

Living Well with Dementia Toolkit

Training



BRIGHAM HEALTH
BRIGHAM AND
WOMEN'S HOSPITAL

HARVARD TH. CHAN
SCHOOL OF PUBLIC HEALTH



Agenda

Background	10 minutes
Living Well with Dementia Toolkit	20 minutes
Implementation of the Toolkit	20 minutes
Training Video	30 minutes
Role Play Exercise	30 minutes

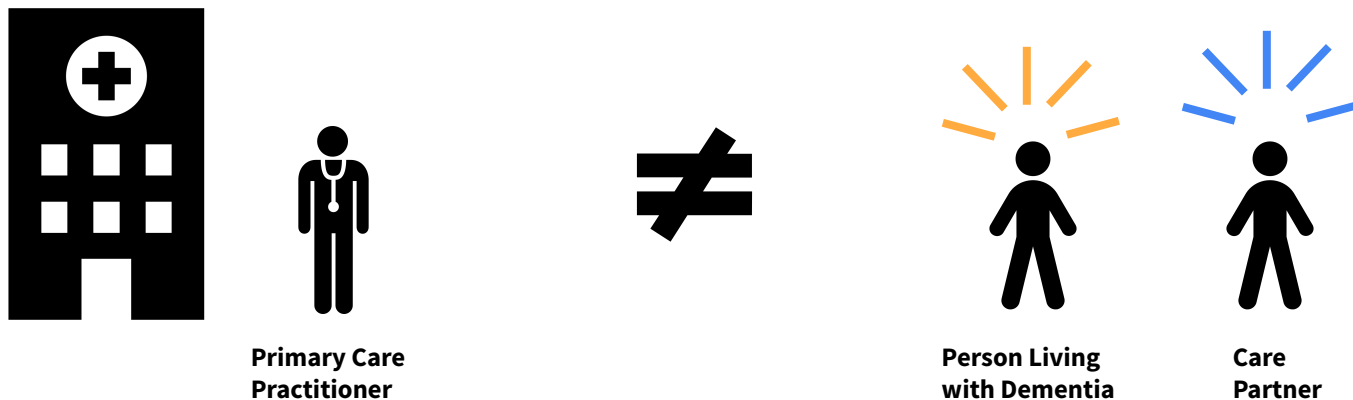
Background

The Problem



Overarching Problem

There is a [big gap](#) between how the system is designed and what people most need. The health system is not designed to meet the most critical needs of patients living with dementia and their families...



... leaving them largely on their own to cope with the tremendous impact of dementia on their lives

We Call These Systemic Breakdowns “Know-Do Gaps”

Gaps between what we know should be done, and what actually occurs in our health care and public health systems.



What we KNOW...

We know dementia **impacts the entire family system.**

We know dementia impacts people's **entire selves and lives.**

We know that **higher quality of life and wellbeing matter most** to people.

We know we can **help people live well with cognitive disabilities.**

We know that facing **dementia without support can be traumatizing.**

GAP

What we DO...

We focus on either the **person with dementia** or the **primary caregiver.**

We see dementia as symptoms, such as **memory loss or behaviors.**

We focus on **treating** (e.g., medicines). We optimize for **safety at all costs.**

We say that there's **nothing we can do** because we can't cure or treat it.

We leave people feeling **unseen and unheard** - and **all alone.**

We aim for **families** to **achieve a good quality of life while living with dementia** by helping them to have the knowledge, skills, and support **to adapt to changes big and small throughout their journey.**



WHO: We are focused on whole “families” living with dementia

FROM

PLWD OR Caregiver



TO

Whole “Family” System



**BIG
SHIFTS**

- Captures the breadth of impact that dementia has on a person’s closest relationships
- Highlights a different set of problems - more relational than individual
- Requires negotiation of needs among people in the system
- Acknowledges that dementia is too big for any one person to carry on their own

WHY: We want to help people achieve better quality of life for the whole “family” system

FROM

Symptoms and Safety



TO

Quality of Life and Balance



**BIG
SHIFTS**

- Captures the depth of impact that dementia has on a person and their daily lives
- Prioritizes what people say they really need and what really matters most to them
- Balances a complex set of needs vs. optimizing for one particular need (e.g., safety)
- Opens up a world of opportunities to make people’s lives better vs. there’s nothing we can do

WHAT: To achieve better quality of life, families need to be more prepared, equipped, and supported

