You Can Live Well With Dementia

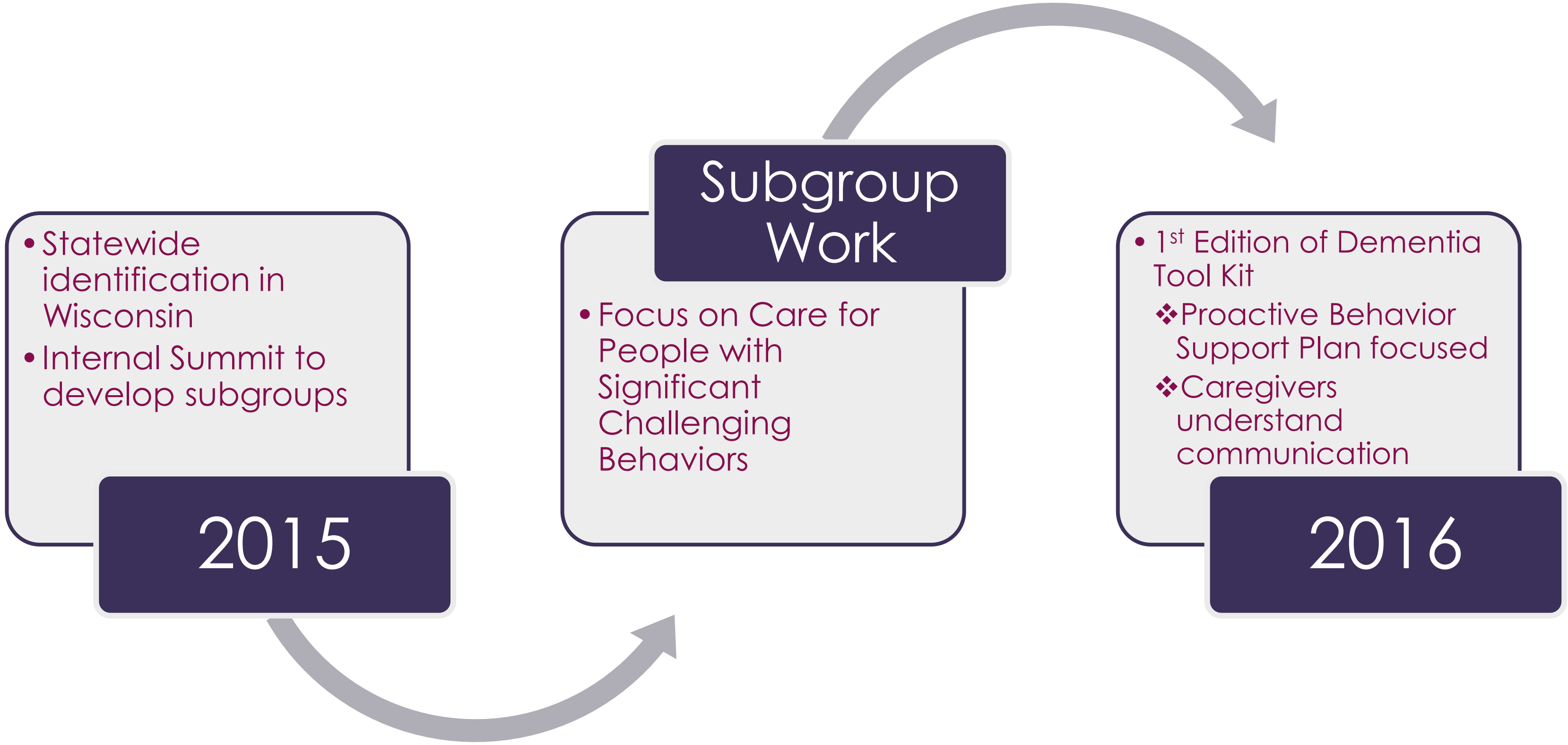
NOW AND IN THE FUTURE

INCLUSA

Overview

- **The Dementia Tool Kit**
    - **A Tool for Self-Advocacy**
    - **A Tool used to Improve Quality of Life**

Why was the Toolkit Developed?



- Statewide identification in Wisconsin
- Internal Summit to develop subgroups

2015

Subgroup Work

- Focus on Care for People with Significant Challenging Behaviors

- 1st Edition of Dementia Tool Kit
  - ❖Proactive Behavior Support Plan focused
  - ❖Caregivers understand communication

2016

What Is the Dementia Tool Kit?

THE TOOL KIT CONSISTS OF 5 DOCUMENTS:

- Script for Use
- My History Form
- My Future Form
- Observation Form
- Behavioral Communication Flow Chart
- Plan of Action

Why Use The Dementia Tool Kit?

- PROMOTE SELF-ADVOCACY IN PREPARATION FOR WHEN INDIVIDUALS NO LONGER ARE ABLE TO DO SO
- SO LOVED ONES LIVING WITH DEMENTIA CAN HAVE PERSONALIZED SUPPORTS
- FOR CAREGIVERS TO UNDERSTAND THE PREFERENCES OF THE INDIVIDUALS THEY SUPPORT

The Dementia Tool Kit Support Understanding:

- The type & level of dementia … ***NOW***
- The person & who they have been
  - **Personality, preferences & history**
- Other medical conditions & sensory status
- The environment – setting, sound, sights
- The whole day… how things fit together
- People - How the helper helps -
  - **Approach, behaviors, words, actions, & reactions**

Does the Dementia Tool Kit Work?

