

## The Advocate/Caregiver Checklist

for dealing with seriously life-limiting and terminal illness

The most important factor in being an effective advocate/caregiver for your loved ones is to realize that you may be the only person who has the full picture of their history, overall condition and preferences.

- Remember: Medical personnel are trained as problem solvers, not counselors.
- Even in the most proactive hospital or clinic, the focus is likely to remain symptom- and process-oriented, not patient- and family-centered.
- Requesting a Palliative Care Consultation at diagnosis or onset of serious illness can give you support and resources for balancing good medical care with compassion.
- Palliative Care promotes the alleviation of emotional, psychological and existential suffering as well as the treatment of specific physical symptoms.
- Palliative Care also takes the position that “family” is whoever the patient designates as part of their circle of comfort, care and presence

Following is a list of suggestions to help you be more effectively assertive when dealing with medical personnel, particularly in hospitals, skilled nursing facilities and senior living institutions. This is a palliative approach to healthcare that you can implement yourself.

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- Develop a clear understanding of the patient’s preferences, concerns and Goals of Care so that you can advocate for those issues whenever necessary.
    - The “bottom line” question for the person who is ill: “What is more important to you? Quality of life or quantity of life?”
      - Most people choose quality over quantity, but medical treatment often places more emphasis on quantity. As advocate, you may have to work to balance the two.
    - Completing a Medical Orders for Scope of Treatment (MOST or POLST) form is an essential Advanced Directive for anyone who wants to ensure that their preferences are honored if they become incapacitated or unable to speak for themselves
    - *Five Wishes* is a good tool for starting and documenting the conversation about end-of-life issues
  - Accompany the person who is ill to medical or other professional appointments, especially those in which diagnosis, prognosis and treatment options are discussed.
  - Take copious notes and maintain them in some type of file, notebook, or binder with dividers for easy access to the various aspects of the patient’s medical care.
    - Throughout my husband’s illness, I maintained four binders:
      1. Medical items, including: research on cancer and its treatment; alternative modalities; receipts for all hospital visits, tests, treatments and medication; contact information for all of my husband’s practitioners; and mileage driven to medical appointments—for tax purposes
      2. Benefits and financial concerns
      3. Funeral arrangements and end-of-life matters
      4. Will and estate documents
  - Be sure you know what the patient’s medical plan covers and ask for help if you need it.
    - Many health-care providers or insurers offer the services of a social worker to help with questions about coverage, Medicare regulations, getting copies of reports, etc.

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- Ask questions and keep asking until you understand the information you are being given.
- Understand the patient's rights and yours as patient representative to request or refuse certain types of treatment or to dispute the length of hospital stays.
- You also have the right to request a Palliative Care consultation, which is available at most larger hospitals and clinics.
- The patient or Medical Power of Attorney (POA) will need to fill out HIPPA forms regarding who may have access to personal health information.
  - Make sure you get this done right away to avoid any problems with the flow of information between the health care providers, you, and any other interested parties who have a need to know current status of the patient.
- Write out all the pertinent contact and emergency phone numbers and keep them safely accessible.
  - Also be sure to have the patient's social security number, Medicare card and secondary insurance information available, as they are likely to be requested at each medical appointment, emergency room visit, hospital or skilled nursing facility admission.
- Just in case:
  - Train at least one other person to act as your back-up.
  - Make sure you always have some cash on hand for emergencies.
  - Keep your gas tank at least half full and your cell phone charged
  - Make sure you have some favorite foods in the pantry
  - Keep a flashlight with fresh batteries where you can find it in the dark should the lights go out
- If the patient is your spouse or domestic partner, be sure you know the location of bank accounts, lock boxes, investments and financial records.
  - If you are not comfortable keeping track of your own finances, hire an accountant or trusted person to make sure you pay your bills on time.
  - This is especially important for caregivers who are exhausted or grieving.
- DO NOT put the patient's original will document in a lock box unless it is yours.
  - Lock boxes are likely to be sealed until the will goes through probate
- I highly suggest pre-paying for funeral arrangements.
  - Funeral costs go up regularly, so buying now will probably save you some money later.
  - Making some of these decisions early in the process (even if the illness is not considered terminal) alleviates incredible stress and uncertainty at the time of your loved one's passing.
  - Talking about your own desires for a service can provide a lot of comfort to your family.
- Hire an attorney or make sure that you have access to legal advice with regards to your state's requirements for probate, estate bank accounts, etc.
- Get your legal documents in order as soon as possible and try to do this while everyone in your household is well and/or able to make important decisions on behalf of themselves as well as potential survivors and heirs.
  - At the very least, complete a Last Will and Testament, a Living Will and appoint a Medical Power of Attorney (POA) who may speak and make decisions on behalf of the person who is ill—based on the patient's preferences