Find Your Way: A resource guide for family and friends who are caring for persons with serious or advanced illness

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INTRODUCTION

INTENDED AUDIENCE: This document is for family members and friends of people who have developed a serious or advanced illness. This project is a part of a larger effort to improve access to quality health care and provide support to rural patients and families. We have intentionally developed an online version of this booklet in addition to a print version as we want to make this freely available full text to patients and families everywhere.

AN OPEN LETTER TO THE FAMILY MEMBERS AND LOVED ONES OF A PATIENT

If you are reading this, you or someone you care about is likely struggling with some illness. Ensuring that your loved one gets the best possible care is very important to you right now. You are hoping for the best possible outcome.

Serious illness is scary for patients and families. While many great advances have been made in modern medicine, the healthcare system is often confusing and frustrating.

One or more doctors are taking care of your loved one and likely ordering many diagnostics tests and procedures. You are likely feeling somewhat overwhelmed by the amount of medical information you are getting. It can be difficult to figure out what is going on and how best to help your loved-one.

Being a family member of someone who is very sick is also exhausting. Your everyday life has been turned upside down. It is easy to neglect your own needs. In order to help and care for someone else you also need to take care of yourself. This guide offers practical advice for how to support your loved-one, your family, and yourself during this time of stress.

If you live in a rural area and have to travel a considerable distance to avail yourself of quality health care services, the burden of extra time spent travelling should be carefully tracked. Care giver stress may set in early and this is something to be mindful of.

Disclaimer: Please note that every person and family is different, unique. Not everything written here will match your situation and your needs. We do hope you find some information in this guide that can help you and your family find your way through this difficult time.
Receiving bad news about an illness

You are probably reading this because you have received some bad news about your loved-one’s health. It may be that s/he was previously healthy and is now ill or your loved-one may have had a chronic illness, which is entering a new and challenging phase. Regardless, your daily routines have been altered and your lives has been disrupted and perhaps forever changed. Beyond the natural sadness accompanying bad news, everything seems so disorderly and chaotic with numerous unanswered questions. What is going to happen next? Why are they doing so many tests? Who are all these doctors and nurses? Why is each person saying something slightly different? Do these doctors even talk to each other to figure out the treatment plan? Who is the main doctor and for how long? How do you navigate the complex medical bureaucracy? What immediate and long-term changes are in store for your family, as a result of this illness?

You may find it difficult to understand what is going on with your loved-one and overwhelmed by all the decisions that have to be made. The healthcare system can be very confusing.

For some patients with a serious illness modern medicine may be able to provide a cure, enabling them to get back to being “as good as new.” But for many, this will not be possible. The challenge is to find a new balance in your lives. Finding and creating order amidst the chaos of serious illness is both a matter of practicality and something most people feel they need to do so they can cope with stress.

II. Managing chronic and serious illness: First Things First: Get organized

You will have to try to understand medical terms and will have to deal with numerous doctors and nurses. The sheer volume of new information as well as the “busy”ness of the clinicians working in a fast paced system will be stressful. Additionally, you have to deal with the day today uncertainty of new lab tests and procedures and wait for the results. You are at risk of getting confused and overwhelmed very quickly. It is crucial that you have a good understanding of the situation as you may have to make some high stake decisions. One of the first things to have to do is to get organized! We suggest that you obtain a small notebook/ or an electronic notebook and keep it with you.

You may use this notebook to jot down ideas or questions that you have, to make “to do” lists, and to keep track of who the various people are caring for your loved-one and how to contact them.

You will likely think of questions you want to ask the doctor the next time you see her/him. You should make a list of these questions. You might copy suggestions and lists of questions from this booklet that you think might be useful. You may also want to create files for different types of paperwork – medical records, business cards, bills, and insurance paperwork for example.
Teams and Teamwork

More specifically, it is a cooperative effort between **two teams** – the medical team and the family team. Usually, both teams are working very hard. However, problems may arise because of poor communication between these teams. From your side, you may find it very confusing as to who is on the medical team and what they are doing. Similarly, on the medical side, the clinicians may be confused as to who you are – what role you have in the family, who other important family members are, what the circumstances of your family are, and how your family usually deals with illness. Sometimes, there is confusion even in the family as to who will do what.

