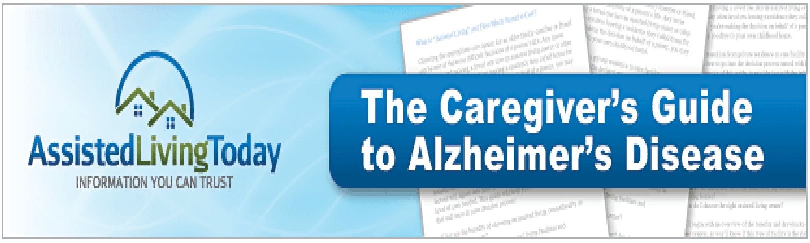

20
MEMORY CARE EXPERTS
on Caring for Alzheimer's and Dementia Patients

Caring for loved ones with Alzheimer’s Disease or Dementia can be a confusing, emotionally taxing and overwhelming experience for caregivers and family members. Often, it’s tough to know where to turn to get the best, most informative answers to your questions about Alzheimer’s care. With that in mind, we reached out to 20 memory care experts to tap into their years of experience and collective advice on the topics of Alzheimer’s Disease, Dementia and memory care. We asked each of our 20 experts three important questions on memory care and compiled their answers into a comprehensive caregiving guide to Alzheimer’s Disease and Dementia.

Meet Our Panel of Memory Care Experts

Get to know the Alzheimer’s and Dementia care experts that helped us put together this valuable resource for caregivers. We’ve created a Twitter list so you can follow all their updates on Twitter: #Memory Care Experts

Judy Berry is founder of the Lakeview Ranch Model of Specialized Dementia Care, founder and CEO of Lakeview Ranch and Lakeview Ranch Healthcare and executive director of the Dementia Care Foundation. She is the 2010 recipient of the Robert Wood Johnson Foundation Community Health Leaders Award and the 2011 recipient of a Purpose Prize Fellow. She teaches caregivers how to meet the emotional, spiritual and physical needs for seniors with Dementia.

Tom and Karen Brenner are founders of Brenner Pathways, a consulting and educational company, and write for the *Alzheimer’s Reading Room Blog* and *The Fisher Center for Alzheimer’s Research Foundation Blog*. They are on-air presenters for National Public Radio, recently won the Professional Journalism Society award for excellence in writing and were keynote speakers at the Alzheimer’s Association’s Education Conference.

Carol Bursak is a speaker, syndicated columnist who writes on caregiving and senior issues for several national publications and the author of "Minding Our Elders: Caregivers Share Their Personal Stories." Her websites www.mindingourelders.com and www.mindingoureldersblogs.com include helpful resources as well as links to direct support.

Emily Caldwell is a science writer at Ohio State University. Her mother, Bonnie, was diagnosed with Alzheimer's Disease in November 2005, and she has been Bonnie's caregiver, helping her mother transition from living alone in an apartment to assisted living and then to a nursing home specializing in the care of Alzheimer's patients. She blogs about her mother here: http://momsbrain.wordpress.com

Ruth Drew, MS, LPC, is the Director of Family and Information Services at the national office of the Alzheimer's Association in Chicago, and has previously served as the Senior Director of Programs at the Association's Oklahoma and Arkansas Chapters. She has presented at national and state conferences concerning Alzheimer's and effective caregiving strategies and has worked to develop programs and grant projects, including an Older American's Act Title III grant for caregiver support.

Holly Eburne, BPE, BScR is a health & wellness coach, writer, speaker. For 29 years Holly has been a Physical Therapist traveling around the world with Canadian National athletes. Since her husband was diagnosed with dementia in 2007, Holly is focusing on teaching caregivers on how to live well…"caregiving changes your life, it doesn't end it". You can visit www.hollyeburne.com for Holly's Dementia Hope Formula.

Merilee Griffin, PHD, is the founder and president of Memo Touch, an interactive device to help those with memory impairment maintain their independence as long as possible while helping to lessen the demands placed upon caregivers. Merilee cared for her mother who suffered from Alzheimer's and recognized that there was a need for a simplistic and easy to use device to help provide daily reminders to those with cognitive deficits. See our memory impairment Q & A with Merilee Griffin.

Eric J. Hall is the founding president and CEO of the Alzheimer's Foundation of America (AFA). He also founded and serves as CEO of the Alzheimer's Foundation International (AFI), an international nonprofit organization designed to raise awareness of Alzheimer's disease and related dementias. Hall also introduced the nation's first Alzheimer's disease telethon, Together for Care, in 2010.

**Cindy Keith** is a RN and consultant who runs M.I.N.D. (Moving In Nurturing Directions) in Memory Care. She is the author of "Love, Laughter, & Mayhem – Caregiver Survival Manual for Living with a Person with Dementia," which is a collection of stories about people suffering with Dementia. You can learn about Cindy at www.mindinmemorycare.com

**Lori La Bey**, CSA, is the founder, president and CEO of Alzheimer's Speaks, a Minneapolis-based advocacy group that provides education and support for those dealing with Alzheimer's disease and dementia. She developed the training series, "Shifting Your Dementia Care Culture" as a battle plan against the dementia epidemic. Lora is a highly sought after speaker, trainer, and advocate for new delivery systems and attitudes towards those with memory loss.

