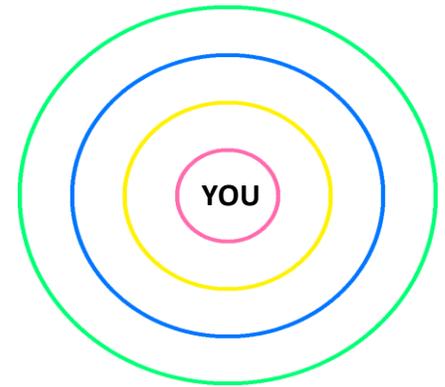


1/15/16

“Connected in Caring”

A gentleman who is providing full time care for his wife who is experiencing moderate memory loss recently asked me how he would ask and accept assistance. He says when he thinks about finding support, he immediately stops because he tells himself that he should be able to do this himself and would see himself as a “mooch.” Those messages or self-talk that are ingrained in us are hard to recognize and can be even harder to change. If you think about it, the message he is giving himself hasn’t changed even though his spouse’s condition and needs have dramatically in ways neither of them would have ever anticipated. She requires hands on care and supervision now and he continues to see himself as the only person who can provide her care.



Unfortunately, this is not an unusual situation in the life of a person with advanced memory loss and nor an uncommonly held belief by a family caregiver. Many not only believe they should provide all the care, but also believe that they are the only ones who can and who do it as well. It is one of the contributing factors to stress, burnout, depression, and other illnesses for the person providing the care. Roughly 30% of caregivers die before those they are caring for! No one in these situations wins when the caregiver “flies solo.” **Caregiving, or for all practical terms, being human is not a solo activity.**

I am more frequently encouraging caregivers I am honored to work with to think about their own support circles and at times put them on paper to create a visual of those close to them. It is all about relationships, and seeing those close to you as you draw them out serves many purposes. It helps to consciously identify our relationships. It refreshes our gratitude for the people who are a part of our lives and for the gifts they bring to enrich our lives. Expressing that appreciation is mutually beneficial and gives that person a chance to appreciate you, too. It may be a clear visual of the fact that you wish to cultivate more relationships or re-connect with some that have become distant. You get to decide how you travel on this two way street of your relationships. It really is a two way street and the relationships vary in what they mean to you—the beauty of them is that different people in our lives bring different aspects. The people may appear a bit further out in your visual because your contact is less frequent or your friendship newer. In my own support circle picture (which I re-do on paper every year), I put family, friends, neighbors, co-workers, my spiritual supports, pets, my primary doctor, and even places. All play different roles in my life and vice versa. I wouldn’t expect my longtime, out-of-state friend of over 35 years to provide my healthcare, but in many ways she contributes immeasurably to my well-being. The person who cuts my hair is only occasionally in my life, but I’d don’t want to think about replacing her. It is great to see those folks in your circles all centered on you! I am not in this life alone.

You, the caregiver, can also use (and I mean “use” in the most healthy sense of the word) your support circle to help you identify those who may be there to assist you and your family member. The two circles will have some overlaps but each will also have some distinct relationships, too. Remember they also have a support circle and while there is some overlap, don’t forget the people who may be uniquely their relationships. You can ask for help and the more specific you are, the better results you will receive.

One caregiver who has taught me many things as she has shared her journey has become quite adept at not only recognizing the support circle for her spouse who now has significant memory loss, but also for herself. She has become so good at reaching out for support for herself and for him to ask in very specific ways that are easy for those who are connected to them to respond. Example: she recently experienced her own injury which caused her to be temporarily immobile. She sent an email to some members of her circle to alert them of her injury. They responded with offers to

help and she followed up with specific requests, such as, “Could you come on Monday or Thursday evening to bring dinner and keep us company?” This allowed those who wished to, know how and when to most effectively be of support.

She also has suggested, “He needs to go out on Tuesday from 9:00-noon.” Old and new folks in his circle have responded, giving him needed stimulation, her planned respite, and all have been that much richer for the experience. Engaging those in your circle builds on your meaningful relationships, gives them an opportunity to give to you, in many cases, repay or pay forward kindness, with a mutually beneficial effect.

