

Youth in Action

A Toolkit for Young Dementia Supporters



Alzheimer Society
ONTARIO

marep
Murray Alzheimer Research
and Education Program

RIA RESEARCH
INSTITUTE
for AGING
Schlegel • UWaterloo • Conestoga



The co-design team collaborated with people living with dementia to create this mural of a garden, showing how each of us is beautiful on our own and that together we are amazing!

Acknowledgements

The development of this Toolkit was led by the Murray Alzheimer Research and Education Program (MAREP) at the Schlegel-UW Research Institute for Aging (RIA), and the Alzheimer Society of Ontario. The Toolkit is a result of collaboration with a co-design team that included people living with dementia, care partners, youth and researchers. A HUGE thank you to this passionate group of individuals for sharing your experiences and ideas to benefit youth and people living with dementia!

This Toolkit was made possible through funding provided by the RTOERO Foundation.

Some of the members of our co-design team!

Ava
Bill
Clara
Donna
Gianna

Gracen
Hazel
Jayce
Kristin
Maggie

Max
Phyllis
Shireen
Tiana

Karen, ASO
Kathy, ASO
Laura, RIA
Emma, RIA

Dana, RIA
Alicia, YCA



Toolkit for Young Dementia Supporters

Who is this Toolkit for?	2
Why was this Toolkit created?	2
Who is a Dementia Supporter?	3
What is dementia?	4
How can Dementia Supporters help?	8
Looking after you!	13
Tips for communicating with a person who has dementia	14
Why are Dementia Supporters important?	18
My Dementia Supporter Action Plan	18
Resources	21
References	22

Who is this Toolkit for?

This Toolkit is designed for kids in grade 5 and up (age 9 and older) who want to become Dementia Supporters! Older or younger kids and their families might also be interested!

They might have a family member who has dementia, they might know someone with dementia in their community, or they might just be curious about dementia and how to help. Anyone can be a Dementia Supporter!

Why was this Toolkit created?

Kids can do a lot to help people who have dementia, but they might not know how.

This Toolkit was created by a team that included kids, people who have dementia, family members of people who have dementia, and other experts! They all hoped that this Toolkit would help kids to:

- Learn more about dementia
- Share what they know about dementia
- Challenge misunderstandings about dementia
- Not feel scared to talk about dementia or talk to people who have dementia
- Hear stories from others
- Become Dementia Supporters!

If you would like to become a Dementia Supporter then this Toolkit is for you! This Toolkit will help you create your **Action Plan** that you can use to support people who have dementia!

How to say "Dementia":
Dementia is a tricky word. It is pronounced "Duh-Men-Sha".
Keep reading to learn more about what it means!



"I hope that kids aren't scared to bring up dementia or even interact with people who have dementia [...] I hope kids will understand how to interact with them nicely"

- Gracen, A Dementia Supporter

"I think it's important to hear other people's opinions and stories, just to learn more and have a better understanding"

- Gianna, A Dementia Supporter



When you see this symbol, it means you can add your ideas to your **Action Plan** on page 21.

My Story: Clara

My name is Clara. My Nana has dementia, she is very friendly and she is a painter. People don't know that dementia affects more than just memory, it also affects emotions. People with dementia can live well with the right support, and I think it's important to support them because I want to improve their lives. Being a dementia supporter is truly an honour and it makes you feel happy to know that you are helping people live their lives to their fullest.

Who is a Dementia Supporter?

Anyone can be a Dementia Supporter! Dementia Supporters are kids who want to support people who have dementia in their family or community!

All Dementia Supporters have goals to:

- Stand up for others
- Make a difference
- Tell their story, and listen to the stories of others
- Learn
- Share what they know about dementia
- Challenge misunderstandings about dementia
- Think outside the box about how things could change for the better

Choose two of the goals that are the most important to you and write them in the red box in your Action Plan!

Every Dementia Supporter is different, because every person is unique! The words below are strengths that Dementia Supporters might have!

