The *Living Well* with Dementia Toolkit

Implementation Guide

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Using the *Living Well* with Dementia Toolkit

Implementation Guide

The Living Well with Dementia Toolkit Implementation Guide provides a practical roadmap for effectively adapting and putting the Toolkit into practice. Drawing on proven implementation science frameworks and real-world case studies, the guide gives practical tips for tailoring the Toolkit to fit various settings and populations. The guide is structured around the EPIS implementation framework and incorporates PDSA (Plan-Do-Study-Act) cycles to support ongoing improvement as the Toolkit is used in practice.

Who should use this guide:

- Clinicians (social workers, dementia coaches, care navigators, physicians, nurse practitioners/physicians assistants, nurses, etc) who work with persons living with dementia and their caregivers
- Quality improvement leaders
- Program managers

The Living Well with Dementia Toolkit was developed by Ariadne Labs with generous funding from the Donner Foundation. This Toolkit was developed using human-centered design and is based on research, evidence and the lived experience of people impacted by dementia.

The Living Well with Dementia Toolkit is available on the website as printable documents for in-person settings or as digital tools for virtual care settings and can be found here: https://www.ariadnelabs.org/dementia-solutions/.

"I think one of the most important parts of the toolkit is that it gives ***a narrative of dementia, of living well.***"

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Implementation Guide

FOREWORD

The Living Well with Dementia Toolkit offers a structured yet flexible roadmap to clinicians, care navigators and other providers supporting people with dementia, their loved ones and care

The Toolkit helps identify what matters most to people with dementia during visits or clinical interactions. It is also designed to focus on quality of life, living well with dementia and adapting to the changes that come with this illness. The Toolkit includes tools to review the impact of dementia on different areas of people's lives, meet common needs and enable meaningful conversations about the often fraught and emotional journey of living with dementia.

We believe there is a way to *live well* with dementia.

We are transforming how people think about dementia by learning from the lived experiences of individuals with dementia and their caregivers. By having meaningful conversations about what matters most to them, we can create more effective support and education plans, helping people live well with dementia.

So how do we shift?

How do we truly show up for people on this journey with dementia — with care that sees them, supports them, and walks alongside them? With the right tools, support, and community, people can live meaningful, connected, fulfilling lives with dementia — and we're building solutions to make that possible.

Introduction

The Living Well with Dementia Toolkit bridges the critical gap between healthcare systems and the lived experience of people impacted by dementia.

Developed by an interdisciplinary team at Ariadne Labs, this toolkit reflects insights from three years of human-centered design and research that engaged directly with people living with dementia, their families, advocates, care providers and dementia experts.

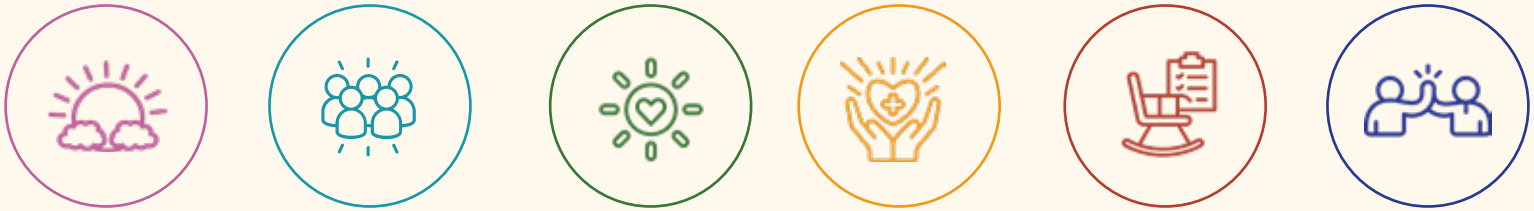
Created to help families develop the knowledge, skills and support to live well with dementia, the Toolkit offers practical tools to navigate each step of the journey with confidence. It offers a flexible roadmap to the changing landscape of dementia that can be adapted to meet people where they are and attend to what matters most to them at any moment in their journey. It addresses the wide range of areas impacted by dementia, with a focus on quality of life for the person with dementia and their supporters, care partners and family.

