Healthcare **Communication** Review

On Healthcare Relationships, Roles, and Resources

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PATIENT ADVOCATES

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Who are Advocates?

Advocate *n* 1. a person who pleads another's cause, specif.., a lawyer
2. a person who speaks or writes in support of something
Webster's New World Dictionary 2nd ed.

Who are these people that Webster describes? They are a diverse set of individuals and organizations that speak for, or act in support of, equally wide varieties of people and causes. Advocates can be found in parents who speak to teachers about their children's education; in family and friends who speak up for one another; in people who appear before governmental bodies to ask that more resources to be directed towards a particular social, environmental or health-related cause, for instance; and in many other individuals whose personal convictions lead them to give of their time and effort to help meet some need other than their own.

There are also numerous professions that call upon their practitioners to, at times, advocate for others. Teaching, social work and religious ministry are some examples. There are, as well, professions where the main, or only, job requirement is to advocate for someone or something – lawyers and lobbyists, for instance. And, finally, whether in the form of political action committees, women's or civil rights groups, environmental groups and so on, organizations get involved in advocacy as well. What does this mean? It means avenues are out there for those who need, or want to be, advocates. □

Who are Patient Advocates and What Do They Do?

Patient advocates also come in all sizes and shapes – individuals and organizations, paid and unpaid. The role these advocates play often depends upon the advocates themselves. Certainly, many fill the role as described by Webster, above. This is especially true of organizations, which often become involved in issues that extend beyond individual patients. For instance, organizations that focus on particular diseases (such as the American Cancer Society) often speak up for all patients with that disease, or at risk for that disease, by speaking or lobbying for more money to be directed towards research, or for changes in public policy and so forth. Individuals who themselves have a particular condition or whose loved ones have such conditions may also advocate for policies and/or research that will help not only themselves but many others who have those conditions. Celebrities such as Christopher Reeves and Michael J. Fox are two such advocates.

When we look at family, friends, professionals and, even, organizations that advocate for individual patients, the role of the patient advocate is further

See Patient Advocates, pg. 2

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From the Editor

For some, seeking the help of patient advocates may be difficult. Perhaps they don't know to whom they can turn or what kind of help is available. Perhaps they are among those who treasure their independence, take pride in taking care of themselves, or don't like to burden others. It's easier for us, in these pages, to offer help for the first level difficulties than it is for the others. The only thing we can do regarding feelings of independence and pride that may create barriers to seeking help is to suggest patients ask themselves these questions: If someone you love were unable to adequately manage all the elements of their care, or whose attention to those details was slowing down their recovery, what would you tell them to do? What would you want to do for them? Don't you deserve the same?

Regarding a reluctance to burden others…this is, of course, admirable. For taking on such responsibilities can certainly be a burden. But it can also be much more than that, for helping others often has its own rewards. Besides the obvious benefit to patients, it provides a means for patient and advocate to connect with one another; to build bridges that provide comfort to both and skills that can serve each beyond the patient/advocate relationship.

Help is also out there for those who would like to be advocates, whether as a paid professional or simply out of love for family or friends. Within these pages, therefore, we offer some resources for finding that help and fulfilling that role. While not for everyone, it can be one of life's better experiences.

Be Well. Judith A. Greenfield

Patient Advocates, *continued from pg. 1*

defined by the National Patient Safety Foundation (NPSF). In their fact sheet on the role of patient advocates they state: "*An advocate is a 'supporter, believer, sponsor, promoter, campaigner, backer, or spokesperson'.*"[1] This clearly suggests that advocates may be called upon to do more than speaking out or writing in support of the patient's particular cause.

One interpretation of this view is to broadly define the patient advocate role as one of helping patients to get their needs met by:

- Helping them take charge of their care (to the extent they can);
- Providing support (practical and emotional); and
- Speaking, and/or making decisions, for patients when they cannot do so for themselves.

See pages 6 and 7 for suggestions on how to help in each of these ways. □

Next Issue
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Winter/Spring 2005
The Costs of Healthcare/Health Insurance

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[1] "The Role of the Patient Advocate" – see **www.npsf.org** and click on consumer fact sheets.

Where to Turn: On Finding and Becoming Patient Advocates

Finding Advocates

You have a physical or mental condition and need help understanding and navigating the healthcare system. The medication that works best for you is not covered by your insurance plan. You're in the hospital and you feel that your needs are not being met. You need help in figuring out your medical or hospital bill. Where can you turn?