FROM

**Confusion, Overwhelm, Isolation,
Constant Crisis**



TO

Clarity, Capacity, Resourced, Adaptive



**BIG
SHIFTS**

- Helps the “family” connect changes in the brain with what they see / experience vs. black box
- Enables the “family” to understand what they will really need vs. discover along the way
- Gives the “family” the knowledge and skills that they most need to sustain the journey
- Takes an adaptive approach that differentiates what’s in and out of our control

Living Well with Dementia Toolkit

The Solution



Living Well with Dementia Guide

ABOUT THIS GUIDE:

This guide can help facilitate meaningful conversations about what matters to you and lead to action plans that help support living well with dementia.



HARVARD T.H. CHAN
SCHOOL OF PUBLIC HEALTH

Families experience dementia as the *whole family*:

dementia affects the *routines, fears, hopes, and needs* of the entire family system. (We use “family” broadly, including friends, supporters and chosen family.)



Living with dementia can feel like a series of unpredictable **ups and downs**, and **cycles of adaptation** with many challenges.

Seeing these changes, adapting to new realities and finding **knowledge, skills and support** can help people live better with dementia.



Our tools are designed to support families navigating different areas of dementia care—**relationships**, **daily life**, **health**, **quality of life**, **dementia support**, and **planning for the future**. We understand that every family has unique needs and priorities, so our tools help them focus and plan for what matters most to them.



Relationships



Daily Life



Quality of Life



**Dementia
Support**



Health



**Planning for
the Future**

The **Living Well with Dementia Toolkit** offers care navigators and other providers a set of tools to help families have open conversations, identify their evolving needs, and create an action plan for living well together.



The tools ensure that the person living with dementia, their caregivers, and their loved ones feel **heard** and **supported** in care decisions and daily life.

A form titled "Check-in" with a "Success Date:" field. It includes a "Topic:" field and a "Name:" field. Below these are six categories, each with a circular icon and a dashed line for notes: Relationships (people icon), Daily Life (sun icon), Quality of Life (sun with heart icon), Planning for Future (calendar icon), Health (heart icon), and Dementia Support (person with brain icon). There are checkboxes for "Met" and "Not Met" next to each category.

Check-in

A form titled "Action Plan" with a "Success Date:" field. It includes a "Check off topics discussed during today's conversation. List any topics discussed:" section with six circular icons: Relationships, Daily Life, Quality of Life, Planning for Future, Health, and Dementia Support. Below this is a "Discussion Notes: Capture and summarize key points from the discussion. Include subtopics where possible that were discussed or mentioned:" section. At the bottom is an "Action Steps:" section with a "What needs to happen?" field, a "Who can help?" field, and a "When?" field.

Action Plan



Conversation Cards

Lisa was recently diagnosed with dementia. Lisa and her daughter, Sarah, have noticed a few new needs and are not sure **how to navigate the changes**.



QUALITY OF LIFE

Lisa misses being an active member in her local church group.



PLANNING FOR THE FUTURE

Sarah wants to support her mom with financial planning but not sure where to start.



RELATIONSHIPS

Lisa misses her circle of friends every so often.



Lisa and Sarah used the tools with a facilitator to discuss and plan some solutions and next steps.



QUALITY OF LIFE

Lisa will carpool to her local church group once a month with her neighbor.



PLANNING FOR THE FUTURE

Sarah will consult a financial advisor who focuses on elder-care.



RELATIONSHIPS

Sarah will plan a dinner with some of Lisa's friends.



Session Date: 10/11/2014

Action Plan

Circle the topics discussed during today's conversation. List any subtopics discussed.

Daily Life	Quality of Life	Health	Relationships	Planning for the Future	Dementia Support
<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>