What you can do

1. Make a list of important clinicians on the medical team, their roles, and how best to contact them.
   - Nurses are at the heart of the care given in any health institution. Please talk with the nurses and find out which nurse is assigned to your loved one. The nurse will be a treasure trove of information and will be an ideal person to support you during this time of stress.

2. Clarify, if necessary, the roles of family members (and friends) in your family network. You may be surprised about how much or how little some of your family members may know about the situation and how they want to stay involved in the process.

3. It is important to identify the person(s) playing the following key roles
   - **Principle spokesperson**: Especially in a large family, it may help to decide on a principle spokesperson for the family. This person will serve as the primary liaison between the medical team and the family i.e. this person will communicate both with the medical team to ask questions and elicit information and then inform the other family members about what is happening with the care and care plan of the patient.
   - **Key decision maker** Figure out who is the key decision maker in the family. (See below for more on this.) If the patient (your loved-one) is an adult who has not lost decision making capacity due to illness and is able to think clearly, then usually he or she is the key decision maker. In this case, you role may be as an advisor. However, if your loved-one is not able to make decisions or wishes that a family member do so instead, s/he will need to identify a person who will serve as the surrogate decision maker.

Please note that the key decision maker and the principle spokesperson are not necessarily the same person though they could be. Commonly, people designate a spouse or significant other as their primary decision maker. Adult children, siblings or close friends can also serve as surrogate decision maker. This role may have been already established, if the patient has left written instructions in a document like a Durable Power of Attorney for Health Care (see below). If not, then often clinicians will turn to the nearest next-of-kin such as the husband or wife of the patient. However, in some families, someone else may traditionally take the lead, such as an adult child of the patient. Whoever
it is, it will help if there is a clear understanding within your family and with your loved-one’s medical team as to who the key decision maker is. Other family members may still have input into medical decisions, but it really helps to have one person taking the lead.

• **Surrogate decision maker and order of surrogacy**: In event that no surrogate decision maker has been identified and the patient has lost decisional capacity, the state law governs who the legal decision maker should be. In Florida, the spouse is the default legal decision maker in situations when the patient is not decisional and has not identified a designated decision maker. In California this is not the case. Check your individual state laws to identify who the legal decision maker would be.

**Durable Power of Health Attorney for Health:**
Appointing a durable power of attorney for health care is a procedure by which the patient identifies a person and authorizes them to be her/his agent to make all decisions for regarding health care. This includes the power to withdraw any type of health care, treatment or procedure, even if the patient may die in the process. The durable power of attorney for health (DPOA) is the patient’s agent only for health care decisions (not fiscal or estate related issues) and is expected to follow the patient’s health care choices directive.

**The DPOA for health care has the power to:**
- Make all necessary arrangements for health care on behalf of the patient. This includes admitting the patient to any hospital, psychiatric treatment facility, hospice, nursing home or other health care facility.
- Request, receive and review the patient’s medical and hospital records.
- Take legal action if necessary to do what the patient may have directed.
- Carry out the patient’s wishes regarding autopsy and organ donation, and decide what should be done with the patient’s body.
- The agent also should not be compensated for services performed in her/his role as a DPOA.
- The DPOA may be reimbursed by the patient’s estate for reasonable expenses that are part of the patient’s care.
The DPOA has the responsibility to:

- Advocate for the patient
- Safeguard the rights of the patient.
- Make health care decisions on behalf of the patient based on patient’s past stated wishes. If you are the designated DPOA for someone, you should have several discussions with them about potential future scenarios and gain a better understanding of their thinking about health and illness.

4. Make sure key clinicians (your primary physician, nurses, and social workers) know who to contact your family and how. Consider writing out contact information and asking that they put this in your loved-one’s chart. This is particularly important for the key decision maker in the family, if this is not the patient.

Developing a Plan

STEP 1: Finding the Facts

Often, the first step in developing a plan is to gather information. Likely, you are trying to learn as much as possible about your loved-one’s medical condition.

A. Make a list of questions: We suggest you start by making a list of questions you have about your loved-one’s medical condition.

