

Alzheimer's & Your Family

Librarian Guide

Welcome, friends.

Thank you so much for choosing to lend this healing kit through your library. The creation and implementation of the kit are up to your discretion, but we offer these recommendations to aid you.

The Goal of This Kit

This kit will not completely heal a family. It cannot undo what has

happened. Instead, it is intended to start families down a path of healing by

- Offering books to share and empathize with,
- Guiding discussions to ensure everyone feels heard and knows what's happening,
- Activities to provide comfort to family members,
- Suggesting acts of kindness to take away the powerless feeling that illness can cast over us,

THE

Children's Books

Conversation Community

Caring

• Sharing community helpers so families know where to start reaching out for continued help.

Together, all these pieces start families down a path of healing of their own design, a path which will be different for everyone. By offering this kit, you are not taking the place of a counselor. You are providing a curated set of resources designed by professionals to aid your community

Who Created This Kit?

This kit was put together by a team of people, including:

- David Moorhead, children's librarian at the Lewiston (Maine) Public Library
- Bonnie Thomas, a licensed children's counselor specializing in art and play therapy

- Megan Emery, guide author and Chattanooga Public Library experience designer and coordinator
- Kirsten Cappy, a children's literature advocate and owner of Curious City

Lending Period

Ultimately, it's up to you. Therapist Bonnie Thomas suggests giving families approximately 2-4 weeks with the kit, with additional time as needed.

Assembling the Kit

Based on the books and replaceable materials you choose to include, you may put this kit into one of the following:

- Backpack
- Wheelable bag/box
- Duffle bag
- Canvas tote

Providing Materials for the Activities

It's up to you to determine how many activities you'd like to provide materials for. We suggest each activity be organized into a clearly labeled individual container, such as a clear plastic tote. We have included labels designed for Avery Label 5164.

A few easy and inexpensive options to start with are:

Make a Memory Box or Jar: Suggested Activity Materials:

- Stickers
- Tissue paper
- Markers
- 1 glass mason jar or 1 new hinged cardboard box
- Glue
- Stamps and a stamp pad, especially individual letters
- Scrapbook papers

- Scissors that cut interesting edges
- Ribbon scraps
- Button

Make a Fidget Pouch: Suggested Activity Materials:

- 2 water balloons per fidget pouch
- $\frac{1}{2}$ cup of rice
- $\frac{1}{2}$ cup of beans
- $\frac{1}{2}$ cup of yarn
- $\frac{1}{2}$ cup of sand

Keep a Journal: Suggested Activity Materials:

- An inexpensive journal
- White paper folded in half and stapled
- Get creative
- Suggested activity materials include:
- Markers
- Large sheets of paper
- Paint
- Paintbrushes
- Tissue paper
- Stamps (especially individual numbers and letters)
- Old magazines to cut up
- Scissors

Make Hot Chocolate: Suggested Activity Materials:

- $\frac{1}{4}$ cup 100 % dark cocoa
- ¼ cup sugar
- Printed recipe

Consider Local Materials

There may be local organizations or individuals that could further help a family in need. Consider including brochures or a custom resource page to your kit.

Materials to Replace After Each Lending Period

- Any/All Handouts
- Activity Materials

When the Kit is Returned

Upon the borrower's returning the kit, the librarian should ask whether there is anything more the library can do to help. There is a lot of information included in the kit which may leave the family with questions, new research to complete, or community partners to seek out. Even if they don't need any assistance upon returning the kit, it's a good idea to offer a gentle reminder that the library is here to help them should they need it.

Designing Your Own Materials

You are, of course, welcome (and encouraged) to create any additional materials. To assist with design:

- Header font is Montara 24 pt.
- Sub-header font is Montara 16 pt.
- Content font is Archer 12 pt.
- The labels were designed with the Avery Label 5164 template
- The Healing Library logos can be found at: CuriousCityDPW.com/category/healing/

Share Your Library & Follow Others

Please share your ideas and questions about the Healing Library with librarian Megan Emery at meganfemery@gmail.com.

We will share new ideas and implementations at:

CuriousCityDPW.com/category/healing/





Book Discussion



Conversation Starters



Book Discussion



Community Helpers



Acts of Kindness

























THE HEALING LIBRARY

Children's Books Conversation Community Caring

Family Materials

Welcome, friends.

This kit has been designed for your use to heal as a family during a period in your lives when a loved one has developed Alzheimer's Disease.

Inside you will find:

- Children's Books with Discussion Guides
- Discussion Guide on Alzheimer's Disease
- Activities
- Acts of Kindness
- List of Community Helpers

This combination offers you an assortment of ways to move forward in a healthy manner.

A variety of art materials have been included that you're welcome to use for projects listed in the Activities Guide. All the handouts inside are also yours to keep if you think they'll continue to be of use to you and your family.

This kit was assembled by a team of people that include a children's librarian, a licensed children's counselor specializing in art and play therapy, a children's literature advocate, and a programming librarian.

This kit is designed to start your journey of healing but not to complete it. There are components of Alzheimer's which will require your continued research, discussion, and investment beyond what the kit provides. The resources listed and Community Helpers Guide will assist you in taking your next steps.

Thank you for taking this step in your healing process. We wish you peace.

THE HEALING LIBRARY: Alzheimer's & Your Family: Start the Journey

BRARY Children's Books Conversation Community

Caring

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Discussion Guide

Getting started talking about Alzheimer's can be tricky. You and your children will most likely be experiencing similar reactions, though they may not be verbalized or processed in the same way. To assist your discussions as a family, try one of these topics. Remember, this is just the beginning of your journey. There is a lot to learn about Alzheimer's, and your family's version of caring for yourselves and your loved one will be unique. The resources at the bottom of this document may be able to assist you as you move ahead.