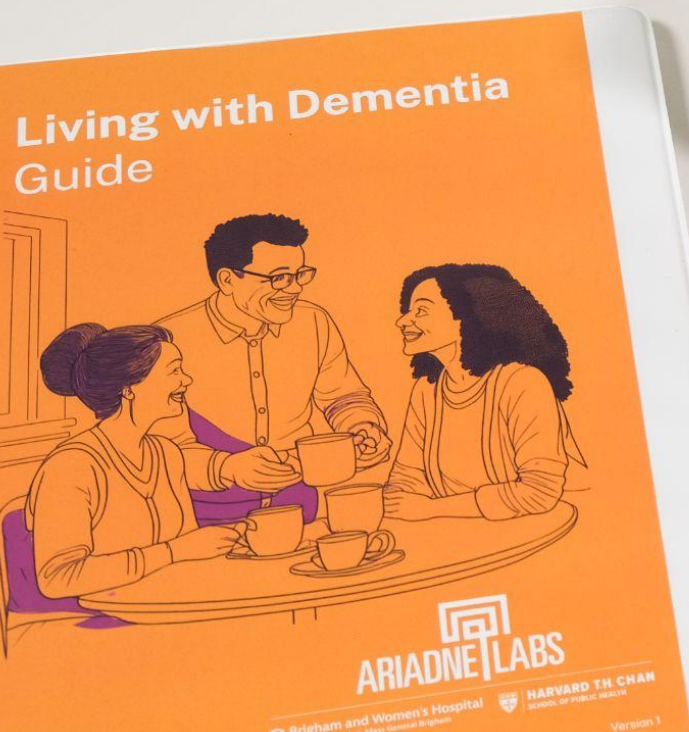
Discussion Notes: Capture and summarize key points from the discussion. Include subtopics and/or emotions that were discussed or expressed.

Lisa misses being an active member in her local church group.
Sarah wants to support her mom with financial planning but not sure where to start.
Lisa misses her circle of friends every so often.

Action Steps:
When creating action steps, explore ways to balance safety with attention to quality of life and meaningful relationships and activities.

What needs to happen?	Who can help?	When?
Dinner with friends	Sarah	in 2 weeks
Schedule appt with financial Advisor		This week
carpool with Neighbor to church		

Living Well with Dementia Toolkit Components



Overview of Tools & Topics



Relationships

Subtopics: Community, Family, Friends, Pets



Daily Life

Subtopics: Transportation, Housing, Routine, Personal Care, Food, Hobbies, Communication



Quality of Life

Subtopics: Spirituality & Faith, Building Hope, Meaning & Purpose, Autonomy, Growth, Belonging, Joy/Pleasure, Behavioral Health, Dignity of Risk, Identity



Planning for the Future

Subtopics: Crisis Planning, Housing, Finances, Legal, Palliative & Hospice Care, Medical Wishes, Decision-Making



Health

Subtopics: Dementia, Medications, Hospitals, Staying Healthy, Medical Providers



Dementia Support

Subtopics: Care Coordination, Adaptive Supports & Technology, Care Partners, Mapping Your Support, Community Resources, Coaching, Respite

Check-In

A worksheet that guides a conversation exploring what is working well and where there are current challenges for the individual and family or supporters living with dementia.

Circle of Support

A worksheet to reflect on, identify and map current and potential sources of support.

Dementia Journey

A visual illustrating the recurrent cycle of change that people experience while living with dementia.



Conversation & Emotion Cards

These provide more detailed prompts and possible solutions for common issues that arise for people living with dementia. These cards focus on daily life and include a set of emotion cards, to help understand the lived experience of dementia.