- Some common questions you might start with:
  - What is the name of the disease (if known)?
  - What causes it? (if known)
  - What do the tests show and what do they mean?
  - What is the prognosis in terms of life-expectancy, the ability to function, and quality of life?
  - What treatments are available and what help might available treatments offer – cure, *life-prolongation*, improved ability to function, improved quality-of-life?
  - What side-effects or trade-offs might be involved in using certain treatments?
  - How best can family members support a person with this particular disease?
  - What options for care exist?
  - How can you know that you are making the right decisions?
• Get what medical facts you can from your loved-one’s providers about his or her condition (with his/her permission). You may wish to pay particular attention to things like:
  ▪ How sure are they about their diagnosis
  ▪ How “serious” is his or her condition (Even for a serious disease like cancer or a stroke, some patients may have a very good prognosis and others may not.)
  ▪ Knowing what they do about your loved-one, do they have any specific concerns about how he/she will do or how the patient’s condition may affect treatment options?
  o What options exist for where the patient might be treated – in the hospital, at home, as an outpatient, or in a nursing home?
    ▪ If you are in a rural or highly rural area, you may not have any nursing homes close to where you live. Check with the social worker to identify the nursing homes close to your home. You may want to consider touring the nursing home ahead of time before transferring your loved there.

Want to learn more about the disease, treatment options, and how best to live with the illness?
  o Ask your medical providers for specific suggestions, such as books to read, Internet sites to visit, or local organizations that may be of help (such as the local chapter of the Alzheimer’s Association or cancer support organization).
  o Contact the major organization(s) associated with your loved-one’s disease. Most common, major diseases (such as cancer, heart, lung, or kidney disease stroke, or dementia etc.) and many rare diseases have organizations, often with local chapters whose mission is to support patients and families living with that disease. These organizations can provide good leads on reputable reading material and Internet links that they have found useful. Often, they keep up with the most recent research and developing therapies. They may also help you connect with other patients and families struggling with similar problems. Such contact may provide emotional support but also very practical advice for how best to adapt to changes resulting from the particular disease. In doing an Internet search, try typing in the name of the disease and something like, “patient support organization.” (Example: Alzheimer’s patient support organization)
  o Visit a patient library. Many hospitals and healthcare organizations have patient (and family) libraries than may provide useful information. If a librarian is available, they may be very helpful in refining your search.
  o Do an Internet search
B. How can I assess the reliability of the sources of information?

- Clinicians, especially doctors, will best be able to answer questions about your loved-one’s specific situation. Do not forget to talk with the other clinicians caring for your loved one. They too will be able to provide a lot of accurate and specific information that is directly relevant to your loved one.
- You may wish to find some information on your own about the particular disease causing the illness, if known, and how best to care for patients with it. The good news is that many more resources are available for patients and families in recent years. The bad news is that there is almost too much out there! It can be difficult to find reliable information that is appropriate to your needs. Particularly in searching the Internet patients and families can become overwhelmed by medical information that is really intended for clinicians. For example, you may read information on a particular medication, which lists all sorts of side-effects, many of which are rare or rather minor. How do get the kind of information you need?

The other big problem in learning about a particular illness is figuring out how reliable the information is. Some patients and family members work very hard trying to understand every medical detail of the disease in question in hopes of finding some therapy or approach that might have been overlooked. This is very natural. However, be careful. There is always someone out there willing to tell you what to do either for a price or because they strongly believe their approach will work – even if there is not really good evidence that it will work. On the other hand, sometimes material on the web, including stories by other patients and families paints too bleak a picture. Your loved-one’s situation may be similar or very different from those you read about. We would just caution you not to get too preoccupied with such a search. It is easy for most anyone to get over their heads in searching for a fix that others have not found. As importantly, in doing such searches, people may neglect other very useful information and advice on how to live with the illness (not just how to conquer it). So just be careful! You are at a vulnerable point in your lives.

Check that the information you find is appropriate for your level of understanding and your need.
Check the credentials of whoever is sponsoring or providing the information. Be suspicious of commercial sites, selling a particular product or approach.
Be prepared for the fact that you may find information that is prone to misunderstanding or is disturbing to you. Remember, not all that is on the Internet is intended for a person in your situation nor may it be relevant.

