Investigating Inclusion–Challenging Assumptions about People with Dementia

# ****Purpose:****

To challenge assumptions about the ability of people with dementia to have a voice, to contribute, and to be meaningfully involved in decision-making by reflecting on the words of persons with dementia.

# ****Preparation:****

* Print out each quote (provided in the quotes summary sheet on the next page) onto a cue card (or use pre-made cue cards, if available).

# ****Materials Needed:****

* Cue cards with quotes printed on them
* Copy of all quotes for each participant
* Notepads and pens for groups to record reflections

# ****Instructions:****

1. Divide Culture Change Coalition members into groups of 3-5.
2. Evenly distribute the quotes to each group.
3. Ask all coalition members (including facilitators) to read the quotes on the cue cards that were provided to them and work together to reflect on the following questions:
   1. Upon reflecting on these quotes, what assumptions exist around persons with dementia?
   2. Were your assumptions challenged or did you learn something new about persons living with dementia as a result of reading these?
   3. How might these quotes influence how we interact with our partners?
   4. What can we take from these quotes to help us in our Discovery Phase?
   5. How do these quotes influence what you think about our Discovery process?
4. Join together as a larger group and share your quotes and reflections.

## Quotations for Reflections:

### ***Quote 1:***

“Several years ago I answered a little advertisement in a newsletter that was looking for people with early-stage memory loss to sit on a committee. This was my first contact with the Murray Alzheimer Research and Education Program (MAREP), at the University of Waterloo… I have formed such a great working relationship – a partnership – with MAREP. It is one that has been built over time to become one of TRUST and STRENGTH. Sherry and all of the staff have allowed my voice to be heard at a time when others have chosen not to validate my comments or for that fact even listen. It is difficult to be heard now when so many people think that I have nothing left to contribute, but guess what, they are mistaken.”

([Murray Alzheimer Research and Education Program](file:///\\filed.uwaterloo.ca\ahs$\CURA\Knowledge%20Translation\PiDC%20Website%20and%20Toolkit\Culture%20Change%20Toolkit--2013\Dawn\Activities\uwaterloo.ca\marep) partner with dementia Brenda Hounam)

### ***Quote 2:***

“But what is so much more important for me is…is still having control over my life no matter how little that control is. That’s what is important to me. And that is why I continue on.”

(Person with dementia, [I’m Still Here Guide](https://uwaterloo.ca/murray-alzheimer-research-and-education-program/education-and-knowledge-translation/products-education-tools/im-still-here))

### ***Quote 3:***

“The person that has the disease [is] sometimes treated like they’re not here anymore….I think that’s very bad because we definitely are still here. And we might not have all our capabilities up there as we used to have, but I think some people treat people with Alzheimer’s disease like they’re not around with the program anymore and I don’t think that that’s totally true. We might not have great days all the time but sometimes we do, and I think that should be encouraged and try and make people more aware of what goes on with people with Alzheimer’s instead of just saying ‘oh they’ve got Alzheimer’s, so I guess they’re not with the program anymore, don’t want to talk to them.’ A lot of people I know will just walk by me or go the other direction if they see me now because they think I’m not the same person, which I’m not but I’m still here and I can still talk you know.

([Murray Alzheimer Research and Education Program](file:///\\filed.uwaterloo.ca\ahs$\CURA\Knowledge%20Translation\PiDC%20Website%20and%20Toolkit\Culture%20Change%20Toolkit--2013\Dawn\Activities\uwaterloo.ca\marep) partner with dementia)

### ***Quote 5:***

“Learning that I can learn even with my dementia was so important. Now I belong to a support group online. It has made all the different to me. I am not so alone.”

(Person with dementia, [I’m Still Here Guide](https://uwaterloo.ca/murray-alzheimer-research-and-education-program/education-and-knowledge-translation/products-education-tools/im-still-here))

### ***Quote 6:***

“Such characterisations stigmatize us as being unable to be trusted, unable to be involved in our own life’s decisions, in our day-to-day living. When should I take a bath? Can I be trusted to spend time alone with my grand-daughter? Can I, should I drive, handle my own money, be trusted to answer the door? We are told we must now resign ourselves to allowing others to take care of us… We are told by many professionals, and even our own loved ones, sign away all our rights… We are expected to trust professionals who have not experienced our cognitive environment, and who were trained by others who have not experienced our cognitive environment. We are expected to trust them to do what is best for us. They believe they know not only what is best, but that they know all there is to know about how best to take care of us. This mind set, this set of assumptions about people like you and me who are living with the symptoms of dementia, this mind set is simply wrong! It’s destructive to me and others like me; it’s destructive to caregivers, to families, to communities, and to the fabric of nations.”

(Taylor, 2008, pp. 30-31)

### ***Quote 7:***

“The more I know, the more empowered I feel…The more information that I have, the more confidence [I have]. It reduces the anxiety that I might feel.”

(Person with Dementia, [A Changing Melody Toolkit](https://uwaterloo.ca/murray-alzheimer-research-and-education-program/education-and-knowledge-translation/products-education-tools/changing-melody-toolkit))

### **Quote 8:**

“As a committee member for the Changing Melody Forum, it has given me an opportunity to contribute experiences from my journey thus far and to advocate for my peers and myself in a social setting with a sense of belonging to promote my personal growth and learning with respect, dignity and well-being.”

(Person with dementia, [A Changing Melody Toolkit](https://uwaterloo.ca/murray-alzheimer-research-and-education-program/education-and-knowledge-translation/products-education-tools/changing-melody-toolkit))

### ***Quote 9:***

“I’m usually very optimistic but this really threw me for a loop….So, now that I’ve got all that straight I’m just far more optimistic. I’ve got plans. Get on with life; yes, and really spike it up…I’m not laying down anymore…I have to fill up my life…I still have a son here that needs lots of help yet, not willing to not be here for him either.”

(Person with dementia, [I’m Still Here Guide](https://uwaterloo.ca/murray-alzheimer-research-and-education-program/education-and-knowledge-translation/products-education-tools/im-still-here))

### ***Quote 10:***

“One of the important things is, is being open about your circumstances, and asking for help and having said [that] both of those things...are extremely difficult to do...so... you’ve got to trust and understand the people you’re being open with and asking for help because I have seen too many cases where they overreact and they’re too quick to take your control away from you...where automatically when you get diagnosed with Alzheimer’s people think that you’re not capable of, of being on your own.”

(de Witt, 2006; de Witt, Ploeg, & Black, 2009, p. 279.)

## References:

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