2024

Dementia Toolkit Guide

Life. Defined by you.

INCLUSA

Table of Contents

Section

Introduction

The intention of the Dementia Tool Kit is to offer an opportunity for individuals to provide guidance around what matters most to them in their life and how they wish for caregivers to meet all needs when they might become unable to express themselves clearly. While the tool kit was initially created to support communication between individuals with dementia diagnoses and their caregiver(s), the value of the tool kit to preplan for when anyone might need the assistance of others to meet their care needs has created value for everyone to utilize the tool kit.

This guide provides an overview of all the components comprising the Dementia Tool Kit. The Script for Use will provide you with a high overview of the intended use for the tool kit. While the My History and My Future Forms were created to be completed by the individual or their family or friends if the individual is not able to complete the forms. The Observation and Plan of Action forms are intended to be used when caregiver(s) are running into a situation where they need help in deciphering the individual's behavioral communications so the caregiver(s) can meet the unmet need the individual is trying to express. The last section of the Dementia Tool Kit is the resource section. This section provides a small look at the variety of great resources available to help individuals diagnosed with dementia and their caregiver(s) to navigate as gracefully as possible the various stages of dementia progression.

Script for Use

This toolkit is intended for use by anyone (residential provider, community member, in-home care, family) caring for an individual who may have dementia.

To navigate the toolkit, use the following documents:

- My History Form
- My Future Form
- Observation Form
- Behavioral Communication Flowchart
- Plan of Action

Care Continuity:

Residential providers are encouraged to keep the forms in the person's chart, readily accessible to staff.

Individuals receiving in-home care are encouraged to have the documents available for their caregivers. If a change in care setting or provider occurs (example hospitalization, respite, new caregiver staff hired) provide these documents for care continuity.

To Begin:

Utilize the My History and My Future forms. The individual should complete their own My History and My Future forms when able. It is recommended to ask family or friends to provide information or complete the My History and My Future forms when the individual is unable to complete the forms independently. Begin this conversation early as the individual diagnosed with dementia being able to participate adds to the personalization of the information gathered. If you are a Residential Provider, you may wish to add these forms to your new admission packet. These forms may be used at care conferences as well to generate conversation regarding the individuals past actions/behavior/norm and how the individual envision their care to look in the future. No need to wait until there is a problem or concern. Being knowledgeable of the individual likes/dislikes, routine, history etc. will allow staff to be proactive using a strength-based process which may fend off potential behavioral communications and will give you a general understanding of who the individual is.

Is there a Problem Behavior NEEDING to be Fixed?

Begin utilizing the Observation form. Complete using specifics to better determine triggers as well as what works to alter the behavioral communication being displayed by the individual. Don't be afraid of documenting the small most unusual details as this may be the trigger. The purpose of the Observation form is to assist you in determining trends as well as triggers. A separate Observation form needs to be created for each specific problematic behavioral communication you wish to track.

Follow the flow chart (next page) or Problem Behavior Flowchart (Dementia Toolkit). Choose the one that works best for you.

Does the behavior put someone at RISK?

- No – This is not really a PROBLEM behavior for the person with dementia. It may be irritating or embarrassing for the caregiver, but it is really a "SO WHAT" behavior.
    - ✓ Learn to let it go!
    - ✓ Leave it alone!
    - ✓ Don't sweat the small stuff!

- Yes – It is time to PROBLEM SOLVE!
    1. Describe the behavior in detail using the ***Observation Form***.
        - Where does it happen?
        - When does it happen?
        - Who is involved?
        - How does it start? Stop?
        - What is said? Done?
    2. Answer these questions using the ***Personal History Form***. Consider emotional and physical unmet needs.
        - Could the level of dementia explain some of this behavior?
        - Could how the person is approached or helped have some impact?
        - Does the person have other medical or psychiatric conditions that might be active or a contributing factor?
        - Could personal history (work, leisure, family, religion, personality, routines, etc.) play a role?
        - Could the environment or cues in it be causing some of the trouble?
        - Could the time of day or personal habits be a factor?
    3. BRAINSTORM with the Puzzle Pieces
        - Partner with all formal supports and actively involved informal supports. You are not alone!
    4. Come up with a ***PLAN OF ACTION***! See plan of action in paragraph below.
        - Decide on **what** to do
        - Decide **who** will do what
        - Decide **how** to do it
        - Decide **when** to start it and when to look again
    5. Are things better?
        - Yes – CELEBRATE! Woo-Hoo!
        - No – RETHINK and problem solve again

Plan of Action

The purpose of the plan of Action is to be available to daily caregivers as a tool to work more effectively with the individuals they support. The Plan of Action is a fluid document and is expected to be updated as new trends and triggers are noted and new interventions are discovered as well as those intervention attempts that become ineffective. A separate Plan of Action needs to be created for each specific problematic behavioral communication needing to be addressed.

