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# ASPN

## Adult Services Practice Notes

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by  
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*The aspen is perhaps the world's largest organism. Although some aspen forests cover acres and seem to be composed of individuals in all stages of life, they share a common root system.*

*ASPN: Adult Services Practice Notes is dedicated to providing information on excellent family-centered social work practice with adults and their families.*

### Welcome

Welcome to the first issue of *ASPN*, a newsletter for social work and other human services practitioners whose clients are older or disabled adults and their families. In the issues to come, we hope to bring you practical information on family-centered practice.

This issue takes up a difficult topic—helping clients and families faced with life-threatening illness think about the circumstances of dying and make decisions about end-of-life care. Social workers and physicians both play a crucial role in the process. We present interviews with two experts on this sensitive topic—Florence Soltys, MSW, CCSW, from UNC—Chapel Hill's School of Social Work, and Marion Danis, MD, from the Department of Clinical Bioethics at the National Institutes of Health.

### Helping Families Face the End of Life

#### Talking with Florence Soltys, MSW, CCSW

*ASPN*: If you could give just one piece of advice about end-of-life issues to social workers, what would it be?

*Florence Soltys*: I think it would be learning great respect for the individual's value system and personality, as well as recognizing cultural and ethnic differences. It is also extremely important to focus on the strengths of the person, not the problems, and work with those—the goals and expectations. One of the things you can do when you work with people who are dying is help them gain control—for some it's the first time they really feel as if they have some control over their lives, as much as they're losing, and they can see the contributions they've made. Remember

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*Florence G. Soltys, MSW, CCSW, is a Clinical Associate Professor at the UNC—CH School of Social Work. She is also Coordinator for Social and Community Development in the Program on Aging at the School of Medicine, and Adjunct Assistant Professor in the School of Nursing.*

#### Talking with Marion Danis, MD

*ASPN*: How can social workers work with physicians to help families make decisions about the end of life?

*Marion Danis*: I've thought lots about this from the physician's and patient's perspective. I think that the big problem is that patients facing the issue of how to come to closure on the end of their life are working from an unrehearsed script—they've never been through this before. They may have been through it with others, but when you're facing it yourself, it's not the same.

A lot of people throughout the United States right now are trying to figure out how to improve end-of-life care, because we've recognized that we haven't been doing it

*(continued, page 2)*

*Marion Danis, MD, formerly a faculty member in the School of Medicine at UNC—Chapel Hill, is Senior Staff Ethicist in the Department of Clinical Bioethics, Clinical Center, National Institutes of Health, Bethesda, MD.*

## Marion Danis continues

quite right. When you look at the way people die, it seems like a very costly venture, and families who talk about how it's gone say that patients have suffered in the process. The American Medical Association, the American College of Physicians, the Institute of Medicine have all recognized that there needs to be improvement in the way we take care of patients, and we need to educate physicians about how to do it.

I especially think families ought to be talking to each other more about how they would like things to go. If they're at all comfortable with this, they need to do it, and even if they're not entirely comfortable with it, they need to at least broach the issue. Patients also need to indicate

who they'd like to make decisions for them.

*ASPN:* Is this maybe one of the places that social workers could help in getting family members to talk to one another?

*MD:* Sure.

*ASPN:* Because people don't have a very good understanding of the process of dying and how to make good decisions, how would the average person—the social worker as a professional, as well as people generally—learn more.

*MD:* I think that families don't necessarily have to know the technical side of things. One thing we all

need to keep in mind is that we shouldn't let technology drive the decision-making process. Families need to know what matters to them—what are their goals and what are their main concerns. When the time comes, they can articulate


those preferences or goals or values and let the physician translate them into particular treatment decisions. So as long as a family can say, "Well, my

grandfather always said he wouldn't want to be alive and be totally dependent," that's a pretty clear statement. It doesn't say exactly what treatments he should

or shouldn't have, but I think if a family said that to a doc, the doc could then say, "Well, let's talk about what treatments are available and which of them we shouldn't bother with if he feels that way." At first blush, this may seem like an overwhelming process, but I think the decisions are not so crucial as good communication, first between the patient and the family, and then between the family and the doc, because often the patient at the very end is not able to participate in the decision.

