

Through Tara's Eyes

Helping Children Cope With Alzheimer's Disease



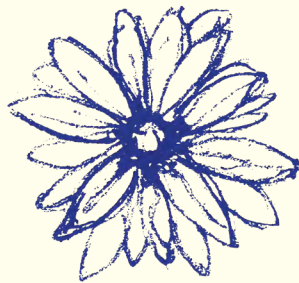
By Kathy Baumann and Erin Connors
Illustrated by Thea Kliros

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**Illustrated by Thea Kliros
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Special Note to Parents and Teachers

No family is ever prepared for a tragedy like Alzheimer's disease. It is impossible to imagine the enormous demands and changes that will affect the patient as well as his or her family. Discussing a sensitive issue such as Alzheimer's with children is never an easy task, but it is an essential element in their sense of well-being and their ability to deal with the disease in their own way.

There are a number of factors that determine how a child will respond to a relative with Alzheimer's disease, including the child's relationship with the patient before Alzheimer's disease, whether or not the patient is living in the same home as the child, and the child's age. Young children often form a special, loving relationship with a confused or forgetful grandparent, patiently taking them for walks, playing simple games, or singing together. Older children and teenagers may be embarrassed by the Alzheimer's patient's unusual behavior. This is particularly true if they think their friends won't understand.

Despite their specific circumstances, all children need a chance to express their feelings, which are likely to reflect conflicts similar to your own—sadness, anger, love, fear. Make it easy for them to talk to you by setting aside a time when they can have your undivided attention. Children also need information. A good explanation of the disease, without being too technical, is necessary if the child is to feel more comfortable with the situation. For young children, explain that their grandparent or loved one is sick, and has a disease that makes him or her confused and forgetful. Sometimes loved ones with Alzheimer's may act strange. If they lose their temper, it's because they're sick, not because they don't love the child anymore. Sometimes children wonder if a loved one's Alzheimer's disease is their fault, or they may wonder if the disease is contagious. Although Alzheimer's disease can strike people in their 40s and 50s, those cases are rare. The disease most often affects people over the age of 65, and is not contagious. Gently and carefully exploring the child's feelings will help bring these worries to the surface so they can be laid to rest.

Don't try to shelter children from the decision-making process. Having a grandparent with Alzheimer's come to live with them will change their lives, perhaps making it necessary to play more quietly or move bedrooms and furniture around. Putting a grandparent in a nursing home may mean there is less money available for summer trips. Children realize that their parents will make the final decisions, but they need to know that their own feelings matter and will be taken into account.

And finally, because dealing with Alzheimer's is so difficult, it's easy to forget that even painful experiences can offer children opportunities to grow. Allowing children to participate in the care of a loved one with Alzheimer's can help youngsters achieve new levels of compassion and maturity. It is our hope that this story about a young girl learning to cope with her grandmother's disease will help your child understand that it's okay to feel scared or angry or confused about the implications of Alzheimer's.

We recommend that you prepare yourself for any questions your child has by reading about Alzheimer's disease on your own. The BrightFocus Foundation offers a variety of free educational material that will increase your understanding of Alzheimer's disease. Call 1-800-437-2423. Also check your local public library for further resources.



My Seventh Birthday



My name is Tara Elizabeth Miller and I'm seven years old today. My birthday is my favorite day of the year because Grandma Spencer and I have a special tradition.

Every year on my birthday, Grandma takes me out to lunch at R.T.'s Restaurant. I can have whatever I want to eat, so I always get a hamburger with french fries and a soda. My mommy and daddy usually don't let me drink soda with my lunch, but Grandma says it's all right because my birthday is my special day.

After lunch we always go to a movie and stop to get an ice cream cone on the way home. Grandma says my birthday is one of her favorite days, too, because it is the day that I was born.





etting ready for my birthday lunch is almost as much fun as going out. Grandma and I picked out our outfits together and then Grandma fixed my hair into a french braid with a satin ribbon. As she was doing my hair, Grandma told me that our birthday tradition will always remind me that she loves me, no matter what. I told her that I will never forget our times together and that I love her, too.

When she finished my hair, we both looked in the mirror to see how we looked in our fancy clothes. Grandma always looks beautiful, and I felt very grown up.

Just before we were ready to leave, Mommy asked Grandma, “How are you feeling today, Mom? Should I join you and Tara for lunch this afternoon?”