I’d like to share a quote from a very wise woman, former First Lady, Rosalynn Carter,

“There are four kinds of people in the world: Those who have been caregivers, those who currently are caregivers, those who will be caregivers, and those who will need caregivers.”

That quote has always reminded me that we are all connected in caring. It is not taking advantage of, nor “doing less than” in reaching out to those in our circles of love and support.

Beth Belmore

1/15/16

8/1/15

“Understanding”

I recently came across this quote:

“If we could look into each other’s hearts, and understand the unique challenges each of us faces, I think we would treat each other much more gently, with more love, patience, tolerance, and care.” - Marvin J. Aston

I have a copy of this quote on the door of my office and on my computer as a reminder for me each day at the clinic. I have decided to also put it on the Memory Project website. Normally I write about topics I hope will be helpful to individuals with memory loss and their family caregivers. This topic of understanding could not be more relevant to all who are involved in the Memory Project.

As we have experienced, memory loss is unique as it becomes known and progresses in each person’s life. While there are many shared experiences for those whose memories are progressively changing, there is no one experience. We can love and support them best when we attempt to understand their changes, related feelings, and how they perceive what is happening to them. They may or may not be able to tell us and are sometimes at completely different places in acknowledging the losses. Attempting to think about what it is like to be them and imagining “walking a mile in their shoes,” may give us some additional ability to be supportive of them.

This equally applies to the primary caregiver(s)- those who are in that daily life support circle of a person with memory loss. I can never write, educate, and advocate enough on behalf of the caregivers. Those experiences all encompass unique challenges that need to be heard, understood, and supported. It is hard for anyone who is not there to understand what day to day life in the home is actually like. Recognition of the challenges of the person experiencing the loss does not diminish the importance of the needs of the caregiver. We know you are in this together and it is to everyone’s benefit when caregivers are also given loving, gentle care!

For those who are in the broader circle around those with memory loss, their family and friends, we need to identify and engage ourselves in understanding their unique challenges, withhold our judgments, and find our own ways to be more gentle, loving, patient, tolerant (accepting) and caring.

The Fox Valley Memory Project is working to continue to reach persons who could benefit from the services as well as increase the broader communities’ understanding by continuing to provide educational presentations. The work of the Purple Angel initiative is also expanding understanding for those who will serve those with memory loss and their family and friends. Leadership of the Project also recognizes and is planning for additional ways to reach out and meet the needs of those who may no longer be as easily able to be active in the community and are at home more of the time.

Beth Belmore

8/1/15

5/1/15

“Your Pharmacy/ Your Partner”

There is a saying, “Drugs don’t work in people who don’t take them.” One of your best allies in maintaining optimum health can be your pharmacist. Understanding that relationship and the ways that both you, as the consumer, and the pharmacy can relate results in not only the best service but also increases the chance for better compliance.

There are several factors for your consideration in making the most of your pharmacy relationship. Busy times at pharmacies can mean more people, more noise, feeling rushed, and having less time to interact with the pharmacist. Ask your pharmacy of choice what is the best day of the week, best time of the day, and if your pharmacy has more than one location, if there a less busy, quieter site. Ask if there may be times of the day when there is more than one pharmacist on duty which would allow for more availability to you. Some pharmacies close over the noon hour. This is information you would want to know when either selecting your pharmacy or scheduling your errands.

Consumers may choose to utilize more than one pharmacy for money saving reasons - getting \$4.00 medications can be compelling! When making that choice, take into consideration the care and assistance you may get from using a single provider that has all your up to date information, knows you and the family member who may frequently be involved, and where you can establish a relationship. That relationship will be even more important if/when the family member/caregiver becomes the primary contact with the pharmacist for his/her family member. Pharmacists can be challenged to provide good service if the person does not know what they are requesting and cannot read or doesn’t understand what is on the pill bottle. They receive calls asking for the “little, round, white pill,” or refills for a prescription that was not originally filled at that pharmacy.

