



# <u>Champion's Guide to Delivering Information Sessions</u> <u>Young People (14-17 years old/grades 9-12)</u>

Adapted from Dementia Friends Minnesota and with permission of Dementia Friends, Alzheimer's Society, London UK.

Thank you for choosing to deliver Dementia Friends Information Sessions to young people.

Dementia touches the lives of millions of people throughout the United States and Dementia Friends was launched to tackle the stigma and lack of understanding of this disease.

You are helping to create a dementia friendly generation of young people who are not afraid to speak about dementia and who understand how they can help people affected by dementia feel involved in their communities.

In this guide, you will find the content to deliver Dementia Friends to participants aged 14 – 17 (9th – 12th grade). Participants will follow along using the Participant Packet.

# **Champion Checklist**

#### **Materials and Resources**

- Participant Packet
- Clock or watch to keep track of time and for 20 second activity
- We are Dementia Friends/I am a Dementia Friend signs
- Action Slips
- o Optional:
  - Dementia Friends Pins
  - o Dementia Friends PowerPoint Presentation and projector
  - Five Key Messages Video (will need access to Internet/YouTube)

# **Champion Preparation**

#### **Determine Audience**

- Contact local high schools or youth groups.
- Contact teachers of Psychology, Health, Economics.
- Offer to demonstrate an Information Session beforehand for the teacher(s) and support staff.
- Think about your network and who has links to schools and community groups involving youth.

# **Preparing for Your Session**

- Ensure that the person introducing you in the Session understands the key messages and positive approach you want to convey. The Session isn't about "how people suffer from a terrible disease."
- Find out if the group you will be talking to uses any group management strategies;
   e.g., "listening ears" or "fingers on lip." Also inquire if they have an established
   system of working with questions; e.g., "think, pair, share," which you can use in your delivery.
- o If using the PowerPoint or showing the Five Key Messages video, find out if the venue has an option of accessing the Internet and projecting the video.
- o If doing the Who is Right activity, make sure there's enough room space.

#### **Dementia Friends Information Session**

Time: 45-60 minutes, in-person

Note: Small group or paired discussion happens throughout the session. Ask participants to sit in small groups (5-7). If small group seating is not an option, everyone will share with the person seated next to them.

#### **Introductions and Housekeeping**

- Share a bit about yourself.
- o I'm a volunteer, enthusiastic about Dementia Friends and being here today.
- o I completed training to be a Dementia Friends Champion.
- o I'm not an expert in dementia and it is not my role to give advice. I may not be able to answer all your questions, but I will tell you where you can find out more.

#### **Brief Session Outline**

- The session will last 45 60 minutes.
- It will include activities, but no breaks.
- I will cover the five key messages that everyone should know about dementia and you will be asked to choose something you can do as part of becoming a Dementia Friend today.

#### **Short Ice Breaker**

**Ask:** How many of you know someone (in your family, community or place of worship) who has dementia or Alzheimer's? Who is the person and how do you know them? Share with small group or person seated next them. (60-90 seconds)

### What is Dementia?

Say: I'd like for you to share <u>one</u> word that comes to mind when you hear the word "dementia." Is anyone willing to share?

Allow participants to answer one at a time, making sure that you repeat their words.

Once you have taken 5 – 6 words from the audience, ask:

#### Are these words positive or negative?

Allow the audience to answer. Repeat the words shared. Point out that many of the words people mention may be negative. Fear and loss are often mentioned.

Optional: PowerPoint Slide 2

Say: Dementia is not a specific disease. It's an overall term that describes a wide range of symptoms associated with a decline in memory or other thinking skills severe enough to reduce a person's ability to perform everyday activities. Alzheimer's disease is the most common type of dementia and accounts for 60 to 80 percent of cases. Other types of dementia include Dementia with Lewy Bodies, Frontotemporal, and Vascular. The goal of Dementia Friends is to increase understanding about dementia and reduce stigma.

Let participants know that the Types of Dementia graphic can be found in their Dementia Friends Participant Packet (page 1)

#### What is Dementia Friends?

Optional: PowerPoint Slide 3

Say:

- Dementia Friends is a global movement to help everyone understand dementia so that people can live well with dementia and feel part of their community.
- Minnesota was the first state in the United States to offer Dementia Friends.
- We currently have [insert number from Dementia Friends USA website] Dementia Friends in the U.S.
- You are helping create a dementia friendly generation of young people.

