

FLIPPING STIGMA ON ITS EAR TOOLKIT

Taking action against stigma and discrimination associated with dementia

A diagnosis of dementia can increase a person's sense of vulnerability. Not only are people faced with challenging cognitive changes but too often many also face needless stigma and discrimination that can make the experience worse.

As such, the discrimination caused by stigma that accompanies a diagnosis of dementia needs to be "flipped on its ear!"

The purpose of this toolkit is to recognize and respond to this stigma and discrimination. It has been designed by people with dementia to help others – including other people living with dementia, the people who support them, and those who do research – to address the challenges of stigma and discrimination.

While you can enter the site in any way you choose, we have tried to make the information as relevant to each group as possible.

Click on any of the options below:

- Persons living with dementia
- Family, friends and care providers
- Researchers

PEOPLE LIVING WITH DEMENTIA

INTRODUCTION

This TOOLKIT was developed by an Action Group of people with dementia to:

- Help other people with dementia recognize and take action when they experience stigma and discrimination associated with dementia or memory loss.
- Demonstrate the stigma and discrimination experienced by people with dementia so that those in supportive roles can be more empathetic and reflective of their contribution to perpetuating stigma and discrimination.

The toolkit aims to:

- Help people recognize common experiences where they may feel discounted and judged as situations of stigma and discrimination occur.
- Develop a range of ways of responding to situations of stigma and discrimination, respecting that every person living with dementia will be different in how they want to handle it, and will have their own skillset.

- Build skills and competence in changing how society views and treats people with dementia.

To do this the TOOLKIT is organized under three main headings: recognizing stigma and discrimination, responding to stigma and discrimination, and Education and advocacy.

RECOGNIZING STIGMA AND DISCRIMINATION

In order to recognize when you are experiencing stigma and discrimination, it can be helpful to know what it is. Here are some descriptions that people with dementia have developed:

STIGMA occurs when other people make assumptions about a person based on their actions and/or appearance. This can be compounded when people find out that you have a diagnosis of dementia, and then they make assumptions based on that diagnosis alone.

DISCRIMINATION occurs when others act on assumptions in a way that leads to the person with dementia being treated as incapable, and feeling judged or deficient in some way.

People may not be intending to stigmatize and discriminate and there are many reasons why this occurs. For example, people may lack knowledge or awareness about dementia, or may be generalizing their assumptions based on their experiences with one person, or from depictions in the media.

Irrespective of the intent, stigma and discrimination can result in someone living with dementia questioning their own worthiness and competence. It is important to realize that when you experience stigma and discrimination, it's not about you personally, it's about the other person's assumptions.

Here are some examples that different people with dementia have shared. You may have had similar experiences or ones that are uniquely different to you. Whether or not you share in the experiences included below, there is power in recognizing and naming stigma and discrimination.

To hear audio recordings of stories from the Action Group here are five options to click on:

*Please know it might be distressing to hear examples of stigma and discrimination, especially if you recognize that this has happened to you.

1. Excluded by others
2. Treated as incapable
3. Judged by others
4. Diminished as a person
5. Feeling disrespected by the medical community

“...my best friend used to come with me (to the doctor’s office) and the doctor talked to her all the time and I just got so fed up I didn’t go with her anymore, I went by myself. And he had to take his time explaining to me, but I asked him just go slow and I’ll get it eventually I’ll get it...” Marcia

RESPONDING TO STIGMA AND DISCRIMINATION

Stigma and discrimination can happen in your day to day interactions with others. Sometimes it is hard to know how to handle it and respond. People have different ways of responding to stigma and discrimination. There is **NO ONE RIGHT WAY**.

This section of the Toolkit provides some ideas and approaches that have been developed in conversation with other people with dementia for responding in day to day life when you experience stigma and discrimination by others.

It is important to be clear with yourself that a situation may be caused by the other person’s attitudes and lack of understanding, and **NOT** about you personally.