*ASPN:* From the physician's perspective, what do you wish people—patients or families—knew about resuscitation, life support, and other technologies. We see CPR on

**One thing we all need to keep in mind is that we shouldn't let technology drive the decision-making process.**



**Families need to know what matters to them—what are their goals and what are their main concerns.**

## Some Background about Advanced Directives and Health Care Power of Attorney

Federal law requires that people entering a health care facility that receives federal funds—hospital or nursing home, for example—must be informed of their right to make an advance directive and/or appoint a health care agent who can manage their care. Patients are *not required* to do either thing. Neither the directive nor the health care power of attorney takes effect unless the patient is so incapacitated that he or she cannot make or communicate a decision about care.

Although the statute allows for much choice on the part of the patient, the model forms it provides—often the basis for those used in hospitals and nursing homes—are more limited. The model advance directive allows patients to choose not to receive extraordinary treatment and/or nutrition and hydration in the event they develop a condition that is "terminal and incurable" or fall into a persistent

vegetative state. The educational pamphlet available from UNC Hospitals, for example, clarifies that "extraordinary treatment" could include using CPR and/or a ventilator to restore heartbeat and breathing, kidney dialysis, artificial feeding, blood transfusion, and chemotherapy and/or X-ray therapy.

The model health care power of attorney form allows patients to designate one or more people to make decisions about health care in the event they cannot make or convey decisions themselves.

For an excellent review of North Carolina's statute, what it covers, and what it doesn't, with a case example to illustrate, see the articles by N. M. P. King and A. M. Davis, "Advance Directives for Medical Decision Making in North Carolina: Rights, Duties, and Questions," in *Popular Government*, Spring (Part 1) and Summer (Part 2), 1997.

television medical dramas, and people always seem to recover.

*MD:* I recently heard one of the people who writes scripts for *ER*. I think they try awfully hard to be accurate, but they're going to be showing the most dramatic cases. Cardiopulmonary resuscitation has a very low probability of working when a person is on the threshold of dying. It is very useful for someone who is generally a healthy functioning person with undiagnosed coronary artery disease who has a cardiac arrest on the street, but otherwise, CPR has about a 10 percent chance of working, if you take over-all statistics in hospitalized patients.

I don't think, though, that patients need to know those very particular numbers. Having worked in the Intensive Care Unit at NC Memorial Hospital and UNC Hospitals for many years, I have felt that the docs and nurses really took a lot of pride in trying to avoid having technology drive decisions. When it became clear that the patient was not going to survive, we would say to families, "You know, we're worried that we're not going to succeed in keeping your relative alive. Is there anybody you need to call? Would you like to use the phone and make

some long-distance calls to family members? They need to come visit now." And then we would set no limits on the visiting hours or the number of people who could be in the room. We would try to stop doing procedures and measurements and say, "We don't want to be in the way of your being here, because this is the most important thing that could happen now. It's time for you to say good-bye."

I think physicians need to get more comfortable with saying to families, "You know, our powers to keep your family member alive are limited, and it's now time for you to be doing what you need to do." I think we need to be more honest about that.

I am very struck by some results that Dr. Laura Hanson got in talking to families in North Carolina over the last year or two. She took death certificates, traced the doctors and families of patients who died, talked to the families about their experiences, and asked what suggestions they had for improving the process around a family member's death. The major point she took away was that families wanted to have

more communication with their docs. They didn't necessarily want to be so much more involved in the decision making, but they wanted to be informed about what was going on, and they wanted to make sure that the patients were not in pain.

*ASPM:* From your experience, what do family members want to know?

*MD:* Because my experience has been in the Intensive Care Unit where we're facing acute life-threatening events, what families asked was very much dictated by each individual's medical situation. What I try to do in my conversations with families is to establish a trusting relationship as quickly as possible so that I learn what the patient was all about and what matters to them. I don't ask how they feel about stopping life-sustaining treatment at the first—you know, I think that is a very common error. We first need to figure out what the patient would have wanted, and the family needs to discover that the doc really does have the patient's best interests at heart. Then you sort out what the medical situation is and start to talk about what

decisions are in keeping with all that. It goes a whole lot more smoothly when you use that kind of approach, in my experience.

*ASPM:* Is there a role for social workers in the counties to help bring the issue up before there's really a need for it?

*MD:* Yes, sure. I think that one of the things we're learning is that there's a real role for what we call advance care planning. Advance directives—a written piece of paper—are not in and of themselves terribly useful or effective. Thinking about them, though, can be an opportunity for starting a discussion, and those kind of discussions would be awfully useful.

