

Family Caregiver Newsletter

Newsletter Date April 2014

The Powerful Caregiver

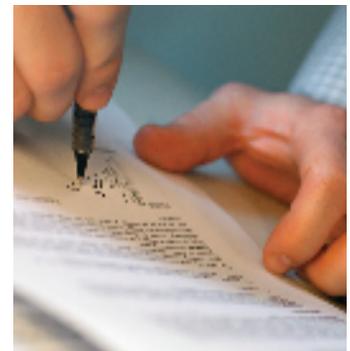
This column is named after the class "Powerful Tools for Caregivers," a six-session workshop on helping caregiving families thrive (not just survive). It is offered in Racine County several times a year.

It is My Choice

Patrick, 78 years old, has been living with Parkinson's Disease for 10 years. Soon after his diagnosis, Patrick and his wife Alma created Power of Attorney for Health Care documents, naming each other as agents to make health care decisions if that became necessary. Patrick and Alma have made the most of their time together: traveling, playing with grandchildren, and talking with each other about all that is important to them. Now, Patrick's disease has progressed to the point where he is in bed most of the time and is mostly unresponsive. Swallowing has become more difficult lately, and he has had significant weight loss. The doctor tells Alma that the only way Patrick can take in enough calories to stay alive is to have a feeding tube. On his Power of Attorney document, Patrick indicated that Alma has the authority to withhold a feeding tube. In many of their discussions Patrick stated that he would not want to be kept alive in that way. Two doctors sign a document activating the Power of Attorney and giving Alma the right and responsibility to make the decision. Alma talks to her children and explains what Patrick's wishes are. Some family members want to try the feeding tube, but Alma explains that it is their duty to make the decision that Patrick himself would make if

he were able. Tearfully, family members hold each other as they inform the doctor that they are following Patrick's wish not to be kept alive with a feeding tube. Patrick receives compassionate care to keep him comfortable until he dies peacefully, surrounded by his loving family a few days later.

Nellie is an 82 year-old woman who has moderate dementia. Her family members are



concerned about her safety. She has left burners on, does not eat or take her medicine regularly, and forgets to lock her door. Family members have found a small, home-like facility where they feel she would be safe and cared for. She, however, is refusing to leave her home, and her family is becoming distraught with worry. They consult with her doctor, call the Aging and Disability Resource Center, and find out that, since Nellie has never made an Advance Directive, they must petition the court for guardianship in order to make decisions on her behalf. This involves Nellie being declared incompetent by a court of law. The family spends precious funds for legal services, take time away from work and family, bicker among themselves about the whole situation, and

Inside this issue:

Advance Directives	1
Community Resources	3
Support Groups for Family Caregivers	4
Caregiver Opportunities	4



**Contact:
Marilyn Joyce
Caregiver
Support
Specialist**

**Aging and
Disability
Resource
Center of
Racine County**

**262- 833-8764
[marilyn.joyce@
goracine.org](mailto:marilyn.joyce@goracine.org)**



continued from front page

experience a lot of anguish. There is an emotional hearing, at which Nellie is present. She is hurt and angry when she is declared incompetent (utterly unable to manage her own affairs). The family member who is named her guardian is instructed to make decisions deemed to be in Nellie's best interest.. In the end, Nellie does go to live at the care facility where her needs are met, but hard feelings and the effects of stress linger for a long time for this family.

Neither of these stories is pleasant. Each depicts difficult decisions and a profoundly sad time in family life. Patrick's story shows a family supporting each other through a decision they make based on Patrick's own wishes. Nellie's, on the other hand, leaves family members dealing with guilt, anger, and perhaps bitterness in the long run. By choosing to think and talk about difficult issues ahead of time and making an Advance Directive document, Patrick gave his family a sense of strength and grounding in their time of grief.

Some people think that the closest relative has the right and responsibility to make medical decisions for a person unable to understand, decide, and communicate on their own behalf. However, this is NOT true in Wisconsin. In Wisconsin a decision-maker must be designated in a properly signed and witnessed Advance Directive.

The maker of an Advance Directive (Patrick, for example) is referred to as the Principal. Designated decision-makers are called Agents. Three types of Advance Directives for Healthcare meet legal requirements for the State of Wisconsin:

- ◆ **Power of Attorney-Health Care (POA-HC)** is a document naming an Agent of the Principal's choice who is empowered to make medical decisions if the Principal is incapacitated (that is, unable to understand necessary information and/or communicate regarding his or

her own health care choices.)

- ◆ **Five Wishes**, similar to the above but a more extensive document where the principal can describe in detail what he or she would like when death is near.
- ◆ **Living Will**, which leaves instructions for the attending physician to follow in specific circumstances.

Some health care providers suggest having a Living Will in addition to Five Wishes or Power of Attorney. When the time comes to make some difficult decisions under specific circumstances, the physician is bound by the choice of the patient who made a Living Will, and the family's role may seem less difficult. The other two documents, however, are much more inclusive and widely useful, and that's why they are recommended. You may also want to establish a Power of Attorney for Finance and Property as well.

The person named as an Agent in an Advance Directive must sign the document indicating that he or she agrees to carry out the wishes of the Principal. Signatures of two witnesses are required, and these are people who attest to their belief that the Principal is of sound mind at the time of the signing. Family members, healthcare team members, and anyone with a financial interest in the person's estate are not allowed to be witnesses. Often friends, neighbors, clergy, or other acquaintances will witness Advance Directive documents.