If you would like to keep this sheet when you return the kit to the library, you are welcome to do so.

What is Alzheimer's?

Alzheimer's is a disease which affects the brain. It can happen to anyone and is not contagious. Over time it reduces a person's ability to acquire, understand, and use the information that surrounds us.

While the exact causes of Alzheimer's is still being learned, we see a high number of senile plaques (a protein fragment called beta-amyloid within all brains) and neurofibrillary tangles (a protein called tau, also found within all brains) in persons with Alzheimer's. The plaques typically get removed from the brain regularly, but those with Alzheimer's instead experience a buildup of this plaque which, as it accumulates, damages and interrupts communications between brain cells. Meanwhile, the tau protein combines with other tau proteins to form long, twisting fibers within the brain that eventually strangle the neuron. This tangle then affects other tau proteins in neighboring cells, causing brain cells to degenerate and die. (Kosik, 2015)

Some Warning Signs

One confusing thing about Alzheimer's is that, although the person is quite sick, they may not look sick on the outside. According to the National Alzheimer's Association, there are ten warning signs for Alzheimer's:

- Memory loss that disrupts daily life
- Challenges in planning or solving problems
- Difficulty completing familiar tasks at home, at work, or at leisure
- Confusion with time or place
- Trouble understanding visual images and spatial relationships
- New problems with words in speaking or writing
- Misplacing things and losing the ability to retrace steps
- Decreased or poor judgment
- Withdrawal from work or social activities
- Changes in mood and personality

If you notice these changes in your loved one, don't ignore them. Schedule a visit with a doctor right away. While your loved one may find the accusation embarrassing, early detection and care are the best ways to help them.

Prepare for Differences in Your Loved One

As you spend time with your loved one, you will see changes in them. They may seem sad, become angry, or do things which you find embarrassing. In fact, they will continue to change for the rest of your relationship together. This can be jarring, especially for children, and especially if you don't see your loved one with great frequency. If this is the case, it will be helpful to discuss with your child what to expect before each visit. Participating in some of the activities in this kit can provide your children with comfort and power during an experience that can leave them feeling powerless.

In addition, here are some things to remember:

 Just because your loved one may cry, become angry, or forget who you are, it does not mean they don't care about you anymore. • Caregivers can also be sad, frustrated, or short-tempered because of caring for a loved one with Alzheimer's. Reassure your child that you, too, still love them.

Common Reactions from Your Child

Children can reflect their feelings differently than adults. According to the **Alzheimer's** Association's publication Parent's Guide: Helping Children and Teens Understand

Alzheimer's Disease, the following are common ways children feel after an Alzheimer's diagnosis has taken place:

- Sad about how the person is changing
- Curious about how people get the disease
- Confused about why the person acts differently or doesn't recognize him/her
- Frustrated by the new ways they need to behave, like repeating words or phrases
- Guilty for resenting the time and resources the person requires from the family
- Afraid of the different ways the person may act
- Jealous of the additional time and attention given to the person
- Worried that others they love may get Alzheimer's
- Embarrassed to have friends or visitors over to the house if the person is home
- Unsure how to behave around the person
- In addition they may not know how to verbalize these feelings. Instead, they may express these things in the following ways:
- Withdrawing from or losing patience with the person with Alzheimer's
- Expressing physical pain, like a stomachache or headache
- Performing poorly in school
- Spending more time away from home
- Not inviting friends over to the house anymore
- Arguing more with others, especially those giving care to the person with Alzheimer's

How to Support Your Child

First, it's important to let them know they are still loved, both by you and the person with Alzheimer's.

Second, provide them with opportunities to share their feelings. That could be aloud in discussions with you, through activities as simple as journal keeping, or by speaking with a counselor or therapist of their own.

How to Start Caring for Your Loved One

As scary as this is for you, imagine how your loved one must be feeling. Their life is changing and will never be the same. As much as you want to get started helping them, it's important you involve their input. Doing so will ensure person-centered care where the loved one retains their sense of identity and control of their care for as long as possible. (Mast, 2013) For example, if your loved one forgets your child's name, how would they prefer this be handled? How would you prefer this be handled?

Keep the Conversation Going

To keep your conversation going, we've included discussion guides with each book in this kit, based on what we've gone over in this Discussion Guide. We recommend reading through each book's guide before sharing it as a family.

Resources

Alzheimer's Association. (2009) "10 Early Signs and Symptoms of Alzheimer's." Retrieved from: http://www.alz.org/alzheimers_disease_10_signs_of_alzheimers.asp#signs

Fisher, N. J., Rourke, B. P., and Bieliauskas, L. A. (1999). "Neuropsychological Subgroups of Patients with Alzheimer's Disease: An Examination of the First 10 years of CERAD Data." *Journal of Clinical and Experimental Neuropsychology*, 21: 488–518.

Kosik, K.S., (2015) Outsmarting Alzheimer's: What You Can Do to Reduce Your Risk. The Reader's Digest Association, Inc.

Mast, B. T. (2013). "Bringing Person-centered Care to People with Early-stage Alzheimer's." *Generations*, 37(3), 63-65. Retrieved from https://search-proquestcom.libezproxy2.syr.edu/docview/1491202475?accountid=14214 Alzheimer's Association. (2016). Parent's Guide: Helping Children and Teens Understand Alzheimer's Disease. [Pamphlet]. Chicago, IL: Alzheimer's Association



Healing Activities

These activities can be done individually or together as a family. Some will be appropriate to do with your loved one who is experiencing Alzheimer's, and others may be more appropriate done without them. While there may be suggestions for ages that are most appropriate for each activity, do not let this information stop you from using the activity if you know it's the right one for your family.

