

Learning About Alzheimer's Disease and Other Dementias

A Resource for Teachers

August 2016



What is this?

A resource for teaching students in Grades 4-6 about Alzheimer's disease and other dementias. The Discussion Guide is used along with the script for *What Grandma Means to Say*, a one-act play written by author JC Sulzenko. The script can be read aloud or performed in the classroom, a live adaption of the script can be viewed on YouTube, or the story book adaptation of *What My Grandma Means to Say* can be used in lieu of the script. The Discussion Guide contains: information about how to 'set the scene' for your class before reading/performing the script/book; discussion points for after the script/book; FAQs about Alzheimer's disease and other dementias; and activities for teachers and students.

Why should I use this resource?

To teach children about Alzheimer's disease and other dementias. Learning the facts and learning tips to better communicate with people with Alzheimer's disease helps reduce the stigma and isolation that negatively impacts those who are living with this disease. With over 2,400 Islanders living with Alzheimer's disease or other dementias, and almost twice that number predicted for the year 2038, it's important to use this resource to educate our youth about the disease and to build effective interpersonal skills.

Who are we?

The Alzheimer Society of Prince Edward Island. Behind every person with Alzheimer's disease and other dementias, there are hundreds of people dedicated to helping. The Alzheimer Society is the leading not-for-profit health organization working nationwide to improve the quality of life for Canadians affected by Alzheimer's disease and other dementias and advance the search for the cause and cure. We are located in every province across Canada and in over 150 local communities.

Since 1989, we've been dedicated to providing help for people living with Alzheimer's disease and other dementias and their caregivers. That help comes in many ways. The Society is responsible for raising awareness, providing programs, education, and support services to all those affected by the disease.

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Introduction

With over 2,400 Islanders living with Alzheimer's disease and other dementias, more and more Islanders are feeling the impact of this disease, including children. At the Alzheimer Society of PEI, we believe it is important that all Islanders understand how Alzheimer's disease and other dementias impact the individual living with the disease. Knowing the facts and learning tips to better communicate helps to reduce the stigma which negatively impacts individuals living with dementia.

The Discussion Guide for *What My Grandma Means to Say* is a wonderful resource for teaching students in Grades 4-6 about dementia. The Discussion Guide is to be used along with the script for *What My Grandma Means to Say*, a one-act play written by author JC Sulzenko. The script can be read aloud or performed in the classroom (performance outside the classroom requires notice to and permission from the author). Alternatively, the Discussion Guide may be used in conjunction with the story book adaption of *What My Grandma Means to Say*, with a recorded performance of the play available on YouTube (<http://youtu.be/WsaHth8bm0s>), or it may be used to compliment an on-stage production of the play, performed by local high school students (please contact the Alzheimer Society of PEI for more information about this option).

In the Discussion Guide, you will find:

- Information about how to 'set the scene' for your class before the play
- Discussion points for after the play
- FAQs about Alzheimer's disease and other dementias
- Activities for teachers and students

To enhance students' understanding, along with any exercises suggested in the Discussion Guide, the Alzheimer Society of PEI suggests participating in the Virtual Dementia Tour with students.

Virtual Dementia Tour: This activity simulates impairments that may be experienced by someone living with dementia. A variety of impairments are simulated a number of different ways, such as taping fingers together to mimic difficulties with fine motor control, and wearing vision-reducing goggles to mimic visual difficulties. With these impairments, students are asked to complete basic tasks such as reading and writing. Students experience some of the struggles that may be experienced by someone with dementia, as well as frustration and communication breakdown. The Alzheimer Society of PEI's Education Coordinator can offer the Virtual Dementia Tour in your classroom. Contact 902-370-3135 or education@alzpei.ca for more details.

If you will be utilizing this resource in any capacity, please notify the Alzheimer Society of PEI by calling 902-370-3135 or emailing education@alzpei.ca. We also request that all teachers using the resource complete the following brief evaluation to provide feedback about the resource (it is also available electronically from the Alzheimer Society of PEI).

Resource Evaluation

Teacher: _____ School: _____

Grade: _____ Number of students: _____

Did you read the script, perform the play, read the book, or watch the video?
(Choose one or several) SCRIPT PERFORMED BOOK VIDEO

Would you recommend this resource to other teachers? YES NO

Was the Discussion Guide helpful? YES NO

Would additional information be helpful? YES NO

If yes, what information or materials specifically would be helpful?

Did you perform the Elephant Exercise with your class? YES NO

If yes, please provide any feedback you may have:

Did ASPEI perform the Virtual Dementia Tour with your class? YES NO

If yes, please provide any feedback you may have:

Did you perform any exercises suggested in the Discussion Guide? YES NO

If yes, please provide any feedback you may have:

Any other comments:

Thank you for your feedback and for providing young Islanders with the opportunity to learn more about Alzheimer's disease and other dementias!

Sample Introduction for Students:

Today we're going to (watch a play / read a play/book) called What Grandma Means to Say. The play is about an eleven-year-old boy named Jake, who is going to visit his grandmother. His Grandmother is around seventy years old and she is living with something called Alzheimer's disease. Alzheimer's disease makes it more difficult for people to remember things and causes changes in how people think. Alzheimer's disease is not a normal part of growing old and children cannot get it. Now, let's find out about Jake and his visit with his grandmother!

Reminder for teachers: The heart symbol ♥ is used to identify outcomes that should be addressed with sensitivity. It is important to know your students and to consider what outcomes/issues should be handled with care.

Additional information about risk reduction and brain health can be found in the *Heads Up for Healthier Brains* brochure provided in this package.

If you have any additional questions, or would simply like to discuss this resource further or the topic of Alzheimer's disease and other dementias, please do not hesitate to contact the Alzheimer Society at 902-370-3135 or education@alzpei.ca. We are here to help in whatever way we can to ensure that students have the opportunity to receive this important information.

