East End Neuropsych

2539 Middle Country Rd # 4 Centereach NY 11720

P: 631-737-6434 F: 631-738-1226 eastendneuropsych.com

Living With: A Family Member with Dementia

Dementia is a disease that can bring grief to a family if it isn't handled

correctly. There are so many myths circulating about the illness, and many

people do not understand that dementia is a manageable condition. In fact,

many families living with a dementia patient can find some peace and a

little stability. It just takes a clear understanding of what dementia is and

how it can be managed.

First, everyone must realize the dementia is a symptom of another, more

complex disease or disorder. It isn't contagious and you can't just "come

down with it" like a cold. There is always something else that leads to the

dementia.

These conditions include:

Alzheimer's disease

Narrowing blood vessels (vascular dementia)

Head injuries

- Multiple strokes
- Years of alcoholism
- Brain tumors
- Brain infection
- Vitamin B12 deficiency
- Thyroid disease
- Kidney disease
- Liver disease

Some of these conditions only cause a temporary form of dementia that can be overcome with physical therapy, medication and time. Other forms of dementia are degenerative, so they get worse as the years go on. If your loved one suffers from the latter versions, it is best to make their time with you as enjoyable as possible. To do so, you may have to accommodate the dementia sufferer while the disease is still manageable.

Cause of Discomfort

One of the most well-known and daunting parts of caring for a dementia patient is cause by agitation. When the patient becomes agitated, he can display violent and disturbing behavior that is uncharacteristic of your loved one. Caregivers often feel responsible for the behaviors, but the guilt helps no one. The agitation always has a source. Something physical or medical causes the meltdown. It is not personal most of the time.

The most common causes of agitation episodes are:

- Pain and discomfort from sitting in the same position, illness or injury
- Changes in environment or routine
- Overstimulation
- Lack of sleep
- Hunger or thirst
- Loneliness
- Medications that can cause aggression and agitation
- Being too cool or warm
- Impending medical procedures
- Poor communication
- Routine disruptions
- Poor lighting
- Infections, especially urinary tract infections

Anything that takes the dementia patient out of his comfort zone can cause an explosive and sometimes violent episode that the condition is known for. However, careful consideration of the person's routine, medical requirements and social needs can curb many of the problems before they begin.

Avoiding the Meltdowns

As you and the dementia patient get to know one another, start picking up cues to her discomfort. These will be the signs that help you set the meltdown avoidance plan into motion as the disease progresses. When you start to see those cues, check the environment for uncomfortable conditions. Look at the clock, and consider the routine to rule out medication, hunger, thirst or sleep. Adjust the temperatures, provide a little company or get visitors out of the room. As you get to know the disease, you will find that certain things almost always set the patient off, so those are the things you correct first to avoid a meltdown.

If everything is fine, it is time to distract the patient. Use a favorite item or conversation topic. Maybe it's time for an activity like a walk outside-fresh air is great for dementia patients, and exercise can help too-or another favorite activity. Soothing the patient is important if nothing else works. Soft tones, touching or hugs if welcome (approach the person from the front and slowly) or simply talking is sometimes enough to thwart the dreaded meltdown.

When as patient is asking for a loved one who is deceased (spouse, parent, sibling, pet) Do NOT tell them that the person is deceased, it is like hearing it for the first time, every time you tell them. The aim is to pacify. Tell the patient that they are at work, on vacation, comming soon and then go into a distracting activity.

If the person is asking to go home, it is because they are often looking for the home of their youth that they remember. It is best to say you are home and move on. If they do not accept that say "we are on vacation we can go home in another few days" or other deflective terms that tell them their home exists (even if it does not) and getting there is obtainable but not right now.

Communicating Smart

The way you speak with the loved one suffering from dementia also matters. You must avoid confrontation and too many questions coming too rapidly. If you must ask a question, keep the phrasing simple and leave plenty of time for the person to answer. In fact, all of your communication should be simple, loud enough to hear and clearly spoken. Avoid current slang terms, and try to keep the sentences short if the person is easily confused. Always offer reassurance, and be prepared to repeat statements and questions as needed. Engage the person in conversation regularly to help curb loneliness. Be prepared for answers to are not logical or reasonable. This is called confabulations. If the person can not process what is being asked, the brain knows it needs to produce words that sound like an answer, even if that answer is "no" or completely contradictory. The tone that you ask in will be mimicked in their response.

Present only acceptable options. This allows your loved one to have input on their care and activities but any of the options they choose from your list is acceptable. Do not take no for an answer, that is the brains default word when it can not process what is going on, its a protective / defensive measure and not a valid response most of the time.

Finding Support

Everyone touched by dementia in any way will need an outlet to express their frustrations, joys and fears. That is why many medical institutions offer groups for families and patients. Being around other people going through the same thing can help you and the person suffering from the dementia. It will also give you another chance at an activity that everyone can enjoy. If you can't get out of the house, there are Internet chat groups and rooms. Telephone helplines are also available with the support you need to get through the frustration and tips to help as well.

Maintaining the Medicine

A very important part of living with someone with dementia is maintaining medical treatment, appointments and care. Some of the worst parts of the disease can be brought on by other conditions left undiagnosed or complications due to medication. Keep regular appointments with providers and hire home care if needed to keep your loved one in the best shape possible. Good health is one important way to slow the progression of the dementia as well.

Dementia patients are not untouchable people in our society. They are our moms, dads, aunts uncles and children, who are people full of personality. The dementia is just the disease eating away at the brain and not the person carrying it. So, when communicating with and caring for the patient, remember that she is not acting out, the disease is. Once you have an understanding of what is really going on in your loved one's body, you can help gather and provide the care needed to make that person's life a rich and vital one.

View Resources

- Ncbi.nlm.nih.gov Priorities for people living with dementia: education, counseling, research
- Alzheimers.gov For the people helping people with Alzheimer's
- DH.gov.uk Dementia
- Health.gov.au Know the Signs of Dementia
- Agedcareaustralia.gov.au Help for people living with dementia