

# Preparing for Emergencies: Sweat the Small Stuff, Lead the Way to Empowerment

By Julie Gortze, RN

A sense of control can offer confidence and a feeling of capability within us at very vulnerable times. Many of us have been in medical emergency situations where we have felt so overwhelmed by the overall situation that we brushed aside smaller opportunities to make changes that would have alleviated lesser discomforts and produced better outcomes overall

Those of us affected by chronic diseases are often so concerned about obtaining understanding and appropriate care from medical staff for our complex needs that in an emergency situation we tend to attempt, sometimes even subconsciously, to take on a role too excessive for ourselves. We struggle to make decisions that the physicians should be making, and because we are not physicians, we may not be taken as seriously as we feel we should be. Yet, the reality is it should not be our responsibility to make many of these decisions anyway. We are, or a family member is, ill, hurting, and frightened; in these moments we are often too overwhelmed to think rationally.

After the fact, we contemplate whether better planning would have allowed emergency procedures to run more smoothly, and we realize that planning ahead of time might allow more expedited medical care, a goal we strive for and provides better a sense of control.

So what can we do?

After finding myself in frustrating situations on multiple occasions, I began to think seriously about how I could take back some control in regard to my own health outcomes. I chatted with a friend about this, someone whom I greatly admire, and he recommended sharing the specifics of my particular needs and concerns based on my past emergency experiences with those mostly likely to be around me in a crisis.

As I started thinking about this, I remembered a few things that often became barriers to my requests when my health required an ER visit or hospitalization. One example is lack of a pre-written medication list. In past emergency situations, I was too weak to speak or too “foggy” to remember daily medications when medical staff attempted to confirm my medical history. This task then became a burden for everyone and used precious time that could have been devoted more usefully to other areas of my care. With more reflection, I also realized my body seems to have specific reactions to being ill, such as the feeling of being too chilled, and of being too weak to lift the glass of fluids I am supposed to be drinking, while feeling too powerless to verbally express either of these problems.

Once I started breaking these memories down, I realized there are things I can do to improve possible future emergency experiences, starting with providing myself a sense of order and regulation before an emergency arises. Since I am fortunate to have family and friends I trust will make themselves available to me in times of crisis, I knew it would be beneficial to share

my specific health “tidbits” with them so they might better understand my reactions when ill and have realistic expectations of my behavior when I am forced to seek medical care. However, I knew I should not rely on people remembering these priceless personal details, so I compiled the information on a document and emailed it to my support circle. I also printed out several copies of this document and placed them around my home and car for easy retrieval by others, because I understand emergency situations can and do occur when a person is alone.

The goal of preparing for emergencies is to give the patient and family back some control in an otherwise trying time of medical insecurity. Having prepared a strategy for emergency situations helps to ease apprehension of a possible ER visit and makes thoughts of a potentially frightening encounter more bearable. Knowing what to do provides a better sense of management for the patient and family. Below are the steps needed to prepare a personalized medical and emergency plan.

### **First Step: Making A “Control Packet”**

Once you have organized this set of information, you will be making multiple copies. Start collecting:

- Name and personal information – Type out name, address, phone number, emergency contact information, copies of insurance cards and/or the subscriber number. At the top, in larger letters state any communication problems – ie. “Blind,” “Deaf,” any language barrier, including problems with spoken languages.
- Medication List – Include medication name, dosage, frequency. Be sure to include medications taken on an “as needed” (PRN) basis.
- Allergy List – List medication and environmental allergies as well as reactions or sensitivities to medications or other substances.
- Health History List – List the diseases/illnesses you have been diagnosed with. List surgeries or special procedures along with their dates. Remember, the ER staff cannot read pages of your entire life’s medical history! Stick to the basics.
- Physician List – Include physician’s names (and their specialties), phone numbers, fax numbers, and facility names. Be sure to “star” (\*) your most important specialist, like your mitochondrial or metabolism physician.
- ER Protocol – If you do not have an illness or ER protocol that lists steps for providers to follow when you/your loved one needs emergency medical care, please ask your specialist for one ASAP. A good protocol contains a description of the patient’s most pertinent health history and concerns as well as the basic bloodwork evaluations and treatments needed for patients with this particular medical condition.
- Procedure Protocol – Similar to the ER protocol and derived from the specialist, this info offers basic information on the patient’s specific medical requirements when faced with a procedure like surgery with general anesthesia.
- “Special Personal Considerations” – Write down a few of the most important things you are concerned might be overlooked. Name the symptoms or negative experiences most common to you/your loved one when ill enough to be in the ER or hospitalized. For example, if the patient tends to become too cold when in a fragile state, and usually requires multiple blankets for warmth, write this down. Be sure to also write down one or

two positive experiences, so they can be repeated; for example, realizing you can be a “bad stick,” the IV nurse took the time to raise your arms on pillows and apply heat before making any attempts to insert the IV catheter. Do not go overboard with this list; keep it simple and short so others can pay attention to it.