If you would like to keep this sheet when you return the kit to the library, you are welcome to do so.

Make a Memory Box or Jar

Memory boxes or memory jars are a collection of items (photos, trinkets, keepsakes, etc.) all stored within a creatively decorated box or jar. Collaborate on this project with your affected loved one to create something you can both enjoy together during visits, or for your family to share when they would like a tangible experience. These can be created for a specific memories or relationships or put together honoring multiple memories and relationships.

Create a Memory Game

Create a deck of cards to play the game Memory with, using photos of family members as the subject for the cards. Kids create one deck for themselves and another deck for the loved one to play with (intended for preschoolers and younger school-age children).

Keep a Journal

In the earlier stages of Alzheimers, the affected loved one and the child can each keep a journal of basic events or daily activities. When they visit each other they can share one of their favorite stories and/or pictures from the journal and talk about it.

Make Fidget Blankets, Twiddlemuffs, or Fidget Pouches

A fidget blanket is both comforting and engaging, making it great at soothing anxiety in those with Alzheimer's. Its base is a blanket, but it is adorned with a variety of tactile embellishments. Zippers to pull, soft loops of ribbon to tie or loop fingers in, pockets with small soft treasures inside, snaps to manipulate, and more can be added to your loved one's blanket.





A twiddlemuff is a muff (one of those oldtimey fuzzy tubes you put both hands inside) created with a variety of fiber materials (different types of yarn, wool roving, or fabric) and decorated with other mixed media items such as buttons, sewnon patches, or tassels. Each is unique and created with the wearer in mind. Creating one with the design input of your loved one with Alzheimer's would be an exploration in creativity while also utilizing memories.

After it is created, it will be a tactile memory for your loved one to continue engaging with you, even when you aren't there.

A fidget pouch is a pouch that fits in the palm of your hand and is filled with a material that is interesting in a sensory capacity. Beans, feathers, wool roving, sand, or plastic beads are all things that might go inside. Creating a sensory experience is stimulating for the brain as well as an engaging experience in sensory exploration for your loved one with

Alzheimer's. These pouches can be used to spark discussions about the way things feel and prompt verbal memories of descriptive words to do with sensory observations.

Make a Family Album

Make a photo book of family members to recognize faces, list names of who's who in your family.



Enjoy Music Together

Listening to music, singing to music, playing

music, and even dancing to music can all be beneficial to those with Alzheimer's. (Larsen, 2006) It has been found to trigger memories, and the playing of music is also considered participating in language, which keeps the brain strong. In addition to triggering memories, enjoying time together, and maybe even sneaking in some beneficial physical activity, as Kerer et al. stated, "if, in a disease which destroys memory, musical memory is preserved, even in a subset of patients, this preservation could serve as an important avenue to enhanced quality of life for a group of people who have lost so many other abilities." (Kerer et al., 2013)

Get Creative

Children can create art for those with Alzheimer's. The art will stimulate the mind of your loved one and may also trigger memories. Leaving the art up on a wall can benefit your loved one's brain even after you've left. (Larsen, 2006)

Talk and Touch

Talk and touch can both be very helpful for your loved one. Many patients feel security in the presence of their loved ones, holding hands while walking or talking. Hugging and cuddling can also provide a deeper sense of love and security. In addition, it's calming. Humans are communal creatures, and touch can trigger a release of oxytocin, which makes us feel relaxed and at ease. (Kosik, 2015) Get creative with ways to touch. Try washing a loved one's hair, braiding hair, offering a pedicure or manicure, or giving a shoulder rub.

Laugh Together

Jokes, funny stories, even funny videos are helpful for two reasons. First, Alzheimer's patients can feel depressed in their diagnosis, and some humor can cheer them up while providing new memories. Understanding the punchline is not as important as participating in laughter, which provides pleasure. Second, laughter can be a form of communication during a time when traditional language may be failing your loved one with Alzheimer's. Don't forget to listen for what people are saying beneath the languages they use, whether it be in a traditional sense, laughter, music, or body language.

Make Hot Chocolate

Make some hot chocolate for or with your loved one. Dark chocolate contains flavonoids which help with memory and blood flow to the hippocampus regions of the brain. (Kosik, 2015) Mix up 1 Tbsp 100% dark chocolate powder with 1 Tbsp of sugar. Add the mixture to non fat milk (or water), heat it up, then enjoy it together!

Redecorate

As Alzheimer's progresses, some patients find navigating in a prepared living space helpful. Painting the rooms of their living space different colors can assist them in distinguishing different spaces and purposes of spaces. If your loved one likes this idea, you could choose the colors and paint the rooms together.

Resources

Kerer, M., Marksteiner, J., Hinterhuber, H., Mazzola, G., Kemmler, G., Bliem, H. R., & Weiss, E. M. (2013). "Explicit (semantic) Memory for Music in Patients with Mild Cognitive Impairment and Early-stage Alzheimer's Disease." *Experimental Aging Research*, 39(5), 536-564. doi:10.1080/0361073X.2013.839298 Kosik, K.S., (2015) **Outsmarting Alzheimer's: What You Can Do to Reduce Your Risk.** The Reader's Digest Association, Inc.

Larsen, F. K., Bowman, A., (2006). Learning to Speak Alzheimer's: The New Approach to Living Positively with Alzheimer's Disease. (A book for a positive look towards Alzheimer affected). Dementia, 5(2)rs.



Acts of Kindness

There is a lot about Alzheimer's that can leave us feeling powerless and at its mercy. To combat these feelings, you can do something positive for the world to take back your power and do good. These activities can be done individually, as a family, or with your loved one who has Alzheimer's.

