Dementia Friendly Toolkit

Role Play Simulations for Care and Community Settings

The Center for Aging Research and Education
SCHOOL OF NURSING
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Acknowledgements

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# Table of contents

**Introduction**
- Why dementia? .................................................. 4
- Why role play simulations? ................................. 4
- Why these settings? ........................................... 4
- What will I get out of this? ................................. 5
- How do I use this toolkit? ................................. 5
- How was this toolkit developed? ......................... 6

**Ways to enhance the role play simulations**
- Setting .......................................................... 7
- Equipment ...................................................... 7
- Videos ........................................................... 8
- Going “off script” ............................................. 9
- Tailoring for your group ..................................... 9

**Role play simulations**
- Bank ............................................................. 10
- Clinic ............................................................ 20
- Pharmacy ....................................................... 30
- Restaurant ..................................................... 38
- Store ............................................................. 47
- Telephone ....................................................... 55

**Resources**
- Surveys about the role play simulations .............. 63
- Role play simulation planning worksheet ............ 66
- Community resources ..................................... 67
Introduction

Why dementia?

In Wisconsin, across the country and around the world, communities are growing older. Thanks to medical advances, people are living longer and more active lives.

However, as people age, they are more likely to develop dementia. Dementia refers to different conditions that kill brain cells, damaging memory and other brain functions over time. Alzheimer’s disease is the most common type of dementia.

In Wisconsin, the number of people living with dementia in the year 2040 is expected to be more than double the number from 2015. Some 70 percent of people with dementia are cared for in the community by family members and friends. Many people living with dementia go to stores, restaurants, banks, libraries and other public spaces.

No matter where you work or live, you can help make your community more dementia friendly. Dementia friendly community groups work to increase public awareness, offer trainings and provide supportive environments to people living with dementia and their family members. These groups challenge the myths and stigma that are still associated with dementia.

The role play simulations in this toolkit were designed to help people better communicate with and advocate for people living with dementia. While the focus of this toolkit is dementia, the skills covered can make it easier to communicate with people who have a range of cognitive abilities.

Why role play simulations?

Simulations are role play exercises that help people build skills. They can be simple or complex. For example, fire drills are simulations that prepare people to safely and quickly leave buildings, in case of emergencies.

In nursing and other clinical and non-clinical fields, simulations allow students to practice new skills in a realistic way without putting anyone at risk. Simulations are an active approach to learning that is more effective than simply reading or listening to information.

Why these settings?

This toolkit includes six role play simulations in different community and healthcare settings. Each setting was chosen because family caregivers, advocates and experts told us that it was often challenging for people living with dementia.

The six role play simulations involve:
- A bank, where a person living with dementia is making a deposit
- A clinic, where a person living with dementia has a medical appointment
- A pharmacy, where a person living with dementia is refilling a prescription
• A restaurant, where a person with dementia is ordering a meal
• A store, where a person with dementia is shopping for groceries
• A telephone conversation, where a person living with dementia calls the local library for information

What will I get out of this?

Each of the role play simulations is designed to help you to:
• Communicate with older adults who have dementia or cognitive impairment, and with their family caregivers
• Interact with people with dementia and their family caregivers in respectful and meaningful ways
• Increase understanding of dementia among community members, service providers and front-line and professional staff

How do I use this toolkit?

This toolkit includes:
• Scripts, setting and other details to carry out the six role play simulations
• Suggestions for different ways to use the simulations
• Materials to plan and evaluate the simulations
• Additional information related to each simulation
• Community resources

Some simulation scenarios might be more relevant to your group than others. All will help you practice skills that make communities more dementia friendly.

Leading a group through two simulations—one related to their work or role, and another not related—can encourage people to consider how to be dementia friendly in different parts of their lives.

As we developed this toolkit, we found that it was helpful to ask people to:
• Fill out the “pre” survey
• Watch the “Understanding Dementia” video
• Read over the simulation setting, situation and roles
• Use the single-role scripts, props and equipment to act out the scenario
• Briefly discuss, focusing on the challenges facing each role
• Watch the “Communication Tips” video
• Act out the same scenario again, switching roles and putting as many of the communication tips as possible into practice
• Discuss how using the communication tips changed the interaction
• Fill out the “post” survey

For every six to eight participants, we had one facilitator guiding the role play simulations and discussions. We found that it took about an hour to take a group through two different simulations, repeating each simulation twice.
This toolkit includes scripts for each role play simulation, but they don’t need to be followed word for word. The experience will feel more real if people put things into their own words and allow themselves to react to what others say. Encourage people to “get into” their role, using props and moving around the space as makes sense.

Simulations can be powerful learning experiences, especially if you know or care for someone living with dementia. Encourage people to take the time to process their thoughts and feelings.