Elephant Exercise (Updated Instructions)

While this activity appears in the Discussion Guide, we have provided updated instructions below. The Elephant Exercise has children complete a drawing of an elephant with difficult step-by-step verbal instructions from the teacher. Students are meant to experience the frustration and breakdown in communication which is often experienced by individuals living with dementia.

Before starting this exercise, the instructor will need to draw the visual so that it can be shown to students at the end. **DO NOT SHARE THE NAME OF THE EXERCISE WITH THE STUDENTS.** No further explanations should be shared with students while the exercise is underway. Here are the instructions to read aloud to the students:

1. Please take out a blank sheet of paper and a pencil and follow the instructions I give you. I will not respond to any questions during the exercise. I will read the instructions only once. Here they are:
2. Near the bottom of the page draw two squares about 8 cm apart.
3. At the bottom of these squares draw a series of half circles.
4. At the top of, and joining both squares, draw a rectangle.
5. At the top right corner of the rectangle, draw a circle about the size of an Oreo cookie.
6. Now, imagine that circle is the face of a clock, and at the five o'clock position, draw an "S" half in and half out of the circle.
7. Now draw a second "S" that looks the same, very close to the first one.
8. On the top left part of the circle, draw a smaller circle that is half in and half out of the larger circle.
9. Draw an "S" attached to the top left corner of the rectangle.
10. Now within the larger circle, draw two ovals, one inside the other, the smaller one being in the lower part of the larger one.
11. By now, you each should have something that looks like this (instructor shows the visual).
12. Does your drawing look like this one? If not:
What went wrong? How did you feel?
Were you angry or embarrassed?
Did anyone give up?

Explain to the students that this exercise demonstrates:

- The difficulty a person with Alzheimer's disease might have with understanding instructions.
- The feelings of frustration, giving up, anger, etc., a person with Alzheimer's disease might feel when we are communicating with them.
- The importance of good communication skills; for example, keeping instructions short, simple, and slow.

Curriculum Outcomes

The Discussion Guide and accompanying activities can be used to meet the following Prince Edward Island curriculum outcomes:

Health

Grade 4,5, and 6 General Curriculum Outcome (Relationship Choices):

Students will develop effective interpersonal skills that demonstrate responsibility, respect, and caring in order to establish and maintain healthy interactions.

Grade 4 Specific Curriculum Outcomes:

- Recognize that individuals can have positive and negative influence on the feelings of others ♥
- Describe and demonstrate communication skills and behaviours that show respect for the feelings of others
- Identify and describe ways to provide support to others ♥

Grade 5 Specific Curriculum Outcomes:

- Recognize that certain behaviours may mask underlying feelings
- Practise effective communication skills
- Identify possible changes in family relationships, and explore strategies for dealing with change ♥

Grade 6 Specific Curriculum Outcomes:

- Establish personal guidelines for expressing feelings
- Identify, analyse, and develop strategies to overcome barriers to communication
- Develop strategies to maintain and enhance appropriate cross-age relationships

Language Arts

Grade 4, 5, and 6 General Curriculum Outcomes:

Students will be expected to listen to explore, extend, clarify, and reflect on their thoughts, ideas, feelings, and experiences.

Students will be expected to interact with sensitivity and respect, considering the situation, audience, and purpose.

Students will be expected to select, read, and view with understanding a range of literature, information, media, and visual texts.

Students will be expected to respond personally to a range of texts.

Grade 4 Specific Curriculum Outcomes:

- Explore and discuss their thoughts, ideas, and experiences and consider those of their peers
- Contribute to conversations, small-group and whole-group discussion, showing an awareness of when to speak and when to listen
- Give and follow instructions and respond to questions and directions
- Engage in and respond to oral presentations (e.g., retell a story, sing a song)
- Describe, share, and discuss their personal reactions to texts
- Respond critically to texts by asking questions and formulating understandings
- Respond critically to texts by discussing texts from the perspective of their own experiences

Grade 5 Specific Curriculum Outcomes:

- Contribute thoughts, ideas, and experiences to discussions, and ask questions to clarify their ideas and those of their peers
- Ask and respond to questions to seek clarification or explanation of ideas and concepts
- Contribute to and respond constructively in conversation, small-group and whole-group discussion, recognizing their roles and responsibilities as speakers and listeners
- Give and follow precise instructions and respond to questions and directions
- Engage in, respond to, and evaluate oral presentations
- Describe, share, and discuss their personal reactions to a range of texts across genres, topics, and subjects
- Respond critically to texts by demonstrating awareness that all texts reflect a purpose and a point of view

Grade 6 Specific Curriculum Outcomes:

- Contribute thoughts, ideas, and questions to discussion and compare their own ideas with those of peers and others
- Ask and respond to questions to seek clarification or explanation of ideas and concepts
- Contribute to and respond constructively in conversation, small-group and whole-group discussion
- Give and follow instructions and respond to a variety of questions and instructions
- Engage in, respond to, and evaluate a variety of oral presentations and other texts
- Explain why a particular text matters to them and demonstrate an increasing ability to make connections among texts
- Respond critically to texts by demonstrating growing awareness that all texts reflect a purpose and a perspective

Science

Grade 5 General Curriculum Outcome:

Students will construct knowledge and understandings of concepts in life science, physical science, and Earth and space science, and apply these understandings to interpret, integrate, and extend their knowledge.

Grade 5 Specific Curriculum Outcome:

- Describe the structure and function of the major organs or the nervous system

Physical Education

Grade 4 Specific Curriculum Outcome (4.11 Safety and First Aid - Skilful Movement, Relationships):

- Incorporate safe practices (e.g., warm-up, cool-down, safe stretching, protective responses, proper attire, well-maintained equipment) for the prevention of injury, and investigate basic first aid associated with care of illness and injury resulting from participation in movement activities both in and out of physical education class.

Grade 5 Specific Curriculum Outcome (5.9 Safety and First Aid - Relationships):

- Make decisions about how to prevent and care for common movement activity-related discomforts and injuries (e.g., stiffness, nose bleeds, sprains).