If you would like to keep this sheet when you return the kit to the library, you are welcome to do so.

Notice the Little Things

When with your loved one who has developed Alzheimer's, take time to notice the small things around you which are beautiful. Snowflakes, flowers, leaves, or animals can all have a pleasurable impact on your loved one, distracting him/her for even a moment and reminding them that life is beautiful.

Sign Up for a Charity Event

Walking or running a race isn't just helpful in staving off the effects of Alzheimer's, but the social engagement is also good for brains that have developed Alzheimer's. Meeting new people, sharing in a positive experience with others, and creating new memories as a family are all good for their brains. Adults with larger social networks score better on cognitive tests, even if plaque or tangles were evident. (Larsen, 2006) In addition, not only are you doing something good for your loved one, you'll be able to reflect on the positivity of doing something good for your community too!

Take Care of Yourselves

Caring for a loved one with Alzheimer's is stressful in any capacity. Be sure during this time that you are also caring for yourself. Getting enough sleep, getting regular exercise, eating well, and taking time for yourself will all be critical in balancing this stress.

If you have children who are now worried about more family members developing Alzheimer's, you can reassure them that a healthy lifestyle is the best way to protect themselves against such a development. If this is a concern, go on a walk together outside, plan a healthy meal together, or play a board game that challenges your brain.

Say Thank You

Creating little notes or cards thanking your loved one with Alzheimer's can provide comfort and spark memories for them. These keepsakes can be used to create albums, memory boxes, or just kept on display. Notes might say "thank you for that time you baked cookies with me" or "thank you for that time you made me laugh so hard when..." etc.



Community Helpers

The following are suggestions for types of helpers that may exist within your community. Some are resources for you to look up yourself, others will be more useful for folks who live in remote communities and may need help finding the right people to assist them.

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Support Groups

Many communities have support groups that focus specifically on families, caregivers, or patients. Patient groups are often organized by gender or by the different stages of Alzheimer's.

Therapists

Many communities have therapists that focus specifically on caregivers, children or patients.

Adult Day Care Centers

These are places similar to day care centers for children, where you can drop your loved one off while you're at work, then pick them up when you're finished. Some offer evening and weekend hours and/or transportation services. Most offer services beneficial to your loved one with Alzheimer's.

Assisted Living Facilities

These places offer more permanent living situations for your loved one.

Alzheimer's Association

This organization has an incredible amount of resources. From a virtual library to a 24/7 hotline, if you've got questions about Alzheimer's, they have answers.

Hospital Staff

Asking questions isn't just important for your kids, but for you as well. Utilize your time with hospital staff by asking questions and identifying more resources.

Counselors or Social Workers

Counselors can provide a neutral and nonjudgmental setting for you, your family, or your child to express and process feelings about what it's like to love someone who is affected by Alzheimer's.

A social worker might be assigned to patients in hospitals and facilities for reasons such as helping the patient transition from independent living to a facility.

Nursing Home Staff

These folks won't just be watching your loved one if they join an assisted living facility, they'll be engaging with him/her and can offer valuable insight into their progression, current likes or dislikes, and strategies for how to help them in the best way possible.

Emergency Responders

Should you have an emergency, these people can be reached via 911 to assist you in your emergency and get your loved one the care they need.

Church or Religious Leaders

Many find that religious support can be a source of relief during times of family illness. Even if you don't consider yourself an active member, your religious community can offer support in a variety of ways.

United Way

If you're unsure about local resources, the United Way can be a great way to get started. Calling them can help you find out what's available locally to your and your family

Resources

Kosik, K.S., (2015) **Outsmarting Alzheimer's: What You Can Do to Reduce Your Risk**. The Reader's Digest Association, Inc.

Larsen, F. K., Bowman, A., (2006). Learning to Speak Alzheimer's: The New Approach to Living Positively with Alzheimer's Disease. (A book for a positive look towards Alzheimer affected). Dementia, 5(2)

THE HEALING LIBRARY

Children's Books Conversation Community Caring

Book Discussions



Book Discussion: Grandma

Grandma

By Jessica Shepherd Illustrated by Jessica Shepherd Child's Play International

Oscar loves Grandma, and their time together is always lots of fun. As she becomes less able to look after herself, she has to go into a care home. More and more children are encountering dementia and its effects on their families. This touching story, told in Oscar's own words, is a positive and



practical tale about the experience. The factual page about dementia helps children talk about their feelings and find new ways to enjoy the changing relationship. Jessica Shepherd's sensitive first picture book has grown out of her experiences in a variety of caring roles.

This sweet story with childlike illustrations will provide comfort for your child when you remember all the fun you can have with your loved one, and provides inspiration for activities you can do together as a family and with your loved one to generate new memories while honoring those that already exist.

You and your child may want to read the book one or two times together before using it as a topic of discussion. What's important is talking together, not forcing a conversation or expecting that reading the book will explain it's hidden meanings to your child in place of a conversation with you. Below are some helpful notes you can use or paraphrase when reading the book together. If it's written in *italics*, it's a note for you as a parent to read and consider. If it's written in quotations, it's a discussion prompt for you and your child. Wherever there is a "______," you may insert the name of your loved one living with Alzheimer's. There's no need to use all the notes, just what feels natural or most beneficial for your family.

If you would like to keep this sheet when you return the kit to the library, you are welcome to do so.

Discussion

Pages 3 & 4

"Oscar and Grandma do so many activities together! These are all things that they can still do together because Grandma is still in the early to middle stages of Alzheimer's." What are some things your child loves to do with _____?