We have included strategies for building confidence and tips on how you can speak out. Three options to click on:

1. Deciding how you want to respond
2. Choosing to speak out
3. Know your rights

“sometimes I find that, if you explain beforehand that you’re having a slow day and if I put my hand up and say: guys can you just sort of repeat what you’re saying; right at that moment when you’re not getting it, maybe they can slow the conversation down and laugh about it and help you as you go along...” Lynn

DECIDING HOW YOU WANT TO RESPOND

The first step in **RESPONDING TO STIGMA** is recognizing when an interaction is making you feel inadequate in some way, and naming it as **STIGMA**. It helps to recognize that it is the other person’s attitude and/or actions that are the problem,

because they are making judgements about you that don't reflect who you are. It's NOT about you personally.

"I think it's the other folks, the folks that don't have Alzheimer's that are uncomfortable with us. It's NOT US that aren't acting appropriately, I think for the most part we all still do. But is the group that is supposed to be "OK" that is having trouble with it..." Donna

How you respond is UP TO YOU. Some people find it is intimidating to speak out, but others feel that it is their responsibility to say something, as these can be valuable moments for making change. There is NO "ONE RIGHT WAY".

Here are some suggestions:

1. Sometimes it might not feel like the right time to say something. Recognize when you feel most vulnerable and give yourself permission to take care of yourself first.
2. At other times, you may want to respond in the moment. Value your own wisdom. YOU are the expert of your own experience. It can help to speak from your heart and say what you are feeling.
3. Sometimes talking to a supportive person can help you decide what you want to say or do. This might include talking to a family member, a good friend, or a person at the Alzheimer's Society.
4. Know that everyone has something different to say or offer.

CHOOSING TO SPEAK OUT

Sometimes the choice will be to say nothing. Remember there are no absolute right or wrong options.

Sometimes speaking out does not need to be explicitly saying something. You can respond to stigma with your actions, such as wearing a lanyard to self-identify as a person living with dementia.

To hear about the value of wearing a lanyard to self-identify as a person living with dementia, and as a way of opening up a space for conversation with others. [Click here.](#)

If considering to speak out you may want to ask yourself:

- Is this a teachable moment?
- What will you gain by saying something?
- What might you lose by saying something?

Sometimes having conversations with people can be challenging. It can be useful to explain your needs.

There are some situations where people felt it would be particularly helpful to say something. For example, it can be useful to challenge health care professionals.

KNOW YOUR RIGHTS

You have the legal right to be treated as a capable person.

This doesn't change just because you get a diagnosis of dementia. Read the Alzheimer Society Charter of Rights for people with dementia.

Sometimes people with dementia need help with decision-making and this happens informally. However, it is helpful to know that Canadian law presumes mental capacity and that the only way your rights can be legally removed is through a legal process. For more information about your legal rights visit the “Canadian Centre of Elder Law”.

EDUCATION AND ADVOCACY

To advocate is to educate. Making change can be as simple as having a conversation with a friend, colleague or with a local grocer. But advocacy could also be through more formal communications like a letter writing campaign, meeting with your local politician, or giving a presentation.

Any action or communication that is geared toward changing how others understand and respond to those with dementia is advocacy!

This section of the Toolkit focuses on how people with dementia can be supported as advocates, educators, and leaders in changing others' perceptions about people with dementia.

Three options to click on:

1. Building confidence and competence
2. Resources
3. Flipping Stigma in action.

“With dementia-related publications, so much is changing because more and more information is coming out. As more and more people understand dementia and delivering person-entered care and books, policies get revised and part of that credit for revision comes to our own community, people living with dementia and caregivers who in some cases influence the change of policy.” Jim

BUILDING CONFIDENCE AND COMPETENCE

Not everyone feels comfortable being an advocate. In fact, MOST people don't! But it is possible to develop confidence and competence as an advocate.