Sample Letter to Family

dd/mm/yyyy

Dear Parent/Guardian,

Your child's class will be learning about Alzheimer's disease through a (*play/book*) called *What Grandma Means to Say* by author JC Sulzenko. The (*play/book*) follows a young boy named Jake who visits with his grandmother, who has Alzheimer's disease. The (*play/book*), along with a following discussion and activities, will teach the children about expressing and understanding feelings, along with building communication skills.

This may be a sensitive subject for some children whose lives have been touched by the effects of Alzheimer's disease and other dementias. If you have any questions or concerns, please contact me.

More information on this topic is available from the Alzheimer Society of PEI at 902-370-3135 or education@alzpei.ca

(Teacher's name)

Discussion Guide for

What my grandma means to say

(The Blue Shawl)



A one-act play for children in whose families a person is living with Alzheimer's disease or a related form of dementia.

by JC Sulzenko

INSIDE THE DISCUSSION GUIDE

- Why a play?
- How to use the play
- How to start a discussion after the play: kick-off questions
- FAQs and their answers
- How you can help
- Activities in the classroom or at home
- Books about dementia
- Sources of further information
- "What my grandma means to say": the script of the play
- About JC Sulzenko

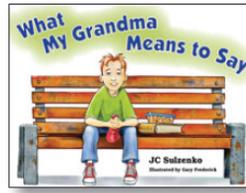
What my grandma means to say (The Blue Shawl)

by JC Sulzenko

THE PLAY AND DISCUSSION GUIDE

This ten-minute, one-act play gives elementary school-aged children (Grades 4, 5 & 6) and their families the chance to learn in a gentle way about how Alzheimer's disease and related dementias can affect a person and what they can do to support the person living with the illness. The setting, created by a performance or reading of the play, encourages children to ask questions in a safe-feeling environment, moderated by a teacher or community member who uses the questions and answers in this Discussion Guide to explore issues children raise about Alzheimer's. This Guide includes sources of further information and suggests activities to build awareness and understanding of such diseases.

To see a pilot performance of the play as performed by a troop of high school students, go to: <http://youtu.be/WsaHth8bm0s>



The Discussion Guide can also be used in conjunction with reading *What My Grandma Means to Say*, the storybook adaptation of the play, which creates a similar opportunity for learning about Alzheimer's.

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For information on the play and access to the Discussion Guide in PDF format: www.jesulzenko.com

For information on *What My Grandma Means to Say*, the storybook: www.jesulzenko.com

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The Alzheimer Society of Prince Edward County: www.alzpec.com (Go to "Contact Us.")

Glebe Montessori School

WHY A PLAY?

Based on a true story, the play lets children share the experience of a conversation between a grandson and his grandmother who is living with Alzheimer's disease.

Alzheimer's poses multigenerational challenges. Often children in families that face a crisis in the health of a loved one only know part of the story. Having only a little information can prove more frightening to them than if they come to understand what is going on.

Through seeing or hearing the play or reading the storybook based on it, children (and their families) gain an opportunity to raise questions and find out what they want to know in a setting removed from the actual situation with which they must deal. Children need the chance to find their place in what is happening and to build their own understanding and strategies, especially since they often are drawn into the role of caregivers.

How to use the play

The play can be read aloud, with all its stage directions as occurs in a "Reader's Theatre" approach (where the reader includes the stage directions and descriptions of the setting when reading the play aloud). The play can be performed in a community setting or at a school. In the classroom, students can be encouraged to take on the roles in the play. (Contact JC Sulzenko at info@jcsulzenko.com if you mean to stage the play outside of a single classroom reading to learn of any applicable licensing requirements.)

Before the play, set the scene for the children (and audience) with the following points as guidelines:

- The play you are about to see/hear looks in on the life of eleven-year-old Jake as he visits his grandmother at a long-term care residence where she lives.
- She is seventy years old and living with Alzheimer's disease (one of a large group of disorders known as "dementias").
- Such diseases cause differences in the ways people remember and how they think.

- Alzheimer's disease is NOT a normal part of growing old. (Young children cannot get Alzheimer's.)
- This is not Jake's first such visit with his grandma, but something very different happens this time.
- After the play, there will be time to talk about what happened to Jake and his grandma and to discuss any questions that come to mind.

Go to page 22 in this Guide to find the script of the play.

How to start a discussion after the play: kick-off questions

After the play, use the kick-off questions (below) to help launch the discussion. Usually, one or two questions will prompt children to ask their own or to raise anecdotes from their own experience.

- How do you think Jake feels after what happened in the garden? (Prompt, as necessary: Was he happy?)
- How did the play make you feel?
- How many of you have heard about Alzheimer's disease before today? Have you heard the names of other illnesses or conditions where people have problems remembering things?
- Why did Jacob become so excited about his grandma when she talked to him in the garden about the birds?
- Do you think Jacob will continue to visit his grandma? What makes you think so?
- What did Jacob and his grandma do together during their visit?
- How would you feel about visiting someone in a place where elderly people live because they need special medical care? (Such places are often called long-term care residences.)
- What kinds of things could you do while visiting someone in a long-term care residence? (See suggested activities later in this Guide.)

FAQs AND THEIR ANSWERS

What is Alzheimer's disease?

Alzheimer's disease is one of a large group of disorders known as "dementias." Alzheimer's disease is the most common form of dementia, making up approximately six out of every ten cases.

These diseases cause differences in what people remember and how they think. People with dementia may show signs such as loss of memory, difficulty in making decisions and thinking things through, confusion, and changes in the way they behave. Sometimes it's difficult to understand what is being said, because the part of the person's brain that organizes the way people speak may not be working well.

How did the disease get its name?

It was named after a doctor in Germany, Dr. "Alois" Alzheimer, who, over one hundred years ago, described the first patient with the disease. He determined how to find out whether a person who has died had been affected by Alzheimer's.

How rare is it?

It's estimated that 1 in 3 people over the age of 85 and 1 in 11 people over the age of 65 in Canada have Alzheimer's disease and other dementias.

Does it happen only in old age?

