A teenager’s guide on Dementia and Alzheimer’s disease:
What it is and what role I play in supporting my loved one

Dementia: What you should know

Dementia (or Neurocognitive Disorder/NCD) is the umbrella term for all forms of dementia. Under the umbrella are MANY types of dementia. The most common are Alzheimer’s disease, Frontal Temporal and Lewy Bodies. Dementia is caused by physical changes in the brain.

For more info on the Twin Cities Jewish Community Task Force, go to:
http://www.actonalz.org/jewish-community
Normal Aging vs. Dementia

**Normal Aging** | **Warning Signs of Dementia***
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Sometimes forgetting names, but remembering later | Memory changes that disrupt daily life
Making occasional errors, i.e. balancing a checkbook | Challenges in planning or solving problems
Occasionally needing help with TV remote, microwave | Difficulty completing familiar tasks
Confusion about day of the week, but later figuring it out | Confusion with place or time
Vision changes related to cataracts or trouble hearing | Trouble understanding visual images or spatial relationships
Sometimes having trouble finding the right word | New problems with words in speaking or writing
Misplacing things from time to time | Misplacing things and losing the ability to retrace steps
Making a bad decision once in a while | Decreased or poor judgment
Sometimes feeling weary of work, family and social obligations | Withdrawal from work or social activities
Becoming irritable when things change | Changes in mood or personality

*A person may experience one or more of these as possible symptoms of dementia. [www.alz.org/10signs](http://www.alz.org/10signs)

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Alzheimer’s Disease: Facts and Figures

- More than 5 million Americans are living with the disease
- Alzheimer’s is the 6th leading cause of death in the US.
- In 2013, 15.5 million dementia caregivers provided an estimated 17.7 billion hours of unpaid care valued at more than $220 billion, which is nearly eight times the total revenue for McDonald’s in 2012
- Thirty percent of Alzheimer’s and dementia caregivers have children under 18 years old living with them
  - **Discussion:** What are the unique challenges of “sandwich” generation caregivers?

Imagine a 70-year old woman who has dementia. There is a full bookcase beside her as high as she is tall. Each book represents one of her skills or memories. On the top shelf are the most recent memories. Memories of her 60s are by her shoulders, those of her 40s and 50s are at her waist, and those of her 20s and 30s by her knees and her childhood at her feet.

Imagine that dementia rocks her bookcase and her books start to fall off, starting with the top shelf first. When her top shelves are empty she might find herself living in the past, lower down her bookcase. If she finds herself living in the 1950s, she may not know the name of the current President or the day of the week. The heaviest books that represent a person’s strengths or passions are often the last ones to fall off the shelf. Once you understand that this is her reality, you can better engage with her to support her.

There are different types of memory. Factual memories are books that will fall quickly. Emotional memories, on the other hand, remain in the memory longer.

With the example of the 70-year old woman, her daughter may visit to find that her mother can no longer remember the daughter’s name. She will, however, remember her feelings from the visit, feelings of love, comfort and support. On the other hand, if the mother and daughter were to argue, the mother might not remember the details of the argument, but she will remember the feelings of anger and hurt from the exchange.

*Maya Angelou once said, “I’ve learned that people will forget what you said, people will forget what you did, but people will never forget how you made them feel.”*
Brain Functions

01 Moving
- Walking
- Catching a ball
- Running

02 Understanding
- Being able to speak, finding the right words
- Understanding what is going on around us
- Finding your way somewhere

03 Thinking
- Concentration
- Making Plans
- Solving Problems
- Thinking before we speak and act

04 Recent Memory
- 5 minutes
- Last week
- Last school holidays

05 Sight

06 Co-Ordination
- Balance
- Understanding what we see, hear, touch, smell

07 Memory
- Being able to remember what we have seen, heard touched, smelt and being able to find our memories

08 Brain Stem

Alzheimer’s Video and Brain Tour

http://www.aboutalz.org/

http://www.alz.org/braintour/3_main_parts.asp
Broken Sentences Exercise

Instructions: Match up sentences from the left column with one of the ends of the sentences in the right column. Write the number in the blank space with the match.

