

DYING WITH DIGNITY - END-OF-LIFE CONSIDERATIONS
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DISCLAIMER: Please recognize that I am not a Medical Doctor. I have been an avid student researching and studying prostate cancer as a survivor and continuing patient since 1992. I have dedicated my retirement years to continued research and study in order to serve as an advocate for prostate cancer awareness, and, from a activist patient's viewpoint, to voluntarily help patients, caregivers, and others interested develop an understanding of prostate cancer, its treatment options, and the treatment of the side effects that often accompany treatment. There is absolutely no charge for my mentoring – I provide this free service as one who has been there and hoping to make your journey one with better understanding and knowledge than was available to me when I was diagnosed so many years ago. Readers of this paper must understand that the comments or recommendations I make are not intended to be the procedure to blindly follow; rather, they are to be reviewed as my opinion, then used for further personal research, study, and subsequent discussion with the medical professional/physician providing your prostate cancer care.

The American Society of Clinical Oncology (ASCO) has published new guidelines for their members, (see: <http://tinyurl.com/finalasco>) among which are these:

Key Elements of Individualized Care for Patients with Advanced Cancer

1. Patients should be well informed about their prognosis and treatment options, ensuring that they have opportunities to make their preferences and concerns regarding treatment and supportive care known.
2. Anticancer therapy should be discussed and offered when evidence supports a reasonable chance of providing meaningful clinical benefit.
3. Options to prioritize and enhance patients' quality of life should be discussed at the time advanced cancer is diagnosed and throughout the course of illness along with development of a treatment plan that includes goals of therapy.

4. Conversations about anticancer interventions should include information on likelihood of response, the nature of response, and the adverse effects and risks of any therapy. Direct costs to the patient in terms of time, toxicity, loss of alternatives, or financial impacts that can be anticipated should also be discussed to allow patients to make informed choices.

5. Whenever possible, patients with advanced cancer should be given the opportunity to participate in clinical trials or other forms of research that may improve their outcomes or improve the care of future patients.

6. When disease-directed options are exhausted, patients should be encouraged to transition to symptom-directed palliative care alone with the goal of minimizing physical and emotional suffering and ensuring that patients with advanced cancer are given the opportunity to die with dignity and peace of mind.

You might ask your Medical Oncologist if he/she is aware of these more recent guidelines.

The following are some important considerations to have a better understanding on what will likely have to be dealt with when a loved one passes on and should be determined ahead of time:

- If your loved one currently does the primary managing of finances, takes care of bills, keeps track of those bills that are paid quarterly, semiannually, or annually, maintains files of those requirements and receipts, and performs minor repairs, it is important that you spend time learning how to assume those responsibilities before it absolutely becomes necessary.
- Make note of the telephone number of the banking facility where finances are maintained or bills may be automatically paid.
- Determine credit cards held, have some idea of balances, know when monthly payments are made and how made, make note of telephone numbers to call when necessary.
- Locate and review life insurance policies and who to contact when necessary.

- Locate and make sure a will has been prepared and is up-to-date; if it has not, insure that a will is prepared. Determine if you are to be executor of the will. If you believe you will not be up to that responsibility, arrange that the will be corrected to name the trustworthy person/family member who is willing to assume that responsibility. This is extremely important.
- Determine ahead of time if prior planning has been performed for funeral arrangements as well as a cemetery plot (many people pay into funeral services and cemetery plots in advance - this can be very helpful since the facility that provides the funeral service will often take care of everything that has been pre-planned).
- Have the name and telephone number of your church/pastor handy.
- Determine the phone number of the Social Security office you must call when that becomes necessary, since if your loved one is your spouse and receives a higher Social Security income than you do, the Social Security Service will make changes so that your future Social Security income is at the amount your spouse received.
- Make note of phone number of those financial institutions, companies, organizations to whom bills are paid each month so that when necessary you can call to report the death of your loved one and advise that the next payment may be delayed but will be made as soon as funeral services have been completed and you have had time to get things in order.
- Check with your loved one's prior employment if receiving a retirement income to determine if you are eligible for any of that retirement. If your spouse is retired military, determine ahead of time the military finance office you must call immediately to report the demise of the retired military person. This, too, is very important. If your military retired spouse paid into a Survivor's Benefit Plan (SBP) so that you would receive a continued percentage of retired income, that military finance office will arrange for that continued percentage to come to you monthly. Go to or call a nearby military facility and ask for assistance to take care of any reporting required when a retired military member dies. They can also assist in arranging military honors at the funeral and

cemetery.