Care Plans w/ Dementia Focus

In a test population of 145 individuals:

- **63%** had plans of care created w/ dementia focused supports

Dementia Related Incidents

Partial Tool Kit completed (no Action Plan):

- **53%** fewer occurrences

Full Tool Kit completed

- **73%** fewer occurrences

Use of As Needed Medications

Additional ***reduction*** reported in use of medications for:

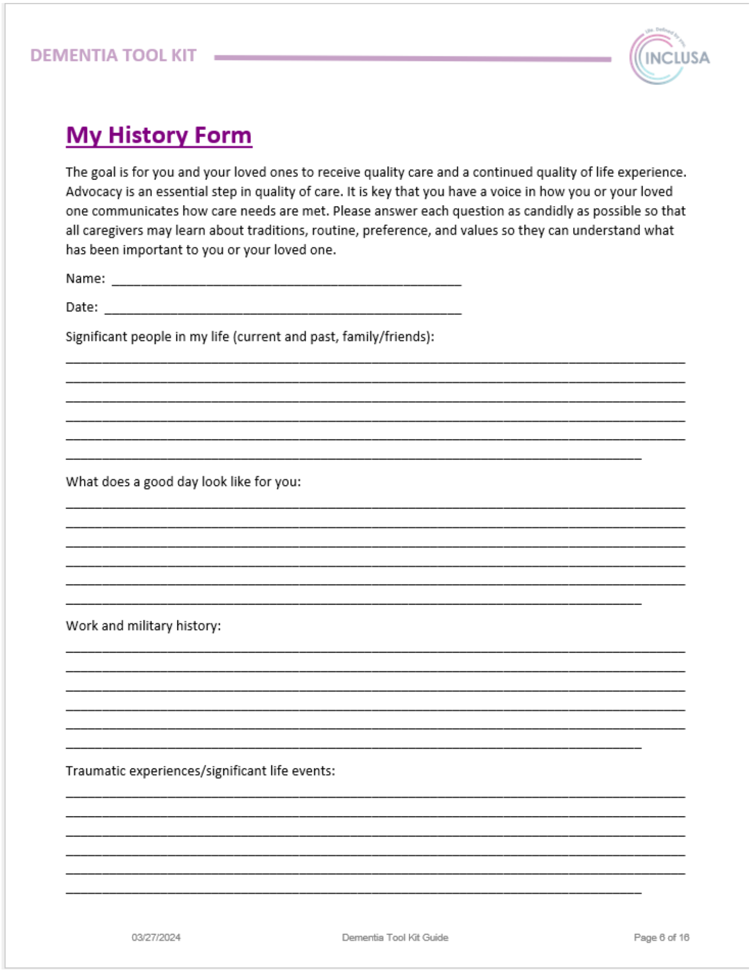
- Anxiety
- Agitation
- Aggression

How Is The Toolkit Used?

- THE INDIVIDUAL CAN COMPLETE THE MY HISTORY AND MY FUTURE FORMS FOR THEMSELVES
- THE INDIVIDUAL'S FAMILY/ LEGAL DECISION MAKER CAN COMPLETE THE PERSONAL HISTORY AND MY FUTURE FORMS FOR THE INDIVIDUAL
- YOU AND YOUR WORKERS MAY PARTNER TO COMPLETE THE PERSONAL HISTORY AND MY FUTURE FORMS

My History & My Future Forms

- THE GOAL IS FOR INDIVIDUALS TO RECEIVE QUALITY CARE AND CONTINUED QUALITY OF LIFE EXPERIENCE.
- ADVOCACY IS AN ESSENTIAL STEP IN QUALITY OF CARE.
- IT IS KEY THAT INDIVIDUALS HAVE A VOICE IN HOW THEIR SUPPORT NETWORK COMMUNICATES HOW CARE NEEDS ARE MET.



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: ______________________________

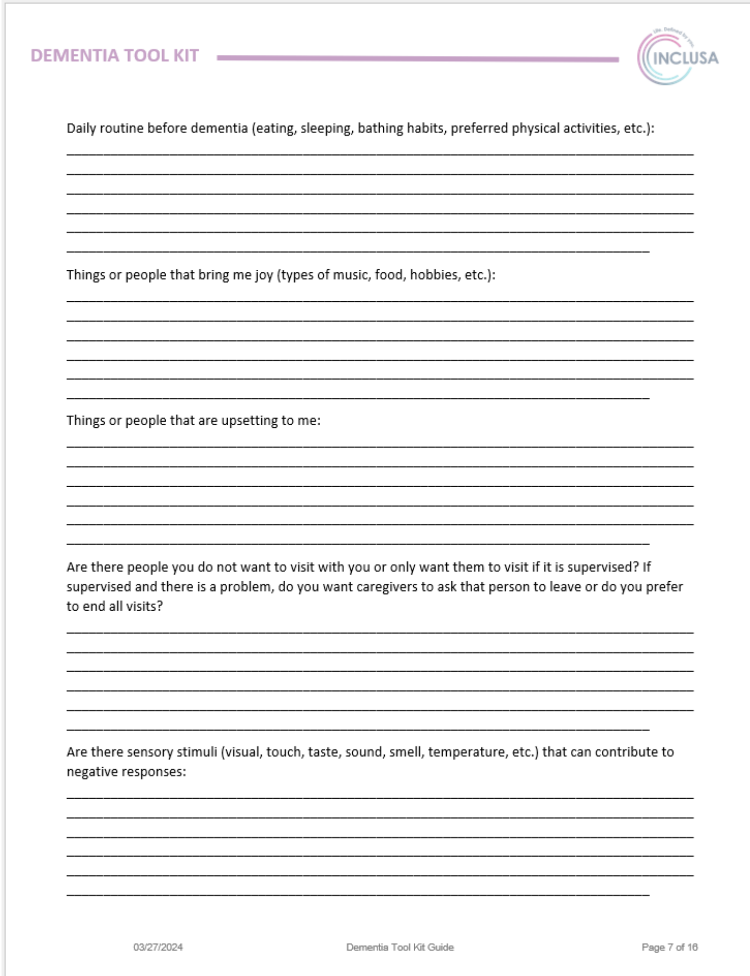
Date: ______________________________

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:



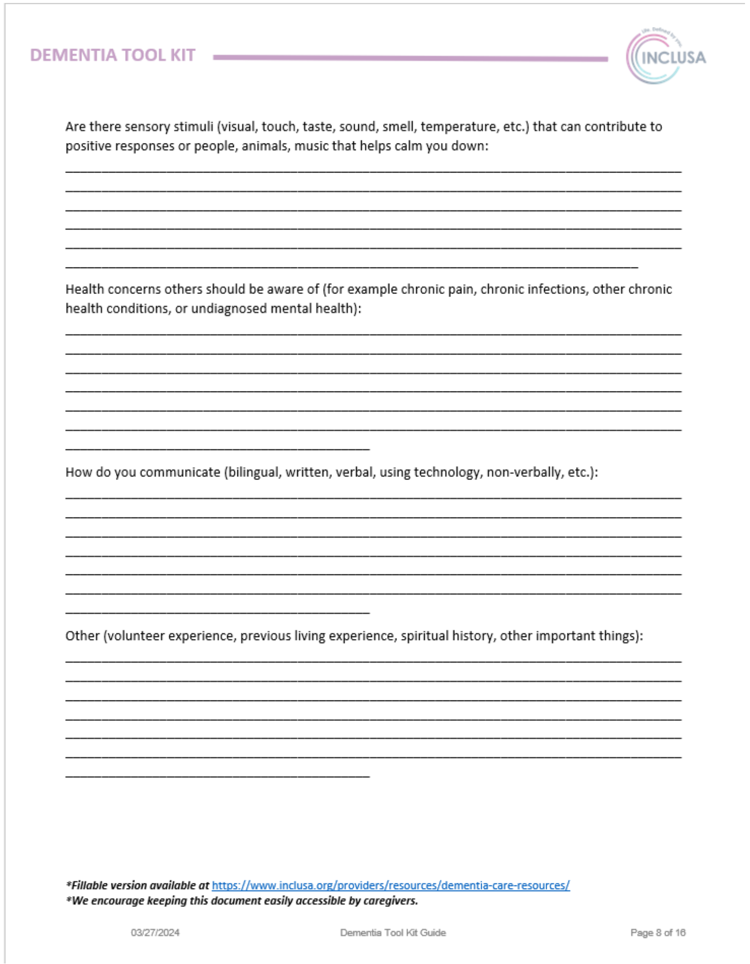
Daily routine before dementia (eating, sleeping, bathing habits, preferred physical activities, etc.):

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:

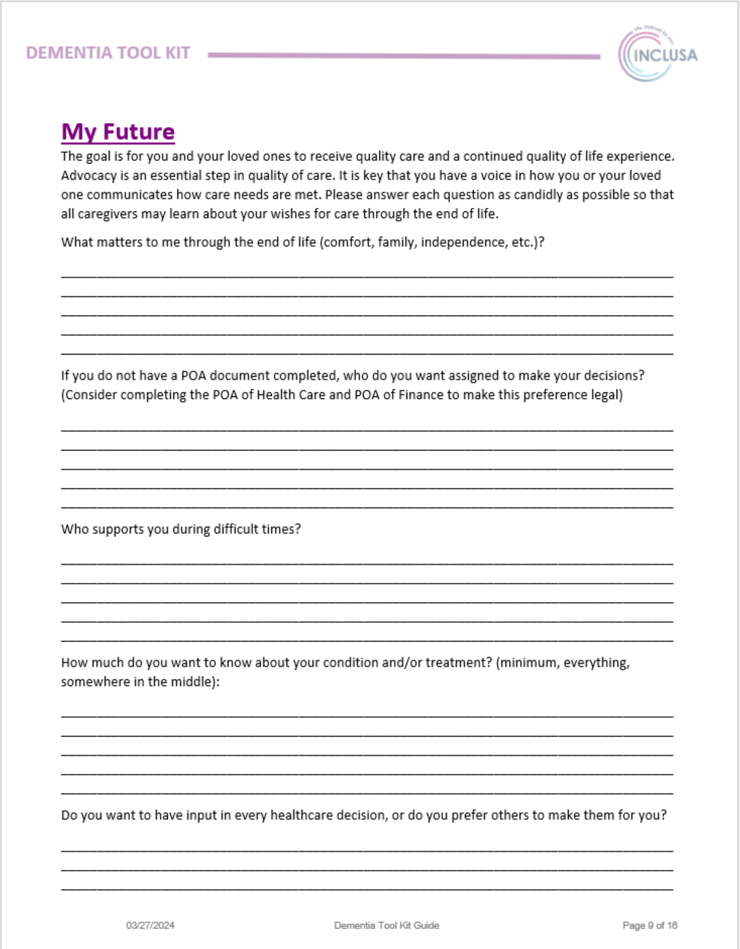
Health concerns others should be aware of (for example chronic pain, chronic infections, other chronic health conditions, or undiagnosed mental health):

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.)?

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____

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)

____
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____
____
____

Who supports you during difficult times?

