

In My World

GUIDE

Short Stories About
Familiar People and Places

L A U R A B O W L E Y

A Guide to *In My World*

In My World is more than a book of short stories; it is an activity for a person in the middle-to-late stages of Alzheimer's disease or another form of dementia to enjoy with a care partner or on their own. Note that people in the early stages of dementia may find this book too simplistic. There are books available for readers who desire a different level of challenge in the form of short novels.

The philosophy behind this book is that people with dementia can and want to be engaged in activities that stimulate their learning and thinking. Boredom—and lack of challenge and purpose—are detrimental to everyone's health, especially people with dementia.

In particular, apathy is a little-understood symptom for many people with dementia. While some people might not participate in an activity because the activity is unappealing, many others simply need support in getting started! When that support is lacking, boredom can quickly set in, setting a downward spiral in motion.

In My World is one answer to boredom. Shared reading is an activity that is simple to implement and fun to do, and surprisingly effective in engaging people in the later stages of dementia and providing the one-on-one interaction needed for the best sort of engagement to take place.

You will notice that *In My World* offers a series of short, one-page stories. This is done to provide the shortest path possible for someone in the later stages of dementia to a destination where they can feel a sense of accomplishment and success at a time in their lives where society provides few, if any, opportunities to feel successful. Rather than thinking of the stories as “too short,” think of them as twelve opportunities for feeling good about one's self, something we can all appreciate.

The Story of *In My World*

At age eighty-five, my mother Betty had a stroke that resulted in significant loss of her cognitive abilities. She had vascular dementia, and even prior to the major stroke, her memory had been deteriorating for some time.

When I first came up with the idea for the *In My World* books, Betty could hold abbreviated conversations. She could not reminisce, but remembered the names of her immediate family when prompted, and smiled and greeted people in the hallways of her nursing home. Betty could count and spell, and although she could read in a limited manner, she would never pick up a magazine. In addition to apathy, Betty was easily bored by text that was too long or that she could not understand or relate to.

One afternoon, in desperation for something to keep us both entertained during a visit, I searched around my mother's room and picked up a coffee table book. It was a big, heavy book full of photos of people and places in her town, but with little meaningful text. I leafed through the book with my mother, making up the story as I went. “Oh look, here's a picture of the mayor and his wife. They have a new baby. Isn't he cute? And here's a picture of the fair. There is a ferris wheel and a merry-go-round and lots of people having fun.”

When we reached the end of the book, my mother said, “AGAIN!” and back we went to page one. By the time we had finished, not only had an hour gone by without me noticing, but most importantly my mother was interested, engaged, learning, and remembering new details, and we had connected over an activity that we could both enjoy.

Based on this experience, and upon realizing that there were at the time few books written especially for people with dementia, I decided to create one

for my mother. I had previously bought preschool flashcards and puzzles for her, but didn't think that she would find books for small children interesting. However, I knew that the book needed to be colourful, easy to read, and engaging. I knew that the illustrations needed to be colour photos of real people in real places, so that she could relate to the pictures and wasn't forced to make sense of someone else's artful interpretative drawing of the world.

We were able to enjoy some happy hours over the book before she passed away on June 7, 2008, and it is in her memory that I now make available the *In My World* books. Thank you for sharing them with us.

Mindset Centre for Living with Dementia focuses on changing the story of dementia. The negative story of dementia, which presents the experience of living with dementia as one full of loss, empty shells, and ghosts, drives our societal attitudes towards people with dementia and dehumanizes the experience of dementia. By changing the story we tell about dementia to one that more accurately reflects the lived experience of dementia as told by the people who are living with it, we can create a society that supports people with dementia in living lives of empowerment, purpose, and inclusion.

Learn more at www.mindsetmemory.com.

—Laura Bowley

How to Use This Book

The book is designed to support a person in the middle-to-later stages of dementia to regain their ability to read, and to give them and their care partners an activity that can be shared and that can lead to enriching discussions and reminiscing.

Short, Stand-alone Stories

Each two-page spread contains a stand-alone story. Readers with short attention spans and limited information-retention will appreciate the one-page stories and will feel a sense of success at the completion of a page. At the same time, because

the book contains twelve photographs and stories, readers with longer attention spans can complete as much as they wish.

Large Colour Photos

Each story features a large colour photograph depicting a scene from “in my world.” Looking at and discussing each photo is a great way to “read” the book, and discussion often heads off in the direction of “This reminds me of . . .” or “I remember when . . .”. Many readers will simply enjoy looking at and thinking about the photos without reading the text.

Text

Each story is printed in a large readable font, with extra space between each line for added readability. The sentences, for the most part, are short. Encourage and support the reader in reading the book out loud. Some readers may be confused about where to start reading; care partners can assist by pointing to the beginning of the paragraph or a sentence, or to a word.