Most people who have the disease are well over sixty-five years old. Sometimes, though not very often, people in their forties and fifties can get it, too.

Alzheimer's is NOT a normal part of growing old. Not everyone's grandfather or grandmother is going to get the disease.

If you are forgetful, do you have Alzheimer's?

Everyone is forgetful from time to time. That's normal.

Is Alzheimer's more common among men or women or the same?

Equal numbers of men and women get the disease. Because women live longer than men in Canada, there are more women than men living with Alzheimer's.

What is the difference between amnesia and Alzheimer's disease?

Alzheimer's is a disease of the brain that affects how a person thinks and remembers. It gets worse over time. Amnesia is a memory disorder that affects how new memories are created or memories of recent events (as defined at www.baycrest.org).

How do you get it?

Is there a way a younger person can know if they will get the disease?

Children do not get Alzheimer's. Young people cannot catch Alzheimer's disease from another person, like the cold or the flu. They cannot catch it by touching or by hugging someone with it.

Scientists don't know why people get Alzheimer's, but they are working hard to find a way to stop it from happening.

People with a family history of Alzheimer's disease do run a greater risk of getting it in later life. This does NOT mean another member of the family will get the disease just because someone in the family has Alzheimer's.

How do you know if you have it?

There is no single test to tell if a person has Alzheimer's. To find out, a doctor does physical tests and looks for problems with the person's memory: how they think, speak, and make decisions, and how these all affect the way the person manages life day-to-day.

Once you have it, do you have to live with Alzheimer's disease?

Yes, you do, but there are medicines that can help manage and ease the symptoms of Alzheimer's. Such medicines do not slow down the disease itself, however. Over time, people living with Alzheimer's disease will need assistance with chores, driving, and getting dressed. Feeling loved and supported by family and friends, eating healthy foods, and exercising regularly can help people live better with this disease and adjust to the changes as they come.

What are the stages of the illness?

There are three stages of Alzheimer's disease: early, middle, and late. Over time, people with Alzheimer's find it harder and harder to do all the different things that they used to do every day like getting dressed or making a meal. Their memory gets worse, they become more confused, they have difficulty making good decisions, and they have problems speaking and finding the right word. They find it harder to concentrate, and their feelings are often mixed up. For instance, they can become anxious or angry for no reason others around them can understand.

Can you die of the illness?

Yes. The outcome of Alzheimer's is passing away. A person with Alzheimer's lives an average of eight years and can live as many as twenty years or more from the start of the signs that they have the disease.

Over time, the body shuts down, because the brain, which is the center of all functioning in the body, including walking, talking, breathing, and eating, is shutting down. Often the person dies from another illness, such as pneumonia, as the person's body has become very weak during the course of Alzheimer's.

Does a person's brain change when they have the disease?

Yes, the brain changes in how it works, and it loses size and weight.

Does the disease affect only the inside of the brain or also what the person looks like?

Both. Because the brain is the control centre for the whole body, it controls the way a person uses their body and, therefore, how he or she may appear. So, during the eight to ten years that a person might live with Alzheimer's, the disease can affect what a person looks like. For example, with Alzheimer's, a person can forget how to move.

If you have the disease, can you forget how to talk?

The disease does change the way people communicate with words. Some people lose all their words. That does not mean they cannot understand some or all of what people say to them or some or all of what is going on around them.

Can medicine help if you take it as soon as you know you have the illness? Can it stop the illness?

Can you get better?

As of today, there is no cure for Alzheimer's, but there are medicines that help manage and ease the symptoms of these diseases.

Is there a vaccine?

There is no vaccine and no way to prevent the disease that we know of for sure, but researchers around the world are focusing on the disease.

Is there a way to prevent Alzheimer's?

Researchers are studying ways to reduce the risk of developing Alzheimer's. Leading a healthy lifestyle and having a healthy diet, along with getting lots of exercise and staying active, can help keep our brains healthy. Protecting your head with a helmet during sports can help protect your brain from injury. In fact, scientists are doing research to learn about any links between brain injury and dementias.

People can exercise their brains at any age by learning something new every day, playing with friends, and spending time with their families.

What does it feel like to have Alzheimer's disease?

People with the disease sometimes may not know where they are or lose words. They may not understand what things are for, which makes them more confused. For example, they may not remember how to use a telephone.

As time goes by, people living with Alzheimer's may not respond to questions or activities in the way a visitor would expect. Talking with them may become one-sided. People with Alzheimer's may repeat a question over and over again, or look out the window. Being there with them, showing affection and interest in them by sharing stories, drawings, and readings with them still matter, though.

Is there any point in visiting someone who has Alzheimer's, even if they don't recognize you?

Yes, there is. People with Alzheimer's disease need to know that you care. When you hold their hand or give them a hug, they will feel your affection.

Can the disease make people angry or upset with their families and friends?

The brain helps a person understand the world around him or her. When Alzheimer's disease changes the way a person's brain works, a person living with the disease sometimes may act in unexpected ways for an adult. If a person becomes angry or shouts, it is likely because he or she feels confused and frightened. Loud noises, crowded spaces, feeling lost or tired can cause a person to act this way. It's not the fault of the friend or family. It's not personal, either.

What can children do if something that worries them happens during a visit to a person living with Alzheimer's disease?

Leave the room where you are visiting. Tell an adult you are worried and ask for help. People with Alzheimer's usually need quiet time to calm down.

What kinds of things can you do when you visit someone who has the disease?

Short visits usually work best. People with Alzheimer's often need help to feel happy and secure. Family and friends can show their affection by holding the hand of the person they have come to see. Bringing something to talk about or do together during the visit is a good idea, such as reading out loud, or looking at books, family photos, or magazines.

Having something to do and a place to go can give visitors and the person with Alzheimer's something positive to focus on while they spend time together. Activities such as looking at a memory box, singing songs, and creating art projects can work well. So can going outside in good weather to look at nature.