Gary Joseph LeBlanc was the primary caregiver of his father for more than eight years after he was diagnosed with Alzheimer's disease and he has just published a collection of his articles in a book named, "Staying Afloat in a Sea of Forgetfulness." He also is a regular contributing writing for the Fisher Center for Alzheimer's Research Foundation.

Joy Loverde is the author of the best seller, *The Complete Eldercare Planner: Where to Start, Questions to Ask, How to Find Help* (Random House, Updated and Revised, 2009). Joy serves as a consultant to employers, manufacturers, senior housing administrators, and other members of the fast-growing eldercare industry, and is a keynote speaker and presenter for renowned organizations such as National Institutes of Health among numerous others.

Terry Lynch is the owner of Strategies for Independent Aging in Wisconsin and is the author of "But I Don't *Want* Eldercare!". Terry serves as Chair of the Wisconsin Board on Aging and Long-term Care, is a Board member of the national Direct Care Alliance, and also serves on the policy advocacy committee of the Alzheimer's Association of Southeastern Wisconsin. He is actively involved in initiatives to reshape Wisconsin's approach to long-term care, principally self-directed in-home services.

Miller Piggott, MSW, is a founding member of Alzheimer's of Central Alabama (ACA) and has served as the Executive Director since 1997. Miller spent over twenty years working for the University of Alabama at Birmingham Center for Aging and for the Alzheimer's Disease Research Center (ADRC). She has been named Professional of the Year by the Alabama Gerontological Society and was named "Health Care Advocate of the Year" by the Birmingham Business Journal.

Jan Robson is the Coordinator of the Dementia Helpline at the Alzheimer Society of B.C. She also facilitates a support group for people with early-onset dementia and delivers workshops to various community groups. Her background is in counseling and community corrections.

Michael Smith has served as Executive Director of the Alzheimer's Resource Center of Connecticut since 1996 and is a Licensed Nursing Home Administrator. Michael is active in local civic groups, the Alzheimer's Association and the Connecticut Association of Not-for-Profit Providers for the Aging (CANPFA), and is a frequent speaker on Alzheimer's Disease and dementia care at national and international conferences.

Karen (Karle) Truman, Ph.D. is the President and Founder of Dementia Caregiver Resources, Inc. She has been a presenter for the professional attendees at national disease-specific conventions. She won a *North American Mature Publisher's Association* (NAMPA) award for her monthly column — *The Caregiver's Path.* Karen currently co-authors dementia-specific training manuals for national corporations, conducts staff trainings, and creates/facilitates expert-panel symposiums.

Lauren Watral, MSW, is the founder of Raleigh Geriatric Care Management in Raleigh, North Carolina. She graduated from Duke University with a Bachelor of Arts (BA) in 1981 and earned her Masters in Social Work (MSW) in 1985 from the University of South Carolina. Lauren has decades of experience in various environments encompassing mental health, substance abuse counseling, and older adult care programming.

Lisa Wawrzonek is the Statewide Education Director for Alzheimer's Resource of Alaska. She is a Certified Care Manager and has over 15 years of experience in the field of dementia care.

Advice for Alzheimer's Caregivers

Question #1 – Share one simple yet practical piece of advice you'd give to family members/caregivers of Alzheimer's and Dementia patients as well as those suffering from non-Alzheimer's Dementia.

Judy Berry

Always VALIDATE your love ones feelings and emotions. Don’t take away control of their lives because of our own fear, and when issues arise ask ourselves, “Does it REALLY matter?

Tom and Karen Brenner

In our Brenner Pathways memory support program, we encourage caregivers (both professional and family caregivers) to try and engage by listening carefully to the person for whom they are caring. We encourage caregivers to:

1. Make eye contact
2. Listen quietly
3. Wait patiently for the person to finish the thought
4. Understand the emotion behind the words when the words don’t seem to make sense

Carol Bursak

Don’t argue. For example, I instinctively knew that my dad, who was thrown into instant dementia by a failed brain surgery, could not mentally comprehend the real world. I had to join him in his. When he told me Lawrence Welk had contacted him to be a guest bandleader, well, okay, why not? I got him a director’s wand and let him direct Welk’s band on TV.

What you are aiming to do here is validate the person rather than argue over meaningless issues. In other words, if the person with dementia insists the sky is green and the grass is blue, you agree. What does it hurt? If possible, join the fun, as I did. It makes things easier (well, sometimes).

Obviously, there are things you can’t agree with. If the person with dementia is paranoid and accusing people who are not stealing of stealing from them, you can’t agree. You need to find ways to distract, re-direct, and when necessary, kindly let them know you’ll “check into it.”