FACILITATOR FEEDBACK

"When we start professionals, future clinicians, with this framework, even if they've never interacted with someone with dementia before, their baseline outlook is moved towards seeing ***the possibility of a good life with dementia.***"

***Families* experience dementia as the whole family**, *affecting the routines, fears, hopes and needs of the family system.*

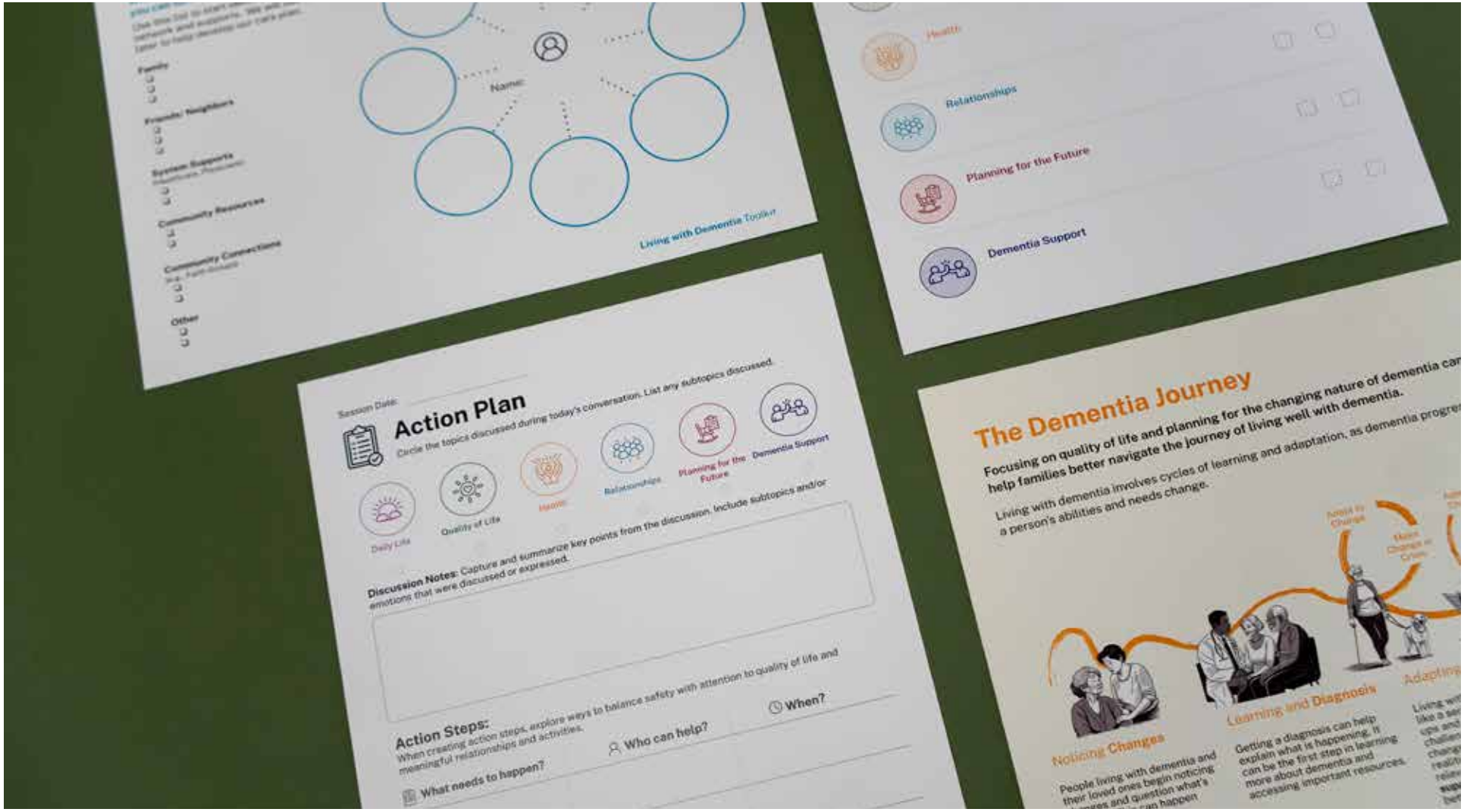
Our toolkit focuses on six key areas that families encounter while navigating the complexities of dementia care:



Daily Life **Relationships** **Quality of Life** **Health** **Planning for the Future** **Dementia Support**

*We use the term “families” to include biologic and chosen families, the people whom the person with dementia deems part of their closest inner circle.

The *Living Well* with Dementia Toolkit Overview



FACILITATOR FEEDBACK

"The toolkit is a lot more person-centered for the person with dementia by identifying what's important to them and bringing them into the conversation more.

It has been a shift from what I was originally trained in, which seems to be much more focused on managing behaviors and safety and anticipating problems."

