

alzheimer's 95 association®



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# acknowledgements

Dementia Conversations was developed with a workgroup representing chapter offices throughout the country. The Alzheimer's Association would like to thank the following individuals who contributed to the development of this program: Chapter workgroup participants include:

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Constituent Services National Programs Committee

Product Development and Mission Partnerships Corporate Initiative

Corporate Initiatives

**Chapter Relations** 

## introduction

The *Dementia Conversations* program is designed to meet the needs of the following audiences:

- People noticing changes in seniors they are close to who have not received a dementia-related diagnosis.
- Care partners of those in the early stage of a form of dementia.
- Other family members who do not see themselves as caregivers.
- Long-distance caregivers.
- Hands-on caregivers of people in the middle to late stages of a form of dementia.

The settings for which this program is designed to be offered include:

- The workplace (In-person programming or webinars offered by Association staff and/or volunteers through Corporate Wellness programs, Employee Assistance Programs, Human Resource Departments, etc.)
- The community (in-person programming offered by Alzheimer's Association staff and/or volunteers).
- Online (Narrated program offered through the Alzheimer's Association's e-learning site).
- Online (Live program offered via webinar), either:
  - Presented entirely live by a staff member or volunteer, or
  - Presented as a broadcast of the narrated program, with intermittent and/or a final Q&A period.

The flexibility of this program and the use of the associated Tips document allows presenters or users to accommodate a variety of audience needs, and to customize the program to fit the time available. The program has been designed to be delivered within both 60 and 90 minute time frames.

## instructions

The Dementia Conversations program has been designed to be presented and guestions fielded within a 60 minute time frame. Because the program will frequently be offered in corporate settings, the program can easily be delivered in a one hour lunchand-learn setting.

Although this program offers 3 difficult conversations along with tips for having those conversations, participants will be attending for a variety of reasons and their reasons for attending go beyond those topic areas. For some, questions and concerns will arise that are pertinent to issues surrounding dementia. These concerns and questions will typically have a clinical component, whether overt or not. For that reason, we suggest that the program be offered by individuals with clinical or dementia-specific training.

The Dementia Conversations program can be accessed in the Programs and Services/ Education Programs area of Insite. As with other consumer education programs, Dementia Conversations offers videos of people whose lives have been affected by a form of dementia. In this program, the videos depict working care partners and caregivers who have had these difficult conversations with their family members, and they offer their insights. The videos tend to be the most dynamic and memorable parts of our programs, and the impact that they have on audiences is significant. As with all Constituent Education Programs, it is recommended that the program be delivered using PowerPoint Viewer rather than any other tool. The directions for downloading and using PowerPoint Viewer are contained in the document titled Download and View PowerPoint Presentations.

This section of Insite also contains the following collateral material to assist with the program:

- A customizable promo card.
- A customizable flyer.
- A customizable poster.
- A *Tips* handout that lists the tips covered in the program and refers participants to Association resources.
- Handouts of the slides.

A significant change from past programs is that this program contains two slides per video. The first slide contains only a still shot of the person ready to speak, but not the video. The second slide contains the video set to auto-launch when the presenter clicks to it. Setting the program videos up this way allow presenters to use their remote control to advance all slides including those containing videos. In this way, presenters will not need to return to their computers to start the videos.

If 90 minutes or more is available for your presentation, you may also want to invite a person with dementia to attend and share personal perspective about how these issues were approached in his or her family, what went well, what could have been changed, etc. This sort of engagement of a person with dementia can serve to educate the attendees while reducing stigma about the disease and empowering the speaker.

Finally, as you present this program, be sure reinforce the role of the person with dementia. When addressing significant issues with someone who has Alzheimer's or another form of dementia, that person and his or her perspective should be incorporated and reiterated throughout the delivery of the program.



Welcome to the Alzheimer's Association's Dementia Conversations program. This program is designed to help you talk with your entire family, including the person with signs of dementia, about some challenging and often uncomfortable topics related to Alzheimer's and dementia.

These discussions may not be easy to have for you or for the person experiencing changes in functioning. There is the fear of hurting those we love, facing changes related to aging and dementia, and being forced to deal with difficult family dynamics.

You may try to wait until the time is "right" to have these conversations, but in reality, that time rarely occurs. The sooner these discussions can take place, the better. This way, the wishes of the person with dementia can be included as much as possible and unexpected situations can be avoided in the future.



