

4

Caregiving Guidelines

It is best to assume that one day you will need full time care for all your personal needs. You will need someone to dress you, cook for you and help you eat, bathe you and help you with visits to the toilet (or bedpans, diapers, catheters). It's no fun to think about this, but by imagining this and outlining your personal style, you begin the plan for bringing in the right people when the time comes, and this will make all the difference in your quality of life.

Should you move to an assisted-living community or stay at your home and bring in care? Most people assume that staying home is better. With professional caregivers, it can be a wonderful experience, although it will be a lot more expensive than moving to a community. Most important is who will oversee caregiving. By definition this will not be you. If your advocate is not a good people manager – someone who can hire well and fire when necessary – you will be better off in the professional setting of an assisted-living community.

Selecting an assisted-living community or recruiting excellent caregivers for home is perhaps the single most influential task in keeping your quality of life at a positive level through your final days. Do not wait until you must rush a decision. You must not settle in your quest to find a community or caregivers who can understand and provide the lifestyle you want. I recommend that you and your advocates utilize agencies and informal referral networks as you seek recommendations for options.

Some key factors to assess and communicate that identify your care lifestyle:

Informal (staff is a companion in regular clothes) vs. Formal (staff has a title and uniform)



Social (likes lots of visitors and company at meals) vs. Quiet (prefers just a few visitors and eats alone)



No Television* vs. Lots of Television*



** It may seem trivial, but how you like to spend your “down time” becomes very important as you become less mobile. Television viewing is a common occupation for those less active. If you prefer reading, music or quiet you need to make this very clear.*

5

Last Words

When you reach your very last days, all your administrative loose ends are tied up, you have accepted that the time has come to let go and you have had the last important conversations with your family and friends. So what do you want to hear at this time?

It's important to communicate this now. You may not be able to speak during you final days and hours. Many people do not know what to say in the presence of someone who is dying. In the absence of direction they may dwell on their own grief and confusion, which you will not be able to assuage. At the very end, you will be inwardly focused, and your advocates and caregivers will respect your need for quiet time.

There may also be moments when you experience anxiety, and at that time, you will want to be reassured that whatever you are worrying about is going to be fine. These reassurances will help you as you decide when it is time to let go of these concerns.

Some questions to discuss with your advocates:

In addition to my advocates, I would be happy to have the following people visit me during my last days:

_____	_____
_____	_____
_____	_____

If I appear to be worried, it is likely that I will want to be reassured about the following:

1

The Plan

If and when I am not able to make my own decisions, based on consciousness or mental competency, the people I trust to make decisions and carry out my plan are:

When I am no longer able to feed myself and manage my own personal hygiene (bathing and bathroom tasks), I would prefer to:

- stay at home* and hire full time professional caregivers
 - move to a residential community with healthcare professionals
 - move in with the following relative* and hire caregivers to supplement family
-

If my physician believes that I am within six months of my end of life, I would like to enroll in a hospice* program and I want my family and caregivers to follow the palliative care outlined by the hospice medical team:

- Yes
- No

If terminally ill, and if legal in my state of residence, I want to complete the process that would allow the option of physician-assisted suicide:

- Yes
- No

Of possible measures to extend life when it might otherwise end, I DO NOT WANT the following procedures to be administered:

- | | |
|--|--|
| <input type="checkbox"/> CPR | <input type="checkbox"/> Breathing Machine |
| <input type="checkbox"/> Feeding Tube | <input type="checkbox"/> Antibiotics (pneumonia) |
| <input type="checkbox"/> Surgery (Fractures) | <input type="checkbox"/> Surgery (blood clots) |
| <input type="checkbox"/> Other | |

Other things I want to be a part of my End of Life plan:

** If you would like to die at home, an additional benefit of hospice enrollment is that no police investigation of your death is required. Without hospice enrollment it is the law that deaths occurring at home are investigated.*

2

Advocates

Your advocates are the people who will be your public face when you cannot speak for yourself. Having more than one advocate has multiple advantages: you increase the chances having an advocate on hand in an emergency and you build in the ability for your advocates to consult and guide each other when you are not able to participate in the discussion. Your advocates' most important role is to communicate what you want in emergency medical situations, and also your wishes with regard to end-of-life care. While you will have these decisions documented, a strong advocate insures that your decisions are followed. In addition to dealing with medical decisions, your advocates will organize the communication you want as your end of life approaches.

When recruiting your advocates, try to score as many of these attributes as possible:

- | | | |
|---|--|---|
| <input type="checkbox"/> Knows you well | <input type="checkbox"/> Makes friends easily* | <input type="checkbox"/> Organized |
| <input type="checkbox"/> People management skills | <input type="checkbox"/> Not afraid to ask questions | <input type="checkbox"/> Good listener |
| <input type="checkbox"/> Wins respect of others* | <input type="checkbox"/> Cool under pressure | <input type="checkbox"/> In good health |
| <input type="checkbox"/> Has time to help you | <input type="checkbox"/> Adapts well to change | <input type="checkbox"/> Lives near you |

Top advocate candidates:

Discussion guideline for your first conversation with Advocates:

- Start by explaining why you want an advocate, and why you think they would be the right choice.
- Review your one-page Plan document and allow yourselves to have an open conversation about all the possible scenarios at end of life.
- Ask your advocate choice if they really want to do this. It's OK for them to say no. Your advocate has to want to be there for you.
- Plan a meeting to introduce your advocates to your internist and other key doctors. By meeting them, seeing them as your chosen advocates and understanding the detailed discussions that have taken place, your medical team will be familiar with and ready to rely on your advocates when the critical time arrives.

** When the going gets tough, you will encounter emergency rooms and hospital stays. Your advocate must help the staff to prioritize your needs. A person who makes friends and earns respect is more likely to achieve this than one prone to drama and blame.*

3

Hospital Readiness

It is important that you are ready for the very high likelihood of an emergency room visit, or the arrival of EMTs (emergency medical technicians) to your home. By definition it is impossible for you to predict when this will happen or what will be the cause. The only thing you know for sure is that an emergency room is an often chaotic place where no one knows you when you arrive.

Preparing a Medical Emergency Packet will speed the time it takes for you to be admitted into the system and for the appropriate treatment to begin. It significantly reduces the risk of errors in your treatment. A MEP will also affect the dynamic of your situation in ways that are hard to measure but critical to your care: the doctors and medical staff will instantly realize that you and your team are intelligent, that you have discussed the possibility of medical emergency and that you respect the need to present your full medical picture. The creation of mutual respect will help your team get the attention and care of the staff for you.

What's in your Medical Emergency Packet?

1. One-page summary of your medical history, current meds and all information required for admission forms (download separately)
2. Copy of your ID and insurance cards (front and back) .
3. Copy of your DPOA (Durable Power of Attorney for Medical Decisions)
4. Copy of your DNR (Do Not Resuscitate Order) on YELLOW paper.

Fold all four documents in half, and put in a 6"x9" brightly colored envelope. In large print on the outside, write your name and "Medical Emergency Packet" and list the contents.

Make enough packets so that you can give one to each of your advocates and close family and friends. They should keep the envelope in their cars so that they will not have to look for it. Keep an extra taped to the refrigerator, in the event that you are home alone and have to call 911, you can direct the EMTs to the packet. EMTs are trained to look for DNRs on refrigerators, and so you have the best chance of having your medical information with you on arrival at the emergency room.