



FAMILY CAREGIVER NEWSLETTER

JUNE 2012

Support Group and Event Information Inside

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

Shouldering the Burden of Decision-Making

Anna is an 87-year-old woman who as a teenager was imprisoned in a concentration camp. Her son Andy, 56, lives an hour away with his wife Carol. Anna has severe arthritis and impaired joint mobility. She also has a hoarding habit. Her home is strewn with papers, containers, clothing, and trinkets – most everything she has ever possessed. Anna has memory problems; she can't make phone calls and forgets to wear her Lifeline button. Andy and Carol worry constantly about Anna and they have found an assisted living facility that could accommodate her needs. Anna won't hear of it! Last week she fell. Reluctantly Andy realizes that for his mother's safety, he needs to become her decision-maker.

Lawrence has early Lewy Body Dementia. He has periods of disorientation and hallucinations. He also has times when his thinking is clear and based in reality. Friends and family members help his wife Lila by staying with Lawrence so she can get away. Lila knows that her husband's periods of clarity will eventually diminish and he will live more in a world created by his illness. She wonders whether she will be able to continue caring for him at home indefinitely. Who will make decisions for him when he can't do so himself?

There may come a time in caregiving when a loved one cannot make reasonable decisions on his or her own behalf. A family member must obtain the legal right to decide certain things for that person, including where he or she will live. That power is granted through either a **Power of Attorney** document completed by the care receiver earlier, or through a **Guardianship** granted by a court of law. If a family is united and prepared, this milestone can be a relief because some safety issues are resolved. Under other circumstances it can be expensive, time-consuming, and very upsetting. Power of Attorney and Guardianship can both apply to finances as well as health and safety. For this article, we will only consider Power of Attorney for Health Care and Guardianship of the Person.

Power of Attorney for Health Care: This is a document which appoints someone (an **agent**) to carry out a person's (**Principal's**) wishes when that person is unable to make or communicate his or her own choices. The document can be completed at home. Two witnesses (who are not related to the principal, are not involved in the principal's health care, and have no stake in that person's finances) must sign a statement that they believe the principal to be of sound mind at the time of completing the document. The Power of Attorney document asks specific questions about life-sustaining measures and end-of-life decisions. The agent agrees to make decisions based on the person's values and wishes. It also states that

the agent may admit the person to a nursing home or community-based residential facility (CBRF) for short-term stays for recuperative or respite care. The principal has the choice of answering “Yes” or “No” to give the agent permission to “to admit me... for a purpose other than recuperative care or respite care.” (In other words, residential long-term care). If the answer is “no” and a move to a care facility is necessary, a family must file for guardianship.

Adult Protective Services (APS): This is the county agency that responds to calls about abuse or neglect (committed by oneself or others) of vulnerable adults who are in unsafe or potentially dangerous situations. It is staffed by professionals who can help a family decide what needs to be done. Any concerned person can call Adult Protective Services (**638-6752**), and the caller’s confidentiality is protected. A professional visits the home and gathers information to determine if the person is safe. If the person’s living situation is deemed unsafe, APS may recommend that the person be moved to a safer environment, the least restrictive environment that can meet his or her needs. If that person refuses to move, APS will recommend guardianship or protective placement.

Let’s say Alice lives at home alone, often forgets to eat, and is losing weight. Her daughter calls the APS unit. It is decided that nutrition is the major concern, and home-delivered meals are tried, along with close monitoring by Alice’s family, as her needs may increase in the future. Let’s say Harry repeatedly leaves his house at night and gets lost, even though his wife has tried every approach, home modification, and gadget on the market to prevent this. The police find him one night and ask APS to investigate. The upshot is that Harry can no longer live at home as he is not safe. He must move to a locked care community, and his wife becomes his guardian.

Guardianship: When you see a family member acting self-abusive or self-neglectful, or when you observe another person abusing or neglecting that family member, you may decide you should become that person’s guardian to protect his or her best interests. Guardianship is a legal arrangement decided by the courts. It is only put in place when the family member (Proposed Ward) is declared incompetent by a court of law. Incompetence in a guardianship hearing is defined as a person’s being “substantially incapable of managing his or her property or care for himself by reason of infirmities of aging, developmental disabilities, or other like incapacities.” [Sec. 880.01 (5) Wis. Stats.] It must be based on medical and other expert opinions.

Guardianship is a rather complicated process, designed to make sure everyone’s interests are served. As soon as a petition is filed, the court assigns a Guardian ad Litem to oversee the person’s (Proposed Ward’s) best interests during the process and to make recommendations regarding the Request for Guardianship. The Proposed Ward may be represented by an attorney. The person petitioning for guardianship must show evidence that this is necessary, and may also need an attorney. Guardianship papers are served to the Proposed Ward, and a hearing is held at which he or she is present.