## Slide 2

The changing needs of the person often signal that it's time to talk. We have heard from many people who tell us that some of the most difficult conversations they had with their parent or family were about:

- Going to the doctor to get a diagnosis or medical care,
- Deciding when it is necessary to stop driving, and
- Making plans for managing finances and legal documents to be sure the person's wishes are carried out and the costs of future care are covered.

Keep in mind that as we talk about each of these conversations. we offer a variety of approaches. Not all of these will be appropriate for each person. The approach that will work best for you will involve your customizing it to fit the needs and preferences of the person with symptoms and your family.

#### Presenter's note:

It can be helpful to include a person with dementia in your presentation if time permits. This will allow the participants to hear from someone who has been on the receiving end of these conversational initiatives, with perspectives on what worked well and what interventions were less successful. See p. 7 for details.

## Slide 3

Today's program will:

- Share some tips for breaking the ice and having difficult conversations around some of the most common issues that arise when someone shows signs of Alzheimer's or dementia.
- Help you plan ahead and build a care team that works and communicates well to reduce some of the stress that can accompany a disease like Alzheimer's.
- Give you the opportunity to hear from people who are dealing with similar issues. These individuals will share how they handled these challenging conversations.
- Connect you with helpful resources to enhance quality of life for everyone involved.

## Presenter's note:

At this point in the presentation, you will be setting the stage for the idea that attendees may not think of themselves as caregivers, but may notice changes in those seniors close to them, and that this signals the need for a conversation.

## Slide 4

You may not think of yourself as a caregiver, but you may be noticing some changes or signs in the person you care about that are causing you concern.

Often, we find ourselves avoiding or talking ourselves out of difficult conversations around these issues, for several reasons.

- Sometimes our family members say they don't need our help.
- We assume that other family members who live closer are taking care of things.
- We fear that we might take away the person's sense of independence.





The family disagrees about whether or not there is a problem.

#### Presenter's note:

This is the point at which, if time permits, you may choose to include a person with dementia in the presentation to discuss how discussions took place within his or her family, what worked well and what might have been changed, etc.



## Slide 5

Sooner is better than later. Do not wait for a crisis to occur before having these conversations. You can actually avoid a crisis by talking about the issues and taking action in advance. By talking early in the disease process, you'll be able to hear directly from the person with dementia about his or her wishes while the person can still contribute and be part of the planning process.



## Slide 6

Despite the difficulty of these conversations, they need to take place to ensure the person's safety and well-being. Successful conversations start with being prepared in advance.

**Develop a plan for how to "finesse" the conversation** – how to introduce the topic in a way that will be gentle and minimize resistance. The use of "finesse" goes beyond honesty. It involves understanding how difficult this conversation can be, and thinking about how best to gently position the discussion for a positive outcome. Also consider what you will do regardless of how the person responds.

- For example, ask the person whether he or she would want to know if you have noticed any changes in functioning. In most cases, the person will say "yes", thereby allowing you to begin the discussion.
- If he or she says "no", that he or she would not want to know about what you've noticed, focus on the fears that accompany these changes and how important it is to talk about

the changes openly. The actual conversation about the changes you have noticed may need to take place in a separate conversation.

## Slide 7

## Take notes about the changes you see.

- Begin observing and note examples of behaviors that concern you.
- Take notes after you see something of concern so you can accurately talk about what you've noticed.
- Write things down so you do not forget the important points you want to cover, and bring those notes with you when you have the conversation.
- Be prepared to talk about your own feelings. Use "I" statements and try to avoid any suggestion of blame or criticism of the person so he or she is less likely to get defensive or angry.
- Be gentle in your discussion, keeping the person's feelings in mind. You want to avoid having the person with changes feel "ganged up on".

## Slide 8

**Practice in advance.** Rehearsing talking about sensitive topics with other family members will help you feel more comfortable when you have the actual conversation with the person with symptoms. Consider possible solutions to offer during the conversation.

#### Slide 9

Initiate the conversation at a place and time when the person is relaxed, well-rested and comfortable. Sit close to the person, use empathy and speak from your heart about your concerns.