Even if you are able to deal with situations such as these, the physical and emotional strain of doing so can slow your healing process. For that reason, it's often best if someone else can help. While friends and relatives can be effective advocates for you, [see pgs. 6 & 7], assistance is also available from a variety of healthcare professionals and organizations – in many cases, without charge to you.

Help From Professionals

To whom can you turn? As has been stated in prior issues of the *Review*, your physicians are a good first place to turn. In addition to, perhaps, being able to speak to your insurance company about getting the particular medications or treatments you need, they might help you speak with family members who don't agree with your choices. Or they might provide good leads for finding the kind of help you require. The thing is, you need to let them know the questions or problems you have and then ask for their suggestions and help.

Assistance is available from healthcare professionals and organizations – in many cases, without charge to you.

Patient advocates are also available within hospitals and nursing homes. Your nurses and aides, for a start, can be very helpful. Though it may not always seem like it, many are in this field because they want to help and the feeling that they are doing just that often gives them great satisfaction. If, on the other hand, you have concerns about those caregivers – or anything else about your stay – many hospitals provide patient representatives (also called patient advocates) to help you set things straight. If you have concerns about how you'll manage after you leave the hospital, its social workers can also be of assistance. If the hospital's patient representatives or social workers don't come to you, ask to see them.

Many states, as well, operate an ombudsman program for residents of nursing homes, other long-term care facilities and, in some cases, hospitals. Trained ombudsmen are assigned to facilities where they visit with residents and, when necessary, speak to facility staff on their behalf. To learn more about ombudsman programs or to see if they are available in your state, contact the National Long Term Care Ombudsman Resource Center at 1-202-332-3375 or visit **www.ltcombudsman.org** and click on "Find your State Ombudsman". In New York State, visit **www.ombudsman.state.ny.us** or call the state's Office for the Aging Senior Hot Line at 1-800-342-9871.

Help From Organizations

Disease- or condition-specific organizations such as the American Cancer Society (**www.cancer.org**), the National Mental Health Association (**www.nmha.org**) or the like, are good places to turn for help in understanding and managing not only the specific condition, but the healthcare process as well. By contacting these groups you can, at the least, find the chapter nearest you and learn what advocacy services they offer. To find these groups, check the resources on the next page. Or ask your physicians. Just remember to check the credibility of organizations to which you consider turning.

If your concerns relate to insurance coverage or paying your portion of healthcare costs, the Patient Advocate Foundation (PAF) offers free help and do-it-yourself information to individuals who are experiencing chronic, life-threatening and debilitating illnesses. A PAF subsidiary also offers some financial assistance to patients who meet their eligibility requirements. Call **1-800-532-5274** or visit **www.patientadvocate.org** to learn more.

If your need is for help with sorting out medical bills and you are a senior citizen, AARP offers free help through their Medicare Medicaid Assistance Program. Contact your local Office for the Aging to see if, where and when this service is available in your community. For a fee, private claims advocates (**www.claims.org**) and Medical Billing Advocates (MBA) [**www.billadvocates.com** or **1-540-387-5043**] provide similar assistance. MBA helps patients find and correct billing errors, negotiate reductions in balances due, and also sells a how-to guide for those who would do-it-themselves.

*See **Where Turn** on pg. 4*

Where Turn *Continued from pg.3*

New Developments in Patient Advocacy

A new, and somewhat controversial, development in patient advocacy is emerging – boutique medicine. In this instance, doctors make themselves exclusively available – 24 hours a day, 7 days a week – to a limited number of patients who pay a high annual fee (in the thousands). Their services often include house calls and accompanying patients to specialists, etc. Patients who participate will still need health insurance.

Similarly, membership organizations are being formed specifically to help patients manage the healthcare process. Their offerings, which may relate to disease prevention as well as management, often include the services of a patient advocate. The cost of these memberships can be high – in the tens of thousands. For those who are interested, such organizations can be found in Internet searches. If you enter *"patient advocates" + organizations*, at **www.google.com**, these organizations' sites should appear on the right as sponsors. Remember to check their credibility.

Becoming Advocates

If called upon by family or friend, you may simply find yourself in the role of patient advocate. If, on the other hand, you wish to take on this role in a more formal capacity – either as a volunteer or professional – where can you turn? For volunteering, you can turn to the same types of organizations described here – many of which will welcome your interest. Ombudsman programs, for instance, often utilize volunteers. If you're interested in helping individuals as they approach their end-of-life, hospices offer volunteer training programs. Or AARP utilizes volunteers to help seniors covered by Medicare or Medicaid. The key is to figure out your area of interest and then approach appropriate organizations to find out about their volunteer opportunities.

