



What Happens Next?

A booklet about being diagnosed with
Alzheimer's disease or a related disorder



Created for you by others with a diagnosis of dementia



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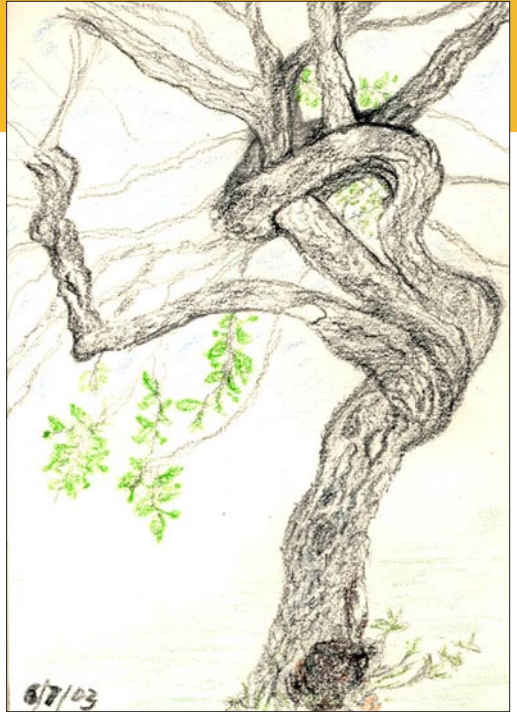
Flowers Illustration by Syd

Introduction

As Americans live longer, more of us will develop dementia in our older years. New knowledge and techniques are helping doctors detect signs of the disease earlier than ever before. An earlier diagnosis gives people with the disease and their families more time to get the right treatment and to plan for the future.

More and more resources are available to help people with early-stage dementia cope with their feelings and the practical aspects of everyday life. Early-stage support groups are one of these resources. Joining an early-stage support group can help you and your family learn about the disease and get useful advice about living with dementia. A support group also can connect you with others in similar situations and enable you to confront the anxiety, sadness, anger, or fear that you might be experiencing.

This booklet was developed by the early-stage support group at the Northwestern University Alzheimer's Disease Center in Chicago. The authors chose to share their thoughts and feelings because they wanted to help others who also are facing the beginning stages of dementia. Here, you'll find firsthand views about a diagnosis, what to expect, how to talk with others about the disease, and more. You'll also find a list of helpful organizations that offer written materials about dementia, information about support groups and services, and ways to get involved in research that may help others in the future.



Tree Illustration by Jenny

Introduction *(continued)*

Our goal in publishing this booklet is to offer encouragement to those who have been diagnosed with early-stage dementia and to let you know that you are not alone. We also hope to help empower you to stay active in your care and decision making, just as the support group members quoted here have done. Finally, we encourage you to try to keep a positive outlook and to stay engaged in family and social activities, hobbies and pastimes, and creative interests that you can continue to enjoy. In doing so, you can take an active role in making the years ahead as rich and fulfilling as possible, despite the challenges.

How We Reacted to Our Diagnosis

Everybody is unique, and this news has different meanings for everyone. These are some of our first reactions, and some advice about how to deal with the news:



“The first thing you should know is that it’s not that bad. Everybody thinks it’s horrible, but it’s not that bad.” - *Les*

“I got the diagnosis and I thought I was going to die, then I thought I might not.” - *Les*

“Not being sure of my diagnosis... I was so scared.... I didn’t know which way to go.” - *Evelyn*

“Dementia... I hate that term.” - *Elizabeth*

“Don’t overreact. Get support. Try to avoid getting sick with worry.” - *Elizabeth*

“This is a major attack on your confidence. You think ‘*This isn’t fair, why me?*’ It helps to talk to others who are going through the same thing—to understand how they are experiencing it.” - *Gerrit*

“So you have Alzheimer’s. Let’s talk about it.” - *Les*

Limitations

There's no denying it, dementia—even in its early stages—is going to stop you from doing certain things. This is how we felt:



“Some of the simple things I used to do in the past, I just can’t do.” - *Gerrit*

“I want to do something and I can’t. I want something I can do.” - *Evelyn*

“Sometimes it’s good to forget about what limits you and find something else to do.” - *Les*

“My golf game is gone, mostly because of physical limitations.” - *Gerrit*

“I used to run 3 or 4 times a week and now I can’t. I miss it. The legs just aren’t what they used to be.” - *Al*

“Being told you should not drive is the first thing everyone thinks is terrible.” - *Les*

Fighting Spirit

Many of us feel that keeping up a fight and staying hopeful helps us to cope and stops the disease from slowing us down as much as it could:



“I’m fighting it [accepting my diagnosis]. Deep down I know I’m wrong but I’m still fighting it.” - *Al*

“You can keep fighting it.” - *Les*

“That doesn’t mean I’m going to win.” - *Al*

“If you can’t cope with it, you’re going to be depressed. You have to keep positive, or you’re going to be crawling under the covers.” - *Elizabeth*

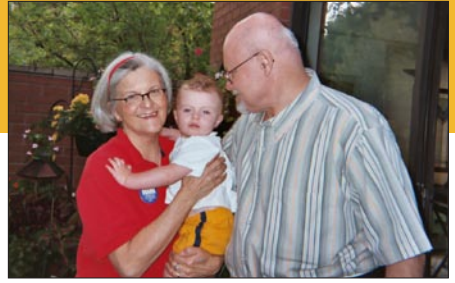
“I test myself to make sure I can still do things right. I pass, I funk. But I’m fighting it.” - *Al*

“You either face it and fight it, or give up.” - *Al*

“It may be an uphill climb but you just do it anyways.” - *Elizabeth*

“We are all early-stage and we are all going to be late-stage, but I’m not going to moan and groan on the way there. You have to live your life.” - *Sydnee*

Ways to Cope



Being diagnosed with dementia will create some changes. These are some of the ways that we cope:

“I’ve absorbed my diagnosis into part of who I am. It’s not as important to me now that I’ve come to terms with it. Getting over that hurdle is the hardest part.” - *Jenny*

“Changes happen. They can be good changes. I was never a helping person, now I have learned to help others.” - *Les*

“Laughter is the best medicine.” - *Jenny*

“I find that keeping busy is terribly important. You have to keep looking forward.” - *Jenny*

“I’m still me with kinks.” - *Joan*

“After all, a kink is just a twist. It’s not a horrendous thing.” - *Jenny*

“I have found it extremely positive to find out as much as I can about others who are affected.” - *Jenny*

“I’m going to have to make the best of this, and that’s what I’m doing.” - *Elizabeth*

“Activity is the best thing.” - *Les*

More on coping:

Some of the activities that we do to help us relax and get a break from stress include:

- Gardening
- Spending time with pets
- Going out with friends and family
- Volunteering
- Getting fresh air and exercise
- Listening to music

How to Tell Family and Friends



Once you've gotten used to the idea of your diagnosis, you may want to start letting those close to you know. This can be difficult. Here are some of our thoughts:

"I've been selective in letting people know. Certain people will not do the right thing with the information. Some people don't know how to talk to you anymore. They are afraid of the 'weird things' that may happen to you. It's a problem. But certainly my direct family and friends know. You get all sorts of questions. Your kids have a very healthy way of looking at it. They know you have to cope. I don't know if my grandchildren know. I left that up to my daughters." - *Gerrit*

"They recognize that I have some kind of disease. They are very understanding and accepting." - *Les*

"Denial keeps you from telling many people. Being part of the support group has helped me become more comfortable and talk about my diagnosis. Some of my friends still don't believe me because I don't fit into their idea of what AD looks like. They don't think there's anything wrong with me." - *Gerrit*

"It took me a while to tell people because I was in denial. But then I wanted to start helping people with the diagnosis, so I started talking about my diagnosis more." - *Les*

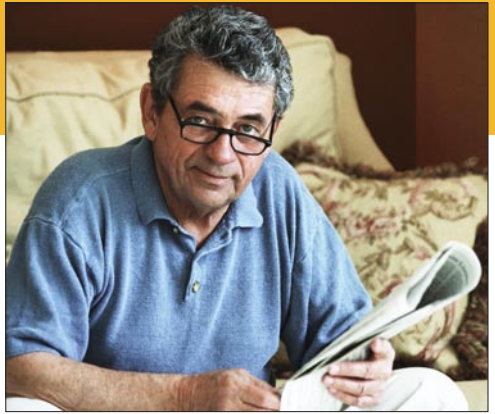
"I've stopped telling people if it's not necessary." - *Gerrit*

"The people you tell first are the ones you've shared a lot with. If you don't know them well, then why would you talk about it?" - *Elizabeth*

"There are people I don't see often. They don't see me change." - *Gerrit*

What to Expect

It's difficult to predict how you may feel after you hear about your diagnosis:



“After a while it mellows. After a point it doesn’t

bother me. You realize you can live for quite a while and that you can have a decent life.” - *Les*

