



Dementia and I/DD: How You Can Help Support People and Their Families

Many people with I/DD, particularly people with Down syndrome, are at risk for dementia. Adults with Down syndrome are more likely to have dementia in their life, with 30 – 40% of people with Down syndrome having dementia by age 50. The average age of the 'onset'—that is, when we first notice changes—in adults with Down syndrome is age 52. This percentage increases as people age.

Receiving a dementia diagnosis or knowing that you may one day have dementia can be scary for people with I/DD and their families. As a result, people may be less likely to talk about these issues or plan for how they may deal with this issue in the future. The uncertainty around planning can result in poorer health outcomes for people with I/DD who experience dementia and their families.

The Arc Wisconsin, the Down Syndrome Association of Wisconsin (DSAW), and Wisconsin Upside Down have sought to learn more about what information people and their families would like to have around dementia and what they need to better plan for the future. Through tools such as focus groups and surveys, our organizations have reached out to both self-advocates and family members, targeting outreach to individuals with Down syndrome. The intent of our conversations was to better understand what both self-advocates and families need to make their experience in talking about and living with dementia more positive. We asked specific questions of self-advocates separate from family members to see if there were differences in their responses. Twenty people attended a June 6, 2019 focus group hosted at the Down Syndrome Association of Wisconsin and more than 60 people from across Wisconsin responded to the survey.

This brief shares the thoughts from both people with I/DD and their family members about how they would like to learn about this disease, the ways they can feel better supported, and resources that would be helpful. We encourage you to use this resource to better understand how you can support and talk to someone with I/DD about their risk for dementia and ensure they feel in control of their life, even as things change.

Key Findings:

- » People are in search of resources to help them prepare and live with the risk for dementia.
- » Self-advocates want to know most how this will impact their daily life and what they like to do each day.
- » There are differences in the way family members think about dementia as compared to loved ones with I/DD; families want to protect and tell their loved one not to worry while self-advocates say they want to learn more about health issues.
- » Most people we talked to did not have a comprehensive plan for the future in place.
- » Self-advocates want their input to be considered. They want to be respected and heard.

INSIGHTS BY ISSUE:

What do you want to learn about dementia?

Both self-advocates who responded to the survey and who participated in focus groups said they most wanted to know how dementia might impact their daily life and what they do each day, including how it would impact their relationships with family and friends.

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I have Down syndrome, I want to learn more about my health.

– Self-advocate from focus group

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I would want to know the truth and have my family members stay calm and take it easy with me.

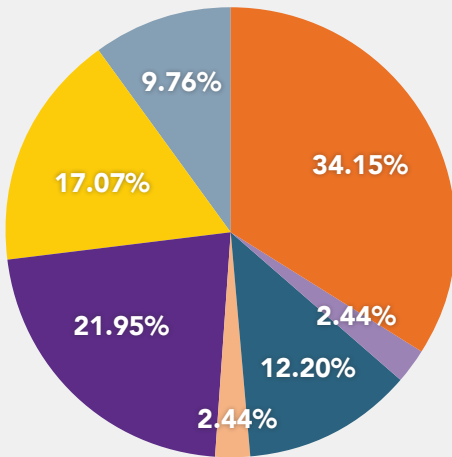
– Self-advocate survey respondent

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Family members also thought that the impact on daily life was the most important information to have as they learn about the risk for dementia but ranked stories and advice from other families as the next most important.

WHAT FAMILY MEMBERS AND OTHER SUPPORTERS RANK AS MOST IMPORTANT TO LEARN ABOUT (41 people total)



- How it may impact daily life and what people do each day
- How it may make people's bodies or minds feel
- How it may impact relationships with family and friends
- Whether the person will need someone to help with daily activities
- Stories from other people with disabilities who have the illness or condition
- Advice from people with disabilities on how to deal with the illness or condition
- Something else

How do you want information to be provided to you?

Getting the right type of information, in the right amount, in the right format, at the right time was particularly important to self-advocates.