Opportunities also exist for those who want to become professionally involved in the field. Sarah Lawrence College, in New York State, offers a Masters Degree in Health Advocacy (visit **www.sarahlawrence.edu**). Additionally, online training for hospital patient representatives is now being offered. The Society for Healthcare Consumer Advocacy, a division of the American Hospital Association, has collaborated with Cleveland State University in the development of an Online Patient Advocacy Certificate Program. Visit **www.shca-aha.org** for more information.□

Resources for Finding Disease- and Condition-Specific Organizations

Government-sponsored health information site:
www.healthfinder.gov
Click on 'Directory of Organizations'

American Academy of Dermatology
www.aad.org
Click 'Public Resources' then
Click on 'Patient Support' in left panel.

Coalition of National Cancer Cooperative Groups
www.cancertrialshelp.org
Click Patient Advocate tab at top, then
Click under "Locate a Group" in side panel

National Institute of Diabetes, Digestive and Kidney Diseases (NIDDK)
www.niddk.nih.gov/index.htm,
Click on a disease category listed under
'Health Information'

National Organization for Rare Diseases
www.rarediseases.org
Click on 'Index of Organizations' or
Call: 1-800-999-6673 (voice mail only) or
ph 1-203-744-0100

Back Issues
Healthcare Communication Review

Some back issues of the *Review* are still available or you can read their articles by visiting the Project's web site at **www.healthcarecommunication.org**. Click on 'Articles'

Topics:
(on understanding and managing)
- Surgery and Hospital Stays
- Medications
- Women's Health Concerns
- Cancer
- Building Relationships and Trust
- Making Healthcare Decisions
- Patient Activation

Using Family and Friends as Advocates

You've approached your family and friends (those you trust and with whom you can be yourself) and have asked for help as you go through one or more steps of testing, diagnosis, information seeking, treatment, office visits, hospitalizations and so on. One or more of them have agreed. Now, in order to make the most of this help, you need to begin by clarifying, for yourself, exactly what kind of help you want. Then you have to tell them.

This is especially important when you ask them to accompany you to an office visit, to a procedure, or to the hospital, for instance. Do you want them to simply be there, as a second set of ears or for moral support? Or do you want them to take a more active role – one that calls upon them to speak up, if necessary? What will make it necessary, in your mind? All too often, it seems, parents accompanied by adult children – or young adults accompanied by parents – become the third parties in the room. How often have you experienced, or heard of, doctors and advocates talking to each other about the patient as if the patient was not in the room? Neither intends to dismiss the patient in this way (or even feels comfortable with what is happening) but it happens anyway. [See pg. 6 for tips on how to avoid this.]

Begin by figuring out exactly what kind of help you want.

Questions you might ask yourself, therefore, are:

1. What kind of help do I want? Help in:
   - "holding my hand" moral support?
   - Asking questions?
   - Giving answers?
   - Doing research?
   - Understanding treatment options?
   - Making treatment decisions?
   - Dealing with insurance companies?
   - Watching out for me in the hospital?
   - Figuring out my medical bills and insurance coverage?

Then let your advocates know.

2. What level of help do I want when they come, with me, to my doctors or to the hospital?
   - Do I want them to simply observe and tell me what they heard?
   - Do I want them to hold back until I either ask for their input or involvement or have clearly forgotten or misunderstood something?
   - Do I want them to take charge?

Another important question to ask yourself is what access to information do you want your advocates to have? Do you want your doctors and other healthcare professionals to speak freely with them about you? If you do, then now, more than in the past, you need to make sure that your doctors, healthcare facilities and insurers have been told that this is what you want. That's because of the new Health Insurance Portability and Accountability Act (HIPAA). One part of this law, enacted in April of 2003, establishes rules for protecting the privacy of health information. [Details can be found at **www.hhs.gov/ocr/hipaa**.]