One big issue for people with chronic debilitating illnesses, their families, and physicians is when it's been enough—when they've switched from chronic debilitating illness to a terminal phase. This is often hard to figure out, and I think the experts don't have the answer about how to deal with that dual agenda of managing chronic disease and facing end of life. People on the front lines may have a lot to contribute to thinking about this. I think that if social workers can help with the process, it would be a very valuable contribution. 🌱

**Families want to have more communication with their docs. They want to be informed and to make sure that the patients are not in pain.**



## Florence Soltys continues

that the family, and you, are losing the person, but the person who is dying is losing everything.

Reminiscing is something I help people do—going back and looking at where they've been and what they've done. Looking back helps them put their lives in order and gain perspective. Viktor Frankl said in his marvelous book, *Man's Search for Meaning*, that "All of us need to leave knowing the things we've done, the things we've loved, the things we'll leave behind with meaning, and the things we've believed in." I've never yet worked with someone who wished they'd spent more time at the office—always more time with family or other relationships. I think you have to be a person who's willing to listen, because I think listening becomes really one of the major focuses of working with people who are very sick. And I don't mean that it's actually what they say, it's what they don't say also.

*ASPN:* What is the social worker's role in helping people with advance directives?

*FS:* Social workers have a very strong role. There are lots of ways to help—interpreting terms, negotiating the maze of services, helping to meet both concrete

and emotional needs. Managed care has produced lack of continuity with health care providers, and this makes advocating with them with clients and families more important now than ever.

In institutional settings, it is often the social worker

who is given the responsibility for talking to people about care when they're dying. If social workers are going to do this, they first have to be comfortable with their own deaths, because if they are not, their anxiety and discomfort comes through to the client. They also have to know the laws of their state, since each is different. North Carolina has one of the best sets of laws in the country, thanks to the Bar Association and Medical Association, but a lot of people do not trust the medical system with advance directives.

*ASPN:* In what sense?

*FS:* I've seen times when unwanted care was given, but people also fear the directives could be used to deny services. It's important for the client to talk to the family and to their health care provider, even if they have directives in place.

One of the problems with advance directives is

what you do with them. Too many people take them home and put them in their locked box and nobody knows they're there. They need to go to your attorney, physician, and family, otherwise they may be ineffective—not there when the decision needs to be made.

It's a problem in nursing homes, that the advance directive doesn't go to the ER with the client, so no one there knows about

treatment preferences.

*ASPN:* How can social workers get more comfortable with working with people who are dying?

*FS:* There are a variety of things: taking classes, taking hospice volunteer training, maybe visiting with people in a program where it's relatively safe, so that you do just a little and work toward moving on to more time. Some people will never want to do this.

They're not comfortable with it, and if that's the way they feel, they shouldn't do it.

I really feel strongly that you need an interdisciplinary team to work with people who are dying, because I think no one person can meet all the needs. I use the family and caregivers as part of the team, combined

with the physician, nurse, social worker, PT, to put together a package to meet the needs of the individual. Spiritual leaders are very important, too.

*ASPN:* How easy is it to put a team together in a rural area?

*FS:* As a matter of fact, the rural areas I've worked in have some of the most sophisticated teams in North Carolina. One thing that happens in rural areas is that social workers may have an expanded role. It's a challenge because it stretches your imagination, but you also have neighbors and ministers who know these people individually.

I think that spirituality—and by that I mean a comprehensive philosophy of life and the values systems—is an area that social work needs to look at more strongly. I think it impacts the way people accept death, how they deal with illness, how they look at all sorts of things.

I think quality versus quantity of life becomes an issue for people. Some people may say to you, "I want to be on every machine and be here as many days as I can" and others will say to you, "I don't want the machine at all. What I want to do is be in charge of

**"All of us need to leave knowing the things we've done, the things we've loved, the things we'll leave behind with meaning, and the things we've believed in."**

—Viktor Frankl

## Florence Soltys continues

my life and control as much as I can.”

*ASPM:* How can the average person find out more about the consequences of making some of these decisions? Whose job is it to help people understand the medical implications?