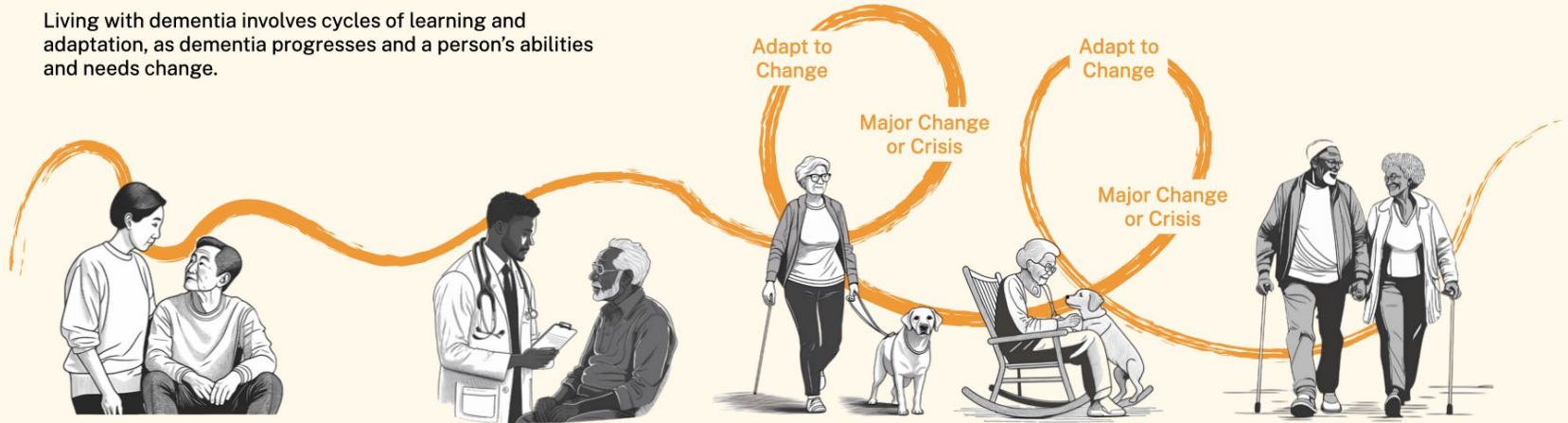
Action Plan

A worksheet to identify and document actionable next steps for solving problems and adjusting to new needs.

The Dementia Journey

Focusing on quality of life and planning for the changing nature of dementia can help families better navigate the journey of living well with dementia.

Living with dementia involves cycles of learning and adaptation, as dementia progresses and a person's abilities and needs change.



Noticing Changes

People living with dementia and their loved ones begin noticing changes and question what's going on. This can happen slowly over years.

Learning and Diagnosis

Getting a diagnosis can help explain what is happening. It can be the first step in learning more about dementia and accessing important resources.

Adapting to Daily Life

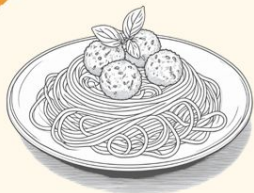
Living with dementia can feel like a series of unpredictable ups and downs, with many challenges. Seeing these changes, adapting to new realities and finding **knowledge, skills and support** can help people live better with dementia.

Planning for the Future

Anticipating changes down the road and preparing for future needs can help families navigate the dementia journey with greater confidence, support and comfort.

Finding New Ways to Connect

Beth hangs out with her friend and neighbor Sita. They usually go out for dinner once a month. Since Beth's dementia has progressed, they're finding new ways to connect and spend time together.



Having dinner together



Listening to music



Playing with Beth's dog

Dementia Check-in

Assess the family's strengths and needs across the 6 key topics



Using the Check-In

Use the form to take notes for yourself as needed. Go through Check-In topics, asking the following questions for each topic.

- What is going well for you in this area?
- What is not going well for you in this area?

*If a person or family comes in with an agenda, listen to their concern and try and place it within one of the categories; and then move on to ask about the other categories as well.

Using the Emotion Cards

After completing the Check-In, pull out the emotion cards. Lay them on a table or surface near you. Ask each person present to pick 1 or 2 cards about how they are feeling about dementia right now.







Identifying What Matters

Based on the Check-In, you may be able to identify one or two main topics where families need more support. In addition, the use of the Emotion cards may identify the topic areas that most need attention for this family right now.

Session Date: _____

Check-In

Assess the 6 dementia topics. Ask what is working well and what challenges exist for each topic.

Topic:	Notes:	Going Well	Needs Support
 Relationships		<input type="checkbox"/>	<input type="checkbox"/>
 Daily Life		<input type="checkbox"/>	<input type="checkbox"/>
 Quality of Life		<input type="checkbox"/>	<input type="checkbox"/>
 Planning for Future		<input type="checkbox"/>	<input type="checkbox"/>
 Health		<input type="checkbox"/>	<input type="checkbox"/>
 Dementia Support		<input type="checkbox"/>	<input type="checkbox"/>

Conversation Cards

Discuss family's strengths, challenges and needs



Focusing on What Matters:

Pull out the one or two main topic cards that you have identified (either through the Check-In or through the Emotion Cards) as important to the person or family you are with. Turn over the first main topic card to reveal all of the subtopics in that area. Share this with the interviewees. Try to narrow down a more specific area for discussion. You might say:

- Which of these areas would you like to talk more about today?
- How are things going for you in these areas?

You may also point to subtopic that has already been clearly identified in prior steps.

Using the Prompts

Use the question on the back of the subtopic card to start a more in depth discussion about what is happening for this family right now. Use the prompts as needed to go deeper into the conversation. The card also contains some general ideas for next steps that may be helpful for each subtopic. Don't be limited by these ideas however. They should be bolstered by what you know about your local resources and supports.