If you have questions, please feel free to reach out to:

Inclusa Dementia Network
Email: qualityinnovation@inclusa.org

My History Form

The goal is for you and your loved ones to receive quality care and a continued quality of life experience. Advocacy is an essential step in quality of care. It is key that you have a voice in how you or your loved one communicates how care needs are met. Please answer each question as candidly as possible so that all caregivers may learn about traditions, routine, preference, and values so they can understand what has been important to you or your loved one.

Name: ____

Date: ____

Significant people in my life (current and past, family/friends):

____
____
____
____
____
____

What does a good day look like for you:

____
____
____
____
____
____

Work and military history:

____
____
____
____
____
____

Traumatic experiences/significant life events:

____
____
____
____
____
____

Daily routine before dementia (eating, sleeping, bathing habits, preferred physical activities, etc.):

____
____
____
____
____
____

Things or people that bring me joy (types of music, food, hobbies, etc.):

____
____
____
____
____
____

Things or people that are upsetting to me:

____
____
____
____
____
____

Are there people you do not want to visit with you or only want them to visit if it is supervised? If supervised and there is a problem, do you want caregivers to ask that person to leave or do you prefer to end all visits?

____
____
____
____
____
____

Are there sensory stimuli (visual, touch, taste, sound, smell, temperature, etc.) that can contribute to negative responses:

____
____
____
____
____
____

Are there sensory stimuli (visual, touch, taste, sound, smell, temperature, etc.) that can contribute to positive responses or people, animals, music that helps calm you down:

____

____

____

____

____

____

Health concerns others should be aware of (for example chronic pain, chronic infections, other chronic health conditions, or undiagnosed mental health):

____

____

____

____

____

____

____

How do you communicate (bilingual, written, verbal, using technology, non-verbally, etc.):

____

____

____

____

____

____

____

Other (volunteer experience, previous living experience, spiritual history, other important things):

____

____

____

____

____

____

____

***Fillable version available at** https://www.inclusa.org/providers/resources/dementia-care-resources/*
We encourage keeping this document easily accessible by caregivers.

My Future

The goal is for you and your loved ones to receive quality care and a continued quality of life experience. Advocacy is an essential step in quality of care. It is key that you have a voice in how you or your loved one communicates how care needs are met. Please answer each question as candidly as possible so that all caregivers may learn about your wishes for care through the end of life.

What matters to me through the end of life (comfort, family, independence, etc.)?

____
____
____
____
____

If you do not have a POA document completed, who do you want assigned to make your decisions? (Consider completing the POA of Health Care and POA of Finance to make this preference legal)

____
____
____
____
____

Who supports you during difficult times?

____
____
____
____
____

How much do you want to know about your condition and/or treatment? (minimum, everything, somewhere in the middle):

____
____
____
____
____

Do you want to have input in every healthcare decision, or do you prefer others to make them for you?

____
____
____

If you cannot eat or drink on your own, do you want artificial nutrition and/or hydration?

____
____
____
____
____

How much pain is acceptable to you? Do you want to be pain-free even if it means being less alert/awake?

____
____
____
____
____

At the end of life, do you want medication to make you more comfortable even if it makes you less alert/awake?

____
____
____
____
____

What do you worry about most regarding your future?

____
____
____
____
____

Do you prefer treatment that focuses on quality of life or quantity of life?

____
____
____
____
____

Do you prefer to spend your last days in a facility or at home?

____
____

____

____

If you cannot manage safely at home, are you comfortable moving to a facility?

____

____

____

____

____

Do you want CPR, ventilator care, or other lifesaving measures? If so, to what extent?

____

____

____

____

____

When you die, do you want to be alone or have others with you? If others, who? If family members have something planned, do you prefer they cancel if able to stay with you or would you prefer they go, even if that means you may be alone when you die?

____

____

____

____

____

Are there any spiritual or religious preferences you want honored?

____

____

____

____

____

***Fillable version available at** https://www.inclusa.org/providers/resources/dementia-care-resources/*

We encourage keeping this document easily accessible by caregivers.