A Dementia Supporter can be:

Find the following words in the puzzle. Words are hidden → ↓ and ↘

- KIND
- WISE
- A LISTENER
- DEDICATED
- POSITIVE
- A LEADER
- PATIENT
- HELPFUL
- CARING
- HARD-WORKING
- PASSIONATE

V	H	A	R	D	W	O	R	K	I	N	G	J	L	Z	T	D	B
Q	A	P	A	T	I	E	N	T	X	Q	A	H	M	Z	W	P	K
O	L	C	R	V	Q	P	F	A	H	Z	N	K	Y	B	A	A	D
U	E	A	H	O	N	M	P	X	S	E	W	Q	X	W	F	L	E
D	A	R	L	Q	V	Y	O	G	K	O	L	F	B	L	G	I	D
O	D	I	R	X	O	W	S	Q	R	E	R	P	K	H	J	S	I
I	E	N	P	A	S	S	I	O	N	A	T	E	F	H	K	T	C
Z	R	G	U	D	S	G	T	W	Q	J	S	K	W	U	H	E	A
C	M	M	O	S	R	W	I	I	N	W	O	L	I	X	L	N	T
E	P	B	Y	E	Y	D	V	C	N	A	Y	A	S	N	L	E	E
O	A	V	I	H	J	Z	E	U	D	N	K	Z	E	Z	D	R	D
M	M	P	K	K	G	E	L	J	C	T	T	P	X	A	S	C	T

Choose a few of the strengths from the list above - or think of a new word - that best describe you! Write them in the orange box in your Action Plan!

What is dementia?

Hear it from kids! What dementia IS:

"Dementia is always changing. For example, someone might show more changes when they're tired."

- Tiana, a Dementia Supporter

"Dementia can affect a person's memory and sometimes physical health, like their balance."

- Hazel and Max,
Dementia Supporters

"Dementia can make you forget some things like birthdays, names, and words when you're speaking."

- Jayce, a Dementia Supporter

"Dementia is more common when you're older but you can get it when you are young too."

- Max, a Dementia Supporter

What dementia IS NOT:

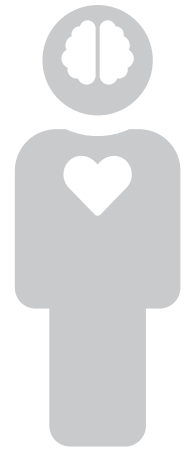
- Dementia is not contagious
- Dementia is not something to be afraid of
- Dementia does not affect every person as they get older

When someone has dementia, changes happen in their brain and stop parts of their brain from working the way they should¹. Dementia changes the way people **think, feel and act**¹. The brain continues to change over time and the changes affect the person's everyday life.

There are different types of dementia. For example, Alzheimer's Disease is one type of dementia, but there are many more, like Vascular dementia, Frontotemporal dementia, and Lewy body dementia. Dementia looks different in each person, even if two people have the same type of dementia.



Dementia is not always obvious, here are some changes you might notice.



You might notice changes in the way people:

Think: Memory, thinking, problem-solving, communication

- For example: They may forget people, things or places², or they might have trouble with speaking, reading or writing.

Feel: Mood

- For example: they may get upset or frustrated more easily.¹

Act: Movement, balance, seeing, hearing

- For example: They might see things that aren't there. They might have trouble with their balance. They might need more help with activities like cooking and getting dressed.

Kids have said that most people their age have a lot to learn about dementia.

Hear it from kids!

"They also don't know that, with help, people with dementia can live very well!"

- Jayce, a Dementia Supporter

"When I talk about my Grandma at school, they have no idea what I'm talking about."

- Ava, a Dementia Supporter

"When we talked about dementia at school, only one or two knew about dementia and they thought it was just a memory problem."

- Max, a Dementia Supporter

"When we talked about dementia at school, only one or two knew about dementia and they thought it was just a memory problem."

- Max, a Dementia Supporter

"People might pick on someone with dementia because they don't understand."

- Tiana, a Dementia Supporter

"People might make fun of someone with dementia because they're not able to see it."


- Jayce, a Dementia Supporter

"They might feel nervous about how to talk to someone who has dementia."

- Clara, a Dementia Supporter

Adults can sometimes misunderstand dementia too.

When someone doesn't understand dementia, they might believe things about it that are not true. If people believe these myths, they might treat someone with dementia differently, even without meaning to. This often happens when people feel unsure, afraid, or nervous. They might also hear false information from other people, or from movies, TV shows, and books. Being treated differently can make people who have dementia feel sad and excluded.

 The most important thing to remember is that even though people who have dementia might have some challenges or have to do things differently, they continue to live very meaningful lives, learn new things, teach other people, and be part of their families and communities!



Here are some things people might not know about dementia!

 From the list below, check off anything that you didn't know before reading this toolkit!

Every person who has dementia is unique!

