WHEN THE UNEXPECTED HAPPENS

When we start considering the concept of aging, we realize that there are many perceptions of what aging is or isn’t. There are many thoughts on what aging should be – growing older with a spouse, continuing to live in one’s own home and driving, staying physically active, keeping one’s health, continuing to be mentally alert, continuing to do the activities and things you love to do – such as continuing your role in your church.

Everything can change in a heartbeat when an individual and the family receive a diagnosis of dementia, whether it is Alzheimer’s Disease, Pick’s Disease, Vascular Dementia or one of the many other causes of dementia. There can be an immediate sense of loss, fear, worry and confusion. There can be a sense of disbelief, followed by all of the stages of grief as described by Kubler-Ross – denial and/or isolation, anger, bargaining, depression, and finally, acceptance. Many people describe their experiences more like that of a roller coaster, especially when the loss is not a death, and must be dealt with over a slow period of decline with varying symptoms.

It is not unusual for us to ask “Why me?” or “Why my loved one?”. Whenever we reach a new phase in our lives, it is a time of adjustment. It is the same with such a diagnosis – a major time of adjustment. There can be a sense of wanting to get control over the challenges before us. As believers, our faith tradition defines how we live our lives. Our faith can define how we approach a dementia diagnosis and how we cope. Getting a new diagnosis for any chronic illness can be a struggle; there are the emotions to deal with, the constant need to ask ‘what next?’. We must reach out to our faith community, the home church, and let them offer support. The spiritual aspects of our lives do not go away as a disease progresses. The spiritual connection needs to be maintained. Families dealing with...
dementia can give direction to the church family on how they can offer assistance and support. Some families need the church congregation to provide support.

God can give us victory over the challenges we are facing. As the disease progresses, there can be comfort in scriptures, prayer and music for the person with dementia. These are tools that we can use to make an emotional, spiritual connection with the person with dementia. This helps the person with dementia maintain a sense of identity, drawing on strengths and emotions, reaching him or her on several levels. Scripture is something that we have read and heard throughout our faith journeys. Relying on old memories, familiar scriptures can recall old feelings of comfort, well-being and belonging for someone with dementia. When new memories cannot be made, drawing from the strength of old memories can bring that link and connection for the person with dementia. The use of familiar prayers and the process of prayer itself can bring a sense of belonging and comfort.

Likewise, music, including hymns, can also recall old emotions and memories. Music is in an area of the brain that is separate from language; someone with dementia may be able to sing after losing the ability to speak. As a result, this is an excellent way to foster communication and make an emotional connection, again bringing a sense of comfort to the person with dementia as well as the family members.

How do we offer assistance to individuals and their families as they address such a diagnosis? Don’t assume that all roles and tasks around the church must be taken away from someone diagnosed with dementia. Abilities vary and the decline can be gradual. As someone copes with these changes in his/her life, it is important to help that person maintain a sense of self and self-worth. This can be done by maintaining a connection with the church. In one Church of the Brethren congregation the choir and song leader developed Alzheimer’s disease. It was evident as she lost her place in hymns that she was having difficulty. As she progressed in this journey she would sometimes forget that she had given up the job as song leader. This could have become a major issue – “the service was disrupted”, “we aren’t keeping place”, “we only sang two verses of the hymn”. Instead of complaining the congregation let her continue. If she went forward to lead, no one stopped her. The new song leader simply did not go forward to lead. She still had a wonderful voice and could praise God with her gift. She would lead and sing. If only two verses were sung, it was still a celebration. The congregation let her maintain her dignity and the spiritual connection while they rejoiced in the gifts that she could share.
It takes a new way of looking at how we include all of God’s children in worship, and how we use the talents that they have. Does it follow an orderly service pattern? Maybe not, but as we look at Jesus’ example to us, is that the focus He would have us dwell on? We have to look at new ways to help our members cope and how we support them in their spiritual journeys. In the process we may make new spiritual connections for ourselves. Who is to say that the person with dementia is not closer to God than those of us who are supposedly cognitively intact? The following quote from Rabbi Abraham Heschel, from the 1971 White House Conference on Aging, reminds us that it is being in the “moment” that we are one with the spirit of God:

“Older adults need a vision, not only recreation,
Older adults need a dream, not only a memory.
It takes three things to attain a sense of significant being:
   GOD,
   A SOUL,
   and A MOMENT.
And the three are always there.
   Just to BE is a blessing,
   Just to LIVE is holy.”

We must be careful that we do not give the impression that this journey is easy, for it is not. We should never say to someone that “God never gives someone more that they can handle.” While the intent is to say that God is there with us on this journey and we do not have to do it alone, this phrase has put undue burden on people as they try to deal with difficult situations. It can cause people to test their own faith and doubt, at a time when they are overburdened with just getting from one day to the next. To help someone cope with these challenges, we must look at how we communicate and how we provide support.