Use of one pharmacy also means you are able to ask for and receive one up to date list of all your prescribed medications. You can also request that list include the name of the drug, the dosage, the directions, what it is prescribed for, and a description of its appearance. This list is very helpful to the person or their family caregiver especially if medications have become disorganized or unclear at home. A written description of appearance is also important as pills can change in shape and color. Normally when this happens a sticker is put on the bottle noting the change, but this may not be noticed or legible. Not recognizing it and thinking that this is the wrong pill may lead to confusion and reluctance to take it. Vision loss and cognitive losses are the two leading reasons that people do not take their meds as ordered. Using one pharmacy can also help track when refills are needed and timely. It should be a red flag when a 30 day prescription lasts only 22 days or the opposite when the prescription is lasting too long. Forgetting to take medications or forgetting if you have taken them and then taking more are common errors.

When medications change or a hospitalization occurs, take your list with you and when discharged, the list needs to be updated. A pharmacist suggested that you can bring your hospital discharge papers with medication information to your pharmacy and your doctor to ensure good communication. In addition it is your responsibility to keep any over the counter medications or supplements that are being taken on the list. You can call the pharmacy to schedule a time to review your medications and are encouraged to “brown bag” them, bringing them all in, including your over the counter ones.

Pharmacies can also help in the following ways:

- The “child proof” cap on medication bottles can either act as a needed safety measure or make it too difficult for the intended person to open it. Depending on the need, easy open caps may be requested and usually require a one-time signature assuming responsibility for removing the safety measure.
- Know that you can request a smaller supply than prescribed when trying a new drug, but understanding that you may have the same co-pay. This should be discussed with your doctor as you may need to try different medications for varying periods of time to know if they will be effective for you.
- Co-pays on combination drugs may be higher than if prescribed separately. See if they can be prescribed separately if that is the case.
- Drugs can be bubble packed for those living at home to help with the management of what to take and when.
- Several new services and technologies exist to help with medication management at home if someone needs the assistance. Ask for suggestions.

***Thanks to FVMP Executive Coordinating Committee Member, Dave Morton, for connecting me with some of his staff at Morton Long Term Care. Discussions with them generated many of the ideas in this article.**

Beth Belmore 5/1/15

11/1/14

What is Happening to Me?

Why Assessment and Diagnosis is Beneficial

We all forget things at times. Where are those car keys or my reading glasses? Names of persons, places, and things- those nouns- are sometimes words that are lost to many people as they age. One of the favorite memories in my family is how my grandmother used to run down the entire list of children's and grandchildren's names until she came upon the one for the person she was addressing. It was funny and endearing in our family because she remembered the list. Even as time went on, she was able to continue to generally manage her own everyday life.

When a person or their family members begin to recognize that there may be more happening than simple forgetting of something that will be recalled later, then it becomes a different challenge. Recognition of difficulty with problem solving, completing more complex tasks, poor judgment, putting things in unusual places, getting lost, and forgetting trigger concerns that are alarming. It is not unusual for the person to try to hide that these things are occurring and he/she may become very good at coping with and covering for changes. Well-intentioned family may also begin to compensate for the individual by taking on more of the tasks, communication, driving, decision making, and organizing. Denial, embarrassment, fear, and our hopefulness that it will get better or at least not worsen can prompt these actions. These feelings keep the person from addressing what may be really going on and discovering possible causes. The alarms may begin to go off and the emotional walls begin to go up.

Why is it important to push through these feelings as early as possible to reach out for an assessment and potential diagnosis related to memory loss?