“Our birthday tradition is a special time just for Tara and me. I feel just fine,” Grandma said. I didn’t understand why Mommy wanted to go with us today, since she had never asked to come before.

Earlier in the day Grandma called the restaurant and asked our friend Marilyn, the waitress, to put some daisies on the table. Daisies are our favorite flowers. Grandma also brought a camera along so Marilyn could take a picture of us for my photo album that I keep under my bed.





As we were walking to lunch, Grandma was acting strange. She asked me where we were going, and then she couldn't remember how to get to the restaurant. At first I thought Grandma wasn't feeling well, but then I remembered that she likes to play jokes on me, so I laughed. "You're being silly, Grandma," I said, and I grabbed her hand and led her to R.T.'s.

Every year during my birthday lunch, Grandma tells me about the day I was born. "Seven years ago today, your dad called me in the middle of the night to say you were on the way," Grandma said. "I drove right to the hospital to see you, Tara, because you were my very first grandchild."

After lunch, Marilyn brought Grandma a party hat and me a birthday crown. We put them on and she took a picture. After lunch we went to the movies, and then we stopped for my favorite ice cream, chocolate with chocolate sprinkles. When I was a little girl I could only have one scoop, because I couldn't eat the ice cream fast enough and it would melt all over me. But today, Grandma let me have two scoops with chocolate sprinkles on each scoop! Grandma said, "You can have a big cone because you're a big girl now, Tara. You are ten years old!"

I laughed. "I wish I was ten, Grandma, but I'm only seven years old today! You're always joking!" Grandma just smiled, and we started walking home eating our ice cream cones.

We were still two blocks from home when we saw Mommy walking up the sidewalk towards us. She looked very relieved to see us. "I've been looking for you," Mommy said, "you are 20 minutes late and I was getting worried."

"Why were you worried, Mommy? We are having fun," I said. Mommy looked like she was going to cry, and she took our hands and walked home with us.

Before going to bed, I went to give Grandma a kiss goodnight and thank her for my birthday celebration, but when I went into her room she was already asleep. She must be tired from our big day, I thought. I'll thank her in the morning.





What is Happening to Grandma?



A few weeks after my birthday, summer vacation began. Mommy, Daddy and I always go to the beach for two weeks as soon as the school year ends. Grandma doesn't like the hot sun and the sand at the beach, so she always stays home. Mommy says the real reason is that Grandma likes the peace and quiet while we are gone.

This year, though, Mommy told me that Grandma would be coming with us. I was so excited. "I'm going to tell her about all the fun things we can do together," I said. But when I went to talk to Grandma, she got angry and walked away without saying a word. The next day, I asked Mommy why Grandma was going to the beach with us if she really didn't want to go.

"Daddy and I don't want to leave Grandma here by herself because her memory is not as good as it used to be," Mommy said. I agreed and told Mommy that Grandma had said things that didn't make sense when we went to lunch on my birthday. Mommy didn't say anything, but she looked sad.





hen we got back from the beach, Daddy put signs around the house so Grandma wouldn't forget where anything was. There was a sign on the bathroom door, and one on Grandma's bedroom door that said "My Bedroom." Mommy took the knobs off the stove and put an extra lock on the front door. She also moved the coffee table out of the living room and took up the rug in the hallway.

"Mommy, why are you making all of these changes just for Grandma? She says you and Daddy are treating her like a baby," I said. "That's why she didn't want to come to the beach with us."

"Tara, I'm making the house safer so that Grandma won't hurt herself," Mommy explained. "We are only doing these things because we love her."

The next day, my friend Mary came over to play after school. We were playing in my room when Grandma came in. "Look at the mess you're making in here! Stop playing with those puzzles and pick up every piece now!" she yelled. Then Grandma stormed out of the room.

Mary went home, and I ran to find Mommy. Why is Grandma mad at me?" I cried. "I wasn't doing anything wrong. I always put the puzzle pieces away when I'm finished playing!" I couldn't stop crying, and Mommy hugged me tight.

"It's all right. Tara, don't cry," she said. "You didn't do anything wrong." Even though I couldn't see her face I could tell Mommy was crying, too. I was so confused. Grandma was acting strange, but I didn't know why.





hat night, Daddy and Mommy sat down with me in my bedroom. “Grandma hurt my feelings when she yelled at me,” I told them. “Why did she do that?”