Caring for someone with dementia is never easy. It calls upon every loving instinct we have, as well as mental gymnastics that would make a complicated physics equation look like child’s play. But with AD education, love and outside support, caregivers can learn how to cope.

Emily Caldwell

Essentially, the tip would be: Don’t argue. Early on in the disease, probably before the patient or relatives know that dementia is developing, the patient may say unreasonable things and make wild claims. And that is their reality. It is VERY difficult not to correct them and its VERY common to do just that – try to convince them that they are wrong. And this is a lose-lose situation in many cases. They cannot be convinced, and the caregiver therefore cannot win. It is hard to do, especially for certain personality types, but the best thing one can do in these instances is to try to comfort them about whatever it is they fear or are otherwise imagining, and then redirect them to another topic that is pleasant and unthreatening.

Ruth Drew
One simple tip for caregivers or family members of a person with Alzheimer's or any other dementia is to learn to **calmly meet them where they are**. People with Alzheimer's and related dementias are doing the best they can with a brain that no longer function the way it used to, yet the core person remains.

It's easy to get frustrated and impatient, push the person to conform to the way they used to be, quiz them and correct them– but when we approach them slowly with kindness and calmness, accept them as they are, talk about what they want to talk about, and do what interests them, there are many opportunities for rich connection.

Alz.org has a wealth of information to help not only the person with Alzheimer's but also tools and information to help caregivers and family members deal with the stress and responsibilities of caring for someone with the disease. Our 24/7 helpline (800-272-3900) is a valuable resource, staffed with Masters level clinicians who are always available to provide assistance and additional tips.

Holly Eburne

Live each day like it is your last one; tomorrow isn't guaranteed for anyone. Being 'present' (as simple as focusing on your breath) will reduce worries, fears, and will allow you to focus on what you have–instead of what you are losing, or might lose. All the answers to your problems are in the 'present' moment—not in the past and certainly not in the future.

Merilee Griffin

From the beginning, think about balance: your control and their control; your time and their time; their health and your health. If you things get out of balance and they're running you ragged, everyone's in trouble. Step back and set realistic limits. Be determined that your head as well as your heart will be used to make decisions about what you can and cannot do. So often, caregivers want to make life perfect for their parent – but it never was and never will be. Everything's a bit of a compromise. Enjoy what you can do; don't feel guilty over what you cannot do. Try to keep a balance.

Eric J. Hall

Be proactive to help prevent wandering and to help locate a loved one if he or she does go missing, since wandering is a common and life-threatening symptom of Alzheimer's disease and related dementias and one of the most stressful for caregivers. These steps should include "safe proofing" the person's residence; equipping a loved one with multiple forms of identification that cannot be easily removed; and obtaining some type of "active" tracking system that can help caregivers and/or law enforcement quickly locate someone who has gone missing.

Cindy Keith

"When that elder with dementia is happy, then you are happy—and when they are not happy, you are not happy!" It's important to remember this so every response or interaction you have with that elder ends with everyone smiling. You will often have to change the way you think and react in order to allow the elder to get what they want or at least have the illusion of getting what they want, and not upsetting them.

An example might be if you are the caregiver for your elderly mother who has AD, and you have just served her a sandwich, some fruit and a glass of milk for lunch. You turn away for a few moments to tend to something else and when you again look at

Mom, you see she has put all her fruit and half her sandwich into her glass of milk and has made a mess on the table. She has a big smile on her face and even though you feel frustration and sadness at seeing this, you must respond to her in a positive way to maintain her happiness. If you cannot do that, and you allow your frustration to show, she will become upset because she has no idea she has done anything wrong, and you will then have to deal with her negative mood. You cannot change her, she cannot change, and so the optimal outcome would be to try to let the little things slide off you and even inject some humor into the situation. You might say some thing like “Well Mom, it looks like you’ve made a new dessert!” You haven’t scolded her, or become upset, and she will likely maintain her happiness as long as you are also happy. There will always be time for tears of sadness and frustration when you are not in sight of your Mom, and you will both benefit if you can maintain that happy face in her presence.

Another example might be if your elderly father with AD tells you he’s going to “drive home now,” and you know he no longer has a car and he now lives there with you. Instead of reminding him of that, and upsetting him, you might say something like “Dad, you car isn’t back from the garage yet, and I would be happy to drive you just as soon as I finish with… Why don’t you do this while you’re waiting for me?” This way, you’re giving him hope he will get what he wants, and you’re not arguing with him or reminding him he no longer has a car and cannot drive. If you can redirect his mind to an activity while he's waiting for you, chances are he will forget all about driving home. You can say these things as long as you know he will forget the conversation in a short time. We call them "therapeutic fibs" and it helps them maintain dignity and hope, and it keeps you from arguing with and upsetting him.