Here are some strategies that people with dementia have found useful.

Five options to click on:

1. Create a community of like-minded people
2. Knowledge at-your-fingertips
3. Build confidence for public speaking
4. Organize community gatherings
5. Consider the advantages of advocacy

RESOURCES

The internet can be a valuable source of information for resources, but not all sites can be helpful. Here are some suggestions that people with dementia have found helpful.

- A Changing Melody Toolkit

A Changing Melody is a forum designed by and for persons with early-stage dementia and their family partners in care. Click to learn more

- DEEP: Making an impact together

Sharing the learning on dementia activism from and across the DEEP network. Click to learn more.

- Singapore "Voices of Hope" Program

Through Voices for Hope, ADA wants persons with dementia and their families to partner with us in our dementia awareness and advocacy efforts. Click to learn more

- Our Dementia, Our Rights

Brief guide co-produced by The Dementia Policy Think Tank (member group of DEEP) & Innovations in Dementia CIC. Click to learn more.

- Charter of Rights ASC

As a person with dementia, I have the same human rights as every Canadian as outlined in the Canadian Charter of Rights and Freedoms. Click to learn more

- CanAGE Canada's National Seniors Advocacy Organization

CanAge is working to improve the lives of older adults through advocacy, policy, and community engagement. Click to learn more

- National Dementia Guideline

The National Dementia Guidelines: Disclosing and Communicating a Diagnosis of Dementia help family physicians, nurse practitioners and specialists discuss dementia with patients and care partners. Click to learn more

FLIPPING STIGMA IN ACTION

Watch the videos of several members from the Action Group telling their experiences sharing the Flipping Stigma Toolkit.

- Video of Lynn
- Video of Donna
- Video of Lester
- Video of Myrna

FAMILY, FRIENDS AND CARE PROVIDERS

The Flipping Stigma on its Ear Toolkit was developed by an Action Group of people with dementia to address the stigma and discrimination that so frequently accompanies a diagnosis of dementia.

We invite you to explore the toolkit and consider your own interactions with people with dementia. Whether you are a family member, caregiver, health care professional or member of the community, we hope that you learn from the words of those with lived experience. We anticipate that hearing their voices will be insightful and influence your future interactions with those who live with dementia.

Here are some questions to consider as you navigate through the toolkit:

- Are there ways that I have made people with dementia feel incapable?
- Can I think of a time when I may have spoken on behalf of someone with dementia without first checking with them to ensure that this was okay?
- Have I ever assumed that someone with dementia is not capable of doing something just because I know they have a diagnosis?
- What are ways that I can communicate respect and dignity when I am with someone with dementia?

Tips for doctors and other health care providers from action group members living with dementia.

1. Talk to the person, not their caregiver or spouse.
2. Don't make assumptions. Because everyone is different, be prepared to learn from the people who are your patients and acknowledge the journey that is dementia.

3. Listen to your patients, know them and believe them. Don't get defensive or dismissive of genuine concerns you might hear from people.
4. Encourage people to find purpose in their lives. It is important to acknowledge that people can live "well" with dementia for many years after diagnosis.
5. Be aware of available community and dementia-specific supports. Have pamphlets and resources handy, especially for people who are newly diagnosed.
6. Sometimes the person you are working with might not "look like a person living with dementia."
 - Regardless as to how a person looks, try to give them more time and adequate explanations.
 - Consider a longer appointment for patients with dementia. Be open to patients audio recording their appointments and consider writing down main points for them.

RESEARCHERS

Information for researchers

Involving people with lived experience and expertise is critical in dementia-related research. The Flipping Stigma on its Ear Toolkit is a direct outcome of a Participatory Action Research (PAR) study where academic researchers and people with lived expertise of dementia came together as co-researchers to address the stigma and discrimination that so frequently accompany a diagnosis of dementia.

We invite you explore the toolkit and listen to the Action Group members' words. As a researcher, we hope that you will reflect on your research practice and consider future interactions with those who live with dementia.

