



FAMILY CAREGIVER NEWSLETTER

APRIL 2013

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

The New “Hey, Doc!”

Hank is 78 years old, husband and caregiver to Sally who has a chronic respiratory condition. Sally thinks of herself as very independent and Hank never dares call himself a caregiver in her presence. Yet he does all of the housekeeping, outdoor work, cooking, home maintenance, paper work, and all the other tasks of homemaking. Sally has not been eating much over the past several months and she is noticeably losing weight. She is frequently irritable, and her moods can change instantly. She is very restless at night and lethargic during the day. Hank has noticed that she is taking her medication very sporadically – too often or not at all. Sally’s outbursts and accusations make him feel angry, sad, and sometimes worthless. She insists on going to her medical appointments alone. Hank feels that her doctor needs to know much more than Sally is telling her. He’s exhausted, depressed, and worried.

Susan is a 55-year-old secretary who lives in Racine County. Her older brother David lives across the state. David has no spouse or children and depends on Susan when he needs help. Lately Susan has been concerned about David’s apparent memory lapses. He often calls several times to ask the same question. Once he called because he was driving and had become lost in his neighborhood. Susan pleads with David to address this issue with his doctor, but David just chuckles and changes the subject. Once Susan called David’s doctor’s office, but she was told that David’s case could not be discussed with her. This issue worries Susan greatly, and it is hard for her to concentrate on her work or anything else. She wakes at night and worries about David having a car accident or some other tragedy.

In bygone days, a doctor became almost a part of the families he served. He knew several generations of family members and had plenty of time for a conversation, could readily detect changes in health and behavior, and was able to talk freely among family members. And when the Doc spoke, people listened and obeyed!

Well, times have changed haven't they? There are several basic differences in today's doctor/patient relationship:

- With the burgeoning and aging population, physicians are busier than ever. Most health care providers are now managed by business models that dictate how many people they must serve in a given time.
- Health information is guarded for privacy reasons, and often cannot be shared without the patient's permission. (An exception is with a designated health care agent who is named in an activated Power of Attorney for Health Care or a similar document. See next page.)
- Besides Medical Doctors, other professionals are Health Care Providers. A Doctor of Osteopathy (DO) , Physician's Assistant (PA), or Nurse Practitioner(NP) is able to diagnose and prescribe under the guidance of a physician and may have more time available to spend with a patient and/or family member.
- Nowadays health care is considered more a partnership than a dictatorship. More providers accept the family caregiver as an important member of the health care team. (However, too often, caregivers still feel discounted and helpless.)

Here are a few tips for family caregivers navigating 21st-century medical world landscape:

1. Learn all you can about your loved one's health conditions. This helps you know what to expect, what to report to the doctor, and what questions to ask. You can gather such information from disease-specific organizations e.g. the American Heart Association or the Alzheimer's Association, or from some reliable health information websites. Gathering information is a good job for family members who are young, computer lovers, or who live too far away to offer help with direct care.

2. As a caregiver, you need a good rapport with the rest of the team at the office or clinic. Learn the office routine. What is the chain of communication? When is the best time to call, and when are calls returned? Are emails answered in a timely fashion? Is it best to ask for the office nurse first?

3. Be assertive. Don't be intimidated by a hurried brush-off. Don't accept an appointment three weeks away for a situation that is intolerable today. Describe your problem in a descriptive, matter-of-fact way. Use "I" messages: "I am ___'s caregiver." "I notice..." "I need..." "I must ..." "I can't..."). Make sure you understand what you are told, and clarify it if you're doubtful. Thank the professional kindly, but don't feel "guilty" about taking time. Remember you are a vital member of the team.

4. You can request an appointment for a consultation. These are longer than regular visits and are usually not billed. A provider has more time to listen to you, discuss issues, and work with you.

5. Even though the professional may not be forthcoming with information about your care receiver, you can give information you feel has some bearing on the health care plan. Medical professionals are concerned about respecting their patients' rights to privacy and decision-making. Some family members forget that old age does not take away these privileges. So the health care provider may be cautious until you describe what your role is in the patient's life. You don't have to be a POA to talk to a health care provider on behalf of someone you care for.

6. **One issue you may eventually want to discuss with your family member's care provider is when hospice services may become appropriate.** People don't have to be bedridden and close to death before hospice service can start. If your loved one's health is declining, he or she is not expected to get better, and the care needs are increasing, inquire about hospice. This can ensure that your loved one has the best and most comfortable quality of life possible during his or her remaining time. It also provides help and support to your family. It may mean curtailing some medical treatments that prolong life but not health, so it is a decision that the care receiver should participate in if at all possible.

7. **Some provider/patient/caregiver relationships just don't work well.** If dealing with the health care provider is giving you stress instead of support, you may need to think about finding a different team to work with. Interview potential providers and be straightforward about what you need from them. Act like a good shopper, a wise consumer, an effective communicator, and a key member of the health care team!

8. **If you are named as your care receiver's agent on a Power of Attorney (POA) for Health Care, you'll need to ask about ACTIVATING the POA** when you feel your care receiver can no longer make health care decisions on his or her own behalf. Activation requires the signature of two doctors (or a doctor and psychologist). Most medical offices have the necessary form to activate POA. This establishes that you are entitled to receive all necessary information to make informed decisions for your loved one's health care.

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.

Knock, knock! Who's there? It's the Doctor! Is it difficult to transport your care receiver to and from the doctor's office? There are resources that will send a physician to your home. They also offer lab work, EKG's, X-rays, and other procedures. They can work with you even if you may choose to also keep your present health care provider. Two such agencies are listed in the *Community Resource Directory* (page 20)

You can request a copy of the *Community Resource Directory* from the ADRC or find it (with up-to-date revisions) by visiting: www.adrc.racineco.com.

Health Information Organizations and Websites can be found on page 29 of the *Community Resource Directory*. Gather information (or ask someone else to) on the health conditions that make caregiving necessary.

Support Groups for Family Caregivers

First THURSDAY 10:30AM-12Noon

Alzheimer's Association Group — APR. 4

For Families Dealing with Alzheimer's and other Dementias

Lincoln Lutheran Office Building, 2000 Domanik Drive, 4th Floor

First FRIDAY 12N-1PM

APR. 5

“Caregiver Connection” Telephone Group

Call 262-833-8762 to pre-register.

Second Tuesday 1:30-3:00 pm

APR. 9

Yorkville United Methodist Church

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

Second Saturday 10:30AM–12N

APR. 13

Atonement Lutheran Church, 2915 Wright Ave., Racine

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

Third Wednesday 1:30-3:00 PM

APR. 17

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

Third Thursday 6:00-7:30 PM

Alzheimer’s Association Group

APR. 18

For Families Dealing with Alzheimer’s and other Dementias

Atonement Lutheran Church, 2915 Wright Avenue, Racine

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

Other Events for Caregiving Families

Powerful Tools for Caregivers

A highly acclaimed class to help family caregivers advocate for their own well-being and thrive (not just survive) during their caregiving years.

Wednesdays from April 17 – May 22, 6:00-7:45 PM

See Accompanying Flyer

Caring: It’s not the hard part of Caregiving

A FREE evening of information and inspiration for family caregivers

Monday, April 15th, 5-8 PM

Racine Marriot (Includes dinner!)

See Accompanying Flyer

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