While the importance of maintaining patient confidentiality has long been understood, this law sets national standards which, if not met, holds healthcare professionals and facilities accountable – even subject to criminal penalties. With this increased emphasis on privacy, the following recommendations of the National Patient Safety Foundation (NPSF) seem especially important.[1] You should, they say, make sure that:

- You tell your healthcare professionals who is acting as your advocate.
- You spell out the role you want that advocate to play and how much information may be shared with them.
- You let your other family members know this.
- If you want your advocate to be the one who conveys your wishes to your physicians and other caregivers, tell both them and other family members, that this is the case. This way you help reduce any confusion that may arise regarding who speaks for you. Finally,
- Make sure your advocate has all the necessary contact information for your family, doctor, drug store, etc. and that they, in turn, have your advocate's contact information.□

[1] See **www.npsf.org/download/patientadvocate.pdf**

Family and Friends as Advocates

There is much that you can do if asked to help loved ones as they go through the process of dealing with an illness. While what you end up actually doing for them will depend upon what they specifically need and ask of you, chances are you will have the opportunity to help them take charge of their care (to the extent they can) and/or to provide practical and emotional support. You might even be called upon to take charge (which may include making the decisions) when they cannot do so for themselves. The question then becomes, how can you best do these things? What follows are some suggestions – beginning with what you can do if asked to go with them to the doctor.

Before the Visit: Clarify Their Goals and Your Role

Let's say your mother has asked you to go with her to the doctor but has not yet stated her goals for the visit, or told you how you can help in achieving them. The first thing you might do, then, is to ask her what she wants from the doctor and how she wants you to help. In this way, you are encouraging her to start addressing these important questions and clarifying for yourself what is expected of you. Equally important, you are also helping her to understand that she is still in charge – to see that you will not be treating her like she's in her second childhood. If she is having trouble figuring out what, precisely she wants you to do, you can run through her options – for instance: *Do you want me to just listen or to speak up if I have a question or think you have forgotten something?*

Ways to help:

- ***Help patients take charge***
  (to the extent they can)
- ***Provide Support***
  (practical and emotional)
- ***Make Decisions***
  (when necessary)

During the Visit: Help While Staying Out of the Way

Let's assume you have been given the go-ahead to speak up if you feel it necessary. How can you do this without encouraging the doctor to start talking to you and not your mother – leading her to feel as if she's invisible? One way is to speak up in a way that keeps your mother actively engaged with the doctor. That is, instead of *you* telling the doctor what she has forgotten, remind her of what that was or of the question she meant to ask. For instance, you might say: *Mom, didn't you tell me that you felt dizzy the other day?* or *Mom, didn't you have a question about the medicine?* Similarly, if the doctor starts speaking to you, either asking you a question that your mother can answer or when explaining his or her findings or recommendations, you can try to bring your mother back into the conversation by turning to her and asking: *What do you think about this? Do you have any questions about…?* It's not that you should avoid a relationship with her doctor. In fact, it may be valuable to establish one, especially if your involvement will be long-term. Rather, it's that you should avoid a doctor-advocate relationship that interferes with the doctor-patient relationship.

After the Visit: Give Practical and Emotional Support

Perhaps the outcome of your mother's visit is that she has to take certain medications or see a specialist or modify her lifestyle. Practically speaking, you might help by calling for appointments, checking insurance coverage, getting the medication, researching the condition and so on. Perhaps the most helpful thing you can do, however, is to help her process the visit – to make sure she understands what the doctor said, to give her the opportunity to express her feelings about it and to figure out what she wants next. One way to do this is to use the Ask-Tell-Ask approach.[1] Originally developed to help doctors communicate with patients, it is also a good tool for patient advocates.

You might begin by suggesting that you both talk about the visit and then ASK:
What did you learn from this visit?
What are your choices?
What does the doctor want you to do?
What can you expect if you don't do anything?

If you agree with her view of things, TELL her so. If not, TELL her what you came away with. Answer any questions she might ask and share any relevant thoughts that you have. Encouraging her to discuss her thoughts and feelings is an excellent way to help your mother begin to sort through all the things she needs to think about. If there is a question about who is right, when you both disagree, then check with the doctor.

Even if, after your conversation, you think she has a better understanding of what had been said by the doctor, ASK her what she thinks now. *Let's make sure we're on the same page…Do you agree that the doctor said this…and wants you to do that…?* Also ASK for her reactions to what you've been talking about. *How does this make you feel?* And if she gives you a one-word answer, invite her to explain. *What do you mean?*

See **Family,** ***pg.7***

Family *continued from pg. 6*

Accept it if she's not ready to talk. At the same time, you can let her know that you'll be happy to listen when she's ready. If she does express her feelings, it will probably be more helpful to her if you simply acknowledge and respond to her emotions by showing that you understand (*Yes, that is hard!*) than if you try to reassure her that things will get better or tell her not to worry so much.