#### Normal Aging vs. Alzheimer's Disease

Say: There are 10 early signs and symptoms of Alzheimer's disease.

Let participants know the 10 signs are found in their Dementia Friends Participant Packet (page 1).

Optional: PowerPoint Slide 4

Read the bolded statements below one at a time. Next read the typical age-related changes found in bold italics. Go through the list one at a time.

1. The first sign is memory loss that disrupts daily life.

What's typical with normal aging?

Sometimes forgetting names or appointments, but remembering them later.

2. The second sign is challenges in planning or solving problems.

What's typical with normal aging?

Occasionally making errors when balancing a checkbook.

3. The third sign is difficulty completing familiar tasks at home, at work or at leisure.

What's typical with normal aging?

On occasion, needing help to use the settings on a microwave or to record a television show.

4. The fourth sign is confusion with time or place.

What's typical with normal aging?
Getting confused about the day of the week, but recalling it later.

Optional: PowerPoint Slide 5

5. The fifth sign is trouble understanding visual images and spatial relationships.

What's typical with normal aging? Vision changes related to cataracts.

6. The sixth sign is new problems with words in speaking or writing.

What's typical with normal aging?
Sometimes having trouble finding the right word.

7. The seventh sign is misplacing things and losing the ability to retrace steps.

What's typical with normal aging? Misplacing things from time to time, such as a pair of glasses or the remote control, and retracing steps to find them.

8. The eighth sign is decreased or poor judgment.

What's typical with normal aging? Making a bad decision once in a while.

9. The ninth sign is withdrawal from work or social activities.

What's typical with normal aging?
Sometimes feeling weary of work, family and social obligations.

10. The tenth sign is changes in mood and personality.

What's typical with normal aging? Developing very specific ways of doing things and becoming irritable when a routine is disrupted.

# **Broken Sentences and Five Key Messages**

Direct participants to their Dementia Friends Participant Packet and ask them to turn to the Broken Sentences section.

Say: This activity will help you better understand dementia and you will learn the five key messages of the Dementia Friends initiative. Match the sentences in Column 1 to Column 2 by drawing a line from each sentence start to the corresponding sentence end. You should have five sentences that make sense.

Complete worksheet with small group or person seated next them. When all have finished, go through the answers one by one.

Say the first part of the sentence listed under Column 1 and ask a volunteer or the group to share what they identified as the response from Column 2.

The complete sentences follow:

#### Say:

- Dementia is not (pause and wait for a response). Response: a normal part of aging.
   This is our first key message.
- 2. **Dementia is caused by** (pause and wait for a response). Response: **diseases of the brain.** This is our second key message.
- 3. Dementia is not just (pause and wait for a response). Response: about having memory problems. This is our third key message.
- 4. **It is possible to have a** (pause and wait for a response). Response: **good quality of life with dementia.** This is our fourth key message.
- 5. **There's more to the person than** (pause and wait for a response). Response: **the dementia.** This is our fifth key message.

Optional: View Five Key Messages video to reinforce the Five Key Messages.

## **Bookcase Story**

Optional: PowerPoint Slide 6

Say: Dementia is caused by a disease that damages brain cells. This damage interferes with how brain cells communicate with each other. When brain cells cannot communicate, a person's thinking, behavior and feelings can be affected.

The brain has many different areas and each one is responsible for different functions (for example, memory, judgment and movement). When cells in an area of the brain are damaged, that area cannot function effectively.

The following story is a good way to illustrate how dementia might affect a person. It's not a scientific explanation.

Everyone's brain is affected differently by dementia. Let's imagine a 70-year-old woman who has dementia. Now imagine there is a full bookcase beside her. Each book inside the bookcase represents one of her skills or memories.

On the top shelves are her memories of facts and her skill for thinking in complex or complicated ways. For people with dementia, the top or outer part of the brain is damaged first. Skills like math, using language and keeping one's behavior in check are in this part of the brain. In our bookcase story, these skills are also books on the top shelves.

When dementia rocks the woman's bookcase, the books on the top shelf begin to fall out. The woman may not remember what she ate for breakfast, or that she has to pay for items at the drugstore or that someone came to visit her this morning.

