

Sharing a Dementia Diagnosis with Family and Friends

Presented by

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THE STATE OF MIND

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Alzheimer's Texas

A privately funded voluntary health organization formed in 1982 to serve Central Texans with Alzheimer's disease and their caregivers.

MISSION

To eliminate Alzheimer's disease and related disorders through the advancement of research and to enhance care and support for individuals, their families, and caregivers.

VISION

To create and sustain a dementia capable Texas in which persons with Alzheimer's and related disorders, and their families, receive quality care, effective treatments, and meaningful support.



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Learning Objectives

- Understand stressors and factors to consider before sharing a dementia diagnosis with family members and friends.
- Identify validating and meaningful ways for both people living with dementia and their loved ones to share a dementia diagnosis with others.
- Learn how to address potential challenges that might arise when sharing a dementia diagnosis.
- Think about and share ways we can apply and educate others about this process.



The Diagnosis Experience

- Receiving any medical diagnosis is a shock, and the person being diagnosed and the people in their support system can feel anger, fear, confusion, and/or denial. Receiving the diagnosis of dementia is no different.
- Many questions and emotions arise for both the person who receives the diagnosis and their social support system/loved ones. When should I tell others about my diagnosis? How much should I share? What will other people think?
- Often, the person receiving the diagnosis feels vulnerable and in need of reassurance and support. They usually look to the closest people to them, family and friends.
- There is no “correct” way to feel when hearing the news of being diagnosed with dementia. Everybody feels and reacts differently, both emotionally and in the processing of the information.
- It’s a very individual and a personal decision to make about who to share this information with and when. There is no right or wrong way.
- Some people might want time to adjust and come to terms with the diagnosis before telling other people. Alternatively, some people might have a reason to tell people more quickly to receive support and/or make plans for care needs.
- Some people living with dementia and/or their family members may even feel a sense of relief at receiving a diagnosis and understanding more about symptoms they have been experiencing or noticing.

Responses to a Diagnosis

- Like the person being diagnosed, family and friends might have reactions including fear, anger, or relief that there is an explanation for symptoms.
- Family and friends may react with denial, or with comments or behavior that reflect their misconceptions about dementia. "But you seem to be fine" or "You're too young to have dementia."
- Stigma or misconceptions about dementia may exist due to a lack of information. These reactions reflect the person's need for more time and/or education before they can respond in helpful ways.
- Family or friends may need time to process this news so everyone can move forward together in a positive way.

When and How to Share:

Important Considerations for the Person Receiving the Diagnosis and Their Loved Ones

- ✓ There are no hard and fast rules regarding how to tell friends and family.
- ✓ No one should feel rushed. Some people chose to not tell anyone about their dementia diagnosis for many months, some people tell others gradually as they see them, and others tell everyone right away.
- ✓ “Who should I tell first?” It can be helpful for the person to start by telling the people they feel closest to.
- ✓ “How do I wish to share the diagnosis?” Many people chose to tell people face to face, by phone, or virtually. Some people choose to share the news in letters, email, or social media.
- ✓ Some people might ask someone close to them to share the news if they don’t want to have a potentially difficult conversation themselves.
- ✓ **The person living with dementia should be in control of who they share their diagnosis with, how they tell them, and when they tell them.**