Lori La Bey

I recommend using a tool called "Your Memory Chip." It's a simple concept and easy to implement. Before every interaction with a person with dementia the caregiver should focus on 3 simple things: **1. Are they safe? 2. Are they happy? 3. Are they pain-free?**

When we focus on these three things, our care is totally about the person and what is in their best interest; or what is referred to as patient centered care. It is no longer about how we as caregivers (personal or professional) feel about what we are doing, or how we feel/respond to their reactions. If someone repeats a story multiple times just ask yourself the three questions. It is no longer about correcting them or getting them to stop. It's about are the safe, happy and pain-free. It's about their comfort and realizing they don't mean to irritate or upset you. Using this tool allows a person to let what used to upset them roll off their back so they can address the important things in life.

Gary Joseph LeBlanc

Lately, I’ve been doing quite a bit of guest speaking and during the process I’ve really enjoyed starting off by asking the listeners, “What do you think is one of the biggest mistakes a caregiver makes?”

The responses vary from, shouting at your loved one, to not taking care of the caregiver’s own physical and mental health. The reality being, all the above answers, and more, are correct. But in my opinion, the worst mistake a caregiver will make is not asking for help.

The result of asking for assistance most of the other problems will likely be avoided. A caregiver needs to learn to inquire where they can attain help right from the beginning of the diagnosis. Further down the road it will become obvious that, as the primary person in charge, you will barely have time to breathe.

Joy Loverde

One of the main reasons why dementia caregivers miss out on much of the financial as well as emotional support that is available to them is because they fail to surround themselves with experts early on. My simple practical tip is to visit the Alzheimer’s Association website and ask to speak with an advisor.

Terry Lynch

My mother’s world was changed by vascular dementia (dementia from brain damage caused by reduced blood flow to the brain.) She told me “It feels like I am losing my mind.”

It’s no secret that life as the primary caregiver of a person with dementia can bring with it — along with its rewards − frustration, irritability and sometimes resentment. I found that nothing helped me conquer these emotions more effectively, and quickly, than putting myself in my mother’s place.

Miller Piggott

Do not rationalize, argue or reason with a dementia patient. They are confused because of the disease process, which causes brain damage. No amount of talking will “set them straight”. Instead you want to reassure and give comfort. We live in a time where we expect a pill to fix whatever ails us. However, the care of a dementia patient is more art than science. Behavioral strategies work better than any pill.

Jan Robson

It’s difficult to narrow it down to just one tip, but I think I can boil down what I want to say to a short phrase: Carpe diem! Seize the day. Alzheimer’s disease and other dementias can be so challenging and so devastating, for those with the diseases as well as for those who care about them, that it can be tough to see beyond the daily grind. But if we make a concerted effort to focus on the strengths of the person with dementia, rather than on his/her deficits, and if we use the journey with dementia as an opportunity to learn to live in the now, life with dementia can still be rich and fulfilling. This does not mean that there won’t be dark days, but it allows for the possibility of joy in the face of tragedy.

Michael Smith

To understand that people with Alzheimer’s disease and other related disorders possess emotional memory, meaning that while that may not remember what you say or what you do, they will remember how you made them feel. Family members and professional caregivers should realize that their tone and approach in communication will shape the course of how successful someone with dementia can feel – which will directly affect that person’s quality of life.

Karen Truman

Getting a proper diagnosis should be one of the very first and most important steps you will take on this journey. Dementia isn't always due to Alzheimer's. Before you conclude that a Loved One's memory loss and confusion stem from an irreversible disease process, get a thorough medical evaluation at a Memory Disorder Clinic (MDC). These clinics are found all across the United States at medical schools, teaching hospitals, and hospitals. These special clinics assess patients and their caregivers with thorough physical, neurological, psychiatric, lab work, MRI's, CT scans, and neuro-psychological testing. A team of specialists meets after all of the tests are completed to give a diagnosis with a 90 – 95% degree of accuracy. They will also follow-up with the family and discuss an appropriate future care plan.

Because of the many stages and ongoing decline of our Loved Ones, it is advisable to have them re-evaluated periodically. It will be in everyone's best interest to see if medications need changing, new research advances could help, and to make sure all of their health needs are addressed. You may also want to explore research opportunities such as: National Institutes of Health – Clinical Trials are held all over the U.S. and are free for participants, and sometimes they compensate you for your time investment.

Lauren Watral

Bathing and shower a person with Alzheimer’s Disease can be a feat worse than death for caregivers! Alzheimer’s patients are notorious for poor hygiene because taking a bath and or shower is uncomfortable and scary to them. Some useful tips to help with this task: Throw towels or shower robe in the dryer so the client can get warm quickly with a warm towel upon exiting the water when they are likely to get cold and chilled.

Lisa Wawrzonek

Educate yourself. First and foremost, find out about this disease and what to expect as well as caregiving tips. Alzheimer’s will affect everyone differently and people will transition through stages differently and knowing why something is happening and how this disease affects the daily life skills and our personalities can make acceptance and understanding as well as caregiving so much better! Education goes for those caring really for anyone. The more you know the better care you can provide.