Trigger Questions

This guide includes Trigger Questions to accompany each story. These questions are meant to spark discussion, and are designed to accommodate various abilities. For example, some questions require only “yes” or “no” answers. Others require factual answers, such as describing an item as “green.” Some questions concentrate on the reader's likes or dislikes, while other questions ask the reader to consider the emotion portrayed by a person in the scene. For readers who enjoy reminiscing or telling their own stories, “tell me about” questions are included.

Hints

While many readers would enjoy reading the book by themselves, the real power in this activity—and in other activities such as music or art—is in the one-on-one interaction that takes place during the

activity. Don't underestimate the power of human interaction—talking, acknowledging, reinforcing success, showing that the reader's words and actions have had an impact on you—as a form of therapy. Basically, it doesn't matter the nature of the activity; it's the human interaction that takes place over that activity that has the greatest potential for having impact and bringing joy to others.

The stories in this book are not sequential. Each photograph and its associated story stands alone, meaning that you can stop and start anywhere in the book. The reader may not approach this book in a linear manner; they don't need to or want to go through a book sequentially or work through every page. Go with the flow and watch the reader for signs of boredom, stress, or enjoyment.

Care partners reading *In My World* with a person with dementia should be mindful to “let go of their realities,” or—more importantly—what they think the reader's reality ought to be. Rather, be with the person with dementia, wherever that may be.

The reader may not wish to look at a particular photograph. Watch for negative reactions that a photograph might trigger and suggest that you both move on to the next page.

Be mindful not to correct the reader and allow the reader to choose the pace. People with dementia report that if they have trouble getting words out or answering a question, often they just need more time. Try to avoid speaking for them, filling in the blanks yourself, or getting frustrated and taking over.

On the other hand, if the reader seems to trail off, care partners should assess the situation and decide whether it's appropriate to pick up the reading where they left off, to encourage the reader to finish themselves, to move on to the next page, or to put the book away for the time being.

The reader might not understand a question. Try rewording it once but don't push it. Move on to another question, or stop asking questions altogether.

Watch for signs of stress that may be caused by frustration, confusion, or other emotions. Assess the situation, move on to another page, or put the book away for now.

The reader may recall details from the book after you have finished it and put it away. If your reader is not too tired, bring the book out again and take a look at the page!

Trigger Questions

The following Trigger Questions are meant to facilitate discussion. Rather than turning the questions into a quiz, use them to spark discussion by looking for the answers together in the text. You will learn what type of questions your reader responds to best and based on this knowledge, begin to make up your own questions. For example, a scripted Trigger Question for a particular photograph might read, “What is the girl doing?” The reader might not know, and may answer “I don't know.” You can say, “She's doing homework,” and then ask an unscripted question: “Did you do homework when you were a child?” The reader might respond, “Yes.” You could then ask, “Is the alphabet homework?” The answer comes back, “Yes.” If you know that your reader can recite the alphabet, you can then ask “What's the first letter of the alphabet?” If a positive response is received, sing the alphabet song!

Be mindful that the questions meant to trigger memories might not trigger memories in all cases. Don't push for a memory as this can cause undue stress for the reader, who thinks he or she ought to remember some event but can't.

If a Trigger Question triggers a “memory” for your reader that you know for a fact is not true, don't correct him or her. Remember: Step into the reader's reality and run with it! The point is to support your reader to have fun and to think; what they are saying is true for them.

Story 1: Annie-May Learns the Alphabet

- Is the mother smiling?
- Is the girl wearing a blue shirt?
- Are they sitting in a chair?
- What is the girl's name?
- Whose lap is Annie-May sitting on?
- What letter is the mother holding?
- What letter comes after "C"?
- Tell me about something that you had to teach [me/us/your children/someone].
- Tell me about one of your favourite activities as a child.
- Tell me about your children/grandchildren.

Story 2: A Summer Picnic

- Is the family having a picnic?
- Are they sitting at a picnic table?
- Are they eating watermelon?
- Do you like picnics?
- Is the dad telling a funny story?
- What is your favourite picnic food?
- Do you like to camp?
- What makes you laugh?
- Tell me about a time when you went camping or had a picnic.

Story 3: A Breakfast Surprise

- Is the family eating breakfast?
- Are the children drinking juice?
- Is the family in the kitchen?
- What is Dad eating?
- What is Mom doing?
- What is your favourite meal of the day?
- Why are Mom and Dad smiling?
- Where is the family going on vacation?
- Tell me about a time that you took a trip. Where did you go? Do you have a favourite place to travel? If you could go anywhere in the world, where would you go?

Story 4: Winter Fun

- Is it winter in the picture?
- Is the snow white?
- Are the children wearing mittens?
- Do you like snow?
- What are the children doing?
- Are the children happy?
- How many children are riding in the sled?
- What season do you like best?
- Tell me about your favourite winter activity. Did you like to go skiing? Sledding? Or would you rather curl up by a warm fire?