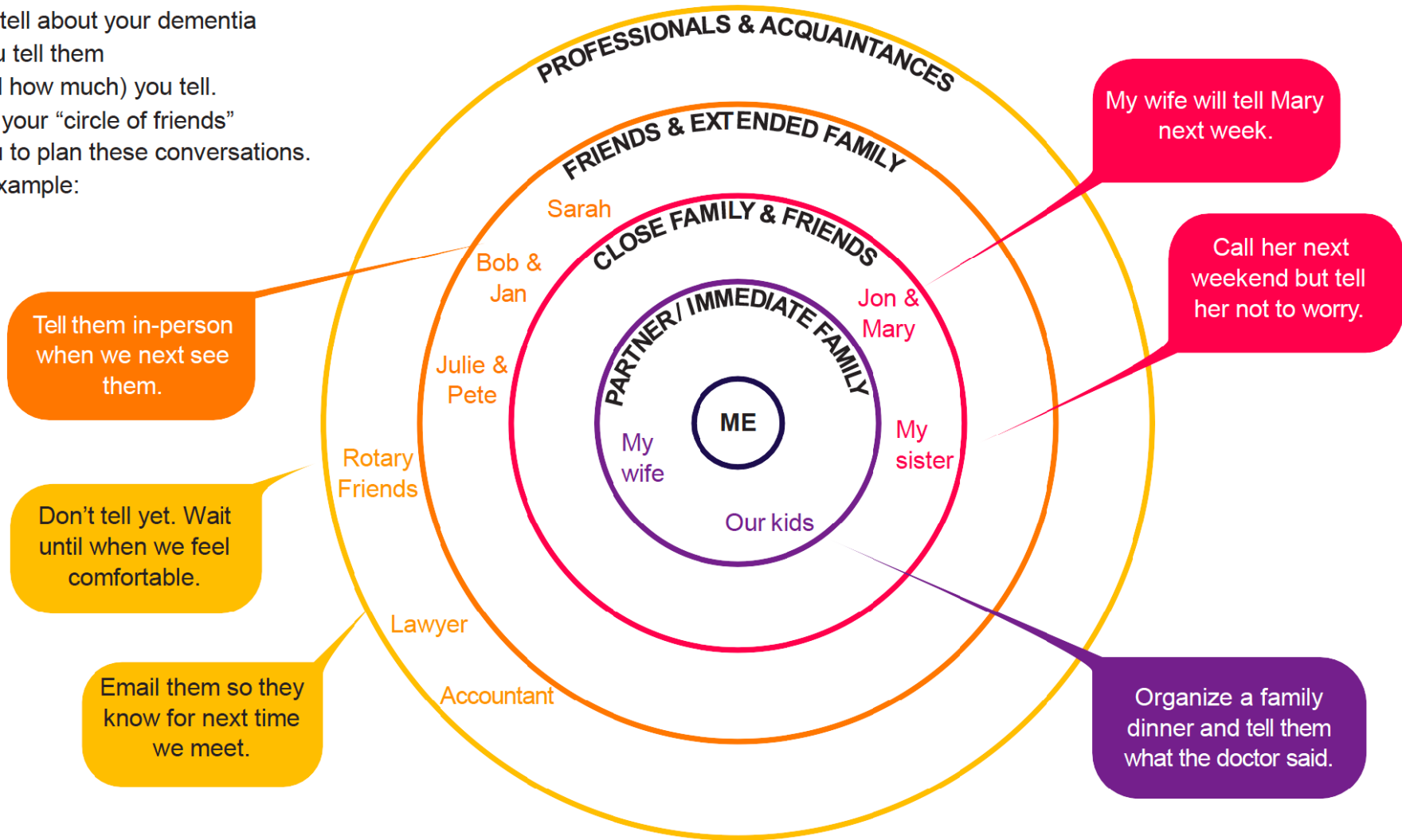
When, and with whom, do I share my dementia diagnosis?

You are in control of:

- who you tell about your dementia
- when you tell them
- how (and how much) you tell.

Drawing out your “circle of friends” can help you to plan these conversations.

Here is an example:



How Can Sharing the Diagnosis be More Positive and Empowering?

- The person living with dementia should be in control of who they share their diagnosis with, how they tell them, and when they tell them.
- Share how they would like to be supported. Give specific examples.
- Share ways they do NOT want to be supported.
- Some people living with dementia find that sharing the diagnosis can be partly a positive experience. Sharing the diagnosis can help friends and family understand what the person is going through, and how they can be best supported.
- Share educational materials and resources about the specific dementia diagnosis. The more that people learn about the diagnosis, the more comfortable they may feel around the person living with dementia.

Sample Language

Person living with dementia sharing how they would like to be supported:

- “I’m still the same person as before, please talk to me in the same way.”
- “If I’m a little slow or forgetful, please give me time. I’d prefer you don’t correct me – I usually get there at my own speed.”
- “I hope this doesn’t change things. I want to keep hiking with the group.”
- “I have trouble with names, so remind me of the names of people we’re going to have dinner with before we arrive.”

Person living with dementia sharing ways they DO NOT want to be supported:

- “I sometimes feel a little useless because you do so much for me. Can I keep doing the shopping even though I may forget things?”
- “I know that I missed a few appointments, which is why you’re in charge of my calendar now. I feel like I don’t really have a say in the schedule though. Can I also put things into the calendar?”
- “I don’t like it when you talk over me when we’re at the doctor. It makes me feel like I don’t have a say in the decision.”

Tips for Speaking with Children About a Dementia Diagnosis

- Consider the child's age, developmental stage, and relationship to the person who has been diagnosed. Adapt the information to the age of the child so it is easily understood.
- It is often better to be upfront about what is happening. It can be more upsetting for children to be aware that there is a problem and not have an understanding or reason for the increased tension within the family.
- Answer any questions simply and honestly, and listen carefully to the child's concerns.
- Explain that sadness and anger are normal reactions, and invite the sharing of emotions.
- Explain what changes a child might expect to see in their loved one and how these changes might affect the family.
- Provide age appropriate reading materials or online resources to help increase the child's understanding:
 - Grandma's Box of Memories: Helping Grandma Remember by Jean Demetris
 - Can I tell you about Dementia? A Guide for Family, Friends and Carers by Jude Welton

Sharing a Dementia Diagnosis:

Tips for Caregivers



- If possible, discuss how the person with dementia wants to handle the situation and get permission before sharing the information.
- Be ready to explain the disease process and its effects.
- Consider providing educational materials from various organizations and websites.
- If needed, let family and friends know about any local or online support groups.
- Tell family and friends how they can help and what you don't want or need.
- Explain what the person living with dementia can still do and how much they understand.
- Give suggestions about how to start talking with the person living with dementia. For example, make eye contact and say, "Hello George, I'm John. We used to work together."
- Keep in mind that some family and friends might also have trouble handling the diagnosis. They might be in denial, have misconceptions about dementia or feel uncomfortable, despite the caregiver's best attempts to help.
- Have a self care plan for after you share the diagnosis.

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Questions?

What do you want us to know?

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