Visitors also can offer reassurance. For example, when a young girl visits her grandfather, who has dementia but still knows his granddaughter's name, she tells him stories about their family. He says to her, "You are my memory."

Do people have to live in a long-term care residence when they have Alzheimer's disease?

Eventually, people with Alzheimer's disease usually need the kind of care and support that is provided in a long-term care residence. These homes are designed specifically to help people take their medication and to assist them with walking and bathing. Such attention is given to them by doctors, nurses and support workers trained to provide medical care to people who have an illness like Alzheimer's disease.

Can music help?

Yes. Music can help stimulate a person's memory and make that person feel good. Sometimes, people with Alzheimer's can remember their favourite songs, even when they may have difficulty speaking in sentences. Music can provide a positive experience during visits from family and friends. It's joyful and fun.

Do service (therapy) dogs help people with Alzheimer's?

Visiting someone living with Alzheimer's and bringing along a pet can often be very comforting to someone with the illness. Check where a family member or friend lives to see if you can be part of a pet therapy program there.



HOW YOU CAN HELP

Visiting someone who has Alzheimer's disease

Because people with Alzheimer's disease need help to feel happy and secure, short visits usually are best. When family and friends visit someone with Alzheimer's disease, they can show their affection by holding his or her hand. It's helpful to bring something to focus on during the visit. For example, something to talk about or do together, such as reading out loud and looking at books or pictures or magazines or singing.

Visitors also can offer reassurance. For example, when a girl visits her grandfather, who has dementia but still knows his granddaughter's name, she tells him stories about his family. He says, "You are my memory."

At times, visiting with the family pet, a dog or a cat, can comfort the person if where the person lives is pet friendly.

What else can families do?

• Create a list of suggestions for visitors

With the family, brainstorm about how you can spend time with the person living with Alzheimer's disease. Some examples: go for walks, bird-watch, play card games, listen to music, sing, eat ice cream.

• Remember past events

People living with Alzheimer's disease like to remember things from long ago. You can help them remember by sitting with them and looking at old pictures, photo albums, books, or magazines.

• Memory Box

You probably have many special memories about spending time with the person who now is living with Alzheimer's disease. Fill a box with five special things that will help you to remember those times when you show the box to the person with Alzheimer's.

The box can be a shoebox decorated with your drawings or magazine cut-outs. It can be an old fishing tackle box or an old purse.

The possibilities of what goes into the box are as endless as your memories. A coin, a letter or postcard, a piece of jewelry, a medal, a baseball or golf ball, and a movie theatre ticket stub are some examples.

ACTIVITIES

FOR TEACHERS AND THEIR STUDENTS (AND THEIR STUDENTS' FAMILIES)

Life story collage

Students can interview a grandparent and/or family members and then create a scrapbook to contain images along with answers to questions such as: Where was the person living with Alzheimer's born? Where did he or she grow up? What is his/her favourite ice cream?

Create your own time capsule

Like the memory box described earlier, students each can create a time capsule. Into whatever container they choose can go examples of what really interests them at that moment in their lives. Almost anything (except food or material that can spoil) can be placed in the time capsule; special objects, photos, and games are good examples. Once filled, decorated, and closed, such time capsules can be put away and kept in a safe place for five to ten years. When the students open their capsules, inside will be objects that remind them about what was important to them when they were younger.

Creative writing

Ask students to write a story about the life of the person in their family or someone they know well who is living with Alzheimer's disease. The story can be fiction or non-fiction. What story could they write for and about a grandparent or a family friend, for example?

Learning about the brain and its functions

Refer to the *Inside the Brain Tour*, an interactive on-line learning tool for educators and students from the Alzheimer's Association: http://www.alz.org/living_with_alzheimers_just_for_kids_and_teens.asp

Read the play aloud with the class or perform it

The play can be read aloud, with all its stage directions as occurs in a "Reader's Theatre" approach (where the reader includes the stage

directions and descriptions of the setting in reading the play aloud), or performed in a community setting or at a school in a classroom.

Encourage students to take on the roles of Jake and his grandma, either in front of the whole class or in pairs, with each other. Consider giving students the chance to exchange roles and share, afterwards, how their feelings changed when they reversed roles.

Here's another approach: seek a partnership with a high school or college drama class, so that older students perform the play for one or a number of elementary school classes or schools. Watch a pilot performance of the play by high school students at: <http://youtu.be/WsaHth8bm0s>. Please note: If your organization wishes to put on a production of the play outside of a single classroom reading, please contact info@jcsulzenko.com to learn of any applicable licencing requirements.

Before seeing or hearing the play, set the scene for the audience, with the following points as guidelines:

- The play you are about to see/hear looks in on the life of eleven-year-old Jake as he visits his grandmother at a long-term care residence where she lives.
- She is seventy years old and living with Alzheimer's disease (one of a large group of disorders known as "dementias").
- Such diseases cause differences in the ways people remember and how they think.
- Alzheimer's disease is NOT a normal part of growing old. Young children cannot get Alzheimer's.
- This is not Jake's first such visit with his grandma, but something very different happens this time.
- After the play, there will be time to talk about what happened between Jake and his grandma and to discuss any questions that come to mind.

Use the kick-off questions and FAQs listed earlier in this Guide to launch and guide a discussion. If there are any unanswered questions, let JC Sulzenko (info@jcsulzenko.com) know what they are so that she can add such FAQs to future editions of the Discussion Guide. You can always contact your local Alzheimer society or national Alzheimer society for more information.

Reviewing the play

After seeing or hearing the play, ask students to write a review or give a talk on how their understanding of such illnesses has changed. Share such comments among the students and with others, even with your local Alzheimer society.