STEP 2: Goal Setting

Once you have some basic facts, consider where you are headed in terms of your loved-one’s illness. Maybe the facts suggest that while things are tough now, a full recovery is possible. If so, great! If your loved one is expected to recover fully from the illness, s/he will likely need help and support immediately after discharge and so will you as you will be caring for your loved one. Plan ahead while your loved one is still hospitalized. Contact friends and family members and explain your situation and ask for help. If a rehabilitation unit or nursing home stay is recommended after discharge from the hospital (example in a patient who has recovered from a stroke but is still too weak to go home from the hospital), discuss this with the doctor. Once you know the plan and have identified a nursing home or rehab unit in a convenient location, you are more likely to have a smooth transition from the hospital after discharge.

What if the facts suggest that full recovery is unlikely? Sad, though this might be, what possibilities exist to make the best of things? Patients and families sometimes become overwhelmed by the many decisions that must be made. They may also have strong feelings about what they believe to be best for your loved-one. Sometimes, arguments break out about specific decisions that must be made. Because strong emotions often come up, it is easy to get into arguments without taking the time to step back and consider a more basic question – not so much, “what should we do,” “but where are we trying to get to?” What are our goals? If the goals of care are clarified, it can be easier to consider specific decisions, what to do, in terms of whether they will help reach those goals or not.

Big Picture Goals

Imagine that you and your family are planning to go on a trip. Usually, you will decide on where you are headed before deciding on details like which road to take to get there. As obvious as this may seem, sometimes care decisions are discussed or even argued about without the involved people agreeing on a common destination. So we encourage you to discuss and clarify what we call “big picture” goals first.

So what type of big picture goals are there?

It may help to consider possible goals along a line or spectrum. At one end of the line the goal might be to cure someone or keep someone alive as long as possible (if cure is not possible). Of course everybody wants to be as comfortable as possible, but at this end of the spectrum there would be a willingness to give up some comfort for the goal of cure or life prolongation. At the other end of the line the goal might be to focus on keeping the person comfortable and enhancing his or her quality of life, but not to try to prolong life. Between these two extremes, there is a large grey area where a personal balance exists between life prolongation and an emphasis on comfort and quality of life. We cannot tell you what the “right” balance is for you and your loved-one. Patients and families with very similar illnesses medically may have a different balance and thus different goals.
Making such a decision regarding the goals of care can be very difficult for patients, families, and clinicians. We encourage you to consider what you think might be best from your point of view, but also to listen to the opinions of others – both clinicians and other family members. Some things that may help you in this include considering:

1. How certain is the diagnosis and the prognosis?
2. How likely are possible therapies to result in cure or a significant prolongation of life? Are there other possible benefits to the therapies beyond this?
3. How difficult are these therapies in terms of discomfort or stress? Does choosing a particular therapy or therapeutic approach restrict in some way access to something else that is highly desired? (For example, certain therapies can only be done in the hospital, thereby limiting care at home as an option.)
4. What alternatives exist to therapies under consideration?
5. How was the person’s health prior to the most recent illness - good health and good quality of life, or poor health with a decreased quality of life?
6. Given what you know of your loved-one, what goal makes the most sense in terms of the way he or she has lived life and his or her values?

Options

In discussing available options sometimes patients, families, and even clinicians forget that care options, doing this or that, are only a way to get to particular goals. When arguments arise about what to do, sometimes people are really disagreeing as to what is the best goal to pursue. At other times, people may disagree as to whether a particular care option will actually get the patient to a mutually desired goal. It may help to compare notes on where the disagreement lies.

What you can do:
(If disagreement arises as to what is best to do)

- Even if you disagree strongly, most people truly want the best for your loved-one. While it is fine to express your opinion, try to respectfully listen to the other’s opinion.
- If you find yourself arguing over a particular therapy or approach with someone, avoid statements that characterize your preference simply as “good” and theirs, as “bad.” Rather, you might ask the other person (and yourself) a couple of basic questions:
  - “What is your understanding of what is going on with [your loved-one]?” It may be that the other person has a very different understanding of how well your loved-one is doing medically. If so, you may be disagreeing not so much on where you are going, as to where you are.
  - “What is it you hope the course of care you recommend or desire will accomplish?” A question like this may help you understand both the other person’s goal(s), but also how they see the option helping get to the goal. You may find that you agree on the goal, but disagree on whether a particular care option will be helpful in reaching that goal. Or, you may
find that there is a more basic disagreement about what goal is appropriate.