Mommy and Daddy looked at each other sadly. “Tara, Grandma is sick. She has Alzheimer’s disease,” Mommy said. Daddy explained that Alzheimer’s disease is a sickness of the brain, so even though Grandma is sick, she doesn’t look different, she just acts different. The disease makes her forget things and say things that don’t make sense. He said that’s why Grandma got angry at me.

“I don’t want Grandma to be sick,” I said. “Will she get better?”

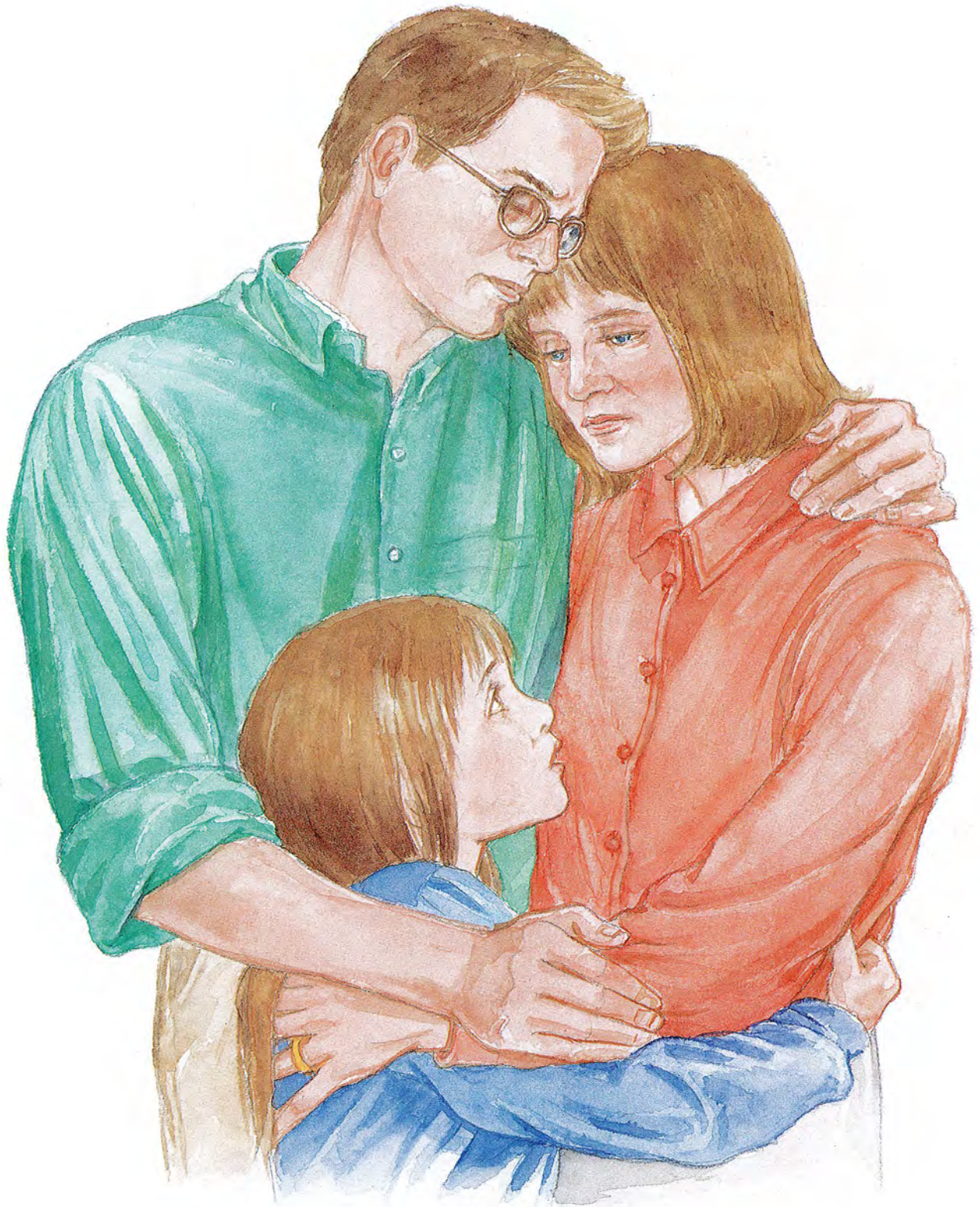
“No, Tara,” Daddy said, “Alzheimer’s disease is not like a cold or the flu. Grandma won’t get better.”

