



September 21, 2010

A Toolkit for Alzheimer's Caregivers

I met Megan Carnarius when I was in search of exceptional memory care facilities in the metro Denver/Front Range Colorado area. Megan is a sought after national speaker on Alzheimer's. She is also the Executive Director of Balfour Cherrywood Village, a memory care and Alzheimer's secure facility, located in Louisville, Colorado.

In honor of World Alzheimer's Day observed on September 21, here is a recent Q&A session with Megan Carnarius, RN, MT, NHA for Part Two of the Series entitled, 'Wisdom for Better Health'.

(Mary) I think your expertise with Alzheimer's patients and their families is invaluable. I only wish my family could have known about you when we were dealing with Alzheimer's. I have heard you say before that a simple task to us is actually many steps to remember for an Alzheimer's patient. Like brushing your teeth is 1) walking to the bathroom, 2) knowing to go to the sink, 3) finding the correct toothbrush, 4) knowing to put toothpaste on the brush, 5) putting the brush inside your mouth, etc.

Question #1: What advice do you have for families or caregivers of Alzheimer's patients to help them assist their loved one through basic daily tasks?

(Megan) I would need to ask a few questions first to the family to tailor my response. Is this person aware they are having challenges and seek out assistance? Is the person unaware about skills or tasks not occurring and resist assistance? In the case of seeking out help, families naturally adjust in the beginning of this process with cueing and reminders. It may be that they need to remind the person it would be a good time to take a shower and the individual is able to go and perform that task without assistance and it was just the routine time/day that is lost due to short term memory tracking. Eventually they might need to hand the person the soap and ask that they wash parts of their body to assure it is happening. This is the loss of moment to moment tracking also caused by short term memory deficits. At a later juncture they will have to assist with hair washing as the individual will not remember how to do this. We start seeing long term memory damage regarding how things function. In a way many memories of how we manage certain tasks are held in the area of somatic memory- muscle memory or habit. Often caregivers can initiate a person's participation by acting out with gestures when words are not helping what you are hoping the person will do. Gesturing brushing their teeth, or sitting on a toilet can help cue in good non-verbal ways that enables the individual to understand.

If a person is resistive to help that creates a whole different set of stressors. How to get something to happen that feels important to quality of life, health and well being when the person lacks insight means you have to pick what is truly important and what can be let go of. An example of this might be someone is extremely fastidious in their every day life but now has memory loss. The daughter might be compelled to keep everything as the parent had done it, try to maintain that standard getting resistance at every turn. The daughter may have to allow the setting or the person to not be as neat and tidy but they are still not endangering themselves. For the caregiver this is a lesson in tempering themselves rather than trying to fight with the person with memory loss. However when it reaches a point that someone is endangering themselves either from a health standpoint or safety – caregivers have to find specific ways to wade in or bring others in at that point for assistance. There are times when resistance makes the job of caregiving very difficult and frustrating, but there are also times when we are able to figure out an approach that works it can feel very rewarding and creative.

The last comment I would like to make about this area is to touch on a concept called “learned helplessness”. Sometimes the person takes a long time doing something and the caregiver becomes impatient. We always have to assess is this person able to do this task or this part of the task and how much assistance we should offer. If they are having a harder day they might not be able to do as much and we help a bit more. The next day or next hour might be better and they are able to participate more. If you take over a task the person is able to do, but you do it for them within two weeks this skill can be lost. Ultimately all these skills will be challenged and lost, but we don’t want to rush this process because of our own needs for perfection or a hurried pace. Giving people time to do things and manage something helps people with memory loss feel more successful and to have a sense of owning their day. They can not reconstruct what happens through out the day but they have applied their energy, used different remaining strengths and did not have others doing everything for them, even if it is in a small way. For the caregiver letting the person manage something also helps keep the caregiving’s role in balance. Ask yourself if I can let this person be in their room and cue starting to get dressed and they continue to dress while I can have my coffee or make phone calls this affords you some space too. This disease progresses over a long period of time and finding ways to preserve your own energy to keep an objective perspective is key for your on going success as a caregiver. Slow down and allow a pace that encourages the person you care for to continue to participate when they are still able.

