

video program guide

I am.

This is My Voice

To whom I may concern[®]




About *To Whom I May Concern*[®]

We learn that people with dementia are more than capable of speaking for themselves, and slowly the stigma is chipped away.

To Whom I May Concern[®] is a performance project that gives voice to men and women who have recently been diagnosed with a progressive brain illness such as Alzheimer's disease. Our goal is to promote a dialogue between these individuals and their peers, caregivers, families and community. Our purpose is to create a forum that encourages understanding, compassion, love and respect.

People living with challenges to their memory and communication can be found everywhere. Countries throughout the world are actively seeking ways to support people with dementia

and their care partners. *To Whom I May Concern*[®] (TWIMC) is playing a part in this movement by raising awareness of the experience of people recently diagnosed through our online programs.

TWIMC Online allows us to go beyond geographic boundaries and connect with people who are already isolated by illness. With a computer and webcam, we bring together people from around the world who have so much in common.

Today we are fortunate to have more and more opportunities to hear about the experience of living with dementia directly from the person diagnosed with the disease. Rather than hearing this experience from a third party such as an educator, doctor, or care partner, we learn that people with dementia are more than capable of speaking for themselves, and slowly the stigma is chipped away.

However, it is rare that we hear from a person with dementia who has not been scripted, who is not being interviewed, whose words are not set within a strict framework that has been constructed by someone else—someone without the disease. And it is even more rare—if ever—that, like a fly on the wall, we get to eavesdrop on a group of people with dementia who are having an honest conversation with each other about their varied experiences of living with dementia. Nowhere in this extraordinary video will you hear the words of an interviewer or a care partner, only the unscripted words of five people, each living in a different city, having a conversation with each other.

The conversation you are about to witness took place during six weekly 90-minute meetings. The group met via video conferencing and their sessions were recorded. These hundreds of minutes of conversation were edited down to 50 minutes, plus bonus outtakes. The editor, Steve White, in consultation with Maureen Matthews, Laura Bowley and the group themselves, deduced a series of themes that repeated throughout the conversations, and the film is structured around these themes. We did not dictate the themes beforehand; rather, the themes presented themselves via the group's conversation.





About *To Whom I May Concern*[®] (cont'd)

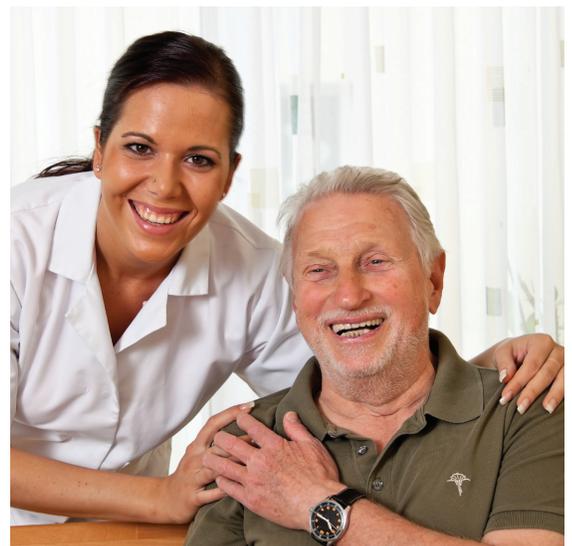
Today we are fortunate to have more and more opportunities to hear about the experience of living with dementia directly from the person diagnosed with the disease.

Why did we choose video conferencing? Why did we risk poor Internet connections, shaky webcams, and dicey audio when we could have flown everyone to a central meeting point and let them talk? Or we could have sent film crews to their homes to film them? Well, there are several reasons:

- The group could not have had six weeks' worth of conversations if we had met and filmed at a central location. At best we would have had a few hours, and we would have lost the ability to follow their lives over six weeks. We would have missed out on Sylvia's "un-diagnosis" and Teresa's losing her nursing license. In previous "live" and online *To Whom I May Concern*[®] projects, we have discovered that it can take a few meetings for some people to come out of their shells, for their true selves to emerge. Meeting centrally for a few hours only would not allow this metamorphosis to take place.
- By recording a video conference, the group felt so comfortable that they forgot they were on camera. The only cameras were their webcams; there was no film crew. As a result we were able to capture a conversation that would otherwise have been affected by the presence of cameras. And the *To Whom I May Concern*[®] methodology is all about communicating what never gets said.
- We were able to have a more diverse group of people included in the project without breaking the bank. Four members of this group come from the USA (Washington State, Tennessee, Arizona, and Florida) and the fifth lives in Wales, UK. The logistics and expense of flying five people with dementia plus care partners, staff and camera crews to a central location to meet could have prevented this project from ever taking place.