Helping In the Hospital

Excellent suggestions for how to comfort and support hospitalized loved ones, while monitoring their safety and care, can be found at **www.carepointers.com** – accessible from your home or local library's computer. The thing to remember, however, is that *how* you say or do something is often as important as *what* you say or do. Being vigilant does not automatically require you to act like a prosecutor. Unless there are good reasons to do otherwise, you may be more helpful if you present yourself, to hospital staff, as a partner in care. Speak up, but be as respectful as you can.

Making Decisions for Others

As happens at times, you may be called upon to actually make healthcare decisions for others. If you are "lucky" the person in question will have already prepared Advance Directives and spoken to you about his or her wishes – making this often-intimidating responsibility just a little easier. [See Thinking Ahead, pg. 8] If no such planning and thinking ahead took place, however, how can you know what the "right" decision will be? Truth be told, you may never be certain that you've made the right decision. There are however, accepted guidelines for surrogate decisionmaking[2] – usually spoken of in terms of end-of-life treatments, but they are appropriate any time you need to decide for someone else.

These guidelines are based on whether or not the patient in question was once able to make his or her own decisions – was considered legally competent. If so, the assumption is made that, over the course of time, you may have been given some clues as to what he or she would want. For instance, she may have responded to well-publicized cases of families fighting, among themselves or with the healthcare system, regarding whether or not to continue life support for loved ones that have been diagnosed as being in a vegetative state. Or he may have responded to the circumstances of friends who gambled that aggressive treatment would allow them to live longer and/or more comfortably. Might your loved one have said:

> *That's what I would do. I want to fight to the end!* or *That's not for me. How well I live is more important than how long I live.*

With this knowledge in hand, you would likely be advised to use a **Substituted Judgment** standard, sometimes called a "subjective" standard, because the goal is to make the (subjective) decisions that you think your loved one would make if he or she could do so – something that studies have shown many decisionmaking advocates have trouble doing.[3]

The **Best Interest** standard is recommended for patients who were never competent (in the legal sense of the word) or whose preferences are just not known. This is sometimes called the "objective" standard, because decisions about what would most benefit the patient are based on a study of likely outcomes of various treatments. To be considered are levels of pain and suffering along with the possible outcomes (best to worst) of treatment and no-treatment options and the chances of success with each.

In the end, however, this is likely to be a subjective decision as well, because what you decide will come down to your own perceptions of what is best – even if you apply a "reasonable person standard", namely, would a reasonable person be likely to make the same choice? The difference is that here you can use your own judgment, whereas in the substituted judgment standard, the decisions you make should be based on your loved one's subjective judgment.

Your goal as a decisionmaker, then, might simply be to do the best you can. When following the subjective judgment standard, this means you should take a long hard look at your decision and ask yourself whose decision it really is – yours or your loved one's – and make sure you decide as you think your loved one would. With the best interest standard, all that can be reasonably asked of you is that you get the best information you can – from doctors and, perhaps, other sources – and use your own best judgment.

Before all this comes to pass, however, the best thing you can do for your loved one is to raise the issue of advance directives and try to talk about what they would want if they couldn't make decisions for themselves. This often-difficult topic may be broached by saying something like: *I've been thinking about what I would want if it reached the point where I couldn't make decisions for myself and am wondering what you would want. I've heard it's wise to prepare advance directives. Maybe we should talk about doing that.*☐

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[1] Developed by W. Clark, MD, M. Hewson, PhD, and M. Fry, MS and advocated by the American Academy on Physician and Patient. See **www.physicianpatient.org** for more information.

[2] See the AMA's statement on surrogate decisionmaking at **www.ama-assn.org/ama/upload/mm/369/report_119.pdf**

[3] See note 2

Thinking Ahead: Preparing Advance Directives and Future Advocates

Few of us care to imagine ourselves needing someone to make decisions for us. And yet it can happen – to anyone. We can either take steps to assure that our voices will be heard, should we be in such a position, or not. We can either make it easier for those who would be our advocates, should the need arise, or not. The choice is ours, at least for now.

Not ready to face these issues? You're not alone. But the sad fact is that you can't assume people will know what you want for yourself or, if they do, that they will be able to overcome any reluctance, they might have, to follow your wishes. You also can't assume that, should your situation require the appointment of a legal guardian, the court will appoint the person you would want in that role. And, according to the American Bar Association, there are several disadvantages to guardianships in that they can be expensive and are not easily terminated because the legal system makes it difficult for people, whom the courts have declared incapacitated, to hire attorneys and get those decisions reversed.[1] What it boils down to, therefore, is a matter of control. To think ahead and prepare advance directives is to maintain some level of control over your life. To put the matter aside is to risk losing that control.