Toolkit Components

The toolkit features a set of tools that includes a Check-In, Action Plan, and Conversation Cards. These address six key topic areas and offer providers the flexibility to pick and choose the resources that best support their families. Each tool invites the person with dementia and their caregivers into the planning and conversation process.

WHOLE TOOLKIT

The Toolkit offers a range of tools to navigate each step of the journey with confidence.

CONVERSATION CARDS

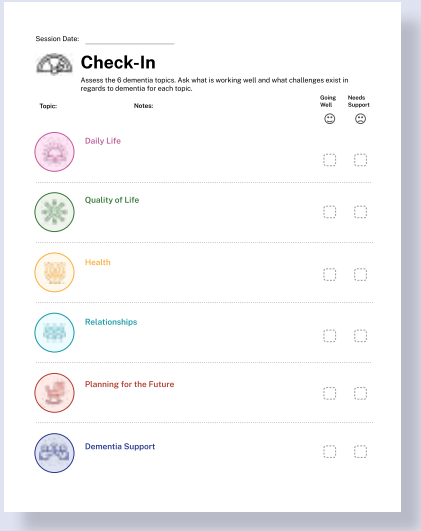
Cards including a range of topics to support facilitating patient and family-driven conversations.

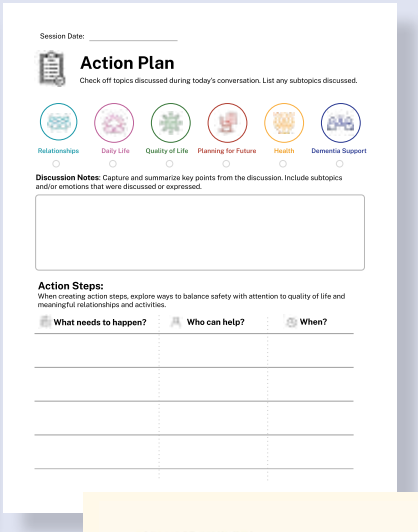
Overview of the Tools

The Living Well with Dementia Toolkit components are intended for a range of settings: clinical or home settings, in-person and telehealth, care navigation and dementia coaching, and clinical dementia care. Below is a description of each tool.

Check-In:

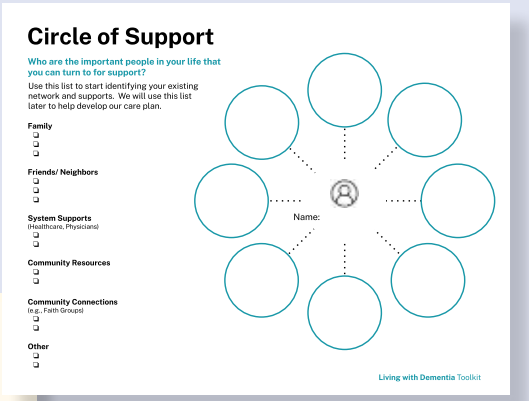
A worksheet to guide conversations about strengths and challenges for individuals and families living with dementia.





Action Plan:

A worksheet for documenting takeaways from the visit or conversation, and actionable next steps.



Conversation & Emotion Cards

These cards offer detailed prompts for common daily challenges in dementia, including emotion cards to help express feelings and identify support needs.

Dementia Journey:

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

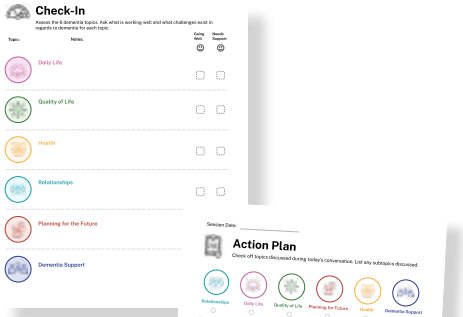
Circle of Support:

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

Using the Tools

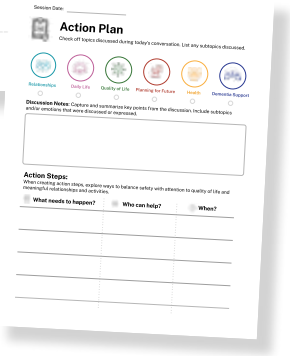
Dementia Journey:

A visual that can be used to describe the journey with dementia as a process of change and adaptation that occurs over time. It offers a way to talk about balancing planning for the future and adapting to changes to live as well as one can, one day at a time.