“Depression, it’s ok to feel this in the beginning.” - *Les*

“You are going to be shaken out of your boots.” - *Elizabeth*

“It’s not uncommon to go into denial.” - *Elizabeth*

“There’s nothing wrong with being angry sometimes.” - *Elizabeth*

“This is a major attack on your confidence. You think ‘This isn’t fair! Why me?’ It helps to talk to others who are going through the same thing to understand how they are experiencing it.” - *Gerrit*

“You still have a fairly long life. Let’s do something fun about it!” - *Les*

“Since my diagnosis, I want to help others more.” - *Les*

Our Experience with Doctors

Your relationship with your doctor is very important. Here are some of our experiences:

“They often go too fast so I try and ask them to slow down.” - *Les*

“I am very satisfied with my doctor. He speaks everybody’s language and takes time to meet with me.” - *Gerrit*

“I have a very good team of doctors and it’s worked out well.” - *Sydney*

“I have a partner who has the courage to ask the questions that need to be asked.” - *Gerrit*

“I make the doctor tell me everything I need to know. I won’t let him leave before I’m done.” - *Les*

“I go into my doctor visit prepared with things to discuss.” - *Sydney*

“I trust my doctor so I am willing to take his advice about medication and treatment.” - *Gerrit*



More about doctor visits:

Taking a family member or friend with you when you visit the doctor can help you feel more confident. He or she can help remind you about things you planned to ask and help you remember what the doctor says.

Your relative or friend may also want to discuss things with your doctor, such as:

- *What to expect in the future*
- *Sources of information and community services*
- *How to maintain their own well-being*

For More Information

To learn about support groups, services, research centers, clinical trials, and publications about AD, contact the following:



Beach Illustration by Syd

Alzheimer's Disease Education and Referral (ADEAR) Center

P.O. Box 8250
Silver Spring, MD 20907-8250
800-438-4380 (toll-free)
www.nia.nih.gov/Alzheimers

A service of the National Institute on Aging, the ADEAR Center offers information and publications for families, caregivers, and professionals on diagnosis, treatment, patient care, caregiver needs, long-term care, education and training, and research related to AD. Staff members answer telephone, email, and written requests and make referrals to local and national resources. The ADEAR website offers free, online publications in English and Spanish; email alert and online *Connections* newsletter subscriptions; an AD clinical trials database; the AD Library database; and more.

Alzheimer's Association

225 North Michigan Avenue, Suite 1700
Chicago, IL 60601-7633
800-272-3900 (toll-free)
www.alz.org

This nonprofit association supports families and caregivers of patients with Alzheimer's disease and funds research. Chapters nationwide provide referrals to local resources and services and sponsor support groups and educational programs.

Children of Aging Parents

P.O. Box 167
Richboro, PA 18954
800-227-7294 (toll-free)
www.caps4caregivers.org

This nonprofit group provides information, referrals, publications, and conferences for adult children caring for their older parents. Caregivers of people with Alzheimer's disease also may find these resources helpful.

Eldercare Locator

800-677-1116 (toll-free)
www.eldercare.gov

This service of the U.S. Administration on Aging provides information and referrals to help older people and their caregivers locate local support and services.

Family Caregiver Alliance

180 Montgomery Street, Suite 1100
San Francisco, CA 94104
800-445-8106 (toll-free)
www.caregiver.org

Family Caregiver Alliance is a nonprofit organization that offers support services and information for people caring for adults with AD, stroke, traumatic brain injuries, and other cognitive disorders.

For More Information *(continued)*

National Institute on Aging Information Center

P.O. Box 8057
Gaithersburg, MD 20898-8057
800-222-2225 (toll-free)
800-222-4225 (TTY/toll-free)
www.nia.nih.gov

To sign up for regular email alerts about new publications and other information from the NIA, go to www.nia.nih.gov/HealthInformation.

Visit [NIHSeniorHealth \(www.NIHSeniorHealth.gov\)](http://NIHSeniorHealth.gov), a senior-friendly website from the National Institute on Aging and the National Library of Medicine. This website has health information for older adults. Special features make it simple to use.

This publication lists non-federal resources in order to provide additional information to consumers. The views and content in these resources have not been formally approved by the U.S. Department of Health and Human Services (DHHS). Listing these resources is not an endorsement by HHS or its components.

Acknowledgements

Members of the Northwestern University Alzheimer's Disease Center Early-Stage Support Group meet regularly to provide each other with support, companionship, and new ideas for coping with the changes they are experiencing. Their desire to help others led them to share their experiences and create this project. We are grateful for their courage, honesty, and contributions of photographs and artwork.

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Les's Garden



Elizabeth's Garden



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