Observation Form

Name ____ Behavioral Communication ____

Date (include day of the week)	Time	What occurred (be specific)	How long did it last	What was happening prior to the behavior	Where did it occur	What interventions were tried to end the behavior	How effective was the intervention	Rate both severity and frequency. (see back)	Caregiver initials

Complete the form using specifics to better determine triggers as well as what works to alter the behavioral communication being displayed by the individual. Don't be afraid of documenting the small most unusual details as this may be the trigger. The purpose of the Observation form is to assist you in determining trends as well as triggers. It is recommended to use a separate Observation form for each specific problematic behavioral communication you wish to track to determine trends/triggers.

Describe the behavior in detail using the ***Observation Form***. Be clear and complete in descriptions.

- What was the individual doing just prior to the incident?
- Where did it happen?
- When did it happen?
- Who was involved? Who was present at the time? Who just left?
- How did it start? Stop?
- What was said? Done?

Rate the behavior on a scale of 0-4 for both severity (how much it is upsetting to caregiver or presents risk to individual or others) and frequency (how often it happens)

Severity/ Frequency

0 = non/rarely

1 = mild/occasionally

2 = moderate/sometimes

3 = severe/frequent

4 = very sever/daily

* Fillable version available at https://www.inclusa.org/providers/resources/dementia-care-resources/

* We encourage keeping this document easily accessible by caregivers

Plan of Action

Target Behavioral Communication: ___________________________________

Date(s) Revised: ____________________

Tips

1. Try not to take behaviors personally.
2. Remain patient and calm.
3. Explore pain as a trigger.
4. Accept behaviors as a reality of the disease and try to work through it.
5. When you have met one person with dementia, you have met one person with dementia!
6. Reasoning, explanation, and social norms may no longer be understood. We need to meet them where they are. Trying to bring them into your reality will not be effective.
7. What works today may not work tomorrow.
8. All behavior is a form of communication. What is the person trying to tell you when they display a behavior?

Ineffective Approaches (Score of severity and/or frequency did not change or went up. These are strategies *not* to use)

1. ____

   ____

   ____

2. ____

   ____

   ____

3. ____

   ____

   ____

Effective Approaches (Score of severity and/or frequency went down. These are strategies to use)

1. ____

2. ____

3. ____

4. ____

5. ____

**Fillable version available at https://www.inclusa.org/providers/resources/dementia-care-resources/*
**We encourage keeping this document easily accessible by caregivers*

Resources

(This is a list of some resources available to assist individuals diagnosed with dementia and their caregivers. The list is not intended to encompass all the various great resources available, and we encourage you to explore your community networks and the internet to find additional resources focused on topics important to you.)

Websites:

- Alzheimer's and Dementia Alliance of Wisconsin (**www.alzwisc.org**)
- Alzheimer's Association Wisconsin Chapter: (**www.alz.org/wi**)
- Dementia Care in Wisconsin | Wisconsin Department of Health Services (http://www.dhs.wisconsin.gov/dementia/index.htm)
  - Aging & Disability Resource Center (ADRC): Support for People with Dementia and their Caregivers (http://www.dhs.wisconsin.gov/adrc/dementia-care-specialist-program.htm)
  - DHS Search Results Keyword: Dementia
- Inclusa Dementia Care Resource Website (www.inclusa.org/providers/resources/dementia-care-resources)
  - Dementia Tool Kit Resources
  - Books Written About Dementia
  - Books Written About Dementia for Children
  - Links to websites and recorded trainings related to dementia
- National Institute on Aging (https://www.nia.nih.gov/health/alzheimers-and-dementia)
  - Link to order National Institute on Aging Publications: (https://order.nia.nih.gov/)
- National Task Group on Intellectual Disabilities and Dementia Practices (NTG) (https://www.the-ntg.org/)
  - NTG- Early Detection and Screen for Dementia
  - NTG- Family Support and Resources
- Positive Approach to Care (teepasnow.com)
- University of Wisconsin Oshkosh- Wisconsin Dementia Care Project Learning Center (wwss.ccedet.uwosh.edu/stc/dhsdementia)
- Teepa Snow's Positive Approach to Care (PAC) (https://www.youtube.com/user/teepasnow)
- Wisconsin Alzheimer's Institute (**www.wai.wisc.edu**)
  - Caregiver Resource Guide: CaregiversHomeHealthGuide.pdf

Articles and Podcast:

- Firearms and Dementia: How Do You Convince A Loved One To Give Up Their Guns? (NPR Article)
- The Resilient Caregiver: Empowering Thise Who Serve People Diagnosed with Dementia (Apple podcast)
- Worried About Grandpa's Guns? Here's What You Can Do. (KFF Health News Article)