to ask "what does that mean?" You deserve to understand what is going on.

Knowledge is power, so arm yourself with information about your loved one's diagnosis, medications and treatment plan. Request a family meeting, if needed, for updates or to discuss care plan changes.



Don't be afraid to **Advocate**

If you disagree with the recommendations, don't be afraid or intimidated to respectfully speak with the care staff. For instance, if the recommendation is that the individual needs additional rehabilitation services, don't forget that you have a say in which facility they are transferred to. As the primary advocate for your loved one, you want to ensure that the facility is reputable and, if possible, that you have had an opportunity to visit the facility prior to any transfer. When appropriate, you also want to be sure that it is convenient for you, as you will be continuing your advocacy role in this new setting.

Each facility should have a published "Bill of Rights" for their patients. Ask for a copy and read it over to better understand your loved one's rights while a patient or resident of that facility. For instance, all treatments should be explained prior to being implemented.

Additionally, hospital acquired infections are on the rise. It is completely appropriate for you to ask all health care workers who have direct contact with your loved one if they have washed their hands. Hand washing is an important way to prevent the spread of infection.

Advocating not only allows you to support a loved one through a stressful time, but also helps to make sure they are getting the best care. If possible, visit your loved one at different times during the day to observe how staff is interacting with them. If your loved one suffers from dementia, be sure to make the staff aware of this and ask if the staff has received additional training in dementia care.

Make sure that the staff understands your loved one's preferences. For instance, if your loved one has a strong religious preference, make sure the facility is aware so that they can arrange for clergy or other specialized religious support to visit. If the facility doesn't have religious support available on staff, contact your loved one's religious organization and ask them to have a member visit.

Speak to the hospital's health care **Social Worker or Case Manager**

This is the individual who will help you and your loved one with discharge planning. Will your loved one be going home or will they need further rehabilitation services? What type of services will be needed and how often? Is there any specialized equipment that you will need? Who will be paying for these expenses?

Planning for discharge from the hospital begins at admission for the health care professionals. Their goal is to deal with the immediate crisis and to stabilize the situation. Often patients then move on to rehabilitation facilities or back home for additional services. Talk to the Social Worker or Case Manager about the plans for discharge early in the process. Make sure they know any concerns that you or your loved one have (lives alone, many stairs, wandering, etc.) and be sure that you feel that your loved one's post-hospital needs are being adequately addressed.

Pick a spokesperson **To Speak for the Family**

If there are many family members involved, pick a spokesperson to speak for the family. This is usually the Health Care Proxy as hospital staff is often unable to share patient information without specific authorization. Hospitals are busy places so healthcare providers don't have time to share the same information over and over again with many different family members. Choose one family member to be the point person to communicate questions and concerns with the doctors, nurses and therapists. This person needs to be willing to not only communicate the family's questions and concerns, but to share

information with other members of the family in a timely manner.

There are some wonderful digital tools available to help facilitate communication among family and friends, if your loved one is agreeable. One of them is www.caringbridge.org. This is a nonprofit organization started in 2002 that allows you to create a secure website where information about your loved one can be shared and where friends and family can leave their comments of love and support.

Help keep your loved one's home life **On Track While Hospitalized**

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Be willing to **Ask For and Accept Help**

It is often said that acknowledging that we need help can be just as difficult as accepting it. For caregivers this can be very difficult as your natural state is a giver of support rather than a receiver. But giving without receiving can be an unsustainable practice. You risk giving all of your time and energy away, until you have nothing more to give.

Family and friends will often ask what they can do to be of help. They may not be able to cure the illness or condition that your loved one is experiencing, but they can help lighten your load. Keep a list of what you need to keep your own life running and, if someone asks if they can be of help, let them know what you need. Maybe it's to have your dry cleaning picked up, maybe it's a meal or to feed your cat. No job is too small. People are busy, but many tasks – unloading a dishwasher, sweeping the sidewalk, or making a bed, or picking up milk at the store – can be accomplished in 15 minutes or less.

There are online resources to help you stay organized when it comes to coordinating the helpers in your life such as <http://lotsahelpinghands.com/> or www.takethemameal.com. These web-based systems can help you organize your caring circle of family, friends, neighbors, and colleagues. A Google calendar or a private Facebook group can also help coordinate volunteers organizing well intentioned people doesn't become more work for you



Online Resources

lotsahelpinghands.com

www.takethemameal.com

Bonus: Don't forget to **Take Care of Yourself**

Be a caregiver and/or advocate for a loved one can be very stressful and demanding. Caring for yourself is extremely important. Remember to eat regularly, get your rest, relax when you can, and be kind to yourself as you navigate this challenging role. Taking care of your own health is imperative. You won't be of any good to your loved one if you become ill or overwhelmed yourself.



Seek out support groups

Meeting with others who are experiencing similar challenges can be very helpful by providing validation and encouragement to you. They can often be a great source of information and assist you with problem-solving strategies for difficult situations.



Make an effort to keep yourself connected to your own life

Your family and friends can offer nonjudgmental emotional support. Set aside time each week for connecting with your own support network – even if it's just for a cup of coffee or a walk with a friend.



Set realistic goals for yourself

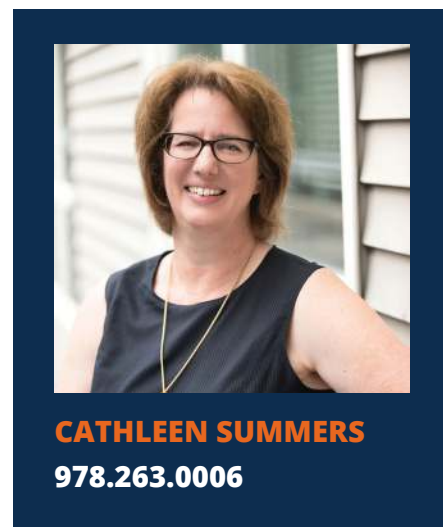
Break large tasks into smaller steps that you can accomplish one at a time. Remember to say "No" to requests that are draining you for energy and personal resources. Let someone else cook this year's Thanksgiving dinner!



About **Generations Law Group**

MAKE US YOUR FIRST CALL IN A CRISIS.

We can help you navigate the hurdles of caring for a parent or loved one who experiences a medical emergency from day one. Cathleen Summers, a nurse attorney with over 20 years of legal experience, has the calm and caring disposition you'll appreciate in a confidant and advisor.




WHAT IS CRISIS PLANNING?


Crisis planning is what you have to do when a parent or loved one is hospitalized, receives a serious mental health diagnosis, or for other reasons suddenly requires significantly more attention.


Your main focus will be getting through the dramatic first few days. When life settles down a bit, you'll be able to consider how this life event impacts the other members of your family across the generations.

- ⊕ Become your confidant and advisor during a crisis.
- ⊕ Help protect and preserve your legacy, relationships and values.
- ⊕ Educate you by helping you plan before an emergency happens in your family.
- ⊕ Bring you peace of mind and security.



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