- Just like all of us, everyone who has dementia is a unique person. This means that dementia will look different for each person. Everyone has different talents, challenges, and things that are important to them.

People who have dementia, just like us, can communicate in lots of ways!

- Some people who have dementia might have a hard time speaking or understanding words - but they can still communicate in other ways like waving, holding hands or a smile. Some people who have dementia, like Bill, can still speak very well.

"I still get up in front of crowds of people and speak, let alone having full conversations with people. And that's not expected."

- Bill, a person living with dementia

People who have dementia live in all different types of homes!

- Lots of people who have dementia live in their own homes, or live with their family members!
- People who have dementia may need extra help, and they might move to a new home where nurses and other carers are there to look after them.¹ These are called long-term care homes. Their families and friends can visit them in the long-term care home just like they did when they were in their own home, and keep helping and spending time with them.¹

People who have dementia can be happy and live meaningful lives!

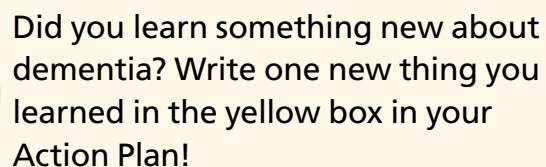
- Even though they might have some challenges, people who have dementia can enjoy lots of things that make their life meaningful - especially with support from their family and community!

People who have dementia can do lots of things!

- There might be things that take more time or are too challenging for someone who has dementia to do - but it's always better to ask and try to include them, instead of leaving them out.

"A lot of times we get told that we don't look like we have dementia, and what I say is: **what does dementia look like?** People don't realize I have a whole lot of living to do!"

- Phyllis, a person living with dementia



Did you learn something new about dementia? Write one new thing you learned in the yellow box in your Action Plan!

"There are still so many things a person with dementia can do, we just need to modify how they do it sometimes. For example, Nana can still play games with you, they just need to be simpler or involve less movement."

- Maggie, a family caregiver

My Story: Ava

My name is Ava and my grandma has dementia. My grandma is good at cooking and making people feel welcome even though she doesn't talk a lot. I live with my grandma and my mom, and I help take care of my grandma by doing anything that my mom needs me to do. Sometimes all my grandma needs is company, someone who will sit beside her and just be in her presence. I think it's very important to help her because my grandma took care of everyone that needed it. So now I take care of her. My grandma has a lot of emotion and she still is herself, even though she doesn't always show it. She makes people laugh and smile.

Keep on reading to learn how Dementia Supporters can help!

How can Dementia Supporters help?

How can Dementia Supporters help someone who has dementia in their community?

Here are some examples of ways you can help people who have dementia in your community.



Check off any ideas that you think you might try, or that you are already doing!

Talk about dementia with your friends, parents and teachers and help them understand what dementia means to you.

Share this Toolkit with your friends, teacher, or local library so that they can learn and become Supporters too.

If people make jokes or hurtful comments about dementia, let them know how that makes you feel.

Help to make the spaces in your community more inclusive and “dementia-friendly”. For example, suggest to your local library or community center that they could put up extra signs to help people who have dementia find their way around.

- Did you know that community organizations can contact their local Alzheimer Society to learn how they can become a Dementia-Friendly Community?

“I don’t really think a lot of people, especially kids my age, really know anything about dementia. So I’ve started talking about it to them so that it’s easier for them to help other people. Because I do think a lot of kids, I do think they really wanna help, they just aren’t really sure how.”

- Clara, A Dementia Supporter

Choose dementia as the topic for your project or presentation at school! Ask an adult to help you contact your local Alzheimer Society, the educator there can give you ideas and resources to share.

Volunteer at your local long-term care home (although some require you to be a certain age or be with an adult).

- You can offer to visit, read books, or do activities with the residents there

Sometimes, it's okay to ask someone if they need help - for example, if they seem confused or lost. But only approach someone you don't know if you are with an adult you trust.

Stand up for people who have dementia if they are being made fun of or excluded.





If you have other ideas of how you could help someone who has dementia in your community that wasn't listed, you can write those down too!

-
-
-



How can you help?

How many ideas did you check off or write down?



Pick one or two ideas from the last few pages that you'd like to try first and write them in the green box in your Action Plan!

How can Dementia Supporters help someone they know who has dementia, or a family member who has dementia?

(If you don't know someone who has dementia, skip to the next section!)

Kids can do a lot to help someone they know or a family member who has dementia!