Elephant exercise

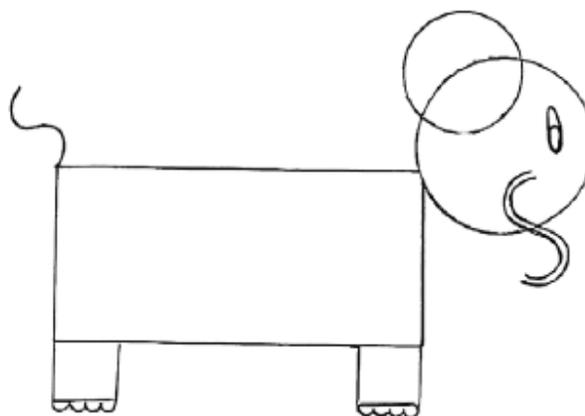
(For junior/intermediate students)

The purpose of this activity suggested by the Alzheimer Society of Ottawa and Renfrew County is to demonstrate how Alzheimer's disease affects a person's ability to communicate—in this case, how the person understands what is going on.

Before starting this exercise, the instructor will need to draw the visual so that it can be shown to the students at the end. **DO NOT SHARE THE NAME OF THE EXERCISE WITH THE STUDENTS.** No further explanations should be shared with students while the exercise is underway. Here are the instructions to read aloud to the students:

- Please take out a blank sheet of paper and a pencil and follow the instructions I give you. I will not respond to any questions during the exercise. I will read the instructions only once. Here they are:
- At the bottom of the page draw two squares eight millimetres apart.
- At the bottom of these squares draw a series of half circles.
- At the top of, and joining both squares, draw a rectangle.
- At the top right corner of the rectangle, draw a circle, the diameter of which is about the same depth of the rectangle.

- Now, if that circle is the face of a clock, at the five o'clock position, draw an "S" half in and half out of the circle.
- Now draw a second "S" parallel to the first, about three millimetres from the first.
- On the top left curve of the circle, draw an "S" attached to the top left corner of the rectangle.
- Now within the larger circle, draw two ovals, one inside the other, the smaller one being in the lower part of the larger one.
- By now, you each should have (instructor shows the visual):



- Does your drawing look like this one? If not:
 - What went wrong? How did you feel?
 - Were you angry, embarrassed? Did anyone give up?
- This exercise demonstrates:
 - The difficulty a person with Alzheimer's disease might have with understanding instructions.
 - The feelings of frustration, giving up, anger, etc., a person with Alzheimer's disease might feel when we are communicating with them.
 - The importance of good communication skills; for example, keeping instructions short, simple, and slow.

BOOKS ABOUT DEMENTIA

FOR STUDENTS UP TO AGE 8

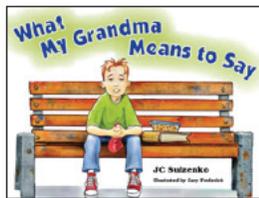
Mile High Apple Pie (2004) Laura Langston and Lindsey Gardiner. Red Fox ISBN 9780099443889

Wilfrid Gordon McDonald Partridge (1985) Mem Fox. Kane/Miller Book Publishers ISBN 0916291561

Grandpa's Music (2009) Alison Acheson. Albert Whitman and Co. ISBN 97808075305

Getting to Know Ruben Plotnick (2005) Roz Rosenbluth. Flashlight Press ISBN 9780972922555

FOR STUDENTS 8–12



What My Grandma Means to Say (2011) JC Sulzenko. www.jcsulzenko.com ISBN 978-1-926962-08-5

Help Wanted: Wednesdays Only (1994) Peggy Dymond Leavy. Toronto: Napoleon ISBN: 0-929141-23-7

The Graduation of Jake Moon (2000) Barbara Park. Atheneum Books for Young Readers ISBN 0-689-83912-x

If I Forget, You Remember (1998) Carol Lynch Williams. Yearling Books ISBN: 0-440-41420-2

STUDENTS 12 AND UP

Coping When a Grandparent Has Alzheimer's Disease (1995) Beth Wilkinson, edited by Ruth Rosen. Rosen Publishing ISBN 0823919471

Daughter (1999) Ishbel Moore. Kids Can Press Ltd. ISBN 1-55074-535-2

Understanding Dementia: A Guide for Young Carers (1996) Kate Fearnley. Health and Education Board of Scotland ISBN 1-87345-286-1

FOR ADULTS

A Dignified Life: The Best Friends Approach to Alzheimer's Care— A Guide for Family Caregivers (2002) Virginia Bell and David Troxell. HCI ISBN 075730060x

The 36-hour Day: A Family Guide to Caring for Persons with Alzheimer Disease (updated 2008) Nancy L. Mace and Peter V. Rabins. Wellness Central/Hachette Book Group USA ISBN 0446618764

When a Family Member Has Dementia: Steps to Becoming a Resilient Caregiver (2006) Susan M. McCurry. Praeger Publishers ISBN 0-275-98574-1

Parenting Your Parents: Support Strategies for Meeting the Challenge of Aging in the Family (2005) Bart J. Mindszenty and Michael Gordon. Dundurn Press ISBN 1-5502-552-x (See also www.mycarejourney.com/blog)

Doris Inc.: A Business Approach to Caring for Your Elderly Parents (2012) Shirley A. Roberts. John Wiley and Sons Canada, Ltd. ISBN 978-1-118-10022-6

SOURCES FOR FURTHER INFORMATION

For more information, you can go to the websites or contact the offices of the Alzheimer society nearest you, or of your provincial or state society or national Alzheimer organization. Local public libraries can suggest good books on this subject for every age group. There also are international organizations and annual conferences with Alzheimer's as their focus.

Here are some examples of websites with information for families and children. (Being mentioned on the list does not imply that the organizations listed endorse the Discussion Guide.):

The Alzheimer Society of Prince Edward Island
www.alzheimer.ca/pei

The Alzheimer Society of Canada
www.alzheimer.ca

The Alzheimer's Association US
http://www.alz.org/living_with_alzheimers_just_for_kids_and_teens.asp

Check out the *Inside the Brain Tour*.