Question #2 – What’s one little known technique (be it an exercise, medical therapy, best practice, etc.) for treating Alzheimer’s and/or Dementia patients?

Judy Berry

DON’T BELIEVE THE MYTHS AND STIGMAS. Always remember your loved one is NOT fading away, they are NOT somehow becoming someone else due to progression of their disability. Continue to communicate with them, recognize their human emotions and needs, right until their natural death. Long after they lose their ability to respond verbally, learn to read non-verbal communication. Emotional needs are heightened when our love one lose their ability to verbally communicate their needs.

Tom and Karen Brenner

When we are trying to engage with people who are living with Alzheimer’s and other dementias, we understand that it is often difficult for them to pull ideas or conversation from thin air. To encourage engagement, conversation and reminiscence, we ask caregivers to put something meaningful in a person’s hand. This meaningful object can be something they once loved (for example, a baseball mitt or a violin) or something from the natural world (flowers, herbs, a cup of snow). This simple act of putting a meaningful object into a person’s hands can be so helpful in starting conversations and creating connections.

Carol Bursak

People with Alzheimer’s need to feel useful just as all of us need to feel useful. It’s instinctive to make things easier for a struggling loved one by jumping in and doing everything ourselves. This can be admirable, but it can also take away any feeling of power that the struggling person has. Help when needed, but do what you can to ask the person with the disease for help as well. Let them do what they can for themselves and find ways to ask for their assistance, especially during the early and middle stages of dementia. Remember that part of human dignity is feeling useful. Preserve that dignity for your loved one in any way you can.

Emily Caldwell

In my mother’s experience, music is a positive stimulant and a comforting sound. Patients seem to enjoy live performances as well as familiar radio/CD songs such as oldies, Christmas songs, things like that. Classical music can be very soothing, too.

Ruth Drew

Music can sometimes transcend the challenges of dementia diseases like Alzheimer’s. Many caregivers tell stories about helping people do things they don’t enjoy, such as dressing or bathing, by starting with a favorite song and continuing singing through the task. Often people come alive in surprising ways when listening to familiar music. People who can’t speak in complete sentences may sing all the words to a song from their childhood.

Holly Eburne

Maintaining social contacts is critical in managing dementia. Everyone wants to feel they ‘belong’ to something bigger than themselves. Being with other people activates the listening, thinking, and language areas of the brain. It also gives them a purpose and reason for getting up in the morning.

Merilee Griffin

I can’t help recommending the Memo for early-stage Alzheimer’s and mild cognitive impairment. When memory loss is creating chaos and confusion for the elder and frustration and stress for the caregiver, the little Memo is practical, convenient, and cost effective. It can’t stop the progression of the disease, but it can make management of it much easier in the early stages.

Eric J. Hall

Redirection is a valuable best practice, which caregivers can use to diffuse challenging behaviors, to cope with communication issues and other problems that may occur, and to assist with activities of daily living. Rationalizing doesn’t work since persons with Alzheimer’s disease experience lack of judgment, loss of verbal skills and diminished memory. Therefore, the better alternative is to redirect the conversation or activity in order to distract the person from what may be bothersome. This technique includes bringing up a pleasant topic, looking through photo albums, or offering a favorite food.

Cindy Keith

Since elders with dementia will begin to lose weight as the dementia progresses, it’s important to help them maintain weight unless they are morbidly obese to begin with. You are probably already aware of how difficult it can be to get your loved one to eat when they don’t want to. One elderly woman in the dementia dedicated Assisted Living facility I used to work in, stopped being able to feed herself with the utensils—she just couldn’t manage the fork or spoon any longer and she absolutely refused to be fed by another person. We discovered that if we “sandwiched” foods and handed her the sandwich, she would eat anything. From then on, she received delightful meals such as spaghetti sandwiches, broccoli sandwiches, mashed corn and pea sandwiches—whatever was being served, she received in a sandwich. She happily continued to feed herself in this manner and she stopped losing weight.

Lori La Bey

I hate to say “treating” as I don’t believe there is a treatment per say, but to me it’s more of an attitude shift that needs to take place throughout the world. A shifting of our perceptions as they relate to our relationships. We need to develop an appreciation for our personal connections and to let go of control. As caregivers, we think we have to protect, control and make things better. But what is “BETTER” to the person with dementia? Is it having their caregiver obsessed with tasks and things focusing on loss, or is it continuing to have an engaging relationship with conversation, laughter and appreciation.

I encourage people to keep “their normal” going. Don’t let the disease win. Learn how to live with dementia not as dementia. I recommend looking at the relationship. What is has been in the past? What do you want it to look like in the future? Then make it happen. You might have to modify how you do some things as the disease progresses, so expand your options and look at alternative ways. Be flexible!