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____
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____
____

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

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____
____
____
____

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

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____

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

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____
____

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

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____
____
____

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

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What do you worry about most regarding your future?

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

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

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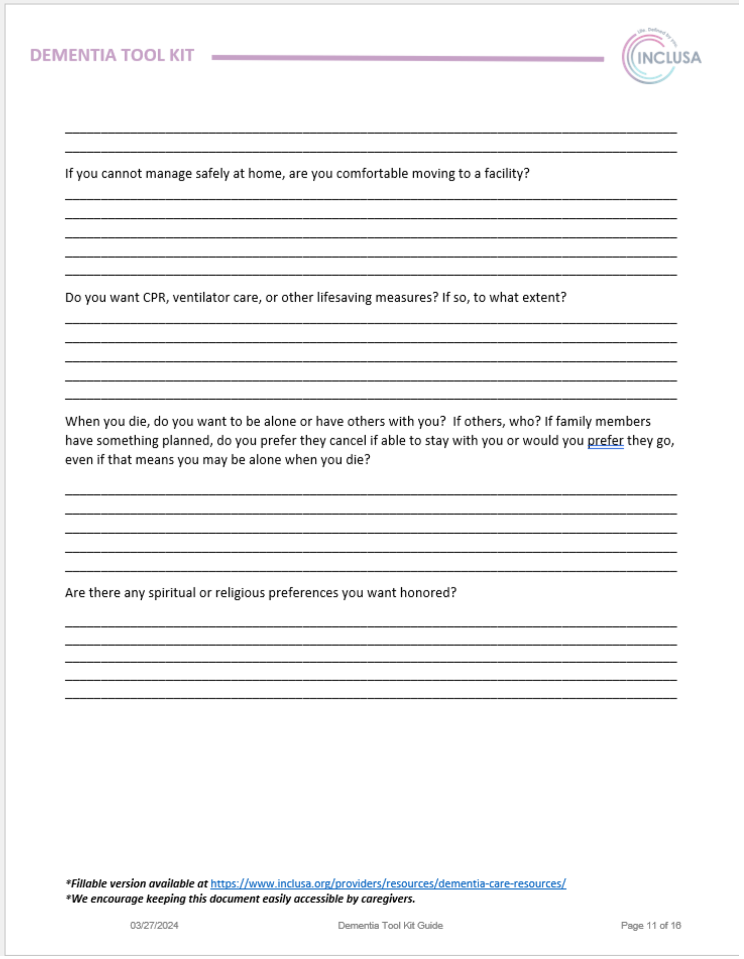

____
____

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

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____
____

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

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____
____
____
____

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?

____
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____
____

Are there any spiritual or religious preferences you want honored?

____
____
____
____
____

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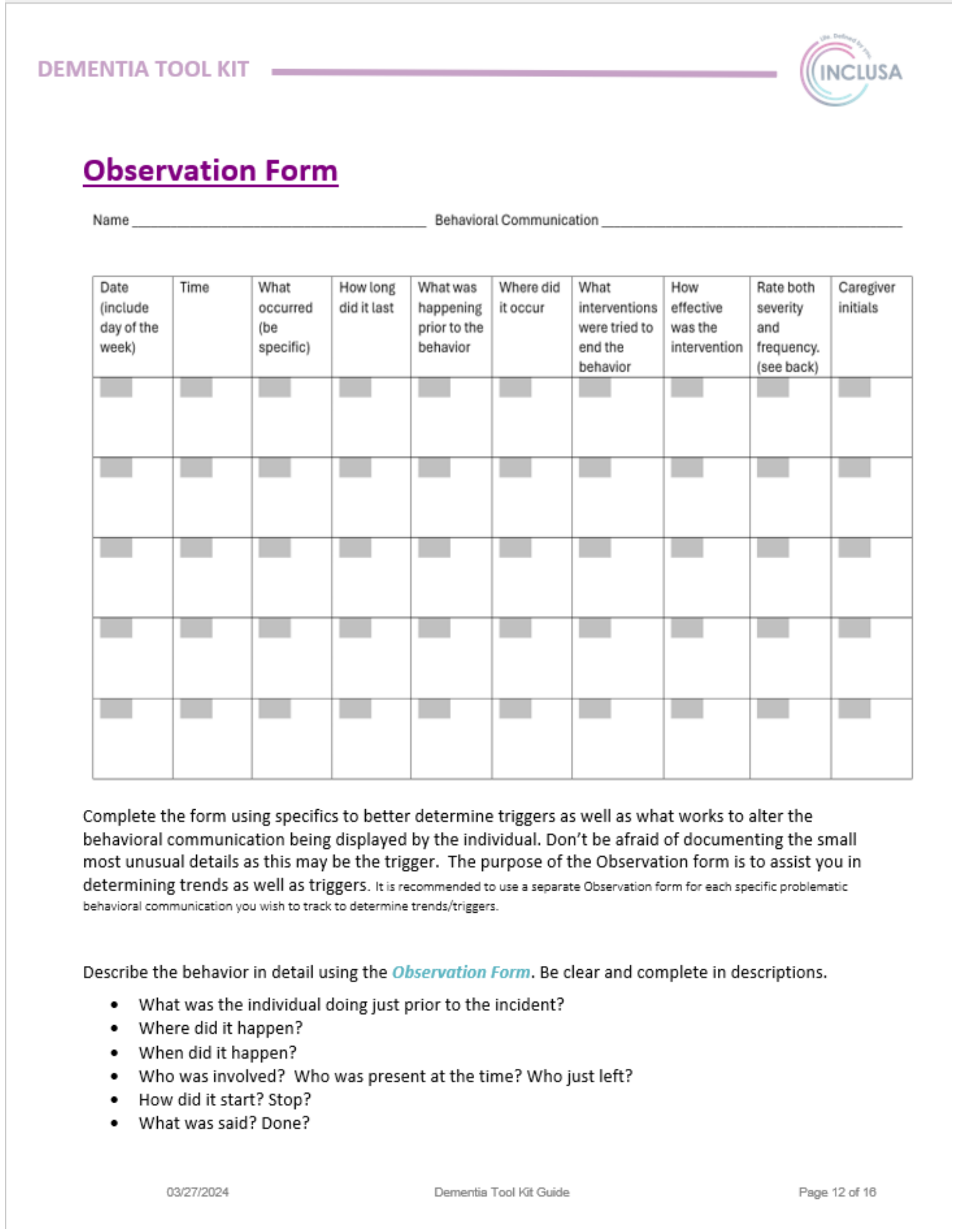
Observation