Some people might not be comfortable acting out the roles. Watching others act out a simulation first might help them feel more at ease.

There is no right or wrong way to play the roles, experience the simulations or respond to discussion questions.

Each simulation includes key “take away” points, to provide context and help wrap up discussions.

This toolkit includes videos as part of the role play simulation process. The videos can be viewed online at care.nursing.wisc.edu. The videos can also be used on their own, as part of dementia friendly trainings for local businesses, agencies or other organizations.

How was this toolkit developed?

A team led by the Center for Aging Research and Education (CARE) at the University of Wisconsin–Madison School of Nursing developed the videos and role play simulations, with input from family members of people living with dementia, dementia friendly community groups, people in healthcare and allied fields, community service providers and businesses.

We wrote the role play simulations and then asked university students from different disciplines and community members to try them out. Each group helped us improve our materials and approach.

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Ways to enhance the role play simulations

Setting

Most of us aren’t used to playing roles in front of other people. Even small changes to the space that you’re in can help people “get into” their roles.

Each role play simulation includes suggestions to make your space more like the scenario setting, by:

- Setting up chairs or tables in certain ways
- Posting signs
- Using props, like phones, wallets, pieces of paper, pill bottles or groceries
- Playing music or other sounds that you might hear in the setting

Equipment

When we lead groups through the simulations, we have those who take on the role of the person living with dementia wear vision-limiting goggles, headphones and gloves.

Wearing this equipment gives a sense of what it might be like to live with physical changes common among older adults, as well as cognitive changes. The equipment makes it difficult to react to changing situations. This challenges the other people to find effective ways to engage those role-playing the person with dementia.

The point isn’t that all people living with dementia have hearing or vision problems. Wearing the equipment adds distractions, making it difficult for the person to focus and process new information while reducing their comfort, movement, hearing and vision.

Equipment that works well with the role play simulations includes:

- **Vision-limiting goggles** – Vision problems are common among older adults. People living with dementia often have trouble telling where objects are in three-dimensional space. We use vision-limiting goggles from LowVisionSimulators.com that approximate macular degeneration, glaucoma, diabetic retinopathy or cataracts. Possible alternatives include dark glasses or safety goggles with yellow cellophane, a plastic baggie or cheesecloth taped over the field of vision. Masking tape can also be used to block parts of the field of vision.

- **Large or thick gloves** – Older adults may have trouble moving their fingers and hands due to arthritis, nerve damage (peripheral neuropathy) or muscle weakness. We use extra-large non-latex exam gloves. Possible alternatives include wearing winter, dishwashing or gardening gloves; wrapping masking tape around fingers; or taping splints on fingers.
• **Headphones** – Hearing problems are common among older adults. Some studies have found that people with hearing loss are more at risk of developing dementia or cognitive impairment. We use mp3 player headphones that play background noise for most simulations. You can download the open source audio tracks that we use from care.nursing.wisc.edu. Possible alternatives include mp3 players, earplugs, earmuffs or cotton stuffed in ears.

Other equipment often used for aging simulations includes canes, walkers and elastic bandages wrapped around knees or elbows, to make it more difficult to move; or a balloon with some flour or cornstarch and dried corn or beans inside, placed on a seat to make sitting less comfortable.

**Videos**

Four dementia-friendly videos, each 7 to 10 minutes long, are available online at care.nursing.wisc.edu. You can use these videos alone or with the role play simulations.

The videos are:

• **Understanding Dementia for Dementia Friendly Communities** – Explains what dementia is, how dementia affects the brain, risk factors and the impact on families and communities

• **Communication Tips for Dementia Friendly Communities** – Lists ten tips to communicate clearly and respectfully with people with dementia or cognitive impairment and shows the tips being used in common situations

• **Tips for Family Caregivers to Make Healthcare Dementia Friendly** – Gives family members tips to prepare for and communicate during medical appointments and shows the tips being used during an appointment

• **Tips for Providers to Make Healthcare Dementia Friendly** – Gives healthcare providers tips to communicate with and advocate for people with dementia and their family caregivers and shows the tips being used during an appointment

When we lead groups through the simulations, we show the “Understanding Dementia” video first. Then we have people act out a simulation and discuss it briefly, before watching the “Communication Tips” video. We then ask people to switch roles and act out the same simulation again, using as many of the communication tips as possible to improve the interaction.

The “Understanding Dementia” and “Communication Tips” videos can also be used as refresher trainings for businesses, agencies and other organizations that have gone through in-person dementia friendly trainings.

The version of the “Make Healthcare Dementia Friendly” video most appropriate for the audience can be used along with the “Communication Tips” video when acting out the clinic role play simulation. The videos can also be used as part of professional development for healthcare staff or as part of workshops for family caregivers.