*FS:* I see that as sort of a team thing. For instance, with the doctor I work with most, I would let her know when a family had a misunderstanding and ask her to talk to them. As another example, I worked with a family where the mother had Lou Gehrig's disease, and the son, who had durable power of attorney and health care power of attorney for her, wanted to know about putting her on a ventilator. What I did was take him to the hospital and show him what a ventilator was, and he made a decision after asking the physician some questions and going to see what it looked like. That's one of the things that you can do.

*ASPM:* Making treatment decisions for a parent or relative sometimes causes conflict in the family. How can social workers or the team help the family deal with that?

*FS:* That's not unusual. We've managed it by having family meetings. Sometimes you may need to meet with people separately within the family and find out what it's really like for them—what their feelings and thoughts are. Then we would meet in the total group, including the person

**We've managed conflict in the family by having family meetings. A lot of really strong feelings come out that go back to childhood, but it can be a growth time for the family.**

who's receiving the treatment or making decisions about care. A lot of really strong feelings come out that go back to childhood, but it can be a growth time for the family. One of the first things I say to families the first time we sit down, is “Here's an opportunity, and it's going to be very painful, but you can make changes that will impact the way you see things for the rest of your life.”

*ASPM:* Many public services social workers work with very old or very ill people. Beyond creating teams when they can, what other advice do you have for them?

*FS:* I think agencies always need to consider how much support and mentoring frontline social workers receive. They may need to develop support groups for their staff and be sure they have people on call. One of

my former students told me about a difficult situation she faced. She was guardianship caseworker for a very elderly woman with advanced Alzheimer's disease. The woman, who lived in an institution, had developed gangrene in one foot and was taken to the hospital. The hospital called the social worker and said they wanted to amputate. She didn't know anything about this client or her history and values systems—all she had was the papers provided by the court. Neither the hospital nor the facility had information about family. To top it off, the medical resident caring for the woman said, “If you don't let me do this, you may as well say you killed

her.” You can imagine how upset she was. Her situation was even more difficult because at the time, her supervisor's position was vacant, so she didn't have anyone to talk to immediately. While the ultimate decision about care was not hers, the resident's behavior was clearly inappropriate. As a new social worker, she needed support not only for the work she was doing, but for the emotional strain of doing it.

This is an extreme example, but it points up what sort of leadership at the agency level could support social workers who face the stress of losing clients and of helping families cope with these difficult decisions. 🙏

### More Information

Starting in November 1997, National Public Radio began airing a series of programs on “The End of Life: Exploring Death in America,” and they have created an extensive web site (<http://www.npr.org/programs/death/>) with transcripts of the programs, lists of organizations that can help people facing end-of-life issues, a bibliography, readings about death and dying, and personal stories from visitors to this web site.

The Public Broadcasting System aired a program entitled, “Before I Die: Medical Care and Personal Choices” in April 1997. Television station WNET's web site, (<http://www.wnet.org/archive/bid/p-description.html>) provides transcripts of the program. The case of “Alan Russo” provides the spark for a discussion on advance directives.

The NC Cooperative Extension Service provides both printed booklets and information at their web site on living wills (<http://www.ces.ncsu.edu/depts/fcs/docs/he364.html>) and health care power of attorney (<http://www.ces.ncsu.edu/depts/fcs/docs/he387.html>), including model forms for each. 🙏

## Florence Soltys's Tips for Working with Dying Clients and Their Families

1. Learn and respect the person's individual value system—including religious, ethnic, family, and other cultural influences.
2. Become comfortable with your feelings about your own death.
3. Help the person find the meaning in his or her life.
4. Know state laws on advance directives.
5. Get the information necessary to help the person negotiate the system.
6. Encourage family meetings to talk about end-of-life issues. Be prepared to mediate or facilitate with individual family members and the family as a whole.
7. Form teams or partnerships with health professionals to advocate for care that fits the person's values and wishes.
8. Talk to other people in your agency about forming a support group for social workers experiencing the deaths of their clients.

### Start the Discussion. What Matters to You?

Which is more important to you, staying alive as long as possible or living well (you define "well") even if you don't live as long as you otherwise might? What things make you feel that life is worth living? Are there conditions that would be "worse than death" for you to be in?

Are there family members or friends who might ask you to make decisions for them? Have you asked how they would answer the first set of questions?

Are there family members or friends you would ask to make decisions for you? Have you talked to them about your preferences?

### **ASPEN: Adult Services Practice Notes**

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