The Alzheimer's Society UK
http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=108

THE SCRIPT

For Livia Janak

What my grandma means to say (The Blue Shawl)

by JC Sulzenko

© JC Sulzenko, 2009



Jacob/Jake:
an eleven-year-old boy



A Nurse:
the attendant at the desk



Grandma:
Jake's seventy-year-old
grandmother



Jacob's Mother:
Grandma's adult
daughter

Voices off stage

Location: A room, a corridor, and a garden in a long-term care residence

The scene:

A boy around eleven years old stands in the open doorway of a long-term care residence room, his back to the audience. He's wearing a baseball cap, jeans, sneakers, and an ordinary tee-shirt. To his left, there's a railing, like one finds along a corridor in a place where people need something to hold onto because walking is difficult for them.

The door to the room is a simple frame without walls so that the audience can see the whole room, with the shapes of a single bed and bedside table inside it. A large bulletin board, covered with family photos and pictures of different birds, can also be seen, as though suspended from an invisible wall. Opposite the frame of the door is the frame of a window. It gives onto a brick wall of another building, perhaps across a laneway that's several storeys below.

Inside the room, a small woman, around seventy years old and dressed in a tracksuit, waits in a wheelchair. She sits almost straight in her wheelchair.

GRANDMA: Hello. You are? ...

JACOB: I'm Jacob, Jake. You remember, Grandma.

GRANDMA: Of course, I do. Of course... You are? You are...

JACOB: Your grandson, Grandma. I'm your grandson. Jake. You know that, Grandma. You know.

GRANDMA: Of course, I do. Of course. Would you like a..., a...

JACOB: *(He looks at the food on the side table.)* A raisin? A candy? A cookie? Grandma, would you like a cookie? *(He picks up the bag of cookies from the side table and pulls one out of the bag.)* See, this is a chocolate chip cookie, Grandma. It's got little bits of chocolate in it. They crunch. Here, have one. *(He hands it to her and munches on one himself.)*

GRANDMA: Ummmm, good. *(Jake nods.)* I've never had a..., a...

JACOB: A chocolate chip cookie? Maybe you're right, Grandma. Maybe you never had one just like this. When I came last Saturday, you tried oatmeal chocolate chip cookies. They're good, too. You liked them a lot.

GRANDMA: I did?

JACOB: Sure. You ate at least three!

GRANDMA: I did?

JACOB: Yup, you did. Would you like to go outside for a walk, Grandma?

GRANDMA: A walk? I'm in a..., in a... *(She looks down at her feet.)*

JACOB: In your wheelchair. I know, I know. I could push it outside. We could sit where the birdfeeder is. We could count the birds.

GRANDMA: Count the birds..., the birds...

JACOB: Yes, let's go outside. Here's your blue shawl, in case it's chilly. *(He picks it up off the bed and hands it to her.)* That's it. *(Grandma tries to put her arms through the armholes, as if it were a sweater.)* No, you don't need to put your arms through, Grandma. It's got no sleeves. Here, let me wrap it around you. Just sit a little forward. *(Jake drapes the shawl over her shoulders.)* Okay. You can lean back now. Isn't that cozy? Here we go.

(Jake pushes her out of the room, down the corridor, past the frames of open doors that hint at many rooms along the hall. As they walk down the hall, they pass a few men and women holding onto railings or pushing walkers on wheels toward the end of the corridor. Other folks sit in wheelchairs at the doors of their rooms. One man uses two canes. His progress is slow as Jake and Grandma pass by him.)

VOICES OFFSTAGE: Coughing, throat clearing

OTHER RESIDENT OFFSTAGE 1: "Alice?"

OTHER RESIDENT OFFSTAGE 2: "Henry?"

GRANDMA: Where are we... Are we...

JACOB: We're going outside, Grandma. We're going outside. To see the birds.

GRANDMA: The birds..., the birds...

(Jake pushes the button to open the door to an enclosed garden. Alcoves hold pots of blood red geraniums that break up the stiff, high planks of the fence that keeps the residents separated from the street and safe, inside the flowered walls. There are a few chairs and tables, perhaps an awning, and other patio furniture. Jake pulls up a chair next to Grandma's wheelchair.)

JACOB: Here we are. Let's sit here. That way the sun won't be in your eyes. I'll lock the wheels. *(Jacob sits down.)* And we're not too close to the birds. We don't want to scare them away. Are you comfy?

GRANDMA: Scare them? Comfy... Am I...

JACOB: Comfy. That's a "yes," I guess, Grandma. Oh, look! A chickadee! *(He points to the feeder.)*

GRANDMA: Chickadee-dee-dee! Chickadee-dee-dee!

JACOB: Yes! That's right. You remember those birds, Grandma! You used to take me on the trail in the winter! *(Grandma nods at each sentence in his description. She becomes more attentive, involved, animated, and understanding at each of his statements.)* We'd bring safflower seeds. You'd put them in our hands. The chickadees swooped down, didn't they? They whirred through the air and landed right in our hands. They weighed nothing. I remember their bright, black eyes and cold, sharp little feet, even if you don't!

GRANDMA: *(She's smiling and nodding her head.)* Chickadee-dee-dee! Chickadee-dee-dee! Look, a cardinal! *(Grandma points at the bird.)*

JACOB : *(Jake sits up straight; stares at his grandma, his face open with surprise.)* What did you say, Grandma?

GRANDMA: A cardinal! See, it's there, in the little cedar.

JACOB: A cardinal? A cedar? *(Jake stands up and bends close so that his face is level with his grandma's.)* Grandma, do you know what you just said?

GRANDMA: Yes, dear. I sure do.

JACOB: *(Jake shakes his head in disbelief.)* You're right about the cardinal, Grandma. There's its mate, too. See? *(He points. Grandma nods.)* And the tree. You knew it was a cedar. That's awesome. That's amazing, Grandma! *(Jake hugs her. He's grinning.)* Wait till I tell Ma.

GRANDMA: Now, Jake, no need to make such a fuss. You know I know all about birds. Taught you how to look for them. How to listen for their songs. How to feed them. Why are you so surprised?

JACOB: Grandma, it's just that... that... *(Jake takes off his cap and twists it.)* You haven't been talking much when I've been over to visit, Grandma. And sometimes, sometimes you forget things.