Self-Advocates Share How They'd Like to Learn About Dementia

- » Tell me in words I can understand. Small words, small paragraphs. Fewer words.
- » Use pictures or videos.
- » Talk with a family member or trusted person.
- » Using technology can help.
- » Repeat information. Slow down.
- » Listen to me. Ask me to repeat if you don't understand.
- » Start early so I have a long time to learn.
- » Tell the truth and stay calm.
- » Don't hide stuff from me. Tell me.

I like to get information in pictures, not with lots of paper. I like to be patient and calm—pictures help me understand better. It makes me more patient and calm—not as scary.

– Self-advocate from focus group

Talking to friends and talking about it makes it less scary. Using smaller terms so that I can deal with it.

– Self-advocate from focus group



Despite overwhelming feedback from self-advocates in focus groups that they wanted to learn more, not all family members or supporters of persons with I/DD who responded to the survey thought that sharing diagnosis information would be helpful.

“ Depending upon the intellectual capabilities of the person, it may be best not to share anything about future possible conditions. It’s too abstract and may cause more worry than benefit. Those who care for the person on a daily basis should be aware so that they could watch for symptoms. ”

– Family member survey respondent

“ The caregivers need to fully understand the diagnosis and what will/can happen so they can best decide how to deliver that to their loved ones. ”

– Family member survey respondent

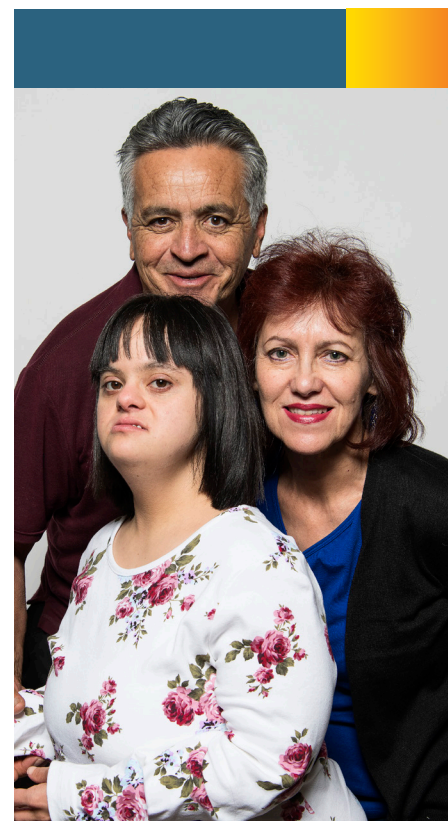
Learning about dementia or getting a diagnosis can be scary. Both self-advocates and families had ideas on how to reduce these fears. Both groups agreed that having a trusted person around them to help was an important thing. Self-advocates also wanted their own family members to stay calm.

“ Sometimes when I have scary dream, if I look at things on my computer or listen to music, it can help calm me down. When I am learning things that scare me, I like people to know what calms me down. ”

– Self-advocate from focus group

“ I really want to talk about it with other people. I don’t (want) my mom to be worried or crying. Makes me sad. You’ll be more relaxed if we are relaxed. ”

– Self-advocate from focus group



Families and supporters had a variety of suggestions for resources that could help them better support someone with I/DD.

Suggestions from Family Members and Other Supporters on Helpful Resources that Should be Developed

- » “How to Talk to a Loved One” brochure or on-line resource
- » Social stories, video, and stories of other families or self-advocates
- » Up-to-date information in different languages
- » Support groups

SELF-ADVOCATES AND FAMILY MEMBERS HAD A LOT OF ADVICE FOR MEDICAL PROFESSIONALS:

Advice from Self-Advocates for Medical Professionals

- » Learn about Down syndrome before you meet me.
- » I need help to not be scared. Give me more information.
- » Take time to listen.
- » If you don't understand, ask me again.
- » I'm not just a person with Down Syndrome. There are other things you should know about me.
- » I have goals for my life. I am a person, not just a disability.
- » I am smart. I can learn.
- » I want to be a good patient. Give me instructions in a way I can understand.
- » I have thoughts about my care.
- » Meet people with disabilities before you become a doctor.
- » Get training on us!

