

Elder Services has published the Q&A Column in local newspapers across the Merrimack Valley for over 10 years. If you have a question or a concern about caring for a family member or an elder in your community, send Rosanne DiStefano, Executive Director an e-mail at Ro@esmv.org.

Question:

When my father was a young man he always looked like a walking advertisement for an exclusive menswear boutique. I remember how proud I was to be his daughter. Since his physical health deteriorated and with a recent decline in his cognitive functioning he has started ignoring his hygiene. I can't convince him to bathe and he wants to wear the same clothes everyday. What can I do?

Answer:

Grooming affects a person's dignity as well as the attitude of anyone around them. Poor hygiene is not only offensive but can negatively impact health conditions. Your father's attitude toward bathing is somewhat commonplace for individuals with dementia. This may not be of any comfort to you but at least it explains the changes in his behavior.

When the most basic task results in a *battle of the wills* it may seem easier to just give in rather than continue the struggle. The trick is to find a smarter, better way to handle the situation. Adapt to the challenge rather than letting the situation become unmanageable.

The goal is to get through the bathing ritual with minimum disruption for the person and the caregiver. Try and figure out what factors are creating the most disharmonies. You may be trying to schedule baths in the morning but your parent has always bathed at night before going to bed. Many of us are creatures of habit, something as simple as a change in our routine can make us feel uncomfortable or resistant.

Some of us are more fastidious than others and can't imagine not wanting to take a bath at least once a day. Your father may do just fine with sponge bathing as opposed to a complete bath a couple of days a week. Be careful not to inflict your own values on your father...this is more of an issue for you than it is for him.

A simple suggestion has been given to other family members caring for someone with dementia. If the person is obsessed about wearing the same outfit everyday, try purchasing duplicate sets of clothing. This will allow you to wash the dirty clothes while they will believe they have on their favorite outfit.

Depending on your father's level of functioning encourage him to do as much as he can for himself. Caregivers sometimes unwittingly takeover without realizing the elder is still capable of doing some tasks on their own.

Create a comfortable environment to encourage your father to maintain a certain standard of cleanliness. It may not be what he was used to but hopefully it will be sufficient. Make sure the water temperature is comfortable and install a heat lamp overhead if the

bathroom tends to be chilly. The ultimate outcome is to set a stage for a more positive experience for both of you.

Question:

One of my family members is in an area nursing home. I am frustrated, disillusioned and angry in regards to communication with staff at the facility. When he was first admitted we were hoping it would be for short term rehabilitation and then he would resume living in his own home. Unfortunately his physician recently told us it isn't realistic to believe he will ever be able to return to the community. All of my complaints or requests are totally ignored by those in charge of his care at the facility. What can I do to try and improve the situation?

Answer:

Good communication is the key to all successful relationships, some people are better at this than others. When effective communication starts to deteriorate a host of other problems soon follow. You clearly are not in a good situation with the management staff and caregivers at this facility. The fault may be yours, theirs or a combination of both. Laying the blame is not going to get you very far so the challenge remains in how to handle the situation.

Advocacy is a very important component of receiving the best of health care in today's environment. Not everyone is comfortable in this role, understands how to plead their case or in some instances even realizes this is something they should be doing. If an individual or family member senses their concerns are being ignored and they are not making any progress it is certainly appropriate to request the facility social worker to act as an intermediary. While the social worker is on staff at the facility they also have an obligation to act in the best interests of each and every resident. The social worker can be a liaison between the family/resident and facility management; clearly identify concerns regarding quality of care and help to resolve these issues by suggesting resolutions. Hopefully in most instances this will be a harmonious approach for everyone involved.

If after making additional efforts the situation does not improve you always have the option of contacting the local Ombudsman Program and taking your complaints to the next level. Every nursing home in the state is covered by Ombudsman Program staff at the Area Agency on Aging or someone in a non-paid position who has been trained and certified. Ombudsman volunteers serve as a link between the resident and administration of the facility. Their goal is to resolve problems and concerns always in the role of an advocate for residents of long term care facilities. If it is determined the situation can not be resolved and their concerns are related to violations of a much more serious level reports may need to be made to the Department of Public Health.

The caregiver's role does not end when the family member or friend is placed in a care facility. The responsibilities may no longer include hands on care or physical tasks but

definitely include a continuation of oversight of your relative's well being. Strong advocates help to keep the balance in this industry and insure the rights of residents.

Question:

My mother has been taking care of my father for the last five years after he suffered a debilitating stroke. She is very devoted to him and never complains. I've noticed she is looking rather frail herself due to weight loss and not getting enough sleep at night. I have called a couple of times to check on them and she sounded like she had been crying but when I ask her what is wrong she denies there is any problem. I am worried she can't keep this pace up much longer. What suggestions do you have?