- **WHAT WOULD YOU OBSERVE**
- **WHAT WOULD YOU DOCUMENT**
- **HOW DOES THIS HELP**
  - ✓ Learning
  - ✓ Quality of Life

Observation Form



Observation Form

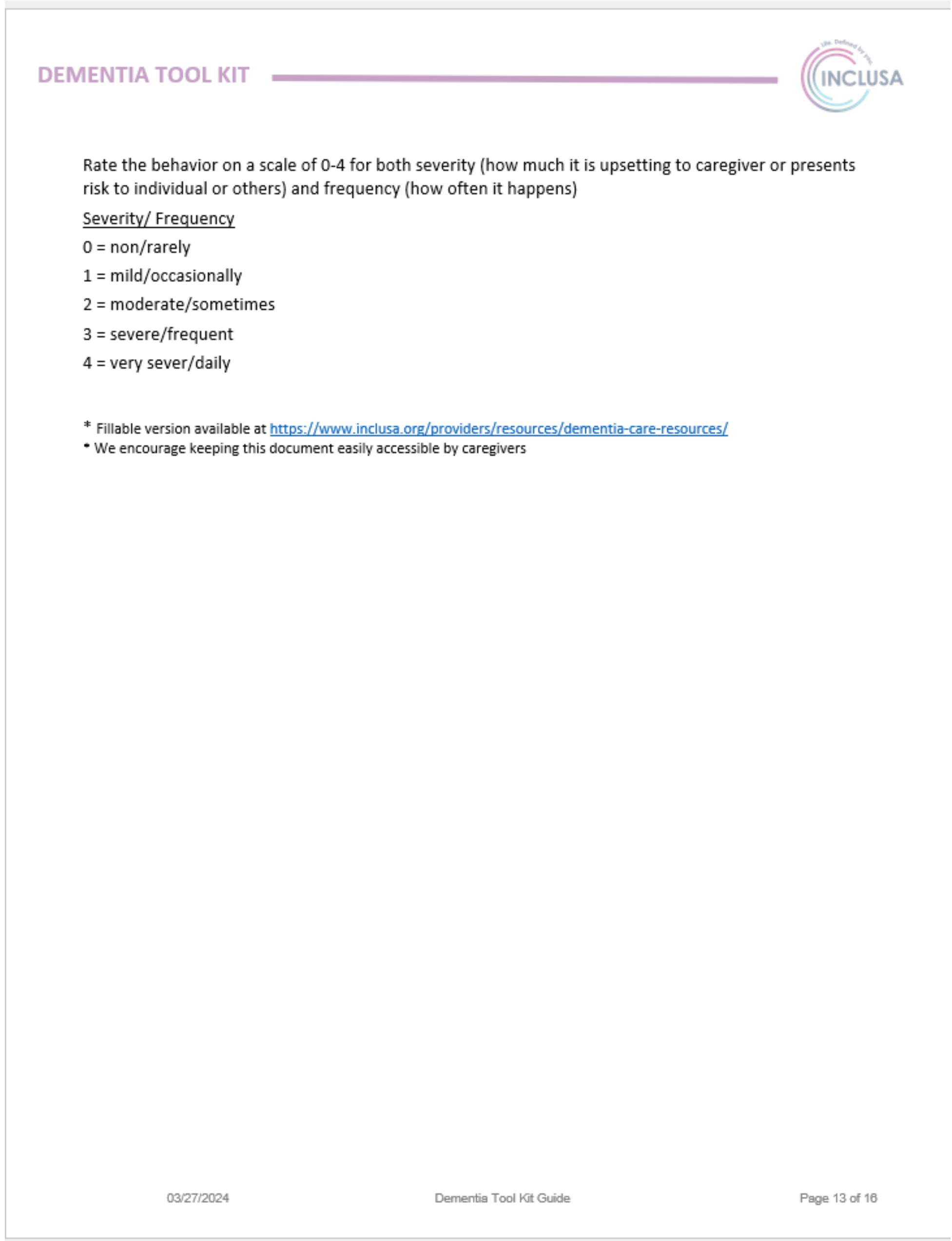
Name ________________________________ Behavioral Communication ________________________________