Encourage them to do these things together on an upcoming visit with ______.

Page 5

"Look at all the loving ways there are to touch Grandma. Touching this way can help people with Alzheimer's feel better. Your hugs can help ______; let's make sure to give them a hug next time we see them."

Page 7

"Asking questions is a good idea. Do you have questions for me? Do you have questions for _____? "

You can write down their questions for your loved one to save for later. You can also write down the questions they have that you don't yet have answers for.

Something to consider is that not every child will need every detail about what's happening. Try to listen to what behind the question. Are they scared? Sad? Angry? Can you address that feeling?

Page 10

"Look, now they're holding hands! That's another very nice touch to make someone with Alzheimer's feel better! You can also do that with _____ next time we see them, if you like."

Page 11

"Ooh! Those cupcakes look like a nice treat! Should we make something special to bring ______ the next time we see them?"

Keep in mind that not all treats may be appropriate for all patients. You should ask their doctor or caregiver what kinds of treats are suitable.

Pages 12, 22 & 23

"Usually when someone with Alzheimer's is upset it's because they're actually confused or frustrated. Do you know what that feels like? What makes you feel better when you feel that way?"

Pages 14 & 15

"Look, a Memory Box! We have the instructions for how to make one of those in the Activities Guide of this kit! Would you like to make one with _____?"

If ______ is at a stage where they can no longer participate in the creation of the memory box, consider making one as a family to share with them or just to keep for yourselves.

Pages 16 & 17

"Grandma has a lot of great stories that Oscar really loves. Do you have any favorites stories from _____?"

Consider creating a picture book together of your loved one's stories to share with them during visits or to keep for yourselves. Suggestions that may be helpful are included in the Activities Guide in this kit.

Pages 18 & 19

"Brushing Grandma's hair is another very nice way to make Grandma feel happy using touch. What are other nice ways we can touch ______ to make them happy?"

- Holding Hands
- Hugging
- Braiding Hair
- Cuddling
- Lap sits

All of these, as well as your child's own healthy suggestions, are welcome.

Pages 20 & 21

"Look at all those fun things to do together! Do you see any you'd like to do with

_____? Any you'd like to do as a family?"

Page 25

"Look! A hug! We just talked about how hugs are a nice way to make someone feel better! Does grandma look happy to get her hug? Do hugs make you happy?"

Pages 26 & 27

This guide is another great resource, with talking points and suggestions to take the book's lessons even further.

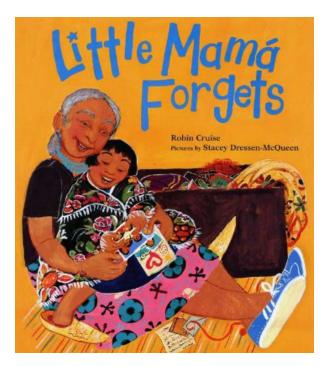


Book Discussion: Little Mama Forgets

Little Mama Forgets

By Robin Cruise Illustrated by Stacey Dressen-McQueen Farrar Straus Giroux

This story featuring a Mexican family will be useful for people who celebrate any Latin American traditions, and any family whose loved one with Alzheimer's lives in their home. Young Lucy tells the story not just of what her Mama forgets, but more importantly of all the things Mama remembers.



You and your child may want to read the book one or two times together before using it as a topic of discussion. What's important is talking together, not forcing a conversation or expecting that reading the book will explain it's hidden meanings to your child in place of a conversation with you.

Below are some helpful notes you can use or paraphrase when reading the book together. If it's written in *italics*, it's a note for you as a parent to read and consider. If it's written in quotations, it's a discussion prompt for you and your child. Wherever there is a "______," you may insert the name of your loved one living with Alzheimer's. There's no need to use all the notes, just what feels natural or most beneficial for your family.

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Discussion

Endpapers

The endpapers of the book show a family photo album full of happy memories for Mama. You can create a memory book for ______ using the instructions included in this kit's Activities Guide.

"Look at all these happy memories! Pictures can help a person with Alzheimer's remember all the fun they've had. Would you like to create an album like this for _____?"

Title page - 5

The story starts on the Title Page with Lucy and Paco sneaking into Mama's room to wake her up.

"Mama's room is filled with so many beautiful things from her life! What are some of the beautiful things ______ keeps around from his/her life?"

"Look! I love that Mama has a piece of Lucy's art up to make her smile! Would you like to create a piece of art for _____? We could make one together, or you could make one all by yourself."

Check this kit for the materials to get creative with. Also, check out the Activities Guide for help getting started with this activity!

"Sometimes people with Alzheimer's forget our names. It doesn't mean they love us any less, it's just harder for their brains to get their words to come out right. Has ______ ever called you by a different name? How did that make you feel?"

Pages 6 - 9

"It's a good thing that Mama lives with her family so that they can help her when she forgets things like the toast, otherwise it could be dangerous for Mama."

Memories can be triggered within your loved one through smell and taste. If you have a favorite recipe he/she used to make, try cooking it together or making a batch to bring the next time you see them.

"That pudding looks delicious. Would you like to cook one of _____'s favorite treats with _____ the next time we see them?"

If your loved one is living in an assisted living facility, you'll want to check with their care providers to be sure this is a good idea or to find out whether they have any dietary restrictions you should know about.

Pages 10 - 12

Memories can be triggered within your loved one through music. Playing their music for them can be beneficial for their brain health.

"Do you know any of _____'s favorite songs? We should play them for _____ next time we're together!"

Pages 13 - 16

The faces on pages 13 & 14 may seem scary to your child. If this is the case, remind them that this is a scary situation, but that Lucy's mother was there to help Lucy and Mama.