Answer:

From what you described it appears your mother has been trying to shoulder all the responsibilities of your father's care completely on her own. This is a red flag and the first area to address. While your mother's devotion is admirable it isn't necessarily a recipe for successful caregiving. It is certainly appropriate for your mother to continue as the primary caregiver and decision maker but it would be in her best interests and your father's to occasionally bring in outside assistance. A home health aide to help with his bathing or a homemaker to handle some of the household chores would allow your mother to occasionally take a break.

You possibly may meet with some resistance if you suggest support from outside sources so be prepared. If your mother's health deteriorates the chances of being able to keep your father at home will be drastically reduced. Emphasize the importance of reducing the emotional and physical stress she has been under which would allow her to continue in her caregiving role. She may or may not even be consciously aware of the strain she has been under. In some instances caregivers need to almost be provided permission to relinquish some of their responsibilities. Most importantly your mother must be told accepting outside assistance is not an indication she has failed as a caregiver.

Look into what options exist in their town. Your father may qualify for skilled services under his Medicare benefit; his primary physician can make a referral to a certified agency for assessment. Find out what resources are available for in-home care that is more custodial in nature. Respite care services would allow your mother to take time off to relax, run errands or focus on her own needs.

It also sounds like your mother would be perfect for a caregiver support group. Her episodes of crying could be indicative of depression or exhaustion, whichever the cause it might be very cathartic for her to meet with other caregivers who are facing similar challenges. It would be perfectly natural for your mother to be struggling with the painful reality of your father's deterioration. It is difficult to watch someone you love slowly fade away and you have no control over the final outcome.

Question:

I am still living at home with my parents and grandmother while I finish my last year of college. My grandmother started showing signs of confusion a couple of years ago and is getting worse lately. She has wandered out of the house twice in the last month yet my mother refuses to accept this is a problem. I am worried something is going to have to be done if my family doesn't make some changes. Do you have any suggestions?

Answer:

Family members caring for someone with Alzheimer's disease or a related dementia frequently encounter obstacles in keeping their loved one at home safe and sound. People even with the best of intentions don't always take the necessary steps to reduce risks because they don't know what to do, what to expect or perhaps on some level they are still in denial.

Wandering is a serious concern and requires immediate action. Your grandmother may not have gone far the two times she left the house but there is no way of predicting what will happen during her next adventure out into the wilderness. It is highly probable there will be a next time. Your family needs to understand she may be walking around a neighborhood she has lived in her entire adult life but with her present cognitive decline the area is essentially uncharted territory. She may no longer have the capacity to recognize her surroundings and know how to return home. This puts the responsibility of keeping her safe entirely on her primary caregivers; it is both a moral and legal responsibility that cannot be ignored.

The first step would be to reassess the locks on all doors in the home. It may be advisable to have slide bolt locks installed either at the very top or bottom of the doors, your grandmother most likely won't even be able to figure out additional locks have been added. Another helpful idea is to hang a bell on the doorknob or above the door to alert others in the household if she attempts to open the door on her own. Some people have even found it helpful to put a stop sign on the door or have hung a curtain over the door.

Register your grandmother with the Safe Return program developed by the Alzheimer's Association specifically for those individuals who wander. The identification bracelet and the network agencies notified if she should go missing might be a critical factor in her being found safe and sound. Some local police departments will keep current pictures on file of local residents who have a tendency to wander away from home or even have their own registry in operation.

It might also be a good idea to consider attaching a device to the bed which would go off if she got up during the night, anyone who is a heavy sleeper might not even be aware if she got up otherwise. Other families have found taking an elder for a walk in the early afternoon diminished some of the restless symptoms and frustrations of being confined to the house. Consult your local Alzheimer's Association for additional information regarding changes in behavior.

Question:

My parents called the other evening and asked if I could come over soon and review information they received in the mail regarding their prescription drug coverage. I helped them sign up for a Medicare Part D plan last year when they both became eligible for Medicare. Are they confused or is this really something they need to do again?

Answer:

Your parents were actually right on target about calling and asking for your help, November 15th through December 31st is the annual open enrollment for Medicare D. Together with your assistance they may have enrolled in the best plan to meet their individuals needs but that does not necessarily mean that plan continues to be their best option. Every fall Medicare beneficiaries should review plans available to make a decision about prescription drug coverage for the coming calendar year.