Question #2: Since Alzheimer’s patients have difficulty verbalizing their feelings, what creative ways can families get information from their loved one?

(Megan) We tend to rely on verbal communication but actually it makes up only 6% of all the communication that is actually occurring. When someone with memory loss has lost their ability to find their words or specifically describe something to us we have to put our detective hats on and observe in all areas to assess what is happening. How are they acting physically? Is something different? Are they grimacing or lethargic when normally active. Are they hyperactive when normally more sedate. Are they rubbing an

area or touching something repeatedly when prior to this change this behavior was not apparent? Are they irritated, more combative, more resistant in some way that is different? Are they anxious, nervous or restless? Is the mood different and not consistent with how they have been in the recent past? Some individuals are having pain and cannot express it. There have been studies done regarding giving persons with dementia Tylenol or Advil and seeing behaviors calm and in hindsight researchers realized their hunches were accurate. These folks were having some forms of pain that they could not identify and it was causing behaviors which felt unrelated but were actually a form of communication. All behavior is a form of communication. If someone is refusing to eat, and swats caregiver hands away, and seems agitated there may be a problem with constipation, a toothache, or some other resolvable issue and may not be a sign of additional decline at this particular juncture. Caregivers armed with these clues can get the right assistance from their medical support practitioners and may find perhaps prune juice is in order or a dental visit and they do not need sedatives, anti-anxiety or psychotropic medications. Sometimes folks with memory loss are bored, don't have enough structure or are simply trying to solve a problem in their own way. Families learn to take their cues from the responses they are getting versus how they expected the person to respond and this openness to feed back, in whatever form it takes becomes their gold standard on how to proceed.

(Mary) Fortunately, health care advances have been made over the years that enable doctors to diagnose Alzheimer's at an early stage rather than mid to late stages of its progression.

Question #3: What do you feel is the most reliable method to date of receiving a timely, proper diagnosis?

(Megan) I have been working with people with memory loss and their families for over 20 years and there have been many advances and improvements in best practices, greater understanding about the disease and its progression and ways to treat or handle some of the challenges that come up but we still don't have a cure. Making an accurate diagnosis can be challenging and ultimately families who chose to have an autopsy done at the end of life have a confirmed diagnosis, but we can get much closer with all that we have learned about this disease and tools we now have to identify it more properly.

Typically there is still an element of ruling other diagnosis out first that may be affecting cognitive ability before jumping to the conclusion that there is a chronic dementia present. Dementia is an umbrella term that specific types of diseases that cause long term cognitive deterioration fall under. Alzheimer's is still the largest group; up to 60% of dementia diagnoses are of an Alzheimer's type. However Cardiovascular dementia, Lewy Body Disease, Frontal Lobe dementia, Picks disease, and dementia's caused by Parkinson's or Lupus as well as other forms fall in this group as well. Clinicians look at many factors when trying to obtain an accurate diagnosis. Because there is an age correlation to Alzheimer's, the older you are the greater the risk, up to 50 % in demographics over the age of 85 this is considered as well. Standard tests are done with a full physical and lab work-ups, cognitive skill and memory drills, listening to the patient

and the family about what daily life is like and what are the challenges there is a developing picture which arises. When they can rule out any kind of infections such as meningitis or sepsis, they have checked for deficiencies such as a lack of vitamin B12 or the correct amount of thyroid, when they do not find excessive cerebral fluid in the brain (Normal Pressure Hydrocephalus) or a cranial bleed of some type that perhaps is creating pressure. Are there medications which perhaps have precipitated this problem and can be changed? Depression has also been found to be a vulnerability to developing dementia later. Some instances the person has dealt with a depression for many years, perhaps untreated, undiagnosed and family at first thinks the depression is deepening and that is why the person is behaving the way they are. There is something called pseudo-dementia that is really a depression and when treated the cognitive symptoms are alleviated. It may also be that the person is depressed because they are feeling changes in their ability and thought processes and it is not a clinical depression but a situational depression. Clinicians will treat the depression, however, if there is no improvement and cognitive changes continue they will need to pursue what is the underlying issue.

