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Hospice Care and Planning

“Five Wishes”: The Health Care Directive with a Heart

Most forms intended for use in carrying out the health care wishes of someone who is unable, on account of illness or incapacity, to communicate those wishes personally tend to be somewhat technical and legalistic. They address some of the issues that ought to be addressed, but the focus is primarily on specific medical and legal issues.

That's not so surprising, when you think about it. Doctors, hospitals and other health care providers who are called upon to act based on these directives do so in the context of specific medical issues that arise, and they have an understandable desire for direction as to those issues. Lawyers and lawmakers who draft the forms have a keen realization of, and thus tend to focus upon, the legal issues that can arise when health care providers and patients cannot effectively communicate directly with one another.

While not surprising, that's also not so good. The real, human issues presented in the context of a final illness, or in the context of a disease like Alzheimer's that can deprive its victim of the ability to communicate effectively for an extended period of time, extend far beyond technical medical and legal issues. Patients also have personal, emotional and spiritual needs that are often, to them, even more important than the medical concerns that provide their context.

Moreover, it is the patient's feelings with regard to those concerns, rather than any specific directions they might give with regard to medical decisions they have never faced – and universally hope *never* to have to face -- that can often provide the key to understanding the decisions they would make, and how they would go about making them.

Traditional health care forms do not offer much opportunity for the person completing them to express his or her thoughts or feelings regarding the important issues that may arise, nor do they challenge that person to think about many of the issues and decisions that may arise. The process of completing the forms is largely confined to initialing a few lines or boxes and then signing at the bottom.

Another problem with the forms used in dealing with health care issues are that there are, frankly, too many. The most familiar of the forms is the living will. Unfortunately, its prominence has produced a very commonly shared misconception among average folks that it is the only form they need to have. Those in the health care community, of course, know better. Any patient should also have a health care power of attorney, and many will also want to have a

health care directive. When the situation arises, a “do not resuscitate” order is also appropriate.

Perhaps worse yet, many of the forms are state-specific. A resident of Missouri or Illinois who needs medical care in another state cannot be certain that his state-statute-based health care power of attorney forms will be honored there.

There had to be a better way. Fortunately, there is.

A group called Aging with Dignity (www.agingwithdignity.org) has developed an alternate form called Five Wishes. It is the first “living will” form that talks about your personal, emotional and spiritual needs as well as your medical wishes. It expresses your wishes for the person you want to make care decisions for you when you can't; the kind of medical treatment you want or don't want; how comfortable you want to be; how you want people to treat you; and what you want your loved ones to know. It does those things in plain, understandable English. It does them in a way that emphasizes the dignity of a sick or dying person.

Five Wishes includes very helpful and thoughtful suggestions for completing it, putting it into use, and changing it if you later choose to do that.

If you look at a Five Wishes form that has been completed by a loved one, you will have a much greater insight into his or her wishes and feelings about health care and the process of dying than you would looking at a living will or health care power of attorney form. For someone charged with the great responsibility of carrying out the wishes of a dying person who has become unable to communicate those wishes directly, it offers a much greater comfort and peace of mind in answering the important questions of “Am I doing the right thing?” and “Am I doing what he or she would have wanted?”

Five Wishes is gaining increasingly universal acceptance. As of its most recent publication, it substantially meets the legal requirements of 40 states, including Missouri and Illinois. Over eight million Americans of all ages have already used it.

Ready-to-use copies of Five Wishes (which is a copyrighted form) are available, with our compliments, to anyone who requests one from us, by contacting us either directly or through any hospice, nursing home, hospital, home health care agency, social worker or attorney kind enough to relay that request to us.

Ask the Expert . . .

HOSPICE IN NURSING HOMES

By: Candace Arana
Hospice of Southern Illinois, Inc.

Q: Can my loved one have hospice care in the nursing home?

A: Yes. Hospice of Southern Illinois provides services to patients wherever home is: their own private residence, nursing home, or hospital. For many people a nursing home becomes their home. Hospice care does not take the place of care provided by the nursing home staff but adds a specialized dimension to end-of-life care. Hospice team members offer expertise in pain and symptom management related to end-of-life issues; enhance personal care given by nursing home staff; provide family counseling; spiritual support and offer volunteer visits.