When you meet with your parents carefully read all correspondence they have recently received. This is the time of year providers will be notifying their customers of any changes taking place with the plans they will be offering in 2010. First of all pay special attention to the premium fees and coverage limitations. Next closely evaluate the formulary associated with the Medicare Part D plan; this is the list of drugs covered by the specific plan. Formularies vary from plan to plan and actually may change from year to year. It is impossible to predict what prescriptions someone may be taking a year from now. The best way to approach this is to choose a plan that covers all drugs your parents are currently taking.

Couples should review all this information as individuals. The plan that best meets your father's needs may not be the best plan for your mother. Do not choose a plan based on the company providing the coverage. In previous years people have signed up for a Part D plan solely due to name recognition only later to discover the coverage was not adequate.

Anyone who has access to the internet can log on to www.medicare.gov and find the screening tool for locating two or three plans that would provide the highest level of coverage based on their medications. Medicare beneficiaries can also make an appointment with a SHINE counselor to receive assistance in making a determination about a plan for the coming year. SHINE counselors located at area senior centers are all certified by CMS and thoroughly knowledgeable of this process. To locate a counselor near you call the AgeInfo Department at Elder Services of the Merrimack Valley 1-800-892-0890. Similar programs are available in neighboring states although the name may differ.

Question:

My father passed away a little over a year ago and last month my mother died very suddenly. My siblings and I always had a close relationship with our parents so I was a little surprised when one of my sisters showed almost no emotion at the funeral home. I cried for days and am still having difficulty accepting that both my parents are gone. Now

I am feeling resentful but don't know how to approach my sister about her aloof attitude. How should I handle this?

Answer:

Grief is a complicated emotion, one that does not have clear boundaries or time frame. People grieve in different ways based on their own individual personalities, relationship with the deceased, circumstances of the death and environmental factors. There is no "right" way to mourn and in some instances a person may not have control over the depth of their grief.

You may be someone who easily responds to stimuli that evokes feelings of sadness, disappointment, and raw grief. You may be so in touch with your emotions that you are comfortable in displaying how you truly feel. Other members of your family may be experiencing grief with the same intensity but they intentionally or unintentionally keep those feelings buried deep inside and see no point in exposing painful emotions to those around them. People may choose to grieve privately, rarely if ever in the presence of others. Just because you are more demonstrative in the grieving process does not necessarily prove your feelings were deeper and more real for your mother than your sister's were.

Your sister may still be in denial to some extent since your mother's death was totally unexpected. She may need a little more time to come to terms with this latest tragedy in your family. The fact that your father passed away in the last year may have had such an impact on her she wasn't ready to handle more grief. This is all speculation and may remain an unknown until the time your sister is ready to openly talk with you about your mother's death.

It is unfair to judge the extent of your sister's grief merely in relation to an outward display of emotion. Show her a little understanding and give her time before even thinking of introducing the subject. Hopefully the two of you will get to a place where you can openly talk about your parents, recount stories of your youth and share your feelings in a healing way.

Question:

My husband and I are in our sixties but not what I would consider "old". We have spent a lot of time talking about what we would do when we both retired and had so much to look forward to. He has had recent health problems which have led to episodes of slight confusion and unsteadiness on his feet. Lately I have been short tempered and my husband tells me he feels like I am blaming him for his disabilities. How do I deal with the changes in our life?

Answer:

Your husband's health status change has obviously impacted your relationship in numerous ways. The fact you are asking for guidance indicates at some level you realize this is as much your issue as it is his. You may not be able to control the changes taking place in his body but you can take charge of how you respond to his health.

First of all it would be unfair and most likely way out in left field to blame your husband for the changes taking place within him. Unless the new diagnosis was a result of drug or alcohol use, or some other unacceptable reckless behavior your husband is not at fault. There are times no matter how healthy of a lifestyle someone leads cancer, heart disease, diabetes or some other devastating condition becomes invasive. Your husband certainly did not ask to become ill so he should not assume responsibility.

Look in the mirror and be honest about your own feelings. It would be perfectly understandable if you were disappointed the future was not going to be the one of your dreams. No one would blame you if you even struggled with depression. Most likely there is a part of you that is frightened about what could happen next. No one ever wants to see someone they love and cherish decline physically or cognitively. Your age leaves you unprepared for this downward spiral, you might have expected this in twenty years but not now.

Odds are the two of you are reacting to the emotions of your husband's health as opposed to putting together a plan or strategy to deal with the changes. You need to openly talk with each other and express how you are feeling. There is no excuse for your short temper or verbal abuse, finding a way to channel and handle your emotions must be a priority. Instead of supporting each other through this crisis you are running the risk of driving a bigger wedge between yourselves.