I used to have elders arrive with their family for a tour of the residence where I worked and they had not seen a physician regarding the changes in their cognitive status. There wasn't enough information about aging and that cognitive changes are not considered a normal part of aging as it has in years gone by. The term senile dementia is completely outdated at this point. Some of these individuals could have had something that in early stages could have been treated and created a different outcome for them. I still have situations when a primary doctor has given the diagnosis but did not order any type of brain scans to confirm their diagnosis. This is now considered standard practice. If you have something going on with your mental abilities, your brain, it is important to get an image of the brain. One of the following a CT scan or MRI or less frequently available a PET scan is important to have, including the opportunity for a radiologist and/or a neurologist to read and confirm their findings with the primary physician. There are situations when a person can not tolerate such a test and this is the reason it is not done, but this is rarer and every attempt to get a baseline image should be pursued. Once a diagnosis is clarified there is no need to check in later and do these tests again unless a fall precipitates that urgency.

When the diagnosis is made there are different treatments and medications that can be used which work to support cognitive abilities. There are also medications which are contraindicated for certain types of dementias. With a clearer idea of what the disease is all involved can prepare and plan better. Knowledge helps us stay objective and be more forgiving when challenges arise. This is not the person's fault it is the disease. Having a sense of what the progression may look like and what is aberrant to that trajectory can help with taking action and problem solving at important times during the process.

Question #4: Unfortunately, not all families have access to you and your staff at Balfour's memory care/Alzheimer's facility. So what advice do you have for families that are handling this situation primarily on their own in their own home?

(Megan) I work with families in the community as well as those that have loved ones in our residence. Everyone is facing challenges that perhaps they have not experienced before. If in the beehive I work in there can be some helpful approach or understanding gleaned and shared it makes our efforts here even more meaningful. Being able to talk to other caregivers about care approaches and other needs as they come up can be very helpful. Find venues which assist you in access to other caregivers.

First things first:

- #1 Get the right diagnosis
- #2 Gather the right medical support team, and other specialists when needed- Gerontologist, Neurologist, Psychiatrist, Case Manager, Therapist, Professional Caregiver, etc.
- #3 Access family, friends, community resources and support
- #4 Put your financial and legal house in order
- #5 What is your back up plan if something happens to you and you can not provide care- short term/ long term?
- #6 Find out about educational resources- Alzheimer's Associations, workshops for caregiver, trainings, etc.
- #7 If possible, investigate home care, respite stay programs, adult day care, and residential programs before you need them. Some places have waiting lists, some may be affordable-others may be all private pay and to know what those costs are can be helpful for planning. It is good to have a sense of what is available in your area even if right now you have no intension to utilize them.
- #8 Contact your local office of aging and see what services you may be eligible for.
- #9 Get a physical. Make sure you are taking care of your own fundamental needs.
- #10 Learn to DELEGATE and ask for help. Do you need someone to cook for you, clean for you, do the grocery shopping so you can attend to the things you are doing with your loved one? Martyrdom breeds resentment. Overwhelm exhausts. Impatience makes guilt flourish. How can you keep your own balance enough to not get into these mood states for very long. It's normal to visit, just not to live there. Support groups and/or counseling services either for yourself and/or the family. In early stages a person with memory loss can also benefit from these services. If you have a faith community there may be some resources you can access during this challenging time for you and your loved one.

Question #5: There has been some controversy over the past several years that Alzheimer's is not a disease but rather a severe form of aging. People in that camp believe that pharmaceutical companies and other health care organizations should invest their time and money on prevention and care instead of finding a cure for a 'disease' that does not exist. What do you think about that?