- **“Is there any additional information that might be useful in resolving the disagreement?”** Sometimes people make assumptions about what is appropriate or inappropriate care. These assumptions usually reflect deeply held beliefs or values that should be respected. However, sometimes assumptions may be based on a misunderstanding of what is being proposed. Getting an outside opinion may help resolve the conflict.

**Who decides?**

Unfortunately, difficult decisions are often required at a time when the patient and family are stressed by the illness and are exhausted.

- Should a certain therapy or treatment be continued or discontinued?
- Where should care be delivered – in the hospital, at home, or perhaps a nursing home?
- If the patient’s heart or lungs should stop working, should clinicians try to start them again by attempting cardiopulmonary resuscitation (CPR)?

You and your loved-one may face these and other difficult decisions. But who decides? Decision making works best when groups of people work together, building upon the special strengths, skills, and experiences of the team. Clinicians possess special knowledge, skill, and experience in treating illnesses like your loved-one’s. However, many decisions to be made are not strictly medical in nature. Deciding upon the best course of action often requires consideration of personal values and the living circumstances of the patient and family. This is where your loved-one and you as a family come in. Nobody understands these things like you do.

**If your loved-one is a clear-thinking adult:**

If adult patients are thinking clearly enough to make decisions on their own, clinicians will go to them first. Most Americans prefer to take the lead in making healthcare decisions, if possible. However, some patients may prefer that someone else, usually a family member, be the principle decision maker - even if they are clear thinking. This is quite common in certain cultures and family groups. This should not be a problem – as long as the patient agrees to let someone else be the decision maker and tells the doctors and other clinicians this. Even if your loved-one wants to be in charge of making his or her own medical decisions, you as family members may play a valuable role. Patients may be able to make decisions, but may still struggle to find the best decision for them and their families. You may be of great help in a variety of ways - by sharing your thoughts and opinions, by finding needed information, and simply by being there for support. Some people cope best with their own serious illnesses by really taking charge of things. They may not welcome others involvement in the process beyond general support. Others feel overwhelmed both by the illness and the responsibility for making such difficult decisions on their own. Such patients need both support and at times a coach – someone who can offer advice on questions to ask and guidance as to how best to proceed.
If your loved-one is not decisional i.e. is unable to or cannot make decisions (or a minor/child)

In some situations it will be very clear that the patient cannot make decisions on his or her own. In such a case, the doctor will try to identify someone, usually a family member, who can make decisions in their stead. If your loved-one has completed an Advance Directive or has appointed a Durable Power of Attorney for Healthcare (DPOA), or similar document (the forms used and their names vary by state) which names a particular individual to be the decision maker if the patient is unable to do so, clinicians will go to that person first. Such forms may also document patient wishes as to the type of care he or she would like to receive or not receive under certain circumstances. If no such form has been completed or the person named in the form is not available, someone else will be sought out, usually the closest next of kin.

If you are identified as the decision maker either because you are named as such in writing or because you are the appropriate family member, what should you do?

In such cases the American medical system has stressed the importance of trying to figure out what the patient would have wanted, if he or she had been clear thinking. For many this makes good sense in encouraging decision making to be guided by the wishes of the patient. However, problems can arise. The most common problem is that other people, even close family members, are unsure as to what the patient might have wanted. The patient may never have considered the particular situation and decision that is being faced. Or it might be that the patient had expressed some broad opinion, but it is not clear exactly how that opinion applies to the current situation. The opinion might have been fairly clear in its general intention, as in statements like, “I want everything done to keep me alive,” or “I never want to go to a nursing home,” but such opinions may be limited in their usefulness in certain situations. What if everything reasonable has been tried to keep him or her alive, but the therapies are not working or are having serious side effects? Very few people “want” to go to a nursing home, but what if care at home is not possible and the patient cannot stay indefinitely in the hospital? In such a situation, we advise that the decision maker still be guided by the values and expressed wishes of the patient, but also exercise some judgment in interpreting these in light of the current circumstances. In such situations, getting guidance from clinicians, other family members, or friends may be particularly helpful.