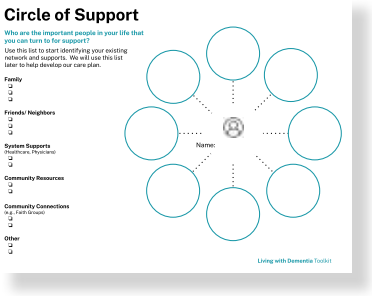
Check-In:

This tool serves as a brief assessment of how things are going for the person with dementia and their care partner in six major areas of life impacted by dementia. It provides an organized way to get a holistic overview of how a person is doing, what is working well and where they might need increased support.



Action Plan:

The Action Plan is used to document next steps, assign responsibilities, and set timelines. This can be recorded on the sheet or in a medical record. It may also involve discussing how to seek help or navigate health and social care systems.



Circle of Support:

This tool helps identify and map the people and resources—such as friends, family, neighbors, clinicians, and community services—that make up a person's circle of support. It can be used to clarify existing social connections, determine who to approach for specific needs, identify gaps, and begin building support networks, especially for those who are more isolated.

Using the Tools

Conversation Cards:

These cards can be used in several ways. Each card provides prompts for discussion as well as initial suggestions for helpful services and support.

- Use the main topic cards to choose a conversation focus, then select one or two related sub-topic cards for deeper discussion.
- Use them as a complement to the Check-In. They can be used to go deeper into a topic that was highlighted during the Check-In conversation.
- Families can use these cards to get a sense of the wide territory impacted by dementia.
- The cards can be used to stimulate discussion in support groups.
- The cards have been used to help train care navigators in the common issues that arise for people, caregivers and families living with dementia.

Emotion Cards:

These cards can be used to quickly identify how a person with dementia or their care partner or supporter are feeling. These conversations offer a shortcut to pressing issues that need to be addressed. The emotion cards also offer a way for people to share their lived experience, to feel witnessed and supported through the challenges of living with dementia.

Introducing the Tools

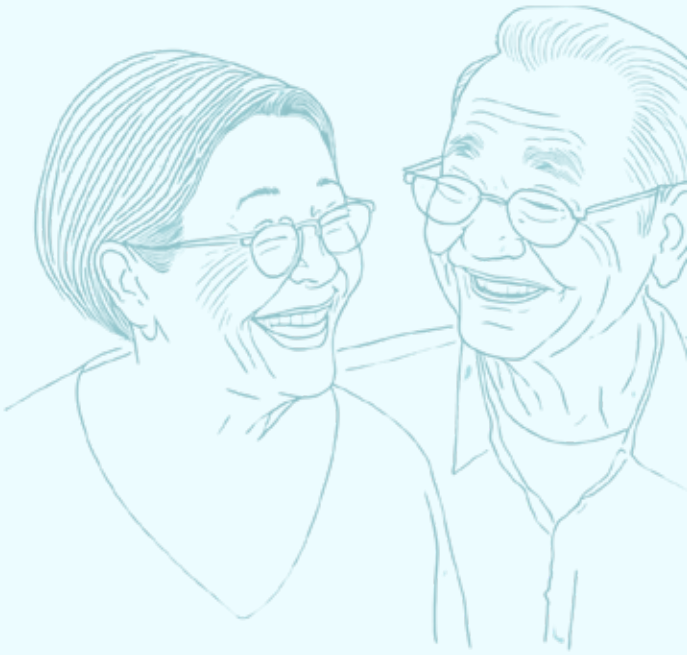
	Introductory Language:	Additional Prompts:
Dementia Journey:	*"Living with dementia involves a process of change and adaptation. Sometimes the change is gradual. Sometimes it is sudden. Everyone's journey is different. I will be here to support you navigate these changes."*	*"Are there any significant changes that you are noticing right now or that you would like to talk about?"*
Check-In:	*"I'd like to ask you a few questions about how things are going for you and how dementia is affecting your life right now. Would that be okay?"*	If the person brings up an issue, consider linking it to one of the six topic areas listed here, and then check in about the other five areas as well.
Action Plan:	*"This is where I want to write down what we have decided to do today."*	*"I know it can be hard to ask others for help. Let's talk about how you might ask these people to help with these tasks we have discussed."*
Circle of Support:	*"Living with dementia is not something one can do alone. It is important to have a circle of support as you navigate this journey. Can you tell me who is in your world? Who might you be able to ask for help?"*	Ask about medical providers, social service agencies, home care workers, friends, family, neighbors, churches, other organizations they participate in, and others who have helped them in the past; be creative in building this circle.
Conversation Cards:	*"Which of these topics would you like to talk about today? Do you want to pick an area or a topic to focus on?"*	*"You mentioned ___ as important to you during the Check In. Here