I started to cry, and then I got scared. “What did Grandma do to get this disease?” I asked. “Are we going to get it, too, if we kiss or hug her?” I had so many questions running through my head.

“Alzheimer’s disease usually happens to older people like Grandma,” said Daddy, “and you can’t catch Alzheimer’s disease by being around someone who has it.”

Mommy explained that as the disease got worse, Grandma would begin to forget more things, and one day she might even forget who we are. “But Grandma told me on my birthday that she’ll always remember me and love me,” I said.

“Tara, even though Grandma might forget our names, it doesn’t mean that she doesn’t love us,” Mommy said. “Grandma doesn’t want to be sick, but she can’t help it. The best thing you can do is show Grandma how much you love her so that she knows she is special to you,” said Daddy.





Grandparents' Day

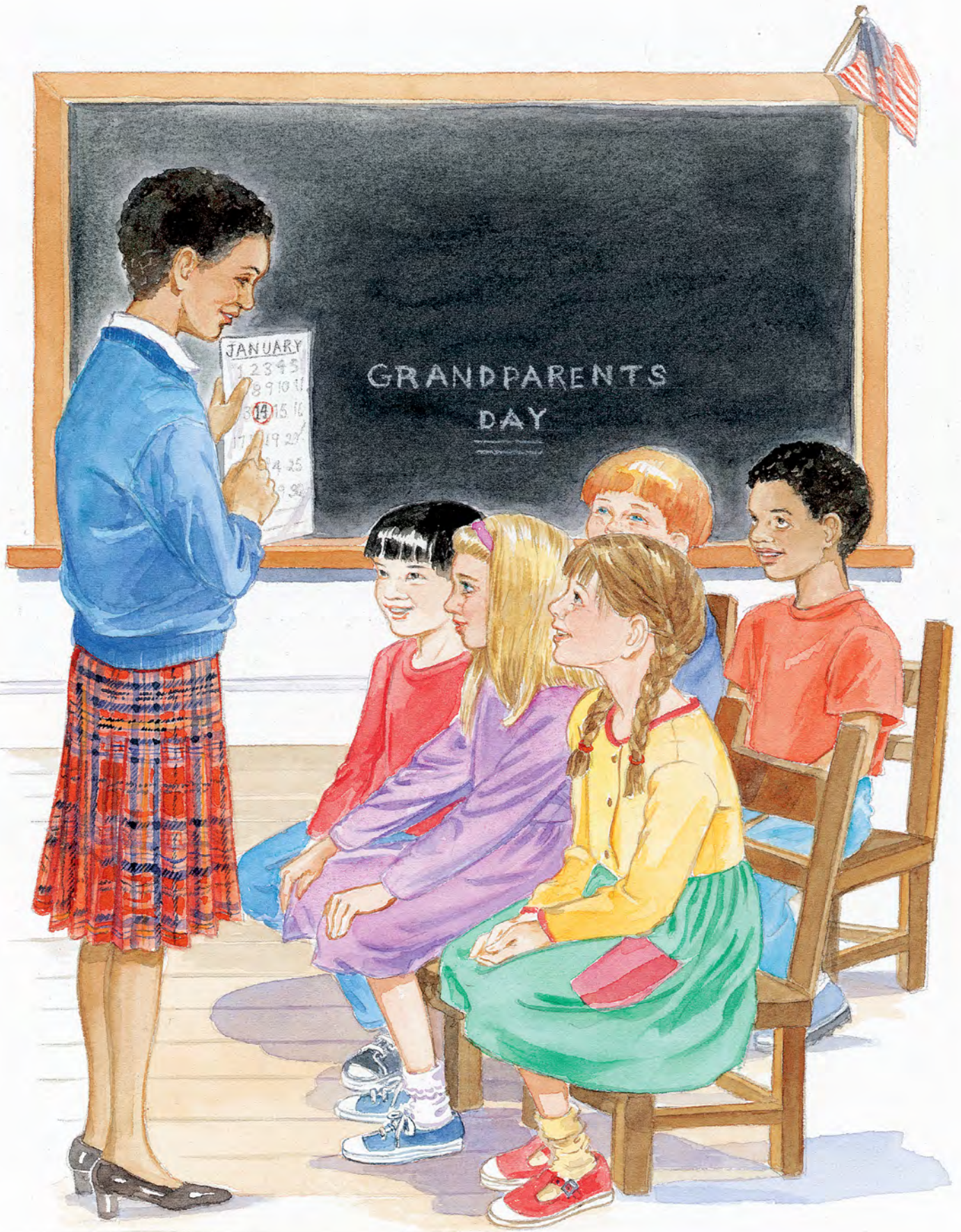
Just before Christmas my teacher, Ms. Quinn, told our class that we would be having a Grandparents' Day. Ms. Quinn explained that our grandparents could come to school to meet our friends and teachers and have lunch. For the next few weeks we would be preparing a special program for them. I wasn't sure I wanted to bring Grandma Spencer, but Grandma and Grandpa Miller live too far away. That night, I told Mommy about Grandparents' Day.