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/
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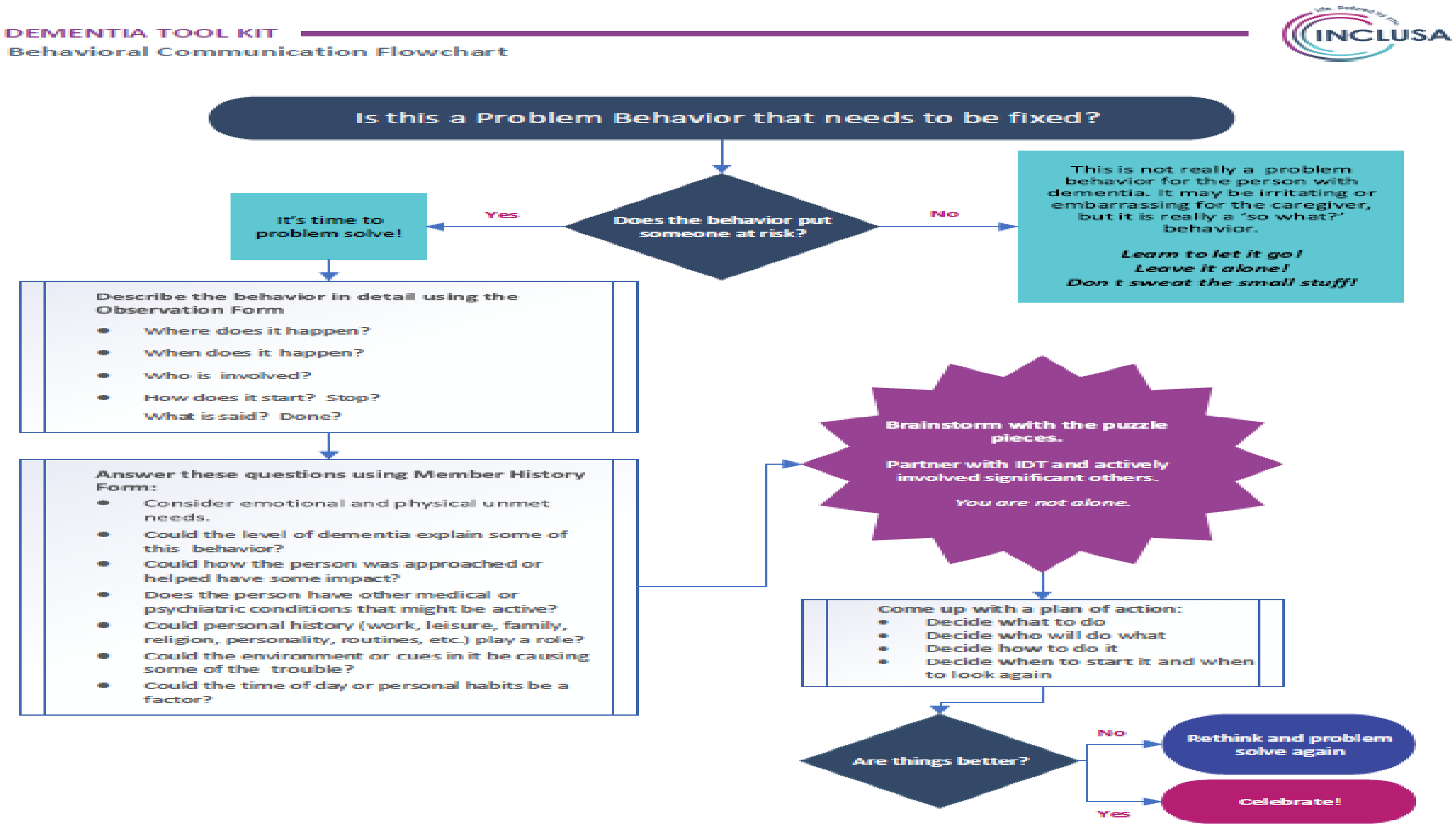
Behavioral Communication

- Individuals ***communicate*** using their words, hand/body gesturing and behaviors to express unmet needs such as discomfort or pain, anxiety, sadness feelings of loss, fear and positives such as excitement, joy, wonderment.
- When it becomes a ***"problem"*** is when the caregiver struggles to fully understand the communication from someone with a dementia dx to best support them and meet their needs.

Flow Chart



DEMENTIA TOOL KIT

Behavioral Communication Flowchart

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Is this a Problem Behavior that needs to be fixed?

Does the behavior put someone at risk?

Yes

It's time to problem solve!

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!

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?

Answer these questions using Member History Form:
- Consider emotional and physical unmet needs.
- Could the level of dementia explain some of this behavior?
- Could how the person was approached or helped have some impact?
- Does the person have other medical or psychiatric conditions that might be active?
- 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?

Brainstorm with the puzzle pieces.

Partner with IDT and actively involved significant others.

You are not alone.

Come up with a plan of action:
- Decide what to do
- Decide who will do what
- Decide how to do it
- Decide when to start it and when to look again

Are things better?