Conversation Cards

6 Main Category Cards



Subtopic Cards

Action Plan & Circle of Support

Identify actionable steps and supports

Action Plan
Check off tasks completed during today's conversation with your information specialist

Notes: Capture all content for this action. It's the discussion, needs, needs of the individual. Not sure where to go next?

Action Steps:
After meeting and talking, go online, then online, and mail, using all the information you will find. Research, information, and resources. Consider necessary to help and resources.

What needs to happen?	Who can help?	When?

Using the Action Plan

Use this document to take notes in the top box on what is happening for the family. Use the prompts on the cards to help brainstorm solutions.

Remember to explicitly address quality of life and the importance of the dignity of risk, as it relates to each topic.

Document action steps, who is doing what and when they are doing it in the last section of this page. Leave a copy of the Action Plan with the family and use a copy for your notes.

Circle of Support
After an information session, you will find out who can help you with your needs and supports. We will provide you with a list of people who can help you with your needs and supports. Use this list to start identifying your needs and supports.

Family
Friends
Community
Support
Information
Needs
Quality of Life
Planning for Future

Circle of Support

Center: Person icon
Surrounding: Eight empty circles for roles

Return to the Circle of Support

Questions to ask:

- 1) Who here can help with this?
- 2) Where can we go for more information or more help?
- 3) Do you want to talk about what it would look like to ask this person for help?

Circle of Support

Who are the important people in your life that you can turn to for support?

Use this list to start identifying your existing network and supports. We will use this list later to help develop our care plan.

Family

- ☐
- ☐
- ☐

Friends/ Neighbors

- ☐
- ☐
- ☐

System Supports

(Healthcare, Physicians)

- ☐
- ☐

Community Resources

- ☐
- ☐

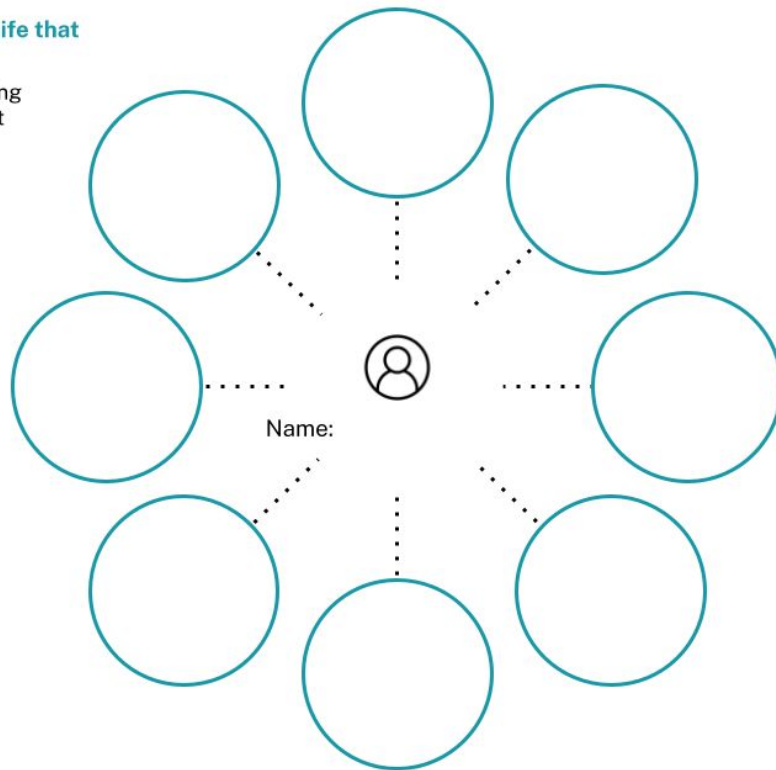
Community Connections

(e.g., Faith Groups)