One of the foundational aspects of *To Whom I May Concern*[®] is that people with dementia get a chance to participate in a group, to gain the confidence to speak out, knowing that others are listening. To interview people separately did not enter into our plans, as this went against the entire philosophy of the project. We could only do this as a group, and only video conferencing would allow us the luxury of doing so, and doing so over time. From previous "live" and online *To Whom I May Concern*[®] projects, advocates with dementia have emerged, including some who have gone on to be international speakers, advocates, and founding members of Dementia Alliance International. This type of change and capacity building does not take place through structured interviews.

Welcome to THIS IS MY VOICE.



Guidelines for the Discussion Facilitator

Timing

Introduction:
5 minutes

Video:
55 minutes

Optional Break:
10 minutes

Talk Back Discussion:
60–90 minutes

Integral to the *To Whom I May Concern*[®] program is the “Talk Back” session, where every audience member has an opportunity to comment and ask questions of the performers.

In this video, the performers are not able to take questions and comments from the audience, but you have a unique opportunity to have an in-depth discussion about what you have heard and seen in this video. This Discussion Guide provides questions that you can use as guidelines for your group discussion.

Your group may consist of people with dementia, caregivers, or other professionals. Should you decide to mix the audiences so that there are people with the disease and caregivers or professionals, be prepared to facilitate a discussion between caregivers and people with dementia, and make sure the people diagnosed with the disease have equal opportunity to voice their thoughts.

Room Set-Up:

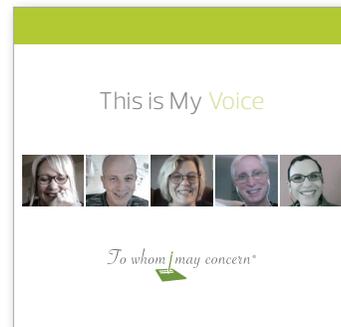
To view the video, you may wish to set up the seats in rows or around a table, depending on how many people you have in the group. For the discussion, it would be best to be seated in a circle or around a table so that everyone can see each other. As the video and discussion may take upwards of 2–3 hours, it would be best to have available refreshments.

Introduction:

Welcome everyone to the group: If the group is small, invite participants to briefly introduce themselves (e.g., name, occupation, dementia diagnosis)

Housekeeping:

Location of washrooms, refreshments, make sure everyone can hear and see the video screen.



Introduce the video:

Read “About *To Whom I May Concern*[®]” on page 2 of this booklet. Read “Dear Viewer” on pages 3 and 4 of this booklet. Answer any questions.

View the Video:

The video is approximately 55 minutes in length. You will see that “bonus features” are also available and discussion questions are included for these short bonus videos. We suggest that you view the main video, have the Talk Back Discussion, and then, if there is time, view the Bonus Features. Ask the audience which Bonus Features they would like to view.

Talk Back Discussion:

We encourage you to view the video ahead of your group so that you are not experiencing your own first reactions at the same time as your group.

You do not need to use all the questions. Based on your knowledge of the video and of your group, you may choose to use certain questions over others.

The questions are divided into three categories: Those focussed on people with dementia, questions for caregivers and professionals (people without the disease), and questions for all audiences. Please read through these questions ahead of time and prioritize which ones you wish to use.

We do encourage you, however, to start with the following question, regardless of the make-up of your audience:

What are your first reactions upon viewing the video?

What surprised you? What didn't surprise you?



Discussion Questions: Main Video

Before viewing the video, brainstorm a list of words that you use to describe a person with dementia.

Questions for People with Dementia

Someone newly diagnosed with dementia comes to you for advice. He or she asks: What do I do now? Based on your own experience and on what you've learned from this video, what advice would you give to that person?

The caregiver for someone newly diagnosed with dementia comes to you for advice. Based on your own experience and on what you've learned from this video, what advice would you give to that person?

Charee talks about what she misses in her post-diagnosis life. What do you miss? How are you compensating for what you are missing?

In the conversations that took place while filming the video, the word "limbo" came up a lot to describe life post-diagnosis. Do you feel like you are in limbo? What can you do to help yourself feel like you are not in limbo?

Has technology helped you? In what ways?

David said, "If you fail to plan, you plan to fail." What should you plan for after diagnosis?



Caption

Questions for Caregivers and Professionals

Before viewing the video, brainstorm a list of words that you use to describe a person with dementia and/or the experience of having the disease, or of the disease itself.