#### Slide 10

When someone in your life exhibits changes in thinking or behavior it is important to be aware that they could be signs of Alzheimer's or another type of dementia. There are changes that are



**typical of aging,** such as taking a longer time to remember names or needing a reminder about how to use the remote control. But you may start to notice issues that go beyond typical aging, like that the individual is getting lost in familiar places, withdrawing at social functions, asking the same questions repeatedly or forgetting recent events. People with dementia typically first recognize signs that have to do with forgetting how to do things they used to do with ease, such as managing money or remembering appointments. Conversations can go more smoothly if reference is made to these changes rather than those that the person has not noticed in him or herself.

Sometimes, the person may be reluctant, fearful or angry when you try to get them to seek help. This can be because of his or her feelings about the disease, or because of the effects of the disease itself. It can also reflect his or her cultural traditions, beliefs or stigma about the disease. But we have some tips and tools that can help you get the individual to the doctor.

It can feel awkward to approach someone about the changes that you have noticed, but many times, the person has already noticed these changes in him or herself and has some concern. The person may be afraid, and denial is one of the most basic ways we all have to protect ourselves from feeling overwhelmed. But the changes might be due to something other than Alzheimer's, and acknowledging this can help the person agree to take action.



## Slides 11 and 12

## Video intro

Let's hear from Donna about the importance of having this conversation.

## Auto-launch of video clip

#### Presenter's note:

Please insert your own comments about the video clip here. Important points from the video:

- It's important to get the person to the doctor to see if the changes are due to Alzheimer's or something else altogether.
- There may be treatments available that can help the person, whether the diagnosis is Alzheimer's or something different, but the person can't receive treatment until they've seen a doctor.
- You can be honest with the person with symptoms about the fact that this medical determination needs to be made in order to receive the best care.

Suggesting a doctor's visit can be all that is needed to get the ball rolling. Other times, just being honest and direct isn't enough, and the person needs more support or direction. Here are some ideas that can help.

## Use words that are most comfortable for the person.

• Be aware that the person may be sensitive to particular words such as "Alzheimer's." For example, you can say, "Let's talk with the doctor about the fact that you're having more trouble doing some things than you used to," rather than "We need to have you see a doctor to do an assessment for Alzheimer's disease."

## Slide 14

## Let the person know that it's time for the Annual Wellness Visit.

 The Annual Wellness Visit, which has been offered at no charge by Medicare since January of 2011, is a visit for developing or updating a personalized prevention plan that can help prevent disease and disability. It includes an examination of the patient's cognitive and behavioral changes that may indicate a form of dementia like Alzheimer's disease. Many older adults have not heard of this benefit, but taking advantage of it can be a way to get the person to have their cognition evaluated.





#### Presenter's note:

The emphasis on this slide should be on the Annual Wellness Visit being a vehicle for getting the person to the doctor's visit, but that the visit should be preceded by providing information about the changes seen by the family members to the doctor. The doctor's visit without this preparation may be less effective.



## Slide 15

## Pair going to the doctor's office with an enjoyable outing.

You may want to suggest going to see the doctor and then doing something enjoyable together, like having lunch at a favorite spot.



## Slide 16

## Invite family to communicate concerns and questions to the doctor, too.

- Whether you are able to be there for the appointment or not, you can prepare a list of your concerns and questions, and provide that information to the doctor before the appointment.
- Because of doctor/patient confidentiality and protections under HIPAA regulations, the doctor will not be able to speak with you about his or her patient without a signed release. If your family member agrees to it, it can be very helpful to get a signed release of information that would allow the doctor to communicate directly with you. The release can be signed at the doctor's office.



## Slide 17

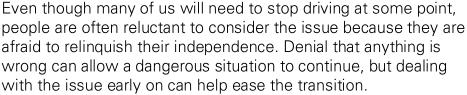
## If still reluctant, try using a "Therapeutic Fib".

There may be times when the person with symptoms is extremely reluctant to see a doctor regardless of your attempts to use reason. People with Alzheimer's often experience a reduced ability to use good judgment and make good decisions. Sometimes this contributes to the person's reluctance to go to the doctor.

In these situations, the person's safety and care comes first. You may need to utilize a technique called the "therapeutic fib" to get the person to visit the physician's office. To get someone to see a doctor, some family members or friends tell the person that a doctor's visit is required by the insurance company (or by the doctor) in order to authorize prescription refills, renew a policy, etc. Invoking this outside authority can help the visit to seem less like a criticism of the person and his or her current level of functioning, so resistance is reduced.