"Is Grandma too sick to come to school with me?" I asked.

"I don't know," Mommy said. "I'll call Ms. Quinn in the morning." Mommy told Ms. Quinn that Grandma has Alzheimer's disease. Ms. Quinn said that if Grandma's doctor said it was okay, Grandma was welcome to come to Grandparents' Day.

The day before Grandparents' Day, Ms. Quinn taught the class about Alzheimer's disease. She explained that when people have Alzheimer's disease, something happens in their brain that makes them forget things or act strange sometimes. She said that no one should be scared of the disease because you can't catch Alzheimer's disease from someone else. Then Ms. Quinn told the class that my grandmother has Alzheimer's disease and that she would be coming to Grandparents' Day.

Ms. Quinn asked me if there was anything I would like to tell the class. All of the kids turned and looked at me. I said, "Even though my grandmother is sick, I love her and I know she loves me." The class was very quiet after that, and I could tell everyone was a little confused. That's okay, I thought. When I first learned about Alzheimer's disease, I was confused, too.





hat night my stomach hurt. I was nervous about Grandparents' Day. As Daddy tucked me into bed he said, "Tara, you should feel proud that you are bringing Grandma to school tomorrow. She is very excited about going and has been talking about it for days."

"But what if the kids at school make fun of Grandma?" I asked.

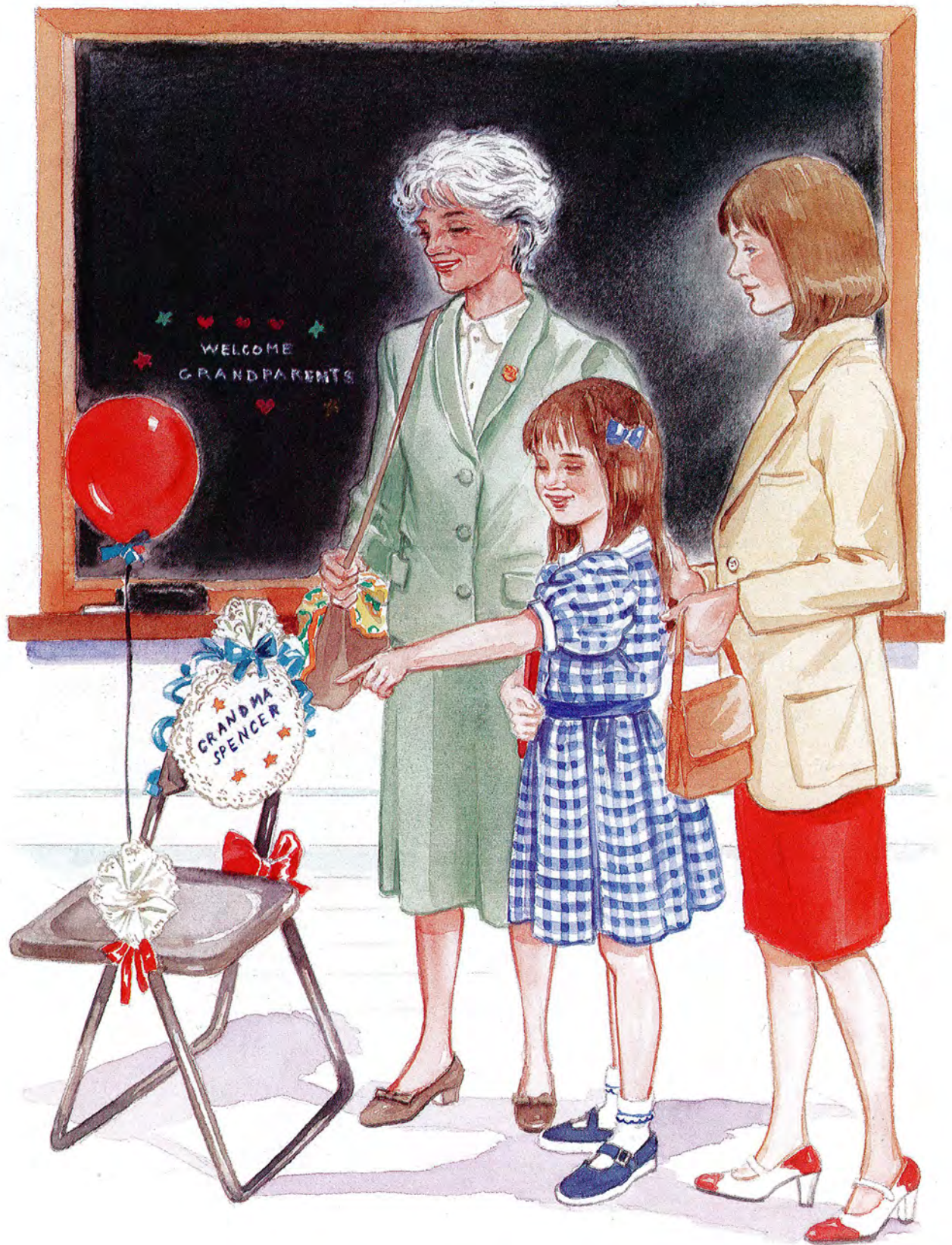
"Don't worry, Tara. If you show the class that you love Grandma, they will love her, too," Daddy said.