Walks outside can be great for your loved one's health. They promote exercise, which is good for our brains and bodies, gives them a chance to get some fresh air and see the beauty around them, and gives them time to spend with their loved ones.

"They're having so much fun! Would you like to go on a walk with _____?"

Pages 17 - 20

"I like that the little girl knows so many of Mama's stories! What are some special stories about ______ that you know?"

Pages 21 & 22

"Look at all those special treasures Mama has! You know, those special treasures help remind Mama of all the good things in her life. We can make something for ______ that will help with their special memories too if you like."

There are instructions in this kit's Activities Guide for you to create a memory jar, memory book, fidget blanket, or twiddlemuff for your loved one.

Pages 23 - 26

Memories can be triggered within your loved one through smell and taste. If you have a favorite recipe that he/she used to make, try cooking it together or making a batch to bring the next time you see them. (This repeats what you said in pp. 6-9 notes above.)

"Mama cooks a lot! What's something _____ cooks that you love?"

Pages 27 - 32

Touch can be very good for your loved one.

"Touch is good for people. It makes them feel better. I like that Mama brushes Lucy's hair and makes her feel nice before bedtime. You could brush _____''s hair and make them feel nice if you want to."

This sweet part of the story reaffirms for Lucy that no matter what Mama forgets, she will always love her.

"No matter what ______ might forget, know that they will always love you."

4

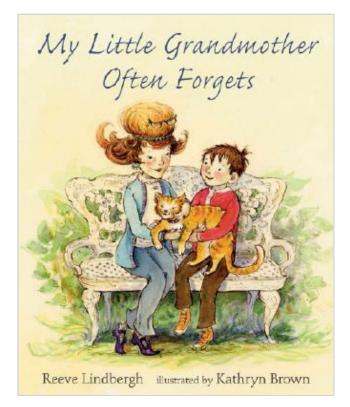


Book Discussion: My Little Grandmother Often Forgets

My Little Grandmother Often Forgets

By Reeve Lindbergh Illustrated by Kathryn Brown Candlewick Press

This rhyming story has fanciful illustrations that are fun to pore over. It is the least sad of all the books, and the rhyming provides some reassurance to kids that this story is like any other. As such, it is perhaps the best story to start with. This book will be especially useful if you're considering taking your loved one with Alzheimer's into your home, because the grandson helps grandma before she comes to live with them, and then later she



says she especially enjoys the move because she gets to be with him.

You and your child may want to read the book one or two times together before using it as a topic of discussion. What's important is talking together, not forcing a conversation or expecting that reading the book will explain it's hidden meanings to your child in place of a conversation with you.

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Discussion

Pages 1 & 2

"Can you find any of those missing things? I bet you can!"

The ring is the only object that isn't actually on the page.

After the child has found a few - "Do you help ______ when they lose things? What are some ways you've helped them?"

Pages 5 & 6

This kind of forgetfulness is one of the ten indicators of Alzheimer's as identified by the Alzheimer's Association. (Alzheimer's Association, 2017)

"Look! They're making a photo album together! We could do that with ______ or as a family and give it as a present to ______. Would you like to do that?"

Pages 9 & 10

"When people have Alzheimer's, their brains get things mixed up. Grandma doesn't love her grandson any less for calling him by his dad's name. In fact, he probably looks like his dad did when he was little, and grandma is just seeing a familiar face she loves, then mixed up their names."

Pages 11& 12

"He's doing a lot to help his grandma! When we love someone, we want to help them and take care of them. What are some ways ______ has taken care of you before? What are some things you could do to help _____?"

Especially if they're activities they've done together in the past, performing these tasks together can be good for the mind of your loved one with Alzheimer's. They will both bring up old memories and provide a sense of comfort.

Pages 15 & 16

"Did you know that for someone with Alzheimer's, just spending time together can be very relaxing and comforting? Sometimes it's hard for them to get their words right or understand your words, so just spending time and using body language (like smiling!) makes them feel good."

Pages 17 - 20

"I like that Grandma and her grandson will get to spend more time together because of how much they love one another. Would you like it if ______ came to live with us? Why or why not? What would change? How would it make you feel?"

Resources

Alzheimer's Association (2017). Ten Early Signs and Symptoms of Alzheimer's. Retrieved from <u>https://alz.org/10-signs-symptoms-alzheimers-dementia.asp</u>.

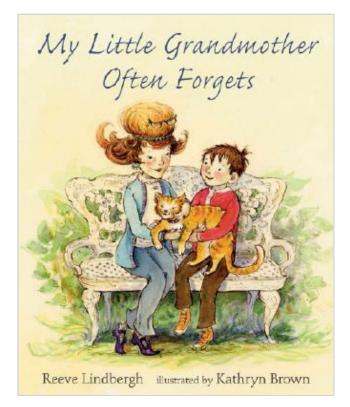


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Resources

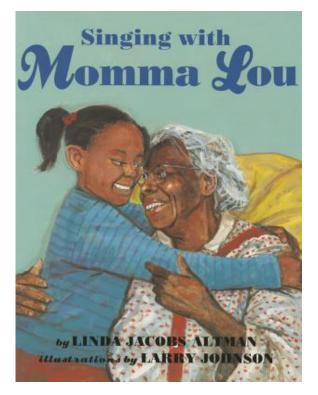
Alzheimer's Association (2017). Ten Early Signs and Symptoms of Alzheimer's. Retrieved from <u>https://alz.org/10-signs-symptoms-alzheimers-dementia.asp</u>.