After viewing the video, do the brainstorming exercise again. What words now come to mind to describe a person with dementia. Compare your new list to the first list. What has changed?

The caregiver for someone newly diagnosed with dementia comes to you for advice. Based on what you've learned from this video, what advice would you give to that person?

Chris talked about his wife expressing her feelings of helplessness. What was she feeling helpless about? Do you feel helpless? What do you think about David's response?

It's been said that "If you meet one person with dementia, you've met one person with dementia." What does this statement mean to you? What was said in this video to back up this statement that no two people with dementia experience the exact same symptoms?



Caption

Compare your journey of seeking a diagnosis to the journeys of Charee, David, Chris, Teresa and Sylvia. How do their journeys compare to yours? Have you had to give up your job, post-diagnosis? How did that feel?



Discussion Questions: Main Video (cont'd)

Now that you have watched this video, what other symptoms would you add to this list?

How will what you have learned by watching this video inform your work/your relationship with a person with dementia?

Questions for All Audiences

What parallels are there between the individual experiences of obtaining a diagnosis?

What are the main themes of this video?

What challenges do the people in the video face due to their diagnoses? Are these challenges different than someone who might be diagnosed with dementia in their 70s or 80s? If so, how?

David said: The label [of dementia] affects how other people look at people with dementia. Do

participants in this video emphasized that staying social is vital for people with dementia; why is socializing important? How have the participants managed to remain social?

Should people with dementia be allowed to die with dignity? What are some of the complexities inherent to people with dementia "dying with dignity?"



Caption

you agree? In what way does knowing that a person has been diagnosed with dementia affect how that person is viewed by others?

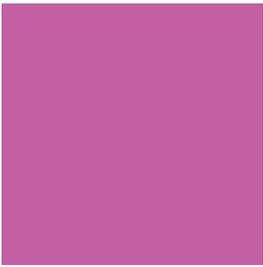
When we think about dementia, memory loss is the primary symptom

that comes to mind, if not the only symptom; dementia is associated with memory loss. Now that you have watched this video, what other symptoms would you add to this list?

What do you think of Sylvia's experience of assisted living? What are the participants in this video looking for in long term care; what is important to them? What changes need to be made to our system of care to accommodate people with younger onset dementia?

What typically happens when people learn that one of their friends has been diagnosed with dementia? Why does this happen? The partici-





Bonus Features



The caregiver for someone newly diagnosed with dementia comes to you for advice. Based on what you've learned from this video, what advice would you give to that person?

Charee's Test

What would you do if you already had a diagnosis but were offered the chance to have another test?

What do you think of Charee's desire for confirmation of her diagnosis of Alzheimer's Disease?

Discussion Questions:

Bonus Feature – Counting Money

What would you be thinking and feeling if you were standing behind Teresa in the checkout line? If you were the cashier?

Knowing what you know now, what would you change about the cashier's response? The manager's response?

How could the situation have been handled differently by staff? By Teresa?

Yes You Have It, No You Don't

Based on Sylvia's experience, how would you describe the typical diagnosis process?

What would you change about the diagnosis process?

What is a person usually told to do immediately upon diagnosis of dementia? What do you think is the impact on a person's life of having a diagnosis reversed?

What qualities are important in a physician?

What are your thoughts on sharing of a person's information between physicians, as described by David?

Teresa's Nursing License

If all possibility of you working in your chosen profession were coming to an end, what would you be feeling?

Reflect on Teresa's words about what her nursing license meant to her.

Let's think about loss. What losses do a person diagnosed with dementia experience? Who is responsible for these losses? Can any of these losses be prevented?

Castle and the Drawbridge

Reflect on Teresa's analogy. What is she saying?

How important are words in communicating with others? Do people communicate in other ways? If so, what ways? What could you do to facilitate communication with someone who has "lost their words?"

Dementia Puppies

In what ways could a service dog assist a person with dementia?

What are some other "out of the box" solutions that could help a person with dementia live at home longer?

Resources

Alzheimer's Association (USA): www.alz.org (1-800-272-3900)

Alzheimer's Society (Canada): www.alzheimer.ca (1-800-616-8816)

Alzheimer's Society (UK): alzheimers.org.uk (0300 222 1122)

Alzheimer's Disease International: alz.co.uk

Dementia Alliance International: Support & Advocacy of, by, and for people with dementia: infodai.org

Living with Dementia: Resources for Living Well
livingwithdementia.uwaterloo.ca