No

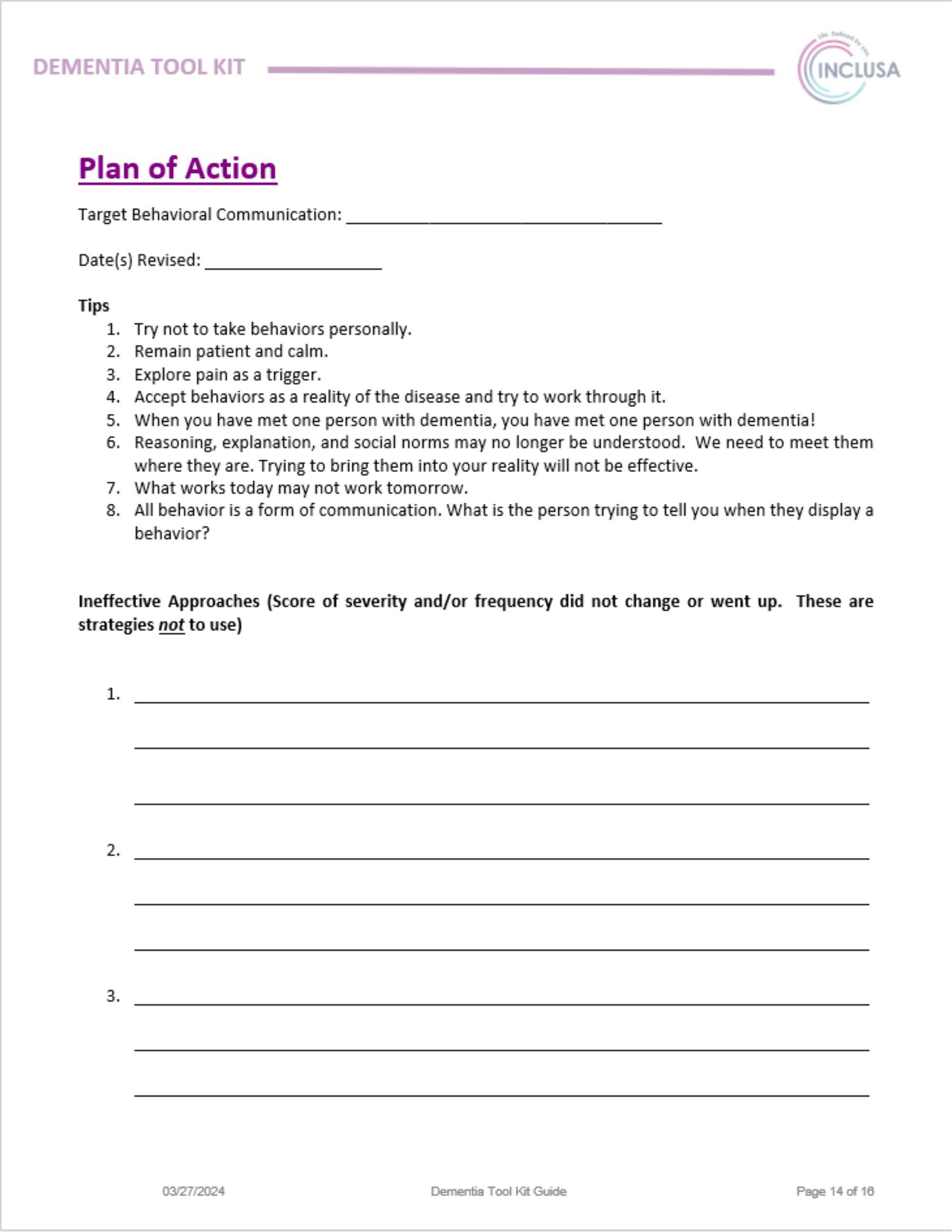
Rethink and problem solve again

Yes

Celebrate!