1. Dementia is not…   ___ ...form of dementia
2. Dementia is caused by…   ___ ...the symptoms will gradually get worse
3. Alzheimer’s disease is the most common…   ___ ...a natural part of aging
4. Dementia is not just about…   ___ ...disease of the brain
5. Dementia is progressive, which means…   ___ ...each person in different ways
6. Dementia affects…   ___ ...losing your memory

Your role in supporting your loved one

- Support your parents who are often the primary caregivers
  - Take care of chores at home to relieve stress from them
  - Ask how you can help
- Visit your loved one
  - This can be hard in later stages of dementia
- Enjoy a hobby together with your loved one
  - Go for a short walk
  - Make a scrap book
  - Listen to music from the earlier years of your loved one’s life
  - Look at photographs together
  - Sit and hold their hand
  - Be in the moment with them, wherever they are at the time
- Treat them how you would want to be treated, regardless of the mood they are in
Communication Challenges

The ability to exchange ideas, wishes and feelings is a basic need. Alzheimer’s disease diminishes one’s ability to communicate, but not the need and desire to communicate. It is a human need to be in relationship with others.

Communication with a person with Alzheimer’s disease requires patience, understanding and good listening skills. As the disease progresses, the usual communication strategies may become more difficult for individuals, and often behavioral expressions become the only way a person with dementia can communicate. When these behavioral expressions become too challenging the caregiver should seek professional advice.

Changes in the ability to communicate are unique to each person with Alzheimer’s and can include:

- Using familiar words repeatedly.
- Inventing new words to describe familiar objects.
- Easily losing his or her train of thought; may experience difficulty carrying on a conversation.
- Reverting back to a native language.
- Having difficulty organizing words logically.

Source: http://www.alz.org/care/dementia-communication-tips.asp#helping

Communication Tips

- Identify yourself
- Call the person by name and make sure you know how the person prefers to be called
- Use short, simple words and sentences
- Speak slowly and distinctly
- Patiently wait for a response
- Repeat information or questions as needed
- Turn questions into statements
  - “Here is a bowl of fruit to eat” instead of “Are you hungry”
- Avoid confusing or vague statements
  - Name the object instead of using “it” or “that”
  - Here is your hat vs Here it is
- Turn negatives into positives
  - Say “Let’s go over here” instead of “Don’t go there”
Communication Tips (continued)

- Give visual cues
  - To help demonstrate a task, point to or touch the item you want the person to use (i.e. using a fork to eat)
- Avoid quizzing or arguing
  - Instead of asking “Did you see the Twins game”, say “I saw the Twins game and we won.”
- Convey an easygoing manner
  - Be positive and use friendly facial expressions and have positive non-verbal communication
- It is OK to be quiet
- Be patient and supportive while offering comfort and reassurance
- Consider what they may be trying to communicate even when they are not able to articulate it
- Meet the person where they are at, be in the moment with them
  - Tune into their reality instead of trying to insist on bringing back to ours.
- Treat the person with dignity and respect

Group Discussion

- Who do you think needs to know more about dementia and Alzheimer’s disease? Think of every type of person you can.
- What types of information or skills do people need to know? Think of everything that would help people better support someone with dementia.
Closing

Some ways you can get more involved in raising awareness for Alzheimer’s disease:

1. Alzheimer’s Association Young Champions:  
2. Walk to End Alzheimer’s
3. Volunteer opportunities with the Alzheimer’s Association and other organizations
4. Share this information with your friends and family!

Sources/Credits:
1. Dementia Friends program, An initiative for ACT on Alzheimer’s
2. Inside the Brain: An interactive tour, www.alz.org, Alzheimer’s Association
3. “The Milk is in the Oven: A booklet about dementia for children and young people”, United Kingdom Mental Health Foundation, [www.mentalhealth.org.uk](http://www.mentalhealth.org.uk)

Survey

- What did you learn?

- What parts of the program did you enjoy the most?

- What parts of the program did you least enjoy?

- What could make the program more interesting?

- What are some other things you’d like to learn more about persons living with dementia?