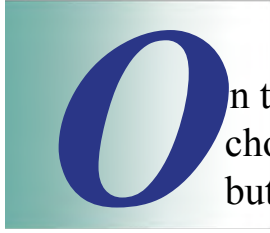
he next morning, I told Grandma how beautiful she looked, even though I knew mommy had helped her a lot. Grandma hugged me tight and whispered, “This reminds me of our special birthday lunches.” I smiled and kissed Grandma’s cheek.

When we got to school, I walked into the classroom with Grandma and Mommy. “Look Grandma, I said, “the class decorated your chair!” They had also put her name on the back of the chair so she would remember where to sit. Grandma didn’t understand why she was getting so much special attention, but I knew she was happy to be at school with me. And I was happy she was there, too. Grandparents’ Day was fun after all.





My First Solo



On the first day of May, my class put on a play at school, and I was chosen to sing a song by myself. I was nervous about my first solo, but I didn't make any mistakes, and I knew my Mommy and Daddy would be proud of me. After the show was over, Ms. Quinn told us to find our parents and go to the cafeteria for punch and cookies. I started to go when Ms. Quinn took my hand and said, "Tara, come with me for a moment." Ms. Quinn took me to Mrs. Finch, my next door neighbor.


"Tara, you're parents aren't here, you'll be coming home with me," Mrs. Finch said. "Your grandmother got lost this morning and your parents spent all day looking for her. But don't worry, she is safe at home now."

I didn't understand how Grandma could get lost, and I was very angry with Mommy and Daddy for missing my solo. I had practiced my song for a long time and they knew it was important to me. How could they have missed it?

When Mrs. Finch dropped me off, I stomped through the living room, right past Mommy and Daddy, and went to my room and slammed the door. Mommy and Daddy followed me up the stairs and came into my room. They hugged me tightly and apologized for missing my play.

"Grandma wandered off this morning and we had to call the police to help us find her," explained Daddy. They found Grandma at the grocery store on Oak Street where she used to shop when Mommy was a little girl. Daddy told me that sometimes people with Alzheimer's disease forget things that happened yesterday, but remember what happened a long time ago. That's why Grandma was at the grocery store, because she used to go there when she was younger.





I was happy that Grandma was safe, but I was mad at her for ruining my play. Mommy made my favorite dinner, spaghetti with meatballs, and chocolate cake for dessert, but I wasn't hungry. I asked to go to my room, and after a while Mommy came in and sat down next to me. She had tears in her eyes and told me how very sorry she and Daddy were for missing my play. She pulled me into her arms and squeezed me really tight. I started crying again. "Grandma ruined everything, Mommy. I am really mad at her!"

"Tara, Grandma's Alzheimer's disease is getting worse," Mommy said. "I know it's hard for you to understand what is happening to Grandma. Sometimes it's difficult even for Daddy and I to understand. When we found Grandma this afternoon, she was very scared, just like you were when you got lost that day at the shopping center. She's very upset about what's happening to her because she knows her memory is slipping away," Mommy said.