- ☐
- ☐

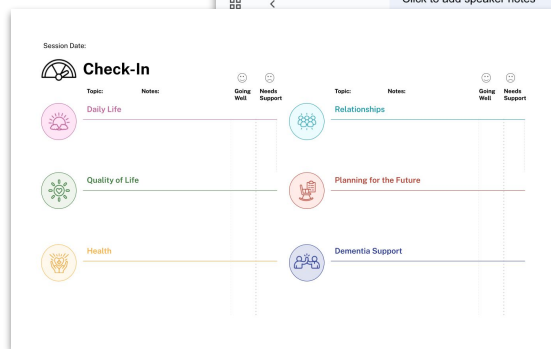
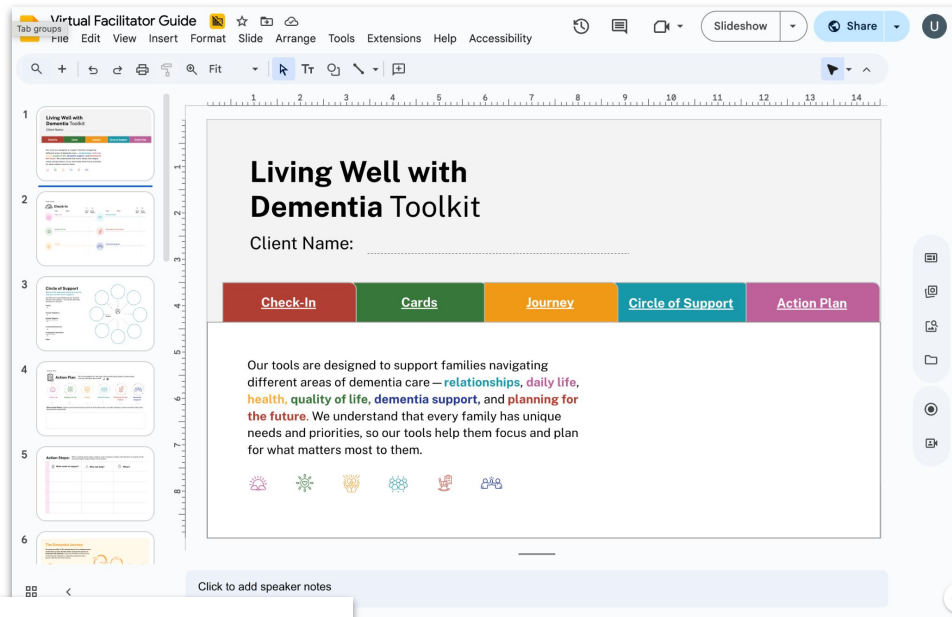
Other

- ☐
- ☐



Virtual Facilitator Guide

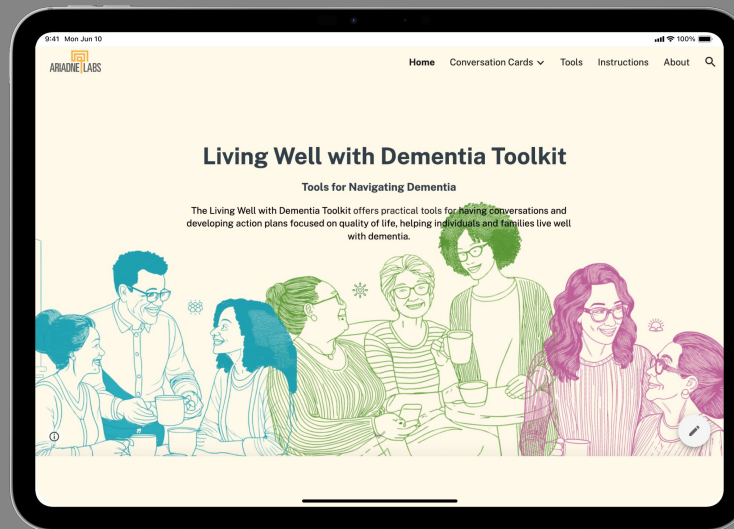
For providers who meet with clients via telehealth and use platforms like Zoom, we have developed a slide deck version of the toolkit to make it easy to share materials on screen during sessions and better support virtual care.



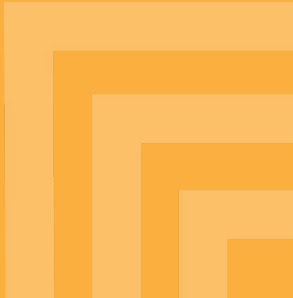
PHYSICAL/ PAPER-BASED VERSION



DIGITAL VERSION



Implementation of Living Well with Dementia Toolkit



Implementation of Living Well Toolkit Instructions



Introducing the Tools

Talking about the tools

Sample Script:

“I’d like to use this Dementia Toolkit to help guide our conversation today. This Toolkit offers a format for us to have meaningful conversations about how dementia is impacting you and your family/supporters. We will then shift from the conversation to the create a plan and action steps that aim to better support you and your family/supporters in living with dementia. How does that sound?”