Here are some examples of how other kids have helped someone they know who has dementia or a family member who has dementia:

Check off any ideas that you think you might try, or that you are already doing!

Be a role model!

- Talk to others about dementia, what you've learned, and how you are becoming a dementia supporter.

Offer to help out with chores around the house - even a little help can make a difference!

- For example, folding laundry, raking leaves, or shoveling snow.

Tell the person stories about your interests, friends and activities. And ask them to tell you stories about when they were young!³

Invite them to be a part of your activities!

"Not a lot of people in my family, other than my Mom, know the first thing about dementia. So I would probably start with educating them!"

- Clara, a Dementia Supporter

"I can show them how to play the sports that I play and after the game I can introduce them to my friends."

- Jayce, a Dementia Supporter



Do things together that you both like - play music, sing, dance, or go for a walk together.³

"I could help them find their way to the stands."

- Max, a Dementia Supporter

If they are struggling to do a task, ask if you can help them!

- You could say, "you look like you're having a hard time, how can I help you?"

Offer to do errands together or help with the shopping!

- You can help them to make a list and check things off as you go.

"I could remind them when I have a game or competition coming up. If it got too noisy, I could find a quiet place for them to relax."

- Hazel, a Dementia Supporter

"If I'm having the family over for dinner, my grandkids help me peel and chop vegetables and help to keep me focused on what I'm doing because I don't multitask very well anymore."

- Phyllis, a person living with dementia

Offer to do big jobs together, then you can spend time together while helping out!

Think about when you do things together like family dinners - are there parts that you can do so there is one less step for the person to remember?

Sometimes large gatherings of people are stressful for people who have dementia. You can look out for them and help them if they feel overwhelmed.

"You can remind me of peoples' names if I forget! Like saying, "here comes your neighbour, _____."

- Phyllis, a person living with dementia

"If it got too loud, I'd make sure they had a place to go if it was overwhelming."

- Hazel, a Dementia Supporter



Help to problem-solve if they get stuck!

- For example, if they've misplaced something and can't find it, ask them if they need help and maybe see if you can help them remember.

Going out in public can sometimes make people who have dementia feel worried. If you're out together somewhere, let them know you're there for them.

Spend time together, and show them that they are important to you!

Try your best to be patient and understanding.³

Focus on what they can do, rather than focus on what they're losing. Find ways to help them use their strengths!

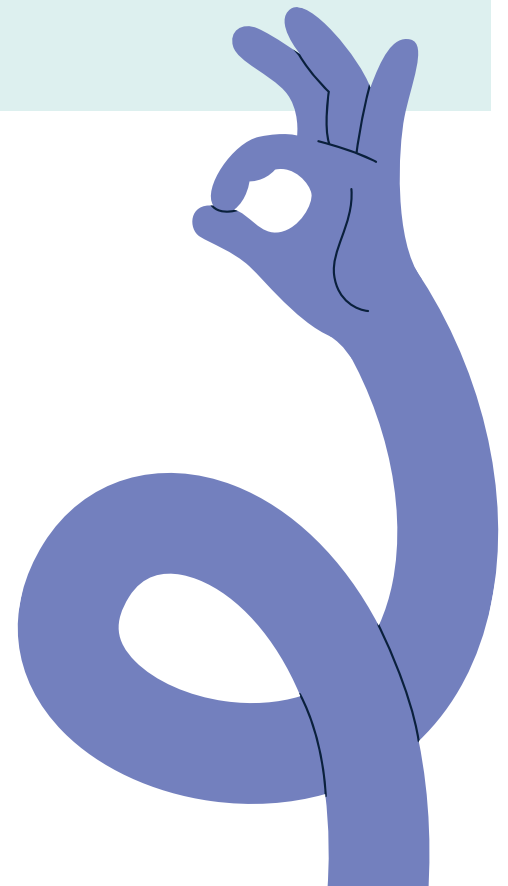
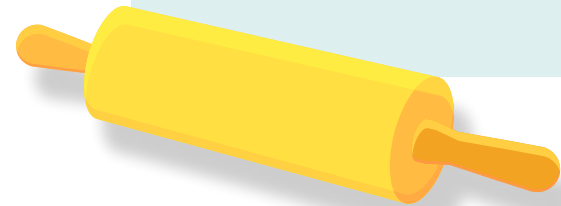
- For example, if you know they're really good at baking, ask them to bake something with you or teach you how!