## Slide 18

As we have heard from others, having a conversation about driving may be one of the first difficult conversations families need to have after diagnosis. You may notice signs that your family member's driving has changed, such as accidents or tickets for moving violations, or things that are more subtle, like new scrapes on the car or garage. You may have even seen the person make mistakes while you were in the car.



#### Slides 19 and 20

## Video intro

Here is Chris, to tell us about how this happened in his family.

## Auto-launch of video clip

#### Presenter's note:

Please insert your own comments about the video clip here. Important points from the video:

- There is no single moment when the decision to stop driving should be made.
- You can incorporate the person's doctor or other professionals to let the person know that it's time to stop driving.







Whether the changes in driving are due to Alzheimer's or not, here are some ideas that people have found helpful when discussing this sensitive topic.

## Plan ahead before an accident occurs.

Before changes in the ability to drive are seen, talk about the fact that the person will need to stop driving at some point. Many families find it helpful to have an open discussion and develop an agreement about how the person would like you to recognize that it's time to stop driving, such as noticing more mistakes on the road or new scrapes on the car. When the time comes, the person may not remember the conversation, so it can be helpful to write notes about your agreement to use later or even ask the person to sign a "driving contract".



## Slide 22

## Express your concern about specific changes you noticed.

- Let the person know that you care about and support him or her, and reinforce that as the reason for your concern.
- Use specific examples to show that these are real problems. "Last week, you did something really different. Here's what happened. That concerned me."



## Slide 23

## Appeal to the person's sense of responsibility and concern for others.

For example, you could say, "I know that you wouldn't want an accident to happen and for you or someone else to get hurt."



#### Slides 24 and 25

#### Video intro

If you anticipate that the person may resist having the conversation about driving, there are ways to make it easier. Here is Sheila talking about how she approached it.

## Auto-launch of video clip

#### Presenter's note:

Please insert your own comments about the video clip here. Important points from the video:

- The safety of the person experiencing changes, as well as the safety of others on the road, is a key issue.
- It helps to have a plan in place that lets the person know that arrangements have been made to allow him or her to continue to go places, do things and be involved with others.

## Slide 26

## Establish a plan for alternate transportation in advance.

Be sure to include transportation to places that will help the person maintain social connections and hobbies, such as going to stores, appointments, bridge club or church. When you talk with the person, provide reassurance that you want to help maintain his or her active lifestyle and that those needs have been included as part of the plan.



## Slide 27

## Incorporate the voice of an esteemed professional and have empathy.

- Ask a physician to write a letter or a prescription stating that the person must not drive, just as Chris discussed in his video.
- Use empathy in your conversation, and think about ways to foresee and minimize the person's sense of loss. Consider talking about this from the standpoint of retiring from driving rather than giving something up.



## Slides 28 and 29

#### Video intro

Here is Wendy talking about a key component to making this conversation a successful one.



## Auto-launch of video clip

#### Presenter's note:

Please insert your own comments about the video clip here. Important points from the video:

- Driving is tied to the person's independence, and taking that away often feels like a big loss for the person.
- Thinking about what that experience is like for the person and using that empathy in your conversation helps make the conversation feel less punitive to the person with symptoms.

It's important to respect the person's sense of independence. while helping him or her understand that you are concerned and that these issues need to be discussed and addressed together.

#### Presenter's note:

At this point in the program, you can direct attendees to the Dementia and Driving Resource Center on alz.org, emphasizing the availability of videos demonstrating having conversations with people with dementia about driving issues.



## Slide 30

One of the ways that we all provide ourselves with choices that maintain our independence is by making legal and financial plans for our futures. Many families do this, only to be taken by surprise when dementia enters the picture.



## Slides 31 and 32

#### Video intro

As medical and long-term care costs in the U.S. rise, families may need to step in and provide both care and help with the person's finances. Let's listen to Chris again.

## **Auto-launch of video clip**

## Presenter's note:

Please insert your own comments about the video clip here. Important points from the video:

Alzheimer's disease and other dementias increase people's cost of living.

- Changes in plans will need to be made and monitored on an ongoing basis.
- It is always good to review existing documents to make sure they are current, but once there is an Alzheimer's or dementia diagnosis, plans that were put in place years before may need to change.
- Care partners also needs to update their forms, since the person with dementia may have been named as Power of Attorney prior to the diagnosis.