As for a specific thing, you could incorporate into a daily routine; for me that would be hands down MUSIC! Music and the arts are one of the last portions of the brain to be affected by the disease. Music is simple, low costs and has amazing effects on multiple levels for both the person living with dementia and those around them.

Remember, music is attached to our emotions. Use it to everyone advantage. Here are a couple of music videos I have of my own mother who is in her end stages of Alzheimer’s disease. Her ability to communicate is very limited, but you will see how music pulls her out and brings her joy. As a caregiver, these videos warm my heart and fill my soul… The value….Priceless!

- June 2009 – http://www.youtube.com/watch?v=XO_ZQy3PyY4

- Summer 2010 – http://www.youtube.com/watch?v=75nIIciQM0o
- December 2010 – http://www.youtube.com/watch?v=BRSWBBE9_Kk

Last, I would like to note one more video, which gives people some ideas about how to interact with someone as the disease progresses: http://www.youtube.com/watch?v=IzysslAWgW8

Gary Joseph LeBlanc

When caring for Alzheimer’s patients, you must learn to use redirection to your advantage. Knowing just when confusion is beginning to snowball straight into delusion, and using simply phrased words, you can create a u-turn in their thought patterns. These are important skills for any caregiver to master. Also, ice cream fixes everything!

Joy Loverde

Effective communication skills lower everyone’s stress level. When speaking with someone who has dementia, focus on the feelings, rather than the facts. This technique allows us to become more present to where the person is in the moment and not where you would like him/her to be.

Terry Lynch

Do everything you can to reinforce that person’s sense of self-worth and that he or she still “matters.” Wisconsin’s excellent Medicaid-funded homecare programs enabled us to bring paid caregivers into our home. They valued my mother and looked past her dementia and physical disabilities to her inner self. Several often reminded her that she was their role model for handling adversity with humor, grace and courage. They asked her advice on many issues related to managing daily life, including relationships with family and friends. They told her how much she helped them and it gave her great pleasure. One of her favorite caregivers told me, “Anyone who thinks Leila (my mother) isn’t smart just because she has trouble remembering things doesn’t know what they are talking about.”

Miller Piggott

Routine and reassurance are the best practice.

Jan Robson

The Alzheimer Society of B.C. focuses on the personal and social consequences of Alzheimer’s disease and other dementias, so I’m not in a position to comment on medical treatment. But our guiding principle certainly speaks to a core belief regarding how to treat people with dementia: “Every person, regardless of their losses, has a core of self that can be reached." We are more than the sum of our memories or the fluency of our speech. Connection can and does happen on a feeling level.

Michael Smith

Communicate with empathy, individualize your approach and provide meaningful opportunities for engagement.

Karen Truman

Often, family members do not want to admit how severe the memory loss has become. They see the same person on the outside and do not comprehend how different their Loved One has become on the inside. Try these ideas:

- Set up a no argue zone
- Keep communication short and simple
- Don't take away what they can do
- Stay on a schedule
- Try to not let your loved one see you get upset

Lauren Watral

Get into the world of the patient with Dementia. Be in their world of reality, not your own. Orient your world to their reality; do not orient the Alzheimer's patient to your world of reality.

Lisa Wawrzonek

Validation - Certainly eating well, exercise, and mental stimulation have potential to slow down the symptoms we might see but when an individual has Alzheimer’s or a related dementia, often their reality is not our reality. We all seek validation in our daily lives but we instinctively what our loved ones to think how we do and we might re-orient somebody which could lead to an argument. Individuals with a dementia might not be able to reason anymore so re-orientation doesn’t always work but validation does. If we validate the reality, validate the concern, it helps us provide dignified care that keeps our loved one safe and content.

Question #3 – What are some important questions to ask if your loved one has been diagnosed with Alzheimer’s or other forms of Dementia?

Judy Berry

- What type of Dementia do they have? Progression of the disease and approaches to care can be different. Learn as much as you can.
- Is there a support system in your community for persons with early stage dementia? If not try to find and connect with other families in the same situation for support. It is critical your loved one is not isolated
- What do we need to do to be proactive within our own lives? What can we do so that we are prepared for changes necessary as the symptoms of the dementia progress, i.e. driving, financial etc?
- What are the educational AND support groups for families available in your community? Take care of yourself, first and foremost. Recognize your own limitations and need for respite.

And if possible, have you and your loved one see the video “Living Outside the Stigma” by Dr. Richard Taylor.

Tom and Karen Brenner

It is important for caregivers to educate themselves by reading all they can about Alzheimer’s and dementia. There are several very good on-line Alzheimer’s communities where very helpful information can be found. (Tom & Karen Brenner are contributing writers to the on-line blogs, Alzheimer’s Reading Room and The Fisher Alzheimer’s Research Foundation Blog.) Caregivers can inquire where they might find On-line and face to face caregivers’ support groups for emotional support. Caregivers should also try and find the most effective strategies for staying connected to the people for whom they care. Both professional and family caregivers can look for classes and local seminars in memory support and Alzheimer’s care at their local Alzheimer’s Association chapter or an adult extension program at a nearby college. Family caregivers should not hesitate to ask other family members, friends and/or professional respite health care workers about the possibility of providing regular time off so that they can take time to care for themselves, to rest and recharge.