I looked out my bedroom window and saw Daddy and Grandma sitting on the bench in the backyard. Grandma's head was on Daddy's shoulder and he was gently stroking Grandma's hair. When I saw them I was sorry I had gotten mad at everyone. "Mommy, what is happening to Grandma makes me sad sometimes," I said. "I wish things could be the way they were."

"I wish they could, too, Tara," Mommy said sadly. "But we are a family, and families take care of each other. Grandma needs all three of us to care for her, now more than ever. Daddy and I love you just as much as we always have, and Grandma loves you, too, even if she doesn't always show it." I promised Mommy that I would help take care of Grandma.





I Will Always Remember

My birthday is coming again in just a few weeks. But this year I'm not looking forward to it as much because a lot has changed. Mommy and Daddy explained to me that Grandma could not take me out for our special birthday lunch. Now Grandma spends a lot of time rocking in her chair and looking through old photo albums. Birthdays with Grandma had been a tradition we always shared, but now my birthday would never be the same.

A few days before my birthday, Daddy surprised me with tickets to the circus. He told me I could bring three of my friends. I was happy that Daddy tried to make my birthday special, but I told him I had already made plans.





On the morning of my birthday, Mommy helped me carry our old card table and two chairs out to the backyard. Daddy cooked hamburgers on the grill while I helped Grandma out to the table. I also brought out our birthday hats from last year. After lunch, Grandma and I sat in the old swing and looked through my photo album.

Mommy and Daddy gave me the birthday present I had asked for, a picture frame with daisies on it. Daisies always remind me of Grandma. When Grandma and I got to the picture in my photo album from my birthday last year, I took the picture out and placed it in my new picture frame. In the picture, I was wearing my birthday crown and Grandma was wearing her birthday hat. We were both laughing.

Grandma looked at the picture and then at me. Even though she doesn't always remember my name now, I think she remembered that day a year ago. I held Grandma's hand for a long time while we swung back and forth on the swing. I was happy that Grandma and I could still spend my birthday together, even if things were different now.





hat night I gave Grandma a kiss goodnight and placed my new picture frame on the nightstand in my bedroom. Now every night before I go to bed I look at the picture and smile. “I miss the fun we used to have, Grandma, but I will never forget what you told me,” I whisper. “I am special to you, and you are special to me.”

I want Grandma to be happy, even though she has Alzheimer’s disease. Sometimes I go into her room and we sing together and draw pictures. Other days, Grandma doesn’t want to play. She sits in her room and looks at the pictures on the wall or at the tree outside her window. During those times I think she is remembering the happiest moments of her life. She looks peaceful, because she knows we love her.



Activities

These activity sheets have been designed to initiate discussion between adults and children about Alzheimer's disease. It is recommended that adults work interactively with children to complete the activities so that children may share their feelings about the disease more freely.

1 Once children begin to understand what is happening in the story, they may more easily relate the story to their own lives. The following questions should help engage children in discussion after reading the book.

1. What was this story about?
2. What part did you like the most?
3. What was Tara's favorite day of the year? Why?
4. Why was Tara concerned about Grandma?
5. What did Grandma do that upset Tara?
6. Why was Tara concerned about bringing Grandma to school for Grandparents' Day? How did her friends react?
7. What did Tara learn about Alzheimer's disease?
8. What can Tara do to help her parents care for Grandma?



2

What do you like best about your grandparent or loved one with Alzheimer's disease? It can be something that you like to do with the person or a specific characteristic of the person.

Handwriting practice lines consisting of solid blue top and bottom lines and a dashed green middle line, repeated 10 times.



3

Draw a picture of yourself and your grandparent or loved one involved in a favorite activity.

4

Make a list of the changes you have noticed in your grandparent or loved one now that he or she has Alzheimer's disease. What change bothers you the most? Why?

Handwriting practice lines consisting of solid blue top and bottom lines and a dashed green middle line, repeated 10 times for writing.



5

How do you think you can help your family care for your grandparent or loved one with Alzheimer's disease?

Handwriting practice lines consisting of solid top and bottom lines with a dashed midline, repeated 10 times for writing.



6

Make a list of the people that you think you can talk to about the changes in your grandparent or loved one.

Handwriting practice lines consisting of solid blue top and bottom lines and a dashed green middle line, repeated 10 times for writing.