> ***Not ready to face these issues?***
> ***You are not alone.***
> ***But, what it boils down to is a matter of control. To put the matter aside is to risk losing that control.***

Advance Directives

Advance directives are documents in which you state your wishes and/or name someone to make healthcare decisions for you if you reach a point where you cannot make them for yourself. One such document is the Living Will. This allows you to state your preferences for end-of-life care, making it clear what forms of treatment you would and would not want. Other documents are Healthcare Proxies and Healthcare Powers of Attorney. These allow you to name someone to act as your agent and make decisions for you, whether at the end of life or not. Some documents combine both. All of these, however, can be changed at any time and they will not come into effect unless and until you lose your ability to understand health information and make decisions for yourself.

There is an important difference, however, between strictly specifying your preferences in a Living Will and naming someone to act as your agent in a Healthcare Proxy or Power of Attorney. A Living Will limits your advocate to making only those decisions you have specified in writing. If you do not say anything about a particular treatment – for instance, antibiotics, dialysis, or blood transfusions – their hands will be tied on those matters. On the other hand a named agent is less limited. In addition to having the legal authority to make decisions for you – even where you have not stated your preferences in writing (with some exceptions) – they can act as your interpreter, analyzer and spokesperson. While it is helpful to state your preferences *and* name an agent, naming an agent is seen as being more important than putting your preferences in writing – if, of course, someone you trust will agree to serve in that role.[2]

Another, more limited, directive is the Do Not Resuscitate order (DNR). Usually offered to hospitalized patients who are seriously ill or at their end-of-life, a special DNR is required for at-home patients who do not want to be resuscitated by emergency medical personnel when being brought to the hospital. Without this special DNR, which is not available everywhere, emergency medical personnel must try to resuscitate any patient whose heart has stopped. To learn more about advance directives, visit **www.abanet.org/media/factbooks/eldtoc.html** and click on questions 31 through 40.

Getting and Preparing Forms

Using a lawyer to help prepare advance directives can be helpful but is not required.[3] If you do it yourself, you can simply put your wishes in writing, or you can use the forms, and follow the instructions, provided by your state. All fifty states, with some variations, provide for living wills and naming healthcare agents. You can either ask your doctors, or your local Offices for the Aging about forms or you can download free state-specific forms and instructions by going to Partnership for Caring at **www.partnershipforcaring.org** and clicking on Download free… In New York State, the Health Care Proxy form and detailed instructions for preparing it (along with information regarding who you can and cannot ask to be your proxy) can be found on the state's web site at **www.health.state.ny.us/nysdoh**. Once there, click on Info for Consumers, then Health Care Proxy Law.

See **Thinking Ahead,** ***on pg.10***

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Promoting Health Partnerships

Thinking Ahead, *continued from pg. 8*

Once you've bitten the bullet and gotten the forms, you must learn about your options, talk with would-be agents, your loved ones, your doctors, actually prepare the directives, and distribute them to doctors and family. If you don't know where, or how, to begin, help is available. Suggestions for broaching the subject with loved ones and your doctors can be found at **www.hcdecisions.org** – click on Sharing Advance Directive. Similar information, along with information about treatment options, can be found at **www.partnershipforcaring.org** – click on Advance directives then Talking…). Or you can call the Partnership for Caring toll-free hot line at 1-800-989-9455. Of course, your doctors and relevant disease- or condition-specific organizations, like those listed on page 4, are great places to start when learning about treatment options.

Communication: The Key to it All

Whether young or old, ill or healthy, advance directives can help ensure that your voice will be heard when it comes to making healthcare decisions – be they minor or major – no matter what. But it's not enough to simply prepare the documents. The key is to talk about them. Talk with your advocate/agent to make sure that he or she will be able to figure out what you would want if you haven't specifically discussed something. Talk with your loved ones so they understand what you want and can support your agent. Talk with your doctors so they will know that you have directives and an agent. And give all of them copies. The best directives in the world will do you no good if no one knows about them.

[1] American Bar Association, *A Professional's Guide to Capacity and Guardianship*, 1996. Or click on questions 18 and 19 at **www.abanet.org/media/factbooks/eldtoc.html**. Barry Yeoman, "Stolen Lives", *AARP The Magazine*, January&February 2004, pgs. 46-51,70-73.

[2] Sabatino, Charles P., "Ten Legal Myths About Advanced Medical Directives," *Clearinghouse Review*, October 1994 or visit site in note 1 and click on question 32.

[3] See note 2. Click on question 38.