



Support Groups for People with a Diagnosis of Alzheimer's or Other Dementia

by Sharon L Stokes



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When diagnosed with a chronic illness of any type, lives get turned upside down. Needs, plans and dreams change immediately with the utterance, "You have Alzheimer's disease." Emotions may be all over the place for the person with diagnosis and the family/friend unit. A valuable tool for many in dealing with the stress of diagnosis is joining a support group. While support groups are helpful for carepartners, they are equally important for the person with diagnosis.

Think of it: You have just been told that you have a disease that will begin to take "you" away from those who love you; memories will begin to fade; names of loved ones will get lost; your life is not your own And Yes – you are angry, scared and devastated. What do you do with these feelings? How do you learn to live well with this disease? How do you find that you are not alone?

Join a support group!!

With diagnosing Alzheimer's disease and other dementia earlier and earlier, Early Stage Support Groups have been found to be very helpful for persons with diagnosis. Some of the benefits include:

- Meeting others with diagnosis and realizing you are not alone
- Recognizing emotional needs
- Learning about the disease and resources available
- Strategic planning for future needs
- Learning how to maximize and maintain abilities (social)

Meeting Others

No doubt, a dementia diagnosis is frightening and discouraging. Realizing you are not alone is often helpful. Sharing with or simply listening sometimes helps one gain perspective. One early stage support group member put it this way: "When I come to support group, I see my friends now. I share with people that understand when I forget words or what I'm saying ... my friends support me through these times with patience, smiles and



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knowing nods. Other people are often impatient with me.” Indeed, meeting others and talking about coping skills as this disease progresses becomes critical.

Emotional Needs

At this confusing, life-altering time, it is important for the person with diagnosis to be heard and to recognize the many feelings or emotional needs – yes, even men!! A full spectrum of emotions awaits each individual at varying degrees:

- Grief (Stage of Grief: denial, anger, bargaining, sorrow, acceptance)
- Self-doubt
- Self-esteem
- Loss of control
- Fear and depression over continued loss
- Search for dignity of self

It helps to look at the discussion of these and other emotions as sharing your heart. You matter!! You need to be heard! One participant shared getting lost while out on a walk in her neighborhood of 40 years. She was afraid and doubted herself. The group supported her with suggestions to be safe and maybe have a walking buddy. Nothing like support from people that live the same challenges!!

Learning About Disease and Resources

While just about anything can be researched online, the best source for information is your local Alzheimer's Association (www.alz.org). The Association has the latest on research, resources available, education for all and many even offer a series of social engagement activities. Carepartners and persons with diagnosis quickly understand that it is important to stay active and connected. Isolation should never be the option!



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Strategic Planning

Since lives are turned upside down, it's critical to do legal and financial planning together while the person with diagnosis can still be a part of the plan. Many find it helpful to work with an elder law attorney. The Alzheimer's Association often has lists for various areas of need including lawyers, consultants helpful with Medicaid, VA needs, long-term care planning, in-home care and care communities. Plan sooner rather than later!

Maximizing and Maintaining Abilities

There is nothing better than feeling valued!! Support groups often bring out that can do spirit as participants share how they accomplish tasks, keep their minds active, stay active physically ... the accolades from peers in the groups mean the world!! As the disease progresses, the support group may take on a slightly different role of social support and encouragement. A professional facilitator can recognize these transitions and support the group in a positive way. Remember: It's not necessarily what you say to someone, it's how you make someone feel!



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