Emotions and feelings are lower down within the bookcase just like they are in the lower or inner part of the brain. This is the instinct area of the brain. Feelings like love, happiness, frustration and sensing respect reside here. As dementia continues to rock her bookcase, the books on these lower shelves stay for a much longer time.

The bookcase story helps explain different thinking skills and memories and the effects of dementia. Facts and complex thinking will fall away quickly. Emotions and feelings will remain longer.

Let's return to the 70-year-old woman with dementia for a real-life example of the bookcase story. A daughter may visit to find that her mother can no longer remember her name. She will, however, remember feelings of love, comfort and support from the visit. Similarly, if the mother and daughter were to argue, the mother might not remember the details, but she will remember the feelings of anger and hurt from the exchange.

As her dementia continues, the woman might lose other thinking skills. She may no longer be able to manage her finances, complete activities she once enjoyed or communicate with family and friends. Dementia affects each person differently.

Remember, dementia also affects the factual and emotional parts of the brain differently.

The top part that manages facts – like faces, names, dates, places – is affected first; those facts are easily forgotten. The lower part that manages emotions is affected later, so feelings and emotions aren't lost as quickly as facts.

The brain stores both recent and past memories. For people with dementia, the most recent memories are lost first; the memories from earlier in life are remembered longer.

After reading the Bookcase Story, let participants know that a graphic of the bookcase is found on page 3 along with a side-by-side image of a healthy brain and a brain with advanced Alzheimer's.

Have participants work with the person next to them. Take 2 minutes to explain the bookcase story and what the image means. Once that partner is done, the next partner will take two minutes to explain. At the four minute mark, ask if there are any questions.

Optional: PowerPoint Slide 7

#### **Communication**

Say: The ability to exchange ideas, wishes and feelings is a basic need! Communicating with a person with dementia requires patience, understanding and good listening skills.

Champion Tip: Prior to the start of the Session, identify one participant who you will ask a question of and choose a relevant question together. For instance, Are you going to the Homecoming dance?, Who is your favorite teacher?, What is your favorite app on your phone? Let the participant know you will ask him/her the question and that they should wait 20 seconds before responding.

Say: People with dementia may have difficulty communicating if we move or talk too quickly.

Ask the participant the agreed upon question in front of entire group. After 20 seconds, the participant should respond.

Say: It may take the person up to 20 seconds to take in what you have said and get out their response.

**Ask:** How did that feel? Allow audience to answer. Repeat the words shared. Common feelings and words may be: uncomfortable, too long, anxious, nervous.

Say: This shows us that we need to allow extra time to allow someone with dementia to communicate.

Let participants know that they can learn more about communication in the Participant Packet (page 4).

Optional: PowerPoint Slide 6

## **Everyday Tasks**

Say: Next I'd like for you to work in your small group or pairs and write a step-by-step instruction list to complete a task you do daily or often.

Optional: PowerPoint Slide 8

Assign one of the following tasks to the group: brush your teeth or make a sandwich.

Say: Make sure that someone reading your list could follow the instructions successfully to complete the task.

- Refer participants to the Everyday Tasks page in the Session Workbook to write their list. Ask the participants to number each step as they go.
- Give the group five minutes to write down the steps that are needed to complete the task. If any of the pairs are not finished after five minutes, stop them and move on. Ask anyone who has not finished to estimate how many more steps they would need and make note of that number.
- After five minutes ask each pair or group to share how many steps they had for the activity. Keep note of how many steps each group had.
- Ask the participants if anyone would like to share their first step. Then ask everyone if they think a step comes before this.
- Ask the participants if anyone would like to share their last step. Then ask everyone if they think a step comes after this.

**Questions to participants**: Did you combine different actions? Could you break them down further?

**Response:** It's easy to combine lots of actions into one step.

Bring the group to the conclusion that the complete list would be very long.

Next facilitate a group discussion:

Ask: When you think about functions controlled by the brain, what is required to complete this task?

Responses may include: breathing, heart function, movement, vision, hearing, coordination, sequencing, memory of what words mean.

Ask: What did you learn from this activity?

Summarize the activity by saying or paraphrasing the following:

- Everyday tasks have more steps than we realize.
- The brain controls everything we do. We use many different brain functions to carry out everyday tasks.
- People with dementia may find everyday tasks more difficult but with support it is possible for them to continue to perform these tasks.
- Being kind and patient can make a big difference.