Carol Bursak

A. Talk with him or her about appointing a Power Of Attorney for finances for the time when it becomes necessary for someone else to handle financial issues, a Power of Attorney for health care, and a will for assets. Everyone should have these documents in order, because accidents happen quickly, but when someone has been diagnosed with dementia, it’s known that cognitive abilities will decline. This makes it essential to get legal situations covered early on.

B. Talk with him or her about the type of care they would prefer as their disease continues to erode cognitive powers. Would they like a combination of in-home care and adult day care for awhile until their needs make a nursing home the only safe option? Or would they like to move into assisted living while they are still doing quite well and can make friends and take part in activities.

C. Do not promise to “never put them in a nursing home.” No one can know what the future will bring. Tell your loved one that you’ll do your very best for their health and safety. You will follow their directions to the best of your ability, but there may be a time where you simply must call the shots. We can never forecast life events, so at some point we must trust the people we have asked to be our voice when we’ve lost our ability to speak for ourselves.

Emily Caldwell

There are so many. And unfortunately, there often are no firm answers because every patient is different. Some things to consider are:

- Is my loved one a good candidate for medication? How long can I reasonably expect medication to be effective?
- Are there any local clinical trials that my loved one could participate in?
- Is there a social worker who can help me manage finances, obtain a power of attorney,

advance directives, etc? Are there lawyers locally who specialize in elder care issues?

- Are there caregiver support groups available in the area?
- What are the best resources for caregivers? (for example, recommended books, websites, things like that.)

Ruth Drew

No two people experience Alzheimer’s or other dementias in the same way – but there are important questions you can ask to allow the person with the disease and yourself, to get the help and comfort needed now.

- What are the current needs of the person with Alzheimer’s in terms of information, social support, medical care, day-to-day assistance?
  - What kind of financial and legal planning needs to be put in place to address current needs and plan for the future?
  - Who is on the support team (family and friends, physicians, attorney and financial planner, social services, clergy, Alzheimer’s Association, etc.)?
  - What is the plan for support of the primary caregiver(s)?

Holly Eburne

Where can I find a list of younger-onset primary caregivers–not an Association or counselor? I want to find those people who are walking in my shoes (past or present) and who have found ways to live a great life. I want to know that I'm not alone. I'm also looking for HOPE and steps to help me when I'm feeling overwhelming sadness, anger or frustration.

Merilee Griffin

Ask immediately about good community resources and other interventions. The sooner you accustom your loved one to adult day care, home health aides, a Memo, rotating family members on duty, and other resources, the easier it will be for them to adjust, and for you to maintain your energy and composure for the long haul. The temptation is to do it all yourself until you're totally drained – and by then it's more difficult to change routines and bring in new people, places, and things. Start now.

Eric J. Hall

- How will the disease progress…what can we expect?
- What medical treatments and behavioral interventions are appropriate to manage the disease?
- What are the side effects, and pros and cons of the drug you are prescribing?
- Are there any clinical trials that would be appropriate for my loved one?
- What changes in condition should we report to you?
- What national and local support services can you refer me to for my loved one and myself?
- Should we be seeing a neurologist, geriatrician or other specialist, and will you be in touch with my other clinicians?
- Are there any lifestyle changes we should be making, such as nutrition or exercise?
- Can my loved one continue with his or her daily routines, such as working or driving?
- What will private insurance, Medicare or Medicaid cover in terms of support, such as adult day programs, in-home care or long-term care?

Cindy Keith

1. How can I connect with a local support group?
2. What options are available for treatment of the dementia that may help to slow down the progression?
3. What non-pharmacologic interventions can be helpful?
4. How often should my loved one be seen in your office?
5. What type of behaviors should alert me that my loved one is having a problem and should be seen as soon as possible?
6. Would you recommend my loved one be seen by a neurologist or geriatrician for a second opinion or to help coordinate care?
7. Are there professionals out there who can help me with day-to-day issues (geriatric care manager, dementia consultant, social workers, etc.)? What books do you suggest I read?

Lori La Bey

For this question, I am going to focus on questions directed to the person with dementia. So often, we get so consumed with the medical condition we forget to talk to the person with the disease and what is important to them. These are questions I would ask in no practical order:

- What is important to you with your care in the days ahead?
- Can you tell me three things that you feel are critical to giving good care to you?
- Who do you want to care for you and why?
- What’s on your bucket list?
- How do you feel about home healthcare and daycare programs?
- Can you tell me when you feel it would be time for you to stop driving?
- Where do you want to live and with whom and why is this important to you?
- When you get scared or upset what is the best thing I can do to calm you down?
- How do you feel about telling family, your friends, coworkers or acquaintances about your disease?
- How do you feel about dealing with your finances and how should plan to deal with them in the future?
- Would you be willing to get your/our paperwork together…will, healthcare declarations, investments, powers of attorney, insurance, bank accountants…?
- Can we build a list of your favorite music… bands, songs…?
- How about we do the same thing for your hobbies and activities you enjoy?
- Can we please go through old pictures so you can tell me which your favorites are and why?