Book Discussion: Singing with Momma Lou

Singing with Momma Lou By Linda Jacobs Altman Illustrated by Larry Johnson Lee & Low Books

This story featuring an African American family shares the story of a granddaughter committed to helping her grandmother remember her life through the grandmother's photos and mementos. Any family considering creating a memory books for their loved one with Alzheimer's will benefit from this story, especially when used with the instructions in this kit's Activities Guide.



This sweet story with childlike illustrations will provide comfort for your child when you remember all the fun you can have with your loved one, and provides inspiration for activities you can do together as a family and with your loved one to generate new memories while honoring those that already exist.

You and your child may want to read the book one or two times together before using it as a topic of discussion. What's important is talking together, not forcing a conversation or expecting that reading the book will explain it's hidden meanings to your child in place of a conversation with you. Below are some helpful notes you can use or paraphrase when reading the book together. If it's written in *italics*, it's a note for you as a parent to read and consider. If it's written in quotations, it's a discussion prompt for you and your child. Wherever there is a "______," you may insert the name of your loved one living with Alzheimer's. There's no need to use all the notes, just what feels natural or most beneficial for your family.

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Discussion

Title page

This page features a few of Momma Lou's items Tamika probably finds during the story.

Pages 1 & 2

Grandma's going to an assisted living facility because she needs help with her daily living activities. This is an indicator of being in the late part of the early stages of Alzheimer's. (Larsen, 2006)

"Going to live somewhere new is a very big change. How would you feel if _____ left their home to live with other grandmas and grandpas? What would change? What would be better?"

Pages 3 - 8

"Tamika seems sad and angry about how this visit went. Sometimes you might feel this way too, and that's okay. ______ is changing, and feeling that way just means you care about them. You can always come talk to me when you feel this way. "

Memories can be triggered within your loved one through music. Playing their music for them can be beneficial for their brain health.

"Does ______ ever sing? What are some songs that make ______ happy?"

Pages 9 - 12

Tamika's Dad does a great job of reminding Tamika why the visits take place each month, and why Mama Lou is so special. If your child is experiencing the same frustrations, you might follow his example and share your own photos, stories, and commitment to your loved one with your child.

Pages 13 - 16

"Look at that. Tamika's idea helped mama Lou! Would you like to bring a photo next time we visit with ______ so you can talk to him/her about a special memory?"

Pages 17 - 20

There are so many things that may spark a memory in your loved one. Mama Lou has a strong connection to her work in the Civil Rights movement, so it makes sense that Tamika would use these clippings and photos to help mama Lou.

"What is something ______ feels strongly connected to? What kind of objects can be used to spark their memory of this special connection?"

Pages 21 - 26

"Mama Lou loves music and is very proud of this important part of her life. It's sad that Mama Lou's Alzheimer's got worse after this, but it's also wonderful that Tamika got to share this moment with Mama Lou. We don't know when it will be our last special moment with ______, so let's be like Tamika and try to make every moment with him/her special."

Pages 27 & 28

"We can honor our loved ones who die or who we lose to Alzheimer's by remembering and telling their special stories and by creating scrapbooks or memory books filled with their photos and mementos. Would you like to create one all about ______ together?" There are instructions in the Activities Guide that you may find helpful for creating a memory book together.

Resources

Larsen, F. K., Bowman, A., (2006). Learning to Speak Alzheimer's: The New Approach to Living Positively with Alzheimer's Disease. (A book for a positive look towards Alzheimer affected). Dementia, 5(2)

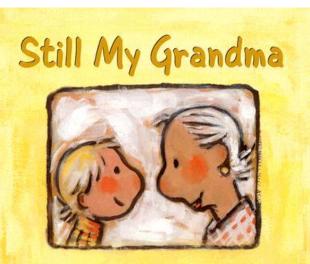


Book Discussion: Still My Grandma

Still My Grandma

By Veronique Van den Abeele Illustrated by Claude K. Dubois Eerdmans Books for Young Readers

This positive story with comforting illustrations will be especially helpful if your loved one will be under the care of an assisted living facility in the future. It should be noted that Grandma does look sad, bewildered, and vacant when Alzheimer's develops in the story, but by



Written by Véronique Van den Abeele Illustrated by Claude K. Dubois

the end she appears happy in her new life. At the end of the story, Grandma remembers her special kiss with her grandchild, indicating that she is in the early to middle stages of Alzheimer's. This message may not be appropriate for children who have loved ones in the later stages of Alzheimer's, as your loved one may not be able to make such recollections.

You and your child may want to read the book one or two times together before using it as a topic of discussion. What's important is talking together, not forcing a conversation or expecting that reading the book will explain it's hidden meanings to your child in place of a conversation with you.

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Discussion

Page 5

"The granddaughter really loves Grandma's treasure box, doesn't she? We have the instructions for how to make one of those in the activities section of this kit! Would you like to make one with _____?"

If ______ is at a stage where they can no longer participate in the creation of the memory box, consider making one as a family to share with them or just to keep for yourselves.

Page 12

The granddaughter talks about how grandma would sing to her "You Are My Sunshine." Singing this song to grandma would have been beneficial, because music can bring up memories. Also, singing to grandma "You Are My…." and letting her fill in the blank could be a beneficial memory exercise. (Larsen, 2006)

Page 13

Mistaking her granddaughter's face for someone else's is considered an indicator of the early stages of Alzheimer's. (Larsen, 2006)

"Does ______ ever confuse you for someone else? How does that make you feel? When someone has Alzheimer's and makes this mistake, it's usually because they are feeling confused, not because they don't love you. ______ still loves you very much."