Action Plan

- TIES EVERYTHING TOGETHER
- PROACTIVE PLANNING
- PROVIDES CONSISTENCY IN CARE
- FLUID RESPONSES



Plan of Action

Target Behavioral Communication: ______________________________

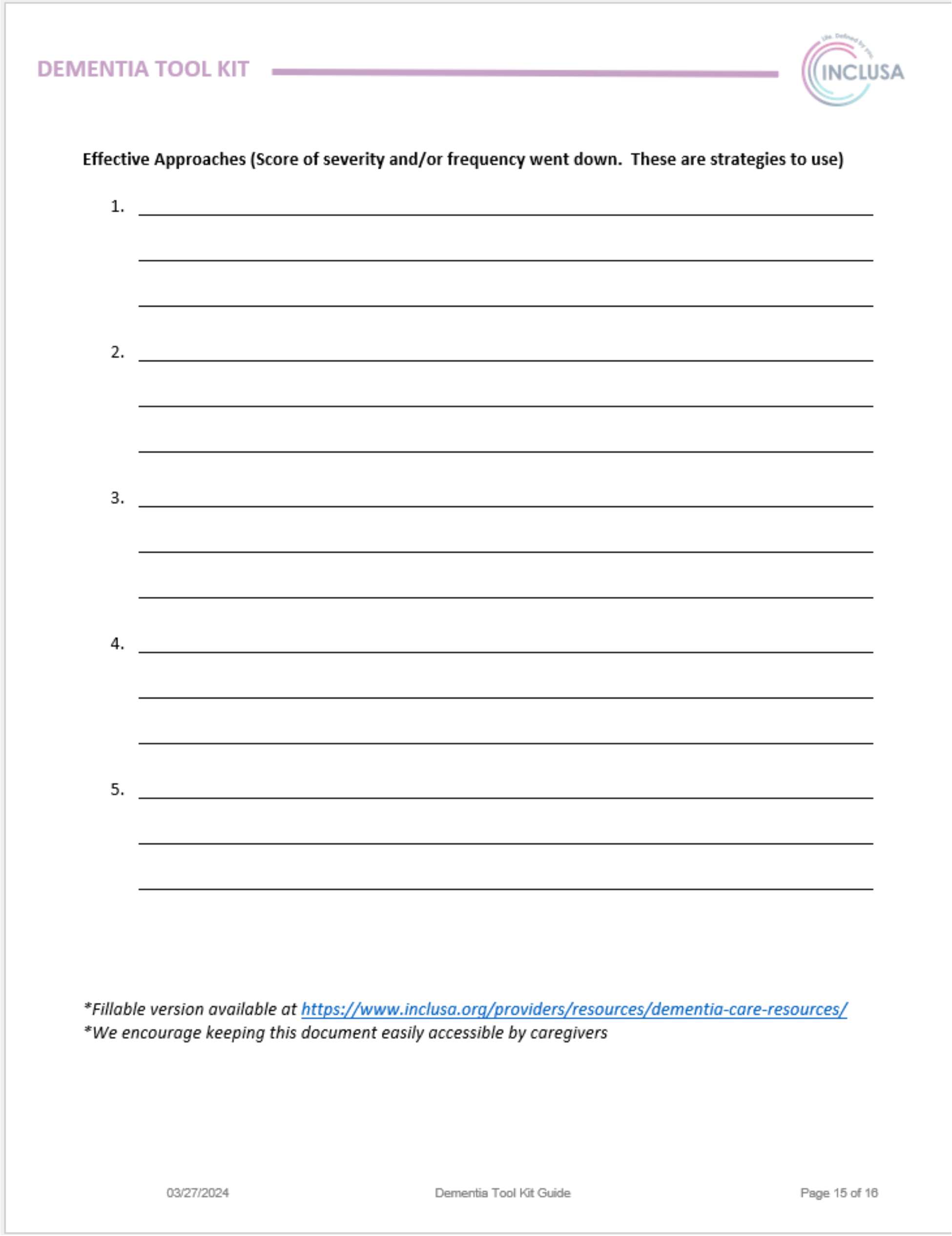
Date(s) Revised: ________________

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. ____
   ____
   ____

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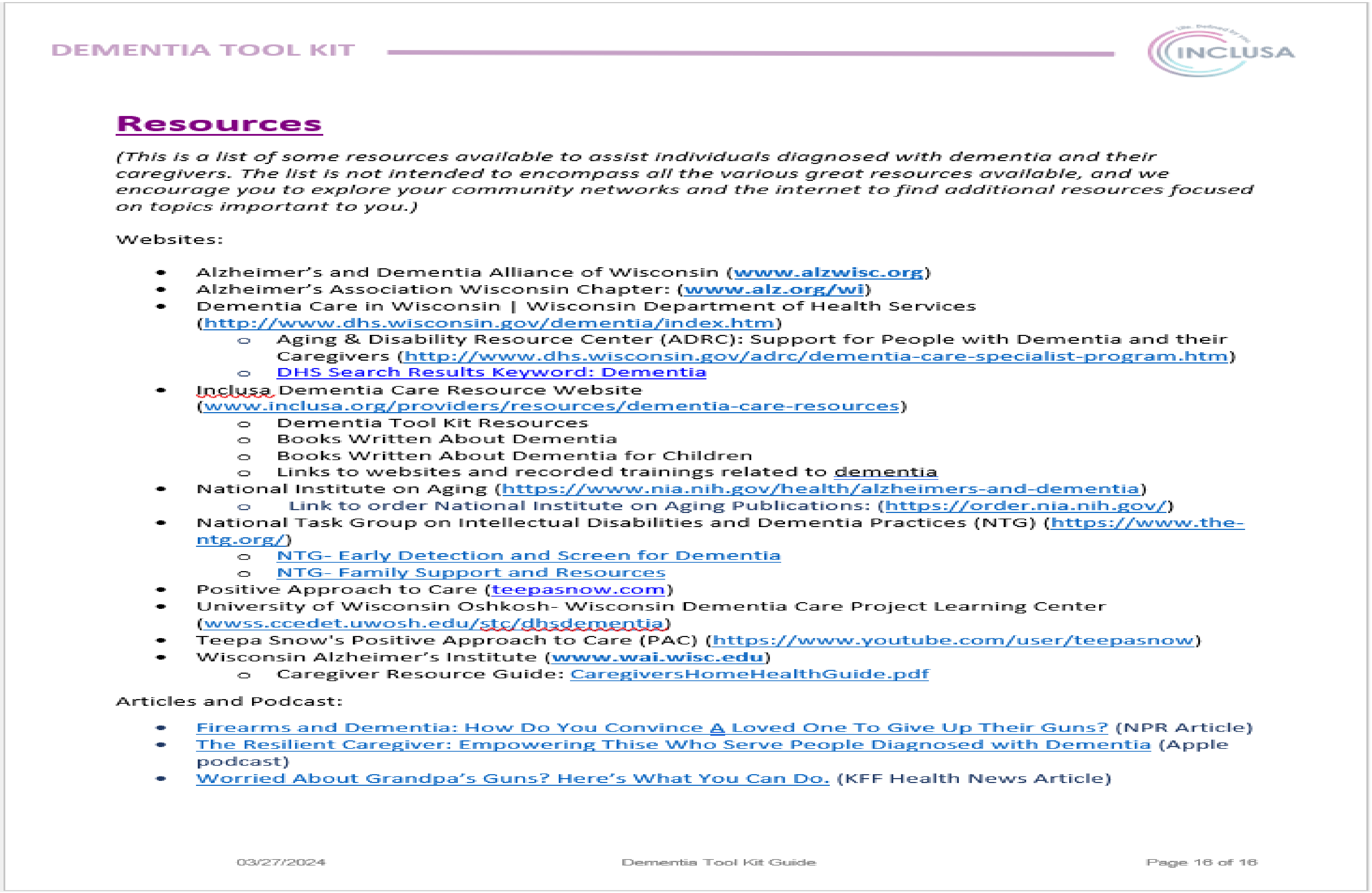
Resources

- **SUGGESTIONS FOR STARTING YOUR EXPLORATION IN UNDERSTANDING DEMENTIA:**
  - Websites
  - Assessment Tools
  - Pod Cast
  - Videos



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)

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Next Steps To Make This Work For You

Questions?

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