- Will you help me gather a detailed personal history on you from family, jobs held, to friends, sports played, vacation areas…? They say this becomes extremely helpful later in the disease and could really be fun to do together now.
- Let’s share our favorite moments with one another?
- Would you be willing to share your experience as it progresses via in writing, video, photos….? I think it would really help me understand what you are going through and if you want, we could share with others to educate them too.
- Can you help me make some notes of your daily routine so we can be sure to incorporate them in the future to help you be more comfortable?
- Will you tell me what irritates you and what you would like to see done differently?

Gary Joseph LeBlanc

I would want to know about when the symptoms started. Trying to find out how far along they are into the disease.

Joy Loverde

How are we going to pay for this chronic illness? That is the number one question to ask.

Terry Lynch

My mother’s original diagnosis was Alzheimer’s. The Alzheimer’s Association put me on the right track. Testing by a physician skilled in geriatric medicine led to an accurate and life-changing diagnosis. We found that her vascular dementia was treatable with anti-coagulant medications. Her memory loss and confusion were not reversed but they were slowed dramatically. From that experience came the question with which I am obsessed– “How does the doctor know it’s Alzheimer’s?” I follow it with: “Did you get that diagnosis from a physician skilled in treating the medical problems of older people?” I of course include plenty of advice, none more important than “Be sure to call the Alzheimer’s Association.”

Miller Piggott

- How can I get involved in a support group?
- How can I learn more about the disease?
- What resources are available in my community to help take care of my loved one?
- What legal resources are available?
- What can I expect?

Jan Robson

I think the most two important ones are:
1. Where can I get some credible information about the disease and how to cope with the changes that are happening? 2. How can I get some support for myself (whether you are a care partner or the person with the diagnosis)? Too often people expect that they will get all of the information and referrals that they need from their doctors, but this is seldom the case. The doctor is the medical expert, but usually you will have to go elsewhere – for example, your local Alzheimer Society – to learn what you will need to live with the disease and make the journey with it manageable.

Michael Smith
The questions you might ask would depend on that person’s stage of dementia. Early Stage – Ask questions of the person with the dementia. What kind of expectations do they have? What are important things that others should know about them? Engage them in planning advanced directives. Ask how you can be a support to them. Moderate – Advancing Stages – This is a period that family members may need to engage others (health care professionals) to assist or partner in caring for someone with dementia. Ask questions of those potential partners that explore their empathic abilities, their creativity, their level of patience, and their level of knowledge and experience with person-centered care.

Karen Truman

Some very important questions to discuss, ponder, and argue about when making decisions about leaving your Loved One home alone can include the following:

- Can they call 911?
- Are they frightened when alone?
- Will they let in strangers?
- Can they recognize family and friends?
- Will they be destructive or could they harm themselves?
- Can they safely use the bathroom alone?
- Will they wander or constantly seek an exit? Place a mirror near the door. The reflection of a person's own face will often stop him or her from exiting the door.
- Can they prepare a meal without assistance?
- Can they distinguish smoke alarms and seek safety?
- Do they have medical issues (i.e.: taking medications/giving shots, wound care, etc.) that needs supervision?

Consult with an Elder Law Attorney as soon as possible to get information on how to pay for future long-term care needs. Was your loved one a veteran? Do they have "hidden" assets? Do they have a pre-need burial account? Have they updated all of their documents (i.e.: Durable Power of Attorney; Health Care Surrogate; Living Will; Will; insurance beneficiary(s); etc.)?

Lauren Watral

- Is there a cure?
- What kind of changes will I expect to see of my wife, mother, father, loved one?
- What changes will I observe?
- What is the life expectancy of someone with Alzheimer's Disease?
- What will MY role be and who can help me though this?
- Are there drug studies or clinical trials available?
- What are the available resources to help me help my mother/father/husband/wife?
- Because I love the knowledge and power one can get from reading, what books would you, the doctor or GCM, recommend I read?
- How often will we need to visit the doctor?
- Will MY life change?

Lisa Wawrzonek

Where can I go to get information and support? We reduce risk of a crisis situation if we have a plan. Alzheimer's specifically is a slow progressing dementia but other health issues can exacerbate circumstances. If we know where to turn to get information or where to go when we're stressed and needing support, we can reduce the risk of a crisis situation or make reacting to a crisis just a little easier. Get to know the resources in your community; join a support group and get involved with an organization that can get to know you and your family so that in any circumstance, you have a place to go when needed.

This guide is available online at http://assistedlivingtoday.com/2012/04/caregivers-guide-to-alzheimers-disease/

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