Follow-up Visit

Session Date: _____

Check-In

Assess the 6 dementia topics. Ask what is working well and what challenges exist for each topic.

Topic:	Notes:	Going Well	Needs Support
 Relationships		<input type="checkbox"/>	<input type="checkbox"/>
 Daily Life		<input type="checkbox"/>	<input type="checkbox"/>
 Quality of Life		<input type="checkbox"/>	<input type="checkbox"/>
 Planning for Future		<input type="checkbox"/>	<input type="checkbox"/>
 Health		<input type="checkbox"/>	<input type="checkbox"/>
 Dementia Support		<input type="checkbox"/>	<input type="checkbox"/>

1 Introduce the Check-in



Inform the participant that you will be asking them a series of questions about how dementia is impacting their life

2 Dementia Check-In



Go through the topics to identify how the family is doing, their challenges, needs, and strengths in each area through conversation,

3 Conversation Cards



Use the conversation and emotion cards to learn more about what is important to the participant.

4 Action Steps



Brainstorm and document solutions and supports. Identify needed resources and concrete next steps.

Using the Conversation Cards



Conversation Cards


These provide more detailed prompts and possible solutions for common issues that arise for people living with dementia. These cards offer a friendly and accessible way to further explore important issues to people living with dementia.



Dementia Support

Dementia is hard. You are not alone. There are many ways to get more information and support.

Dementia Support



Subtopics

- Care Coordination
- Adaptive Supports & Technology
- Care Partners
- Mapping Your Support
- Community Resources
- Coaching
- Respite

How do I **coordinate** all the pieces?

Conversation Prompts:

- Communicating with:
 - Family and networks
 - Healthcare professionals
 - Community organizations
- Medications, schedules, abilities, goals, and wishes
- Identifying who to ask for what
- Centering the person with dementia
- Planning transitions

CONSIDER: Care notebooks; Shared google docs; Care coordinators or navigators (covered by insurance; available through PCP, specialists, Alzheimer's Association, Area Agencies on Aging); Patient Priorities Care

Using the Conversation Cards



Options for use:

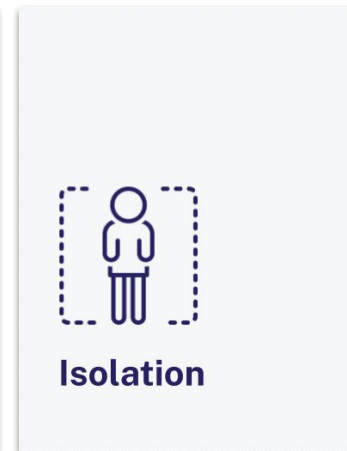
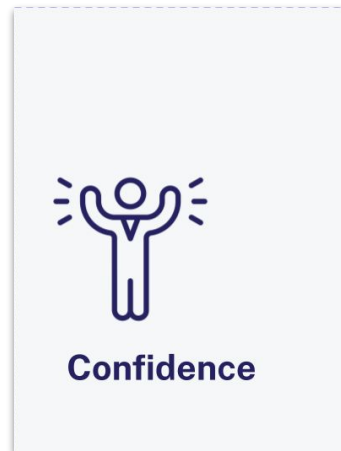
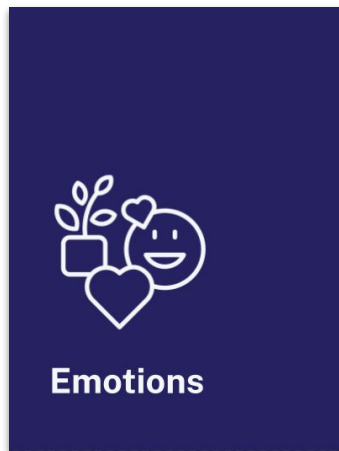
1. Offer the 6 main topic cards to a client and ask them to pick one for discussion.
2. Select a topic of interest from the Check In and then pick one or two subtopic cards to review with its prompts and suggested interventions.
3. These can be easily used in 1:1 visits or as discussion prompts for groups.

Using the Emotion Cards



Emotion Cards

These provide a way to talk about how people are experiencing life with dementia. They can be used to focus a conversation on what is most important at the time of a visit, to normalize the complex experience of living with dementia or to re-focus on positive shared experiences.