Hospice care may improve the quality of end-of-life care for nursing home residents, but hospice is often underutilized by this population.

Individuals need to make their preferences known to family and physicians; too often they are not aware of hospice services in nursing homes or how it is paid for. Hospice services are covered by Medicare, Medicaid/ most HMO's and insurances. Hospice of Southern Illinois will provide services to persons in need regardless of ability to pay.

Would you like to be added to our mailing list for *Hospice Care and Planning* or be a guest columnist? If so, please contact our Director of Community Education and Outreach, Beth Frame, at (314) 567-9292 or (618) 659-9292, or email to beth@coulsonlawgroup.com to be included.

If you prefer to receive your newsletters by email, you may opt-in to any of our publications by emailing beth@coulsonlawgroup.com and putting *Opt-in* in the subject line and the newsletters you wish to receive.

GERIATRIC DEPRESSION RATING SCALE

Brink et al., 1982; Yesavage et al., 1983 - SHORT version - Sheik et al., 1986
(to be completed by a trained clinician)

Date: _____ Time: _____

Choose the best answer for how you have felt over the past week:

- | Yes | / | No | |
|---------------------------|---------------------------|---------------------------|---|
| [<input type="radio"/>] | [<input type="radio"/>] | [<input type="radio"/>] | 1. Are you basically satisfied with your life? |
| [<input type="radio"/>] | [<input type="radio"/>] | [<input type="radio"/>] | 2. Have you dropped many of your activities and interests? |
| [<input type="radio"/>] | [<input type="radio"/>] | [<input type="radio"/>] | 3. Do you feel that your life is empty? |
| [<input type="radio"/>] | [<input type="radio"/>] | [<input type="radio"/>] | 4. Do you often get bored? |
| [<input type="radio"/>] | [<input type="radio"/>] | [<input type="radio"/>] | 5. Are you in good spirits most of the time? |
| [<input type="radio"/>] | [<input type="radio"/>] | [<input type="radio"/>] | 6. Are you afraid that something bad is going to happen to you? |
| [<input type="radio"/>] | [<input type="radio"/>] | [<input type="radio"/>] | 7. Do you feel happy most of the time? |
| [<input type="radio"/>] | [<input type="radio"/>] | [<input type="radio"/>] | 8. Do you often feel helpless? |
| [<input type="radio"/>] | [<input type="radio"/>] | [<input type="radio"/>] | 9. Do you prefer to stay at home, rather than going out and doing new things? |
| [<input type="radio"/>] | [<input type="radio"/>] | [<input type="radio"/>] | 10. Do you feel you have more problems with memory than most? |
| [<input type="radio"/>] | [<input type="radio"/>] | [<input type="radio"/>] | 11. Do you think it is wonderful to be alive now? |
| [<input type="radio"/>] | [<input type="radio"/>] | [<input type="radio"/>] | 12. Do you feel pretty worthless the way you are now? |
| [<input type="radio"/>] | [<input type="radio"/>] | [<input type="radio"/>] | 13. Do you feel full of energy? |
| [<input type="radio"/>] | [<input type="radio"/>] | [<input type="radio"/>] | 14. Do you feel that your situation is hopeless? |
| [<input type="radio"/>] | [<input type="radio"/>] | [<input type="radio"/>] | 15. Do you think that most people are better off than you are? |

TOTAL GDS:

(GDS maximum score = 15)

0 - 4 normal, depending on age, education, complaints

5 - 8 mild

8 - 11 moderate

12 - 15 severe

This scale was developed as a basic screening measure for depression in older adults.

Prorating Scores (What to do if a patient misses a couple items).

If say 3 of 15 items missed, total score is score on 12 completed PLUS 3/15ths of total score to make-up for omitted items, e.g. if they got a 4 on the 12 they completed or 1/3 positive, add 1/3 of the 3 missing or 1 point for a total of 5.

We're on the web!
www.coulsonlawgroup.com

Hospice Care and Planning is written by the attorneys of The Coulson Law Group, Wesley J. Coulson and Joseph Ilges, and is published as a service of The Coulson Law Group, 1001 Craig Road, Suite 224, St. Louis, Missouri 63146; 107 Southpointe Drive, Suite 2, Edwardsville, Illinois 62025. This is for general informational purposes only and does not constitute legal advice. For specific questions, you should consult a qualified

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