While the American medical and legal system has stressed the importance of trying to figure out what the patient might have wanted if clear thinking, this approach to decision making is still very different from how decisions are made in many other countries and cultures. In many cultures family members feel it is their job to decide what is best for a sick loved-one, based on their roles in the family. It can seem quite strange to some to be asked to make an important decision “as if” they were someone else - the sick loved-one. If this is true for you, this is perfectly normal. Different cultures have different ways of handling such things. What is common to all approaches is to try to figure out what would be best in caring for someone who is sick when that person cannot decide by themselves. If the American approach is difficult for you, we recommend that you talk openly with the clinical team about difficulties you are having. Many Americans have the same problem! It can be very difficult if one feels one is being asked to make a
certain decision based on what the patient might have said, especially when your heart is telling you that this is not the best thing for your loved-one.

Patients, especially the elderly and older children, may not be able to make decisions independently, but this does not mean they cannot participate in the decision making process. Patients may lack the ability to make certain complicated decisions, but still be able to make other decisions, such as whether or not they need pain medicine. Determining to what extent such patients can participate is very challenging for both clinicians and families.

**Is it all up to me?**

If you are identified as the person who will make decisions for your loved-one, you may feel overwhelmed by this responsibility. This can particularly be true if and when clinicians are asking you to make a major decision, such as whether to change a major therapy or to discontinue some therapy that seems not to be working. You may even feel that you are being asked to make a “life or death” decision. Indeed, assuming responsibility as the primary decision maker for a loved-one can be a heavy burden, but you should not feel as if you must make the decision alone. Physicians and other clinicians would not recommend a particular course of action if they did not think it was reasonable medically. They share in any responsibility for any decision that is made. You may also benefit from discussion and advice from family members, friends, and members of your community whom you respect, such as spiritual advisors.

**What you can do:**

- If your loved-one is a clear-thinking adult, who wants to direct his or her care:
  - Ask how you might be of any assistance. How involved, or not, does he or she wish you to be?
  - Explore with your loved-one not just the specific decision before you, but the values and reasons underlying his or her approach to healthcare and healthcare decisions
  - Consider commenting on how any decision might affect you and your family – both emotionally and practically
  - Consider “what-if” scenarios:
    - What if he or she could not make decisions – who should instead?
    - Under what conditions, if any, would he or she want to change course? For example, if pursuing life-prolonging therapy, would there be any circumstance wherein he or she would prefer to “switch gears” to an approach more oriented toward maintaining quality of life as a primary goal?
  - If your loved-one has not already done so, inquire as to whether or not he or she would like to complete an advance directive. Clinicians, especially social workers, should be able to help you with this.
If he or she has completed or is completing an advance directive, we recommend your discussing the thinking and values behind your loved-one’s written preferences.

- **If your loved one is not a clear-thinking adult and you are responsible for making medical decisions:**
  - Review any advance directives or written statements by your loved-one regarding their wishes.
  - If your loved-one is able to discuss their preferences, consider including them in the decision making process, adjusted as necessary to their ability and interest in participating.
  - Think about your loved-one’s values and way of life. How he or she has lived in the past may provide a good clue as to what would be important to them, looking to the future.
  - Listen carefully to the clinicians’ explanations of available options. It may help to consider the potential benefit, potential harm or risk of any option under consideration. You should also inquire as to what alternatives to the option might exist.
  - Examine in your own mind what you think would be best for your loved-one. This may or may not be the same as what your loved-one or clinicians would say. If different, this is OK. Your perspective and opinion is still very valuable. Consider sharing this with others involved in the decision.
  - Ask others close to your loved-one, as appropriate, for their opinions. While they may not be the principle decision maker, they may have strong opinions and feelings about what is right. Their lives may also be affected by whatever decision is made. Involving them may help you reach some consensus and relieve you of the feeling that it is all up to you.