"The other night I was feeling quite anxious to be out at a restaurant, and he held my hand under the table. Even something that simple does make a difference!"

- Phyllis, a person living with dementia

"I think it's like really important to spend time with those loved ones and just make sure they know that they're heard. And even if they're taking a while to get their words out, or if they're repeating themselves, still take the time to listen to them and have conversations with them."

- Gianna, a Dementia Supporter





If you have other ideas of how you could help someone who has dementia in your family that aren't listed above, you can write those down too!

•

•

•



How can you help?

Having someone with dementia in your life means lots of chances to help!



How many ideas did you check off or write down?



Pick one or two ideas from the last few pages that you'd like to try first and write them in the blue box in your Action Plan!



Looking after you!

When someone you know has dementia, it can be hard to see and deal with the changes they or the people around you are going through. There also might be changes in your life, and sometimes that might feel OK, but other times it might not.³ Some kids who find out that a family member or friend has dementia say they feel shock, worry, fear or anger.² If you feel any of these emotions, that's okay and you are not alone.



My Story: Gianna

My name is Gianna and both my grandfathers lived with dementia. I've always been super close with my entire family and I spent my childhood with both my grandfathers. They were the two people I would look up to and it seemed to me like they were the strongest people in the world. Slowly, dementia started to take a toll on them both. It seemed like that all of a sudden, they were different. They were more anxious, they were not themselves, they just weren't acting the same. And at this point, I felt confused. I didn't fully understand why this was all happening so fast. Why was he forgetting his own family members' names? I learnt much more through asking questions and through experiences. But I don't want other children to ever have to feel this way. I don't want them to ever think that it's their fault. This is why I think that it's so important to educate all youth about dementia.

These resources might help:



[Alzheimer Society of Canada:](#)

Tips for kids who help take care of people with dementia



[Dementia Australia:](#)

Supporting children and adolescents

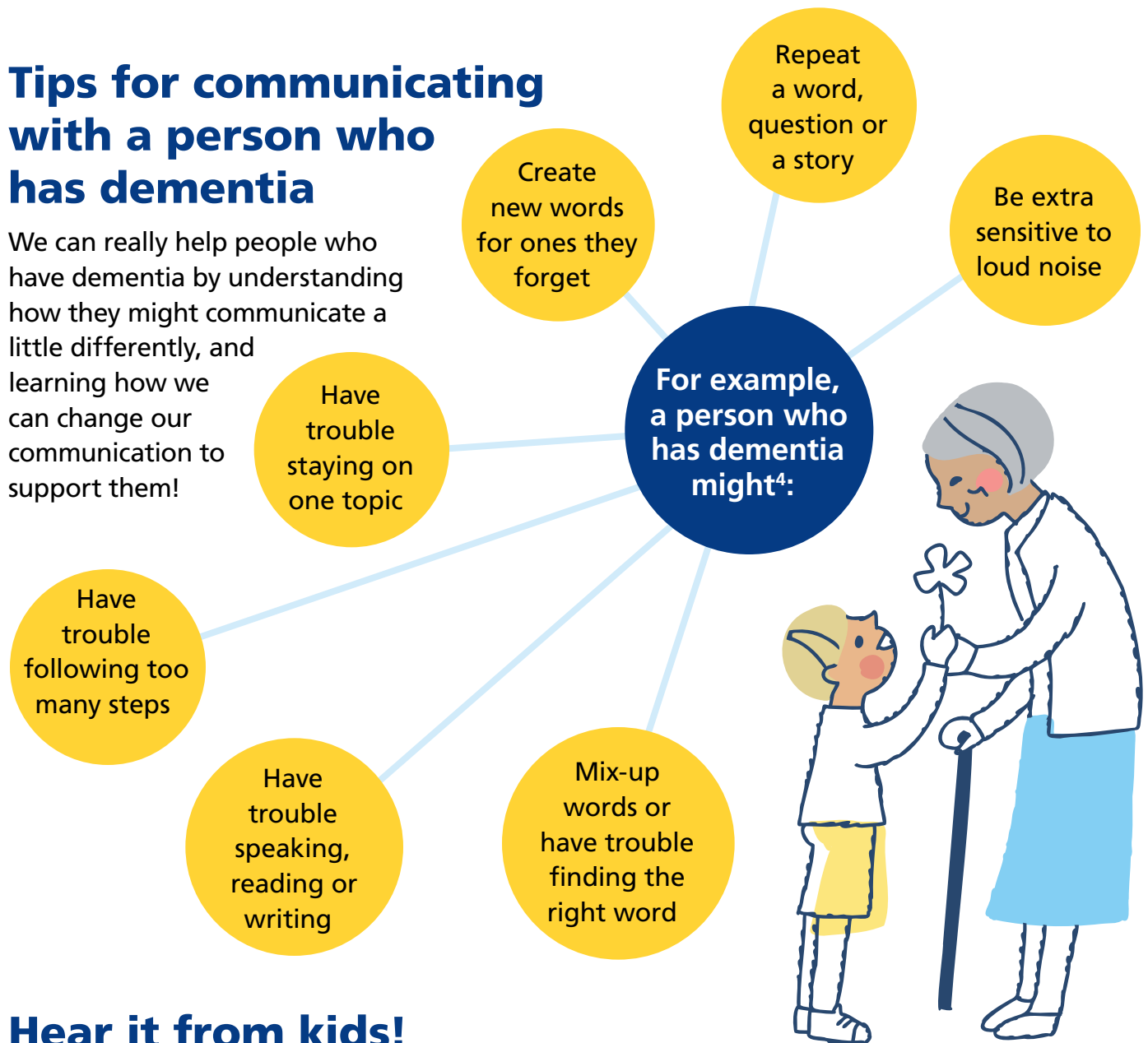


[Young Caregivers Association:](#)

Resources for young caregivers

Tips for communicating with a person who has dementia

We can really help people who have dementia by understanding how they might communicate a little differently, and learning how we can change our communication to support them!



Hear it from kids!

Here is some advice from other kids to help you communicate with someone who has dementia.

- 1 You are talking to your neighbour, Lee, who has dementia. You notice that they are mixing up their words having trouble finding the right word while they're talking to you.**

Do:

- ✓ Be patient to see if they remember. If not, you can try to help them with the word.
- ✓ Try to figure out what Lee meant to say by giving suggestions. You could say, "did you mean _____?"
- ✓ Just continue the conversation if you can or try bringing up a new topic.

Don't:

- ✗ Say "What? I don't know what you're talking about!" because that might make Lee feel bad.
- ✗ Be impatient. Sometimes people who have dementia need more time to think and respond.

2 You are taking a trip with your Grandma who has dementia. On the drive she keeps repeating the same questions, like asking if you remember going to this place before. And she keeps telling stories she has already told you.

Do:

- ✓ Answer her question each time, because it makes her happy to hear the answer.
- ✓ Pretend she didn't repeat it, and listen to the story again. If she is repeating herself it probably means that it's very important to her and she may not remember that she already said it.

Don't:

- ✗ Tell her that she already asked or told you, because it might make her feel bad.

3 Someone ahead of you in line at the library has trouble speaking and understanding what the librarian is saying. They are not able to respond to the librarian's questions.

Do:

- ✓ Pay attention to their face and body language - like do they look happy or sad?
- ✓ Use objects or pictures to help them explain what they mean or to show what you mean.
- ✓ Ask "yes" and "no" questions so they can nod or give a thumbs-up instead.
- ✓ Communicate without using words, like by smiling or you can also try doing things together that don't need words, like puzzles or looking at pictures.

Don't:

- ✗ Speak too quickly.
- ✗ Forget about body language! There are lots of ways to communicate.



4 Your Papa has dementia, and has trouble remembering your name.

Do:

- ✓ Let him know that it's okay.
- ✓ Introduce yourself again, for example, "I'm your granddaughter, _____."

Don't:

- ✗ Ask him if he remembers your name, because it might make him feel bad if he can not.

5 Your Mom has dementia. Your whole family is over at your house for a holiday dinner, and you know she can get stressed by loud noises.

Do:

- ✓ Speak and play more quietly.
- ✓ Remove loud noises around her, like turning the television down in the room she is in.

Don't:

- ✗ Yell or speak at the same time as someone else.



Pick one "Do" tip for communicating that you think will help you support a person who has dementia and write it in the purple box in your Action Plan!





Draw lines to match up the communication challenges with the communication tips!

Communication Challenge

Communication Tip!

Someone is having trouble remembering your name.

Remove loud noises around them, like turning the television down.

Someone is repeating a word, question or a story.

Introduce yourself again.

Someone is mixing-up words or having trouble finding the right word.

Pretend they didn't repeat it, and listen to the question or story again. If they are repeating themselves, it means that it's very important to them and they probably don't remember that they already said it.

Someone is stressed by loud noises.

Try "yes" and "no" questions so they can nod or give a thumbs-up instead.

Someone is having trouble understanding and responding to your questions.

Continue the conversation if you can or try bringing up a new topic. You can also try doing things together that don't need words, like puzzles or looking at pictures.

Why are Dementia Supporters important?

Dementia Supporters are young, and that's what makes their power special!

- You have the power to create change!
- You know lots of other kids and can tell them about dementia in a way that they can understand, maybe even better than adults can! By sharing what you know about dementia, you can help other people be more understanding and inclusive.
- When you talk about dementia and share your story, you make other people feel more comfortable talking about it and help them not to feel alone, especially other kids!
- Because you know that you don't need to be afraid of people who have dementia, you can make them feel more welcome and included in your community.
- Kids remind adults of stories and experiences from when they were young, which can be very special memories for people who have dementia.
- Spending time with your family members who have dementia helps them.
- Doing little things to help people who have dementia, can make a BIG difference in their lives!

"For my Mom, the social aspect of having her grandkids around and visiting lots of family on the weekends - all that communication - helps her!"
- Shireen, a family caregiver

"It doesn't take much to be supportive, even just opening a door or helping me get into a car. Teeny tiny things that may seem normal to others, mean that I can get out and live life."
- Debbie, a person living with dementia

My Dementia Supporter Action Plan


My goals as a Dementia Supporter:

My strengths:

One new thing I've learned about dementia:

One or two things I could try to help someone who has dementia in my community:

Do I need an adult's help to try these ideas?
Yes Not sure Nope

 (if you're not sure, it's always best to ask an adult you trust!)




One or two things I could try to help someone I know who has dementia or a family member who has dementia:

You can leave this section blank if you don't know someone who has dementia!



Do I need an adult's help to try these ideas?

Yes Not sure Nope

 (if you're not sure, it's always best to ask an adult you trust!)

One tip I've learned to help me communicate with a person who has dementia:

A person or group I could share this Toolkit with...

By sharing this Toolkit, you can help others become Dementia Supporters too!



Resources for Kids and Family Members

To learn more about dementia, you can visit these websites:

Organization Website

Alzheimer Society of Canada:
alzheimer.ca

Helpful Webpage

Helping children understand dementia:
alzheimer.ca/kids



Dementia Australia:
dementia.org.au

What is dementia?
dementia.org.au/about-dementia/kids-families/age-9-12/what-dementia-9-12

Organization Website

Helpful Webpage

Organization Website

Dementia UK:
dementiauk.org

Helpful Webpage

Supporting children and adolescents:
dementiauk.org/information-and-support/resources/supporting-children-and-adolescents/



Resources For Teachers and Youth Leaders

Organization Website

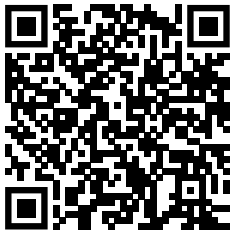
Alzheimer's Society (UK):
alzheimers.org.uk

Helpful Webpage

Dementia Teaching Resources: <https://www.alzheimers.org.uk/get-involved/dementia-friendly-resources/dementia-teaching-resources>



References



[1] Dementia Australia. What is dementia? [Internet]. Australia: Dementia & Alzheimer's Australia Ltd; 2024 May 15 [cited 2024 September]. Available from: <https://www.dementia.org.au/about-dementia/kids-families/age-9-12/what-dementia-9-12>

[2] Alzheimer Society of Canada. Tips for kids who help take care of people with dementia [Internet]. Canada: Alzheimer Society of Canada [cited 2024 September]. Available from: <https://alzheimer.ca/en/help-support/im-caring-person-living-dementia/young-caregivers/kids>



[3] Dementia Australia. What can help for age 9-12 [Internet]. Australia: Dementia & Alzheimer's Australia Ltd; 2024 Feb 1 [cited 2024 September]. Available from: <https://www.dementia.org.au/about-dementia/dementia-my-family/age-9-12/what-can-help-age-9-12>

[4] Alzheimer Society. Communication challenges and helpful strategies [Internet]. Canada: Alzheimer Society of Canada [cited 2024 September]. Available from: <https://alzheimer.ca/en/help-support/im-living-dementia/managing-changes-your-abilities/communication-challenges-helpful>



You can draw a picture of you as a Young Dementia Supporter in Action!