7

Circle the words that best describe your feelings about the changes happening to your grandparent or loved one.

upset

jealous

sad

frustrated

angry

confused

embarrassed

love

frightened

nervous

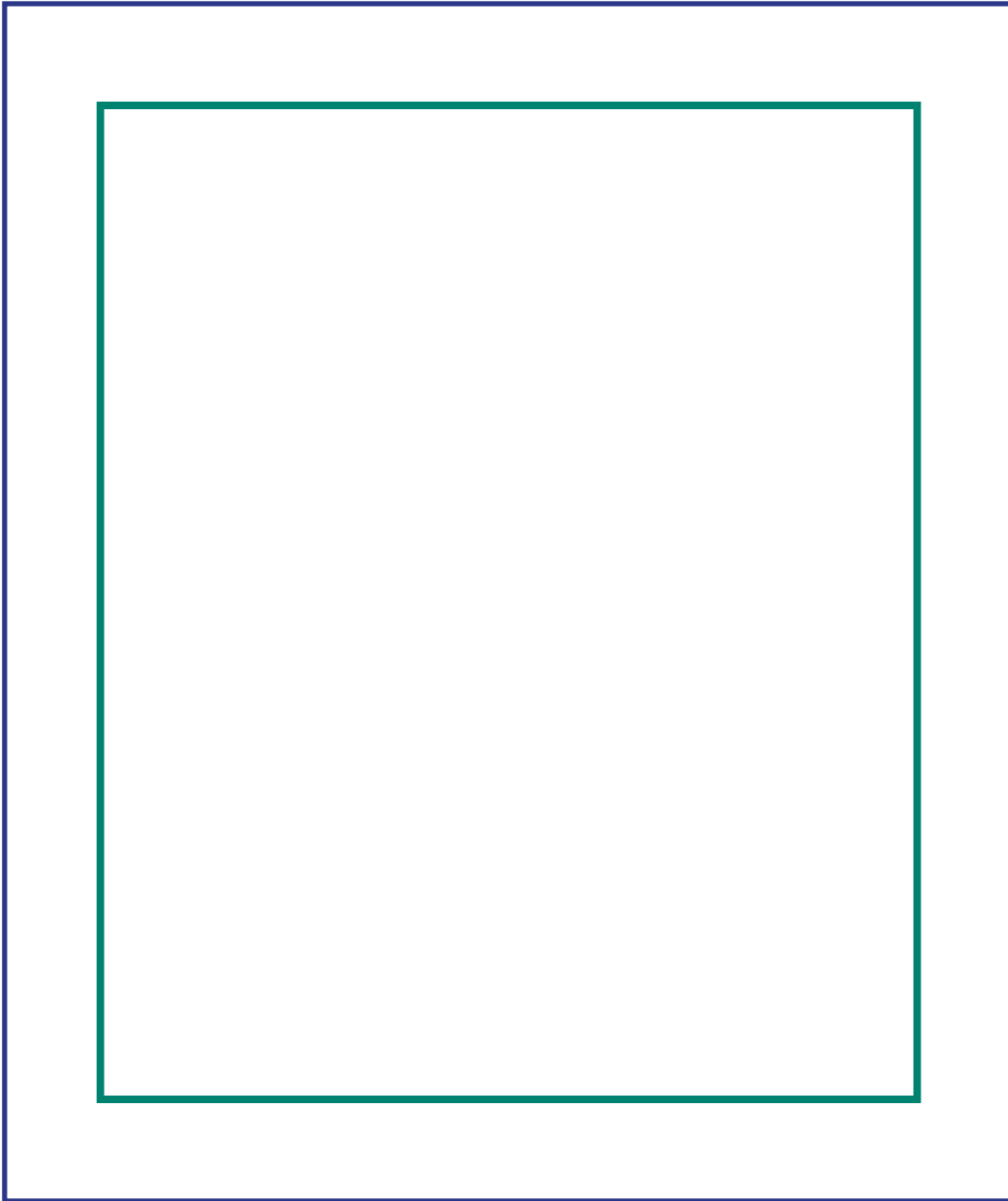
impatient

8

If you could talk to a scientist who studies Alzheimer's disease, what question would you ask?

9

In the story, Tara wanted a picture frame with daisies on it, because daisies remind her of Grandma. Decorate this picture frame with your favorite design, and then draw a picture or put a photograph of your grandparent or loved one with Alzheimer's disease in the frame.





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