- Health Care Proxy Form/Advanced Directive Form – For both adults and children with severe illness, the need for advanced care forms such as Do Not Resuscitate (DNR) orders or state-specific initiatives, such as the Massachusetts Medical Orders for Life-Sustaining Treatment ([MOLST](#) [4]), should be part of emergency planning. These forms are especially helpful for adult patients who are, or may become, unable to speak for themselves while ill. An adult patient should know ahead of time who he/she wants to be making their medical decisions and to serve as the designated health care proxy (sometimes called the “surrogate decision-maker”). Prior to any urgent medical situation, go over these forms with the assigned proxy to make certain the patient’s wishes are clearly understood regarding emergency and life-sustaining care. For parents of children with severe or complex care needs, all caregivers who will be involved in care choices (e.g. both parents, or one parent and a relative, etc.) need to discuss what emergency or critical care interventions they will or will not want for their child, and what they consider an acceptable quality of life for that child, with regard to dependence on different types of technology (such as ventilators or dialysis). These discussions need to occur as part of preparing for emergency situations and not wait for a crisis to arise. Each state has specific laws controlling which forms are legal and how these forms are used, including who may and may not observe them. Be sure to discuss these issues with both the family and the patient’s medical teams as needed. Information by state on Advance Care Directives for adults can be found [here](#) [5]. An overview of the options for children can be found [here](#) [6].

## **Second Step: What to Do with Your Collected Health Information**

Once you have collected all of the information from Step One, make copies of your information, staple them together, and place them in colorful envelopes. Using bright colors makes it easier for people to remember and locate the information as they might become panicked after receiving a call that they are needed in your emergency. Then pass envelopes out to all necessary caregivers, providers, and support people. Finally, strategically place several sets of information in easy to find locations around your home and in your vehicle.

Make Packets for:

- Husband or Wife, all Adult Children (and their spouses), the Health Care Proxy (if you are an adult, you need to have one), your PCP, and any other physicians or member of your health care team with whom you see fit to share. Do not make the mistake of thinking just one person should have this information. Think about all of the places you or your loved one might be when an emergency arises, and make certain people in these locations have a copy of the information. Include a neighbor or two, close friends, a co-worker and/or supervisor, as well as anyone else you feel would benefit from having a copy. Furthermore, your proxy or other support people need to keep the emergency

information where it can be reached. I recently worked with a woman in an emergency situation who needed her emergency information packet. She had given it to just one “responsible” proxy. Unfortunately, when the emergency came, her proxy was at work, and the woman’s emergency information was at the proxy’s home, in a file under her bed, where it was safe, but completely useless to the patient in trouble!

- Town/City Fire Departments – Many towns recommend placing medical information files on the refrigerator as this is a common place for emergency personnel to look. Many fire departments also have containers for your pertinent information, sometimes called “Files of Life,” that may be magnetized for easy attachment to refrigerator doors. I recommend you obtain more than one container and use them for other places you frequent: in the car, in a baby carriage, in a dog stroller, a pocketbook, or in a backpack. Of course, you can also use the colorful envelopes for this purpose, too. Be sure to write “Emergency Info” in big letters that will be noticeable by the busy emergency crew.

### **More Tips!**

- Call your local emergency service and talk to the captain about the best way for them to help you/your loved one during illness and possible needs in an emergency situation. They may not know much about your illness, and usually will be very grateful to have advance information rather than be unprepared if you or a family member has an emergency situation. Some towns’ fire stations file the patient name, disease, and even the emergency protocol right into their computers!
- If you have a child at home who is capable of learning a simple emergency protocol, be sure to practice it with them as a drill. Whether it’s dialing 911, calling a friend, or running to a trusted neighbor, be sure he or she is clear on how to recognize an emergency and knows exactly what to do. A child can benefit from the peace of mind that comes from realizing they know what to do in an emergency beforehand, just like an adult.
- If you are an adult who lives alone, takes frequent walks, or goes on errands, it may be prudent to have a “check-in” person. Let this person know where you are walking or running an errand, and when you are expected to return, then be sure to check in when finished. This person will know to search for you or call the police if you haven’t reached him/her by the scheduled time. This also ensures that, if there were an emergency, the rescue workers would have contact with a person who has your emergency medical file.
- Make a checklist of medical and other items you will need from home. Many supplements may not be readily available in a hospital. Keep these and other difficult-to-obtain or specialized medical supplies together in a bag at home so they can be easily found and brought to the hospital staff. Do you have any other “must-haves”? For example, a cellphone or computer charger? This may not sound like a “life-saving” list, but we all know how frustrating a dead cellphone can be.

- Finally, if you do not already have one, consider investing in a Medical Alert Bracelet. It may be possible to attach most of your medical information to one of these devices. However, before you choose, check with your local emergency crew and local hospital ER to be sure of their capabilities in using different bracelets. I have known people who purchased a USB bracelet, only to realize ambulance personnel in their town or city do not have access to a drive to open the information! You can find more information on these at <http://www.medicalert.org/> [7] and <http://www.roadid.com/> [8].

Although the best scenario for an emergency situation is to avoid distress in the first place, sometimes we face unavoidable emergency circumstances. Preparation for these difficult occasions allows the patient and family to have some control and hopefully less apprehensiveness about the possibility of a future urgent trip. Knowing you have been proactive in your own or a family member's care will enable you to feel empowered and will provide a better sense of security during future emergency situations.