(Megan) Wow! Have any of these people been in clinical settings or residential settings and had the chance to observe individuals with this disease? Perhaps one day I will be proven wrong but to me this is not a severe form of aging. This is a specific disease process. There are definite patterns to what challenges people and in what order these changes cascade. The neural function is impaired and that damage to the brain is evident in their abilities and actions. What about our folks who are getting a diagnosis at 45, 54, 60 years old? How is that severe aging? I am sorry for my sarcasm but do these people want all the research dollars to go to a fountain of youth campaign for their own benefit?

Whenever science investigates something there is an ever increasing awareness of greater complexity. At first view something may look simple and there are assumptions about how it works or what it does, or even what it looks like. Then we have greater levels of magnification, better ways of understanding a process and realize there are many more levels to something than what was first thought. An example of this was what was understood about the immune system prior to the discovery of the AID's virus. We know far more now than we ever imagined about the immune system and continue to learn new things all the time. I feel in every medical arena advances continue to be possible but we have to have a reason and resources to explore them. Six million and more people with this diagnosis are certainly a motivator.

With all these different forms of dementia there are different parts of the brain impacted and different processes. In Alzheimer's, protein amyloid and neural fibril tangles and atrophy are part of the damaging picture. Atrophy can be associated with aging as there is subtle atrophying that goes on in the brain and other tissues in aging. But not to such a severe degree and not with the other two factors involved. With frontal lobe disease, just as the words denote, it is the frontal lobe that atrophies but to an excessive degree, this disease often strikes people in the fifties and early sixties. In Parkinson's, there are different neural chemicals which have been impacted initially versus Multiple Sclerosis where the protective linings to the neural sheaths are disintegrating. Both can lead to forms of dementia that manifests in different ways. I feel we need all the differentiations in the efforts and focus of researchers. Like the road less traveled- different pathways lead to different outcomes. Someone somewhere working on something else may discover the key piece that others missed in their assumptions and approaches. Fortunately researchers are sharing information with each other more readily. Accessibility to information for all of us has so much more ease in this computer age and through the internet.

Question #6: A question that probably many people would want to know coming from you in regards to your own life is what do you do and what do you consume, if anything, to prevent Alzheimer's?

(Megan) Prevention is a difficult question. Over the years I have heard take Vitamin C and E then heard not to. Women should take estrogen to avoid dementia then more research comes out and they shouldn't do that. Advil and other anti inflammatory medication are suggested then it goes out of favor.

I think we have to weigh what we hear, what makes sense to us and try to fit the things we think are good for us into our lives. Having a life you feel good about that doesn't cause you too much stress, fear and depression is important. But we all go through phases in our lives that are difficult and we can't kick ourselves when this happens and add more stress by thinking that way. A person getting separated, divorced or had a spouse pass doesn't need to hear the statistics of how having a spouse leads to a longer life, while they are trying to recover from this event in their life. To all things there is a season. If something is weighing you down for too long, what is too long to you, and how do you address how to change aspects of it to feel there is progress to something better.

We all want to have a certain quality of life and some work more consciously or are able to more fully create it. However I have worked with geniuses with dementia diagnosis, vegetarian star athletes with dementia diagnosis and the most cavalier risk takers who never paid attention to their health and have lived hard lives, without opportunities for higher levels of education who have perfect cognitive functioning as primary caregivers. It's a conundrum and a mystery. I think we do our best but at times our lives are challenged by very big things and at times we have to look deep within ourselves to find our way. Even with coping with this disease that at surface level is wafting off an individual's abilities and sense of what was familiar to them about themselves, I see people with memory loss navigate this with great courage and their essence continues to shine through in some of the most challenging circumstances. We have to remember we are more than the function of our brain.

Megan Carnarius can be reached directly at Balfour Cherrywood Village in Louisville, Colorado. Phone: 303-604-2700

Mary Scroggin-Harris can be reached at Lifelong Wellness Advocates in Boulder, Colorado. Phone 303-539-6916