Things you should know:

- You will need the proper forms. They can be picked up at the Racine County Courthouse, or download them at www.wicourts.gov.
- You may need an attorney.
- You will need documentation. It’s a good idea to start writing things that lead you to believe that your relative needs a guardian. Include times, names, and places.
- You will need to ensure that your family member is seen by a doctor or psychologist for the purpose of filing a report to the court.
- You will need to arrange for transportation to the court hearing for your family member.
- If you are appointed guardian, you will have paperwork, including an annual report.

The guardianship process is not easy for anyone. It takes a conviction that this is in the best interest of your loved one. It takes time and energy and some money. And it takes a lot of LOVE!

Andy, Carol, and their children have a family meeting and decide that Andy needs to petition the court for guardianship of his mother. They obtain and file the appropriate form. A Guardian ad Litem talks to the family and visits Anna. When Anna finds out what is happening, she becomes very angry and refuses to talk to Andy. Andy and Carol attend a caregiver support group, where they feel comforted in knowing that other caregiving families have survived similar tough situations. Anna's granddaughter takes her to a doctor's appointment and the doctor files a report with the court. The day of the hearing, Anna is extremely agitated. The whole family supports Andy, comforts Anna, and lets them both know that they are loved. The court grants Andy guardianship. The judge must read a statement to Anna saying that she is deemed incompetent to make her own decisions. This is a very emotional time for Anna's family. However, they all survive, Anna moves to a safer place, and her family members worry less and sleep better.

Lila's son gets a Power of Attorney for Health Care form from the internet. On one of Lawrence's "clear days," Lila explains to him that she wants to be prepared in case he should be unable to make his own health care decisions in the future. Lawrence agrees to complete the form. They take this opportunity to talk about Lawrence's wishes regarding end-of-life issues. When the nursing home issue comes up, Lawrence says he thinks about that and worries about Lila trying to take care of him until her strength runs out. On the form he indicates that Lila may admit him to a nursing home for long-term care. Two neighbors watch Lawrence sign the form, make sure that he understands the document, and sign as witnesses. Lila give copies of the POA form to their doctor, the local hospital, and their children. Years later, when it is necessary for Lawrence to move to a care center, the natural sadness will hopefully not be complicated by legal turmoil.

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](#) (638-6800 or www.adrc.racineco.com)

Department of Health and Family Services (DHFS) has an extensive website where forms can be obtained for Power of Attorney and Guardianship. www.dhfs.wisconsin.gov

Coalition of Wisconsin Aging Groups (CWAG) offers a wealth of information to the public, including the WI Guardianship Support Center (GSC), which answers questions relating to guardianships, protective placements, Power of Attorney for Health Care, Power of Attorney for Finance, Living Wills, and Do Not Resuscitate (DNR) orders. You can find a flow chart for the process for establishing guardianship of an adult. (1-800-488-2596, Ext. 314). guardian@cwag.org

Alzheimer's Association offers support to families making decisions about a family member with dementia. You may call the Helpline (1-800-272-3900) anytime. Care Consultations are also offered and can be arranged by calling the Helpline or through the ADRC (see below).

Support Groups for Family Caregivers

First THURSDAY 10:30AM-12Noon

Alzheimer's Association Group – JUNE 7

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

Second Tuesday 1:30-3:00 pm

JUNE 12

Yorkville United Methodist Church

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

Second Saturday 10:30AM-12N

JUNE 9

Mount Pleasant Lutheran Church, 1700 S. Green Bay Road

Third Wednesday 1:30-3:00 PM

JUNE 20

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

Third Thursday 6:00-7:30 PM

Alzheimer's Association Group

JUNE 21

For Families Dealing with Alzheimer's and other Dementias

Mount Pleasant Lutheran Church, 1700 S. Green Bay Road

Other Events for Caregiving Families

From the Alzheimer's Association:

Orientation to Early Memory Loss – June 13, 10AM-12 Noon

Understanding Dementia – June 14, 21, and 28

See Accompanying Flyers

Paulette Kisse, Outreach Specialist, will be available for two **family consultations** on June 27th, between 2 and 4 pm. at the Ives Grove County Building, 14200 Washington Avenue, Sturtevant.

For an appointment call **Felicia Elias, 833-8761.**

“TIME FOR US”

A camp for young people connected to someone with memory or neurological issues

Held at Lutherdale Camp near Elkhorn, WI July 29 – August 3, 2012

Call (608) 232-3400 or (920) 734-9638

www.lutherdale.org Scholarships available.

May June “bust out all over” as the (old) song says and may you enjoy deep, belly breaths of fresh summer air! Don't forget to smell the roses.

**Marilyn Joyce, Caregiver Support Specialist,
Aging and Disability Resource Center of Racine County**

262-833-8764 marilyn.joyce@goracine.org