2

Page 14

When Grandma misunderstands what her granddaughter is asking, this is considered an indicator of the middle of the early stages of Alzheimer's. (Larsen, 2006)

"People with Alzheimer's can find words confusing sometimes. They don't always sound right when they hear them, and they don't always come out right when they say them. This can make them sad, because they want to listen to you but things don't sound right, and they know what they want to say but it doesn't come out right. How would that make you feel?"

Pages 14, 17, 21, & 22

During the later part of the middle stages of Alzheimer's, patients can be known to gaze downwards. (Larsen, 2006) Grandma seems to be doing this on these pages.

Page 15

Grandma misplacing her shoes in the refrigerator could be viewed as the kind of confusion that indicates the early stages of Alzheimer's.

"Whoops! What a mix up! Has ______ ever mixed up something like that? What's a nice way we could help ______ if something like that happens again?"

Page 19

Grandma's going to an assisted living facility means she needs help with her daily living activities. This is an indicator of being in the late part of the early stages of Alzheimer's. (Larsen, 2006)

"Going to live somewhere new is a very big change. How would you feel if ______ left their home to live with other grandmas and grandpas? What would change? What would be better?"

Page 21

Grandma is brought cupcakes by her granddaughter. Making the cupcakes together could have been a positive experience to participate in with grandma, perhaps as a day trip for

the family, because it was something she was used to doing with her granddaughter. (Larsen, 2006)

"Look at those yummy kinds of cupcakes! Do you know what ______'s favorite kind of cupcake is? Maybe we can have ______ over soon to make cupcakes together."

Cupcakes may not even be something your loved one likes. Making their favorite is what's important here. It will jog their memory and provide comfort in the familiar.

Not every patient will benefit from outings. Talk to their care providers first to find out if such a visit can be arranged.

Not every patient should have sweets. Talk to their caregivers first to find out what kinds of treats can be made.

Page 22

The granddaughter mentions picking up pretty colored leaves to give to her grandmother. Noticing the beautiful in the world surrounding you builds positive feelings and can remind both Alzheimer's patients and caregivers that there is a lot to be thankful for. (Kosik, 2015) In addition, they could be turned into new treasure boxes together, reinforcing those positive feelings.

"I wonder what those leaves look like? You know, _____ sometimes feels very sad because they have Alzheimer's now. The world is a very beautiful place and if we can help remind _____ of all the beauty, it may cheer them up. What are some beautiful things about where _____ lives?"

Page 23

The granddaughter talks about sitting on grandma's lap and holding hands. The power of touch can be very impactful for Alzheimer's patients, providing both memories and comfort from those they trust the most. (Larsen, 2006)

"Grandma looks so happy to have some cuddle time with her granddaughter! You know, your touch has the power to make ______ feel better. What are some nice ways to use your touch with _____?"

- Cuddling
- Hugging
- Holding Hands
- Lap sits
- Brushing Hair

All of these, as well as your child's own healthy suggestions, are welcome.

Resources

Kosik, K.S., (2015) Outsmarting Alzheimer's: What You Can Do to Reduce Your Risk. The Reader's Digest Association, Inc.

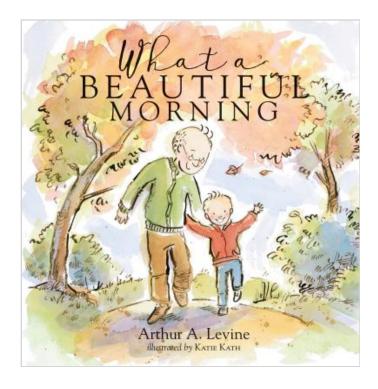
Larsen, F. K., Bowman, A., (2006). Learning to speak Alzheimer's: The New Approach to Living Positively with Alzheimer's Disease. (A book for a positive look towards Alzheimer affected). Dementia, 5(2)



Book Discussion: What a Beautiful Morning

What a Beautiful Morning By Arthur A. Levine Illustrated by Katie Kath Running Press Kids

This story of continuing to appreciate your loved one with Alzheimer's and embracing your new role in their life will leave you feeling reassured, from the tender story right down to the end papers of the book, which mirror Grandpa's shirts.



You and your child may want to read

the book one or two times together before using it as a topic of discussion. What's important is talking together, not forcing a conversation or expecting that reading the book will explain it's hidden meanings to your child in place of a conversation with you.

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Discussion

Pages 7 & 8

"What are some of your favorite songs? Do you and ______ ever sing together? Do the two of you have favorite songs?"

"Music is good for people with Alzheimer's, because music has strong ties to our memories. We can use music in a lot of ways to make ______ feel better. We can dance, sing, or even just listen to their favorite music together!"

Pages 11 & 12

The illustrations here give us a helpful hint for talking about Alzheimer's with kids: Grandpa's confusion is indicated by the washed out gray change of colors in the illustrations. It's a clue that something isn't right and Grandpa feels confused.

"Can you tell me the next time grandpa seems confused using the colors as a clue?" "What are some clues we can think of that help us know when ______ is feeling confused? What should we do when we see those clues?"

Pages 13 & 14, 15 & 16, 17 & 18

"This part of the story seems a little scary and a little sad for Noah. Have you ever felt like Noah? What happened?"

"I really like how Grandma says we should appreciate what Grandpa still has. What are some things about ______ that you still love and appreciate?"

Pages 21 & 22, 23 & 24, 31 & 32

"When grandpa hears Noah sing, he remembers the words and sings with Noah. Look how happy Grandpa is when he's remembering! Music, dancing and singing are all helpful and fun for our brains, things that we can do with ______ when we're together. Do you know any of ______'s favorite songs?"

Page 36

"Holdings hands is another nice thing we can do for _____. It can make them feel better, plus taking a walk is exercise that is good for the brain! Would you like to hold hands or take a walk with ______ next time we see them?"