RESOURCES

Living with Dementia: Resources for Living Well web tool that provides comprehensive information and resources to persons with dementia and their family partners in care for living well and preparing for the road ahead — www.livingwithdementia.uwaterloo.ca/

Alzheimer's from the Inside Out: Gain insight into the experience of living with dementia, from the perspective

of a man with Alzheimer's disease. An excellent book by Richard Taylor, PhD. Available on Amazon.com.

Love, Loss, and Laughter: Seeing Alzheimer's Differently: A beautiful book of photos that gives a different perspective on the experience of dementia. By Cathy Greenblat. Available on Amazon.com

Story 5: At the Amusement Park

- Is the boy's t-shirt blue?
- Is the boy riding on a merry-go-round?
- What is the boy's favourite animal on the merry-go-round?
- What is the boy's name?
- Is Joe having a good time? How do we know?
- What rides do you like to go on at the fair?
- Tell me about a time when you went to a fair or an amusement park. What activities did you like to do at the fair?

Story 6: The Big Putt

- Is the sky blue?
- Is the man playing golf?
- Is the man holding a golf club?
- Will the ball go in the hole?
- How many people are in the picture?
- What colour is the ball?
- What is the man's name?
- What type of golf club is Harry holding?
- Where is Harry's ball?
- What will Harry's score be for the hole, if he makes this putt?
- Tell me about a time when you played a sport. Do you like to play golf?

Story 7: Buying the Groceries

- Are the people shopping?
- Are the people shopping in a grocery store?
- Are the people buying meat?
- Is the woman's name Cheryl?
- What is the man's name?
- Are Cheryl and Stan friends?
- What are Cheryl and Stan buying?
- Why are they buying fruit and vegetables?
- Tell me some of the things in Stan's shopping cart.
- When you go grocery shopping, what food do you like to buy?
- Do you like to cook? Tell me about some of your favourite recipes or dishes to make.

Story 8: The Wedding

- Is the bride's dress white?
- Is the groom wearing a hat?
- Are they walking down the steps?
- What is the bride's name?
- What is the groom's name?
- What are the guests throwing at Ashley and John?
- What is Ashley holding in her hand?
- What flowers are in Ashley's bouquet?
- Tell me about a time you were at a wedding or a special celebration.

Engaging Alzheimer's: Through telephone coaching and/or on-site services, Engaging Alzheimer's provides dementia coaching to families of those with dementia, who will benefit from learning daily activities to help their loved ones. <http://engagingalzheimers.com>

Dementia Specialist Consulting: Consulting, training, comprehensive care coordination and ongoing family support. <http://www.dementiaspecialistconsulting.com>

Dr. Al Power: Author of *Dementia Beyond Drugs* and *Dementia Beyond Disease*, provides families and professionals with a compassionate and relationship-based approach to caring for those with dementia as an alternative to drugs. Books available on Amazon.com.

For services for people with dementia and their families in your area, please refer to your local Alzheimer's Society or Alzheimer's Association chapter.

Story 9: Putting Out Fires

- Is there a fire truck in this picture?
- Are the people in this picture firefighters?
- Are the people holding hats?
- Are the hats yellow?
- How do we know the truck is a fire truck?
- Count the number of people in this picture.
- What does the sign on the truck say?
- What did the firefighters rescue today?
- How do we know when a fire truck is coming down the road?
- Did you ever visit a fire station? Tell me about your visit.
- What is your profession? What jobs have you had? What was your favourite job?

Story 10: Dave's Birthday Party

- Is Dave celebrating a birthday?
- Is there a birthday cake for Dave?
- Did Dave get some birthday presents?
- How many balloons do you count?
- What colour are the balloons?
- How old is Dave?
- What did Dave's friends use to decorate the room for the party?
- What flavour might the cake be? What is your most favourite cake?
- Do you have a lot of candles on your cake?
- Tell me about a birthday party that you attended (or another celebration).
- Was Dave's party a surprise party? Do you like surprise parties?

Story 11: Dancing the Night Away

- Are the man and lady dancing?
- Are the lady's shoes white?
- What is the lady's name?
- What is the man's name?
- What evening of the week do Joan and Harry meet to go dancing?
- Where do they go dancing?
- Who plays the music?
- What kind of dancing do Joan and Harry like best?
- What music do you like to listen to? Do you have a favourite band?
- Tell me about a time when you danced.

Story 12: Our Garden

- Are there apple trees in the yard?
- Did the Smith family pick apples?
- Are apples red?
- What fruit and vegetables do you see in the picture?
- How many people are in the photo?
- What is the man's name?
- What is Steve holding?
- What will Jennifer and Dorothy make?
- What did Steve dig up?
- What did Jennifer and Amy pick?
- Do you like to garden? Tell me about your garden. What do you like to grow in your garden?

Additional resources are listed at
www.mindsetmemory.com/resources