- Stress is being created around the memory loss without identifying the underlying causes that may be able to be treated. Some memory loss is reversible. Some of these causes are related to grief and loss, underactive thyroid, prescription and over the counter medications, lack of vitamin B-12, depression, head injury, and tumors.
- Understanding diagnosis will give you and those around you more time to learn about the illness and begin emotional adjustment to what you now know.
- There are different types of memory disorders. Knowing what it is may give you better information on what to expect and know what may be happening as the disease progresses.
- Interventions such as medication, additional mental stimulation, exercise, and good nutrition may have their greatest benefits if started early.
- You may choose to participate in a clinical trial.
- It allows for you to have time to identify known and trusted individuals in your life. What does your support circle look like? You may purposefully then reach out to that circle for support and develop or strengthen the relationships that you will want or need. This may include your significant other, family members, friends, neighbors, healthcare providers, support programs and services.
- Make the time to have the important conversations with your most significant people about the "what if's" ahead. No one can predict exactly what lies ahead, but you can make your wishes known and help them know what you would want if the time comes that you are no longer able to express yourself. You may be able to get your financial and legal house in order while you are able to make your own decisions. It is truly a gift to those who will be there for you and helping to make decisions.
- You will have some time to think and perhaps act on intentionally leaving your legacy. Are there things you wish to say to particular people? Would you like to record some memories so they will be preserved for your family? Are there special items or possessions you would like to gift?

Voicing your concerns about your own memory loss or that of a family member is a courageous and loving act. I encourage you to open the doors to the information, support, and resources this community has to offer.

Beth Belmore 11/1/14

8/1/14

Balancing Head and Heart: Living a Quality Life

Receiving and living with the diagnosis of any chronic illness signals life adjustments, but particularly when that diagnosis is Alzheimer's or another dementia. The impact affects the person who is diagnosed and ripples out to their family and friends.

One of the most needed supports is access to accurate, understandable information regarding the illness. We want to know what it is, what does it mean in terms of me, and what about the future? Because we have come to rely on medicine's ability to cure, one of the first thoughts expressed to our doctor may be some form of, "How are you going to fix this?" Sometimes it signals a relief in now knowing what we need to face or a confirmation of what has been suspected. Sensing something is not right, but not having answers can be more difficult than the diagnosis for some people. About 6% of persons who responded to a dementia related survey that said if they were faced with a potential dementia diagnosis, it would be easier not to know.

Even when we do know, we may deny the facts for a while. Denial is a strong and protective defense/coping strategy. We may hope the diagnosis is mistaken, that we will get better without having to face this or do anything, or even deny symptoms that are present. If the diagnosis comes later in the progression of the loss, the person may not be able to fully process all the available information, but will still react emotionally. Everyone reacts in their own ways. The diagnosis and subsequent days will be accompanied with a range of emotions and may include: shock, fear, resentment, frustration, loneliness, grief and loss, but also new discovery, joy, gratitude, and meaning. Just like receiving information, not everyone copes with their emotions in the same way. This is normal, but recognizing that it is also important to find a healthy way to express and deal with them.

Gaining knowledge and understanding of the illness is often the key to coming to term with the diagnosis and living a fulfilling life ahead for the person and their families. It allows development of active partnerships with our healthcare and other providers. It provides the substance for good decision making and for looking at what we can do to improve or maintain our own health. Persons with dementia and their families can also share accurate information with others and dispel myths related to cognitive loss. Research confirms that persons who receive diagnoses related to memory loss struggle more with the stigma (than with other illnesses) and that can cause more stress over whom to tell or not tell. As you and your family learn and then educate those in your circle of support, you can help decrease the stigma and increase comfort in facing the changes ahead.

There are lots of sources of information of varying degrees of accuracy and helpfulness: our doctor(s), nurses, pharmacists, family, friends, and neighbors. Add to those the internet, TV medical shows, and print materials. Seeking additional information related to diagnosis, medications, side effects, resources and sources of support, etc. can be very helpful. In a recent survey of those using the internet for medical information, over 60% believed what they found to be accurate and about the same number chose to **not** discuss what they found with their doctors. If what you have found is influencing your care choices, then a discussion with your provider is advised. Have you ever noticed that when people start to talk about their health, everyone has a story either of their own experiences or someone they know? Sharing stories, as discussed in a prior article, can be very healthy. But too much information from others may also be overwhelming, discouraging, or at best, represents only one person's experience. It is good to know your threshold for too much information at one time and it is OK to carefully choose your sources. The decisions that need to be made along the way are best made with the most accurate information about your own or your loved ones' situation along with an awareness/acknowledgement of the feelings surrounding those choices.

Beth Belmore

8/1/14