Some people may have plans in place but may still be uncomfortable discussing their financial status with you. You may also feel reluctant to do anything that may come across as intrusive. Talk about it. Making legal and financial plans early ensures that the person's preferences are included in the plans, and that the family will not need to make rash decisions.



## Slides 34 and 35

It is important to take the time to have these conversations. It can be scary, but it is necessary.



## Video intro

In this video, Julie tells us about how she talks with friends who ask her about having this kind of discussion with her mother.

## Auto-launch of video clip

#### Presenter's note:

Please insert your own comments about the video clip here. Important points from the video:

- Talking about these sensitive issues is a kind thing to do with someone with dementia.
- Our fears about how the conversation will be perceived may keep us from taking this important step.
- Approach the conversation from the standpoint of being with the person throughout the course of the disease and needing these documents in place to help him or her get the best care possible.



## Begin by explaining that you are in this together.

- These discussions may seem to go against some of our social norms and represents a shift in family roles. Understand that having this conversation will help you and the person with dementia make the plans you'll need to get the best care, and will allow you to connect and enjoy your time together in the future.
- It can be tremendously reassuring to let the person know that you will be a part of the process now and in the future. This way, the person you love can feel that you are on the same team.



## Slide 37

## Start by asking questions and gathering documents.

- Think of the conversation as a chance to ask questions rather than to tell the person something.
  - What documents are in place now and where are they kept?
  - Who has copies of the documents and who should have copies?
  - ♦ Who should review these documents? Family? Professionals?
  - Pull documents together and get the ones that need to be completed or altered.



## Slide 38

## Explain that these are standard plans that need to be made as we get older.

Reduce resistance to the process by explaining that having these discussions and completing these documents are things we all need to do as we age.



#### Slide 39

Break the conversation into parts, and try different times and locations.

- If you only had the conversation via phone, try in person. You can also write a letter to get the conversation started.
- Don't feel you have to cover everything in one sitting; it may help to do the planning in smaller segments. You can address the person's finances one day and then talk about legal documents at another time.

## Involve others to help talk about finances.

 Ask a financial advisor to help with the conversation or involve a brother or a sister. Some families make decisions to pool resources to ensure that care can be provided and the expenses paid. It is important to understand the financial situation so your family can help you make the best long-term care choices.



## Slide 41

Just as having these difficult conversations is challenging, caring for someone with Alzheimer's disease is also a challenge. But there are steps you can take to make things easier for everyone involved.



As our veteran caregivers tell us, no one can do this alone. Everyone who provides care for the person is part of a team, and care teams work best when there is good communication. The first step is to begin the conversation by talking with the other people on the care team.

As with any team, your care team works best on when there is an open flow of communication and when decisions are made together. You, the person with dementia and your other family members are at the center of the team, and whether family members live near the person you are concerned about or far away, everyone can participate.

## Slides 42

Families typically look to their primary care doctors to help with making medical plans. Other medical professionals who specialize



in the area of dementia care may be included to make a diagnosis.

#### Presenter's note:

At this point, you may want to distribute a copy of the Principles for a Dignified Diagnosis to assist with the diagnostic process.

Once the diagnosis is made, find out who will coordinate care on an ongoing basis. This is often the primary care physician.

Your care team does not stop there.



## Slide 43

Peers can be a tremendous support to the core care team members. As the disease progresses and care needs increase, friends can offer much-needed breaks and emotional support.



## Slide 44

Everyone who is working and a member of the care team should contact their company's HR department or Employee Assistance Program to ask about caregiving benefits. Families can then look at their pool of resources and make decisions about how to proceed.



## Slide 45

There are community resources available where you work and live. Some are even online so your entire family can have access to information and support.



## Slide 46

No matter whether you want information or support; whether you have questions about memory loss or a dementia of any kind; or whether you are a professional, a researcher, a caregiver or a person diagnosed with Alzheimer's disease or another form of dementia, the Alzheimer's Association has resources for you and is available to help.

In addition to our live programs, we have a rich website at alz.org. Visit our website to get tips about finding and providing care, read about the latest research, and find the tools for your wellbeing. Spend some time exploring all we have to offer for you at alz.org.