GRANDMA: Oh, Jake. It'll take a long time for me to forget what I know. And a long, long time for you to know half of what's in my brain. *(Grandma chuckles and points to her own head.)*

JACOB: Maybe I should call Ma. She'll be so happy to hear about the birds, about the tree.

GRANDMA: Oh, no, Jake, dear. Let's just have a nice time together. Look, a goldfinch near those lilies.

JACOB: A goldfinch! Lilies! *(Jake shakes his head in amazement.)*

GRANDMA: You sound like a parrot, dear. Now, it's your turn. See that black bird with the wide tail? Can you tell me what it is?

JACOB: It's a... It's a...

GRANDMA: Ah ha! Give up? It's a grackle. Time to get out that bird book I gave you. Time to refresh your memory! *(Grandma points at Jake and chuckles.)*

JACOB: *My* memory? You're right, Grandma. You're so right! *(Jake hugs her.)* Look, Grandma, stay here in the garden. Just for a couple of minutes. I've really got to call Ma. I'll be right back.

GRANDMA: Sure, dear. I like it out here. Don't rush yourself. I'm not going anywhere in this thing. *(She pats the arms of her wheelchair, chuckles and waves him off.)*

(Jake pushes the button and runs back into the building, to the central workstation on that floor, where a uniformed nurse works.)

JACOB: I need to use the phone quick, please. Quick!

NURSE: Is anything wrong?

JACOB: *(Everything Jake says rushes out of him in a rapid stream.)* No, no. It's just so awesome! It's my grandma; she usually forgets stuff. Forgets everything. But just now, she knew me and about the birds in the garden. She could name them! I gotta tell my ma to come right over.

I know she won't believe me. How Grandma is cured!

NURSE: Here's the phone. *(The nurse turns the phone around so Jake can use it.)* But look, don't set your hopes too high. Sometimes, people who live here remember some things for a little while and then go back to forgetting again.

JACOB: No way. *No way.* My grandma's back! *(Jake picks up the phone and "dials.")* Hello, Ma? Guess what? You "gotta" come over right now. No, nothing's wrong. But Grandma remembers stuff...

Yes! She remembers my name! And she knows the names of the cardinal and the chickadees. And the cedar tree. She even remembers the bird book she gave me for my birthday... No, I'm not kidding, Ma. It's so awesome...

Yes. Okay. I'll wait with her. We're in the garden. Hurry, Ma. Hurry!

(Jake hangs up the phone and turns it back to the nurse.) Thanks a lot!

(The nurse shakes her head as Jake turns around and runs back down the hall.)

JACOB: *(Jake bursts into the garden. He's smiling like a clown.)*

Grandma, Ma is coming to see the birds with us. She'll be right over.

GRANDMA: *(Grandma smiles.)* That's nice...

JACOB: Look, Grandma, a...? *(Jake points to a blue jay at the birdbath.)* You know what "kinda" bird that is, Grandma. Tell me! *(His smile is triumphant.)*

GRANDMA: *(Grandma smiles back at him.)* It's a... It's a...

JACOB: Grandma? *(Jake loses his smile as he watches his grandmother work the edges of her shawl and furrow her brow.)* Tell me what kind of bird that is. You know the names of all the birds.

GRANDMA: It's a... It's a...

JACOB: What kinda bird? Just say it! Grandma, say it! *(Jake's questions escalate into demands. Now he is shouting.)* Grandma, tell me!

(Grandma starts to whimper. She shrinks away from him and tries to shelter under her shawl. Jake stands up slowly and walks over to her. He puts his arms around her.)

JACOB: It's a blue jay, Grandma. It's a blue jay. See how well you taught me? I knew what bird it was. *(He pats her hand.)* I'm sorry I shouted, Grandma. I'm really sorry.

That's better. You're okay now. *(Grandma nods, smiles a little again.)* It's getting late. Let's go in. Let's go in.

(Jake turns the wheelchair around, pushes the button and pushes Grandma in her wheelchair through the door into the building. We see his retreating back, shoulders slumped, as he pushes the wheelchair away from the garden's light toward his mother, who is walking quickly down the corridor toward them, her face to the audience.)

JACOB'S MOTHER: Hi, Jake. Hello, Mother. How are ...

As she sees Jake shake his head in a silent "no," she stops speaking in mid-sentence. Her smile shrinks to a tight line.

JACOB'S MOTHER: Oh, my darlings. My darlings...

Still facing the audience, she leans down to caress her mother's cheek, then comes around to stand next to Jake. She puts her arm around Jake's shoulders. Their backs to the audience, they together push the wheelchair further into the heart of the nursing home.)

* * *

ABOUT JC SULZENKO

JC Sulzenko, Ottawa poet, author, and playwright, is known for writing workshops and projects she leads with young and emerging writers. Her play for children, "What my grandma means to say," premièred at the Ottawa International Writers Fall Festival in 2009.

The play has been performed and presented to many schools and in community settings since then. A pilot performance by high school students for elementary classes can be seen at: <http://youtu.be/WsaHth8bm0s>

After families, teachers, children, and health care professionals requested the play in storybook form, JC wrote Jake's full story, which General Store Publishing House (GSPH) brought out in 2011. The book is now available from JC at www.jcsulzenko.com. (ISBN:978-1-926962-08-5)

With its focus on Alzheimer's disease and complemented by the companion Discussion Guide for teachers, students, and community groups, "What my grandma means to say" gives elementary school-aged children the chance to learn about Alzheimer's disease and related dementias and what they can do to support someone living with the disease.

JC's poetry has appeared in various chapbooks and anthologies and been heard on local and national television and radio. Newspapers across the country have carried her prose articles. Her books for children include *Boot Crazy* and *Fat poems Tall poems Long poems Small*.

To arrange for a dramatized reading by JC or for more information about JC's poetry workshops and writing residencies : www.jcsulzenko.com; info@jcsulzenko.com. You also can follow JC on Twitter [@jcsulzenko](https://twitter.com/jcsulzenko).

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