The following is an extract from a presentation to Smart Life Forum April 2008 by Medical Oncologist Stephen Strum, M.D., FACP

"End of Life Services (these concepts are applicable all throughout the patients course of illness)

_ Understand the patient's status completely.

_ Know when all reasonable measures have been exhausted to prolong quantity & quality of life, and be honest with patient & family when that time approaches.

_ However, do not categorize the patient as "terminal" when the patient is untreated or has not had the benefit of being evaluated by a physician that may be aware of one or more "secondary" treatments that have not been used and that may extend life in a significant fashion or improve the quality of life of the patient. I have seen many patients who were told they had 6 months to live only to be alive and free of disease 10 years later. Some of these patients have outlived the doctor making that fatalistic prognosis.

_ Make no false or egoistic pronouncements about survival. Remember that MD does not equate with medical deity but should relate to medical detective. Nowhere in the course of another's life should a physician make a pronouncement that a patient has "x" number of years to live based on statistical studies that negate individual variations in patient and in the ability or creativity of the treating physician. To do so is to implant a negative thought form that can psychologically devastate the patient. Moreover, new treatments evolve over a period of months to years and prognoses may dramatically change.

_ Advise the family to express their love. Instruct family & friends that during these end times the most important exchanges with the patient involve sharing joyful times and expressing thoughts of love. The caring physician informs the family not to focus on medical issues if the battle with PC or another life-threatening illness has been lost. Instead, tell them to speak from your heart & soul since they may not get a chance to say the words they want to speak.

_ Inform family & friends to record conversations with loved ones since this is most commonly regretted by those who have not done so.

_ Be generous with analgesia. Do not allow the patient to suffer with poorly controlled pain or complications of terminal illness. Address these issues with tender loving care."

I felt I had likely left several items out of the foregoing, and prostate cancer survivor, continuing prostate cancer patient like I, and friend, Herb Skovronek, provided yet more to be considered:

- o Banks, credit cards, with direct deposit, direct payments
- o Savings account books!
- o Rent/mortgage, Utility bills, Other debts
- o Car title, registration, insurance, service requirements
- o Social Security info
- o Other sources of income, stockbroker, financial advisor, lawyer info
- o Home insurance, long term care,
- o Home problems--e.g., leaks that must be drained routinely, required service on equipment Computer passwords, clues, etc.
- o List of people to contact on death (For example, those of the Jewish faith favor burying within 24 hrs if possible). This means contacts must be made QUICKLY.
- o Short and longer term care of pets, including fish!
- o Vaccination records
- o Where is "stuff" hidden. Yes, some people have cans of money buried somewhere!!!
- o Today things can be pretty easy. Once it's on the computer, it can be updated and it can be electronically sent to all beneficiaries. Other than the actual documents (will, trust, etc.) all this info can be on 5-10 pages.
- o If the patient had a Disabled placard and if you as spouse do not also have a Disabled placard, the placard is to be returned within 60 days of the patients passing. The same would apply if the license plate of the family car is a disabled license plate, that license plate will have to be changed to a regular plate.

The foregoing provides an idea of what is important to look into prior to the loss of a loved one, and preferably well ahead of time. Frankly, these several important considerations should be determined, answered, and listed by

everyone NOW; not wait until "someday." We never know when that someday may come a day too late.

I hope all readers will use this paper to prepare as soon as possible; doing so will certainly ease the likely unmanageable burden that will otherwise be experienced when the information and recommendations listed become required.

Recognizing that most physicians or their medical facilities do not provide counseling regarding end-of-life considerations, this has been addressed in this paper and will hopefully lead to that service being available to patients and their caregivers at their treating physician's facility:

<http://www.medpagetoday.com/PrimaryCare/GeneralPrimaryCare/50696>