One of the online tools that you'll find on our website is Alzheimer's Navigator. We can help you map out a plan to approach Alzheimer's by visiting the Web page at alzheimersnavigator.org. Alzheimer's Navigator to helps guide you to answers by creating a personalized action plan containing information, support and local resources. You can then share your plan with you friends and family, linking them to the materials customized for your situation.

By visiting our Community Resource Finder online tool at communityresourcefinder.org, you can search for local community living services, day programs, medical resources and more. Whether you are in the area or across the country, you can find services to help someone living with dementia and make the contacts you all need to ensure safety and comfort.

A rich supplement to our local supportive programs is ALZConnected, our online message boards with over 50,000 members who share their thoughts, questions and ideas with each other 24 hours a day. Whether you are living with dementia or are close to someone who is, you can come on to read or post about your concerns. Let ALZConnected help you develop plans, find support and discover new coping techniques by connecting with others who are living with dementia or are partners in caring.

Our 24/7 Helpline offers dementia-trained professionals to talk with any time, day or night, every day of the year. Call us at 800.272.3900 when you need information about the disease and meeting its challenge, links to resources or a supportive ear during difficult times. We are here to help.

The Alzheimer's Association has chapters all through the country, where we offer education programs, support groups, and much more. To find a chapter anywhere in the U.S., go to alz.org/findus, where you can search by state or zip code. Once on the chapter's web page, you can see what is being offered in that area.

Finally, the Training and Education Center of alz.org is where you can access programs like this one from the convenience of home. Just go to alz.org/training, and you can find programs and materials that offer the most current information about dementia. treatments and care.

Please contact us and let the Alzheimer's Association partner with you to help ensure your wellbeing.

#### Presenter's note:

Here is the spot to highlight what you are doing at your chapter, including upcoming programs, events and resources specific to the location of this presentation. Flyers and brochures from your chapter can be placed on the resource table along with the Know the 10 Signs and Principles for a Dignified Diagnosis materials.

#### Presenter's note:

Please distribute Comfort Zone and MASR materials or have them available.



#### Slide 47

You can use your voice, your motivation, your interest and your skills to help find new treatments and to enhance services for all people affected by dementia.

Clinical trials research studies are being conducted all over the world to find treatments are safe and effective. Clinical trials are the best way for researchers to find new ways to detect, slow, treat and hopefully someday prevent Alzheimer's disease. The Alzheimer's Association's TrialMatch is a free clinical studies matching service that connects individuals with Alzheimer's, caregivers and healthy volunteers to local clinical trials seeking participants. When you join a clinical trial, you have an opportunity to participate in vital research that could change the course of Alzheimer's disease and improve the lives of all those it affects. Visit TrialMatch online at trialmatch.alz.org or call our Helpline at 800.272.3900 to get started making a difference.

The Walk to End Alzheimer's and The Longest Day are opportunities for the local community to join together in the spirit of grassroots advocacy that is central to the mission of the Alzheimer's Association. Forming a team to support a friend or family member is a direct way to show your concern for the person as well as for the cause, and those who live with the impact of these diseases in their lives are tremendously grateful.

We also encourage you to join us in providing education and support programs to families in your area who are living with Alzheimer's and other forms of dementia. Whether you are a person with the disease, a care partner or caregiver,

or a professional in the field, you can volunteer to use your knowledge and compassion to have a profound impact on those whose lives are affected by the disease.

## Presenter's note:

This is the time to highlight volunteer activities at your chapter and to circulate recruitment materials.

You can also join us to speak up for the needs and rights of people with Alzheimer's and their families, and to help persuade state and federal Congress to increase funding for research and programs. Many caregivers and people with the disease find the experience of advocating to be therapeutic, and it puts a human face on complex policy issues for our legislators.

We need you to help us change the course of Alzheimer's disease for everyone affected, and we welcome you to join us in making a difference.

## Slide 48

Remember that no one can provide all of this care alone, and the sooner in the disease process that you have these conversations, the more smoothly the team can function to provide assistance.





Helping the person you're concerned about begins with talking and having these difficult conversations. On this slide, you can see our website address and our toll-free 24/7/365 Helpline number. Call or contact us anytime. We are here to help you, your family and anyone you know who is affected by Alzheimer's or dementia.

#### Presenter's note:

You can now hand out the Tips sheet and open the discussion for questions.

Are there any questions?



## Slide 50

(No text)