# Who's Right? Activity (optional if time permits)

Champion Tip: Before doing the Information Session, cut apart 5 to 7 of the statements found on page 14 of this document and fold each piece so that the statements are hidden. Details about the person in this activity follow.

You are 73 years old. You were diagnosed with Alzheimer's disease six years ago. You live with your spouse in your own home in the community.

Say: We are now going to complete an activity. Can I have 5-7 volunteers? Please stand side by side with your backs towards the wall.

Champion Tip: The volunteers should have enough space in front of them to allow taking up to 10 steps forward.

Say: I am now going to give you each a slip of paper with details of a person on it. Please quietly read what's on your slip. Don't show anyone or say anything about the person described on your slip.

Say: Now, I want you to imagine being the person on your slip as I read out loud some tasks. If you think you can do the task, take one step forward. If you cannot, you should stay where you are. Some of you have limited details on your slips, so do your best with the information you have.

Read out loud the following statements and remind the volunteers to take one step forward for each task they think they can do:

- Are you able to make a cup of coffee without assistance?
- Are you able to do the ironing?
- Can you vote in an election?
- Are you able to dress yourself?
- Are you able to follow the plot of a TV program?
- Are you able to go to the local grocery store and return home safely?
- Can you still maintain good relationships with your close friends?
- Can you volunteer to read to elementary children?
- Are you able to take money out at an ATM machine?
- Can you complete crossword puzzles?

Once you have read all the statements, ask the volunteers to remain where they are but to look around to see where everyone else is. Point out that they are standing in different places, because of how many steps they took.

#### Say: Can one of you read your slip out loud?

Have one volunteer read their slip and, if necessary, ask a second participant to do the same. Allow the group to conclude that they all have the same description on their slips.

Say: Everyone with dementia is unique.

# Ask: Was anybody right or was anybody wrong in imagining which tasks the 73-year-old with Alzheimer's could do?

No one person was right and no one was wrong.

## Ask: What did we know about this person?

 Not a lot! For example, they could have worked in a café for 30 years and made coffee every day.

# Ask: What did knowing they had been diagnosed 6 years ago add to our understanding?

 Not a lot! They could have been diagnosed at a very early or at a late stage of their dementia journey.

Every person is unique and will experience dementia in their own unique way. And yet, we each have some beliefs about what a person with dementia can and cannot do. And too often, we think that a person with dementia is far less capable than they actually are.

# Ask: How might someone feel if we assume they can or can't do something?

 That person may become angry or frustrated. For example, how would you feel if someone came into your bedroom and started picking out your clothes and trying to dress you when you could do it by yourself?

Some people will retain their abilities and thinking capacity longer than others. However well-meaning we might be, 'doing for' someone rather than 'doing with' them could discourage the person and cause frustration.

# Ask: What did you learn from this activity?

- Everyone has their own perceptions of what someone with dementia can and cannot do. Only by raising our own level of understanding and awareness can we make a positive difference by supporting people with dementia.
- o Remember, it is possible to live well with dementia.

#### **Turn Your Understanding into Action**

Say: Let's take what we've learned today and put it into action.

Optional: PowerPoint Slide 9

#### Say:

- To become a Dementia Friend, you need to support the five key messages and commit to your own dementia-friendly action.
- No action is too big or too small every action will make a difference.

Here are some example actions from young people:

- Call my grandma and be more patient during our conversation.
- Read a children's book on dementia to an elementary class.
- Help my grandpa complete a task instead of doing it for him.
- Talk with my mom about what I learned because my grandma has Alzheimer's.
- Tell others that dementia is a bigger deal than many people think.

Say: Discuss the action you'll choose to do after today with the person next to you (or group). Record your action in your materials so you can take it with you.

- Give the group 5 minutes to discuss their actions and then bring the group back together.
- Ask if anyone from the group would like to share their action.

Conclude with letting people know about community resources.

Thank participants for their time and for becoming a Dementia Friend! Optional: PowerPoint slide 10

Champion tip: Take group photos of participants holding the We Are Dementia Friends and I am a Dementia Friend signs. Make sure participants have signed a photo consent form before sharing publicly. Report the number of Dementia Friends made into the on-line form on the ACT website.

# **Who is Right Statements**

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