Here are some questions to consider as you navigate through the toolkit:

- How are my assumptions as a researcher challenged?
- As a researcher, are there ways that I have inadvertently made people with dementia feel like I see them as incapable?
- In trying to involve people with dementia in research, have I instead contributed to "tokenizing" people with dementia?
- Have I ever assumed that someone with dementia is not capable of taking part in and contributing to research just because I know they have a diagnosis?
- What ways can I make sure to always communicate respect and dignity when I am conducting research with someone with dementia?

ABOUT THE RESEARCH STUDY

Reducing Stigma and Promoting Social Inclusion: Putting Social Citizenship into Practice

This is a four year project funded by the Canadian Institutes of Health Research. This is also a Participatory Action Research (PAR) study. PAR focuses on the co-creation of knowledge for the purpose of supporting social change.

- This type of research is action-oriented and shifts the power relationships found in more traditional approaches to research.
- PAR is conducted in partnership with a community of interest, with collaboration from the group throughout all stages of the study.

For this research study, the community of interest is an Action Group of people living with dementia. The action-oriented focus of this study is to reduce the stigma and discrimination that people with dementia experience on a regular basis.

The Action Group began meeting in June 2019, and since the study began this group has included 16 members. This number has shifted over time and the Action Group currently includes 7 members.

An important and distinctive aspect of the group is that only people with dementia are included, not care partners. Initially, the group met in person once a month. However, when the pandemic started, the group made a successful transition to ZOOM, and began meeting twice per month by request of group members.

Early Action Group meetings were focused on members talking about their experiences of dementia and on coming to agreement on specific actions to take. Once the toolkit was identified as a primary outcome of the study, subsequent meetings focused on development of toolkit content.

The creation of this toolkit has been an explicitly iterative process, with Action Group members providing input and feedback throughout the entire process of development.

Action Group Members: Sherri Adams, Craig Burns, Lester Gierach, Lynn Jackson, Granville Johnson, Myrna Norman, Donna Wager, Rae, Tim Eng, Sarah King, Fred D.

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If you want to learn more about the Action Group who created this Toolkit, and how you can create your own initiative, visit: www.flippingstigmaguide.com
Check out our Newsletter.

CONTACT US at flipping.stigma@ubc.ca

ACCESSIBILITY STATEMENT

The Flipping Stigma on its Ear Toolkit is committed to providing a website that is accessible to the widest possible audience, regardless of circumstance and ability. We aim to adhere as closely as possible to the Web Content Accessibility Guidelines (WCAG 2.0, Level AA), published by the World Wide Web Consortium (W3C). These guidelines explain how to make Web content more accessible for people with disabilities. Conformance with these guidelines will help make the web more user friendly to everyone. Whilst the Flipping Stigma on its Ear Toolkit strive to adhere to the guidelines and standards for accessibility, it is not always possible to do so in all areas of the website and we are currently working to achieve this. Be aware that due to the dynamic nature of the website, minor issues may occasionally occur as it is updated regularly. We are continually seeking out solutions that will bring all areas of the site up to the same level of overall web accessibility.

If you have any comments and or suggestions relating to improving the accessibility of our site, please don't hesitate to contact us at flipping.stigma@ubc.ca. Your feedback will help us make improvements.

ACKNOWLEDGMENT

This toolkit was developed as part of a participatory action research project "Reducing Stigma and Promoting Social Inclusion of People with Dementia: Putting Social Citizenship into Practice: ", funded by the Canadian Institutes of Health Research. The Flipping Stigma Toolkit is licensed under CC BY-NC 4.0.

It was a collaboration between the Flipping Stigma Action Group, co-led by Jim Mann and Deborah O'Connor, and the Centre for Research on Personhood in Dementia research team, co-led by Jim Mann, Deborah O'Connor, and Alison Phinney.