Using the Emotion Cards



Options for use:

1. Ask the participant to pick one or two cards that represent how they are feeling now about living with dementia.
2. When emotions arise during a visit, share the cards to validate and normalize emotions, or to help open up other emotional possibilities.
3. Ask the person with dementia and their caregiver to each pick an emotion card for discussion.

*Although these emotion cards are the most unusual part of the Toolkit, they have been the most impactful for users in understanding what matters to people with dementia and their caregivers, for deepening conversations and connection and for quickly identifying where increased support is needed.

Action Plan


Having an Action Plan helps ensure that these conversations lead to concrete interventions, next steps and support.


- Document the plan here and share a copy with the family
- Document instead in an EHR, making sure the person with dementia and caregiver know the plan and when they will see you again
- If you use an EHR, create a smart phrase for the Check In, to be able to incorporate it into your notes easily
- Users of the Toolkit expressed that writing down the plan made the next steps and plan feel more concrete and likely to occur


Session Date: _____


Action Plan


Check off topics discussed during today's conversation. List any subtopics discussed.



Relationships


Daily Life


Quality of Life


Planning for Future





Health


Dementia Support

☐ ☐ ☐ ☐ ☐ ☐

Discussion Notes: Capture and summarize key points from the discussion. Include subtopics and/or emotions that were discussed or expressed.

Action Steps:
When creating action steps, explore ways to balance safety with attention to quality of life and meaningful relationships and activities.

 What needs to happen?	 Who can help?	 When?

Demonstration

And practice



Training video

Role Play Exercise

Pair up with a peer or colleague and practice the following using the guide. One person should assume the role of a person living with dementia or their care partner, and the other person should assume the role of facilitator.

Imagine a patient you saw recently...

The facilitator should:

- Introduce the guide and its purpose
- Introduce the main topic cards
- Ask your partner, who has assumed the role of the person living with dementia or the care partner, to select one card and facilitate a discussion around the topic.
- Ask your partner to select an emotion card that describes how they feel about dementia right now.
- Then, respond to the emotion expressed and work together to fill out the care plan for the topic selected and emotional issues raised.

When finished, switch roles with your partner.

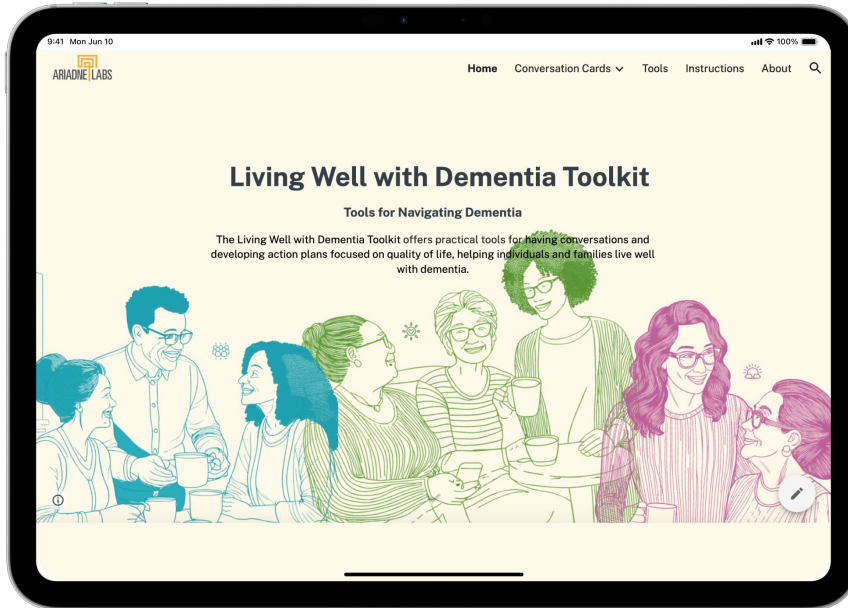
Role Play Debrief



- What questions came up?
- What did you find most effective in introducing the Toolkit?
- What did you find most effective in practicing using the Toolkit?
- How did it feel when you were role playing as the person living with dementia or their care partner?

Wrap-Up

Where to access materials



[Living Well with Dementia Toolkit Website](#)

[Living Well with Dementia Virtual Toolkit](#)

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