In Nellie's case, if she is not able to create an Advance Directive because her dementia has progressed too far, or if she does not give her Agent authority to admit her to a residential facility if necessary, then her family will need to make arrangements for her to stay safely in her home or petition the court for guardianship so she can receive the care she needs elsewhere. Guardianship is a legal process that takes time and can be costly. If Nellie is in imminent danger in her home, Adult Protective Services may need to be called. A worker would then visit Nellie, check for signs of whether or not she is taking care of herself, and assess whether she is able to make her own decisions about taking risks.

... continued from page 2

If the worker deems her situation a danger to herself or others, the guardianship process may be expedited immediately.

It's very important for caregiving families to know that a POA-HC usually does not take effect immediately upon signature. It is to be used only when activated by the signature of two physicians or a physician and a psychologist. These professionals are attesting to their judgment that the maker of the document is no longer able to receive or understand information and/or is not able to communicate to the extent that s/he is able to make decisions about his/her own health care. NOTE: It is possible to have Power of Attorney for Health Care take effect immediately

upon being signed. The Principal of the document can designate it as "durable."

It would be best for ALL OF US over the age of 18 to have an Advance Directive in place. It eases the difficulty of a tumultuous time in family life. However, only about 20% of us do have such preparations. April 16th has been designated National Healthcare Decision Day to raise awareness about making our own choices for living well near the end of life. So please, as you think of Advance Directives, think not only of your care receiver, but also yourself and others you love.



Community Resources

This column highlights some of the many resources in our community. For more, see the Community Resource Directory available from the Aging and Disability Resource Center (262-833-8777) or www.adrc.racineco.com.

Resources for Advance Directives

There is generally no cost to make out a POA-HC and the forms can be found in a variety of places. Check with your local hospital as often the Chaplain's department will assist with the process, or find the documents on line at the **Wisconsin Department of Health Services** (DHS): <http://www.dhs.wisconsin.gov/forms/AdvDirectives/index.htm>.

You can also contact the **Wisconsin Guardianship Support Center** sponsored by GWAAR (Greater Wisconsin Agency on Aging Resources) with questions about both guardianship and advance directives. They can be reached at 855-409-9410. Website is: <http://www.gwaar.org/home/10-articles/aging-programs-and-services/206-wi-guardianship-support-center.html#AdvanceDirectives>

You will also find the Living Will and Power of Attorney for Finance and Property documents at both the DHS and GWAAR websites listed above.

Aging with Dignity

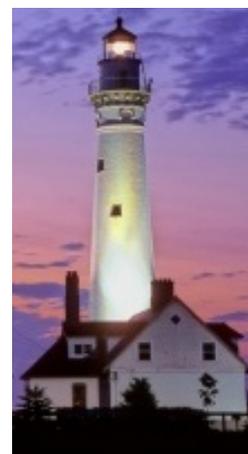
www.agingwithdignity.org
888-594-7437 The **Five Wishes** document was developed by these leading experts in end-of-life care, with the help of the American Bar Association. It can be downloaded and printed from the website for a nominal fee. Some health care providers provide free copies.

National Healthcare Decision Day—Your Decisions Matter.

www.NHDD.org - Information compiled for National Healthcare Decision Day observance.

The **ADRC** also has copies of Advance Directives that can be mailed to you call 262-833-8777

*May I have...
Serenity to
accept the things
I cannot change,
Courage to
change the things
I can, and
Wisdom to know
the difference.*





14200 Washington Ave
Sturtevant, WI 53177

Caregiver Opportunities

If you have conditions such as diabetes, arthritis, high blood pressure, heart disease, chronic pain, anxiety, the **Living Well** Workshop can help you take charge of your life. April 3rd – May 8th Thursdays for 6 weeks 9:30 a.m. – Noon Sealed Air YMCA Cost \$10.00 To Register Call: Ruth 262-833-8762 By: April 1st

Breaking the Silence—Facing Dementia in Communities of Color Wednesday April 9th at Racine Marriott, 7111 Washington Ave. 9 to 11:45 a.m. RSVP 414-219-5159 Wisconsin Alzheimer’s Institute.

Mary Finley, Outreach Specialist from the **Alzheimer’s Association**, will be available for family consultations on Wednesday, April 23rd between 2 and 4 p.m. at the ADRC office located at 14200 Washington Ave (just west of I-94). This invitation is extended to those dealing with **any type of dementia**. For an appointment call Felicia Elias, 262-833-8761.

Support Groups for Family Caregivers

First Thursday 10:30 am-12 Noon
Alzheimer’s Association Group

April 3rd

For Families Dealing with Alzheimer’s and other Dementias
Lincoln Lutheran Office Bldg, 2000 Domanik Drive, 4th Floor

First Friday 12 Noon-1pm

“Caregiver Connection” Telephone Group

April 4th

Call 262-833-8762 to pre-register

Second Tuesday 1:30-3:00 pm

April 8th

Yorkville United Methodist Church

17645 Old Yorkville Rd. (3 Miles West of I-94, Just N. of Highway 20)

Second Saturday 10:30 am–12 Noon

April 12th

Atonement Lutheran Church,

2915 Wright Ave

Park and enter in back of building (on South side).

Third Wednesday 1:30-3:00 pm

April 16th

Burlington Senior Center, Eppers Room,
209 N. Main St

Third Thursday 6:00-7:30 pm

April 17th

Alzheimer’s Association Group

For Families Dealing with Alzheimer’s and other Dementias
Atonement Lutheran Church, 2915 Wright Ave
Park and enter in back of building (on South side)