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If the doctor isn't taking (you) seriously, find one who will. We have numerous ongoing health issues and have been taken seriously most of the time. I don't put up with one who doesn't. Research the doctor out first whenever possible so that this doesn't happen.

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– Parent survey respondent

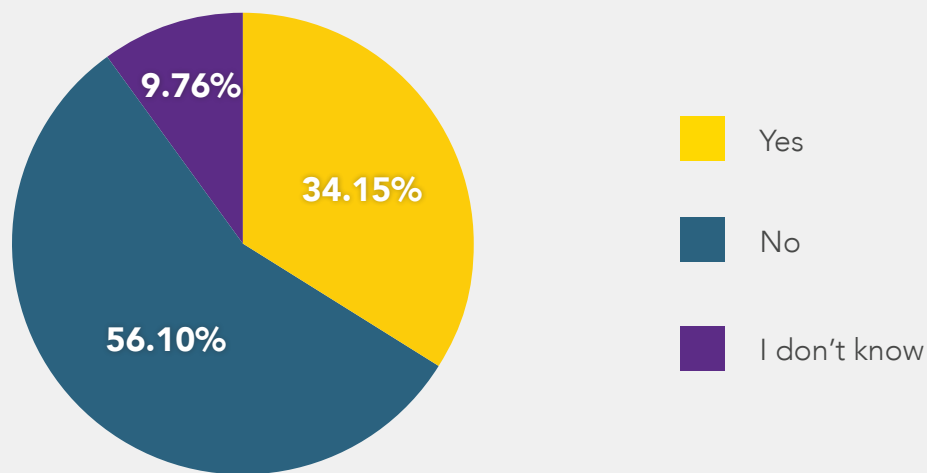




DO YOU HAVE A PLAN IN PLACE FOR THE FUTURE AROUND YOUR LIFE OR HEALTH?

Despite a higher risk of dementia and a desire to learn more, most families who attended the focus group or who responded to the survey did not have a plan in place for the future, other than a financial plan.

DOES THE PERSON WITH I/DD IN YOUR LIFE HAVE A PLAN IN PLACE RIGHT NOW AROUND HEALTH CARE?



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I'm scared about the future for my 9-year-old who has DS. I sometimes feel like I'm a failure as a dad because I don't know everything and I don't have the future all mapped out for her.

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– Parent survey respondent

SUMMARY AND RECOMMENDATIONS:

It is clear that both family members and self-advocates are seeking more and better information about the risk for dementia. Listening to self-advocates on the type of information they need is essential, including designing specific resources for self-advocates. Families could benefit from resources on how to have these conversations with their loved ones to help everyone feel more prepared and less scared. Medical professionals must listen to self-advocates and get more comprehensive training on how to work with individuals and families who are facing a greater risk of dementia. Planning for the future is important, yet many families have not taken steps to put plans in place.



Ensure that medical and social services providers have up-to-date information available to share with individuals and families about their risk for dementia and steps they can take.



Support self-advocates to be more self-determined in advocating for their own health. Fund and promote self-advocacy training and incorporate self-advocacy training as goals in individual service plans.



Ensure that caregiver education and training for family members incorporates strategies that help them support and encourage health care self-advocacy.



Fund and promote caregiver education and training, particularly for families with loved ones at risk for dementia.



Update training requirements and related resources for medical professionals to include role-plays and other required conversations with self-advocates with I/DD. Ensure that medical professionals understand I/DD and how it relates to someone's risk for dementia.



Ensure supports for family members to plan for the future. Include future planning as a component of individual support planning. Find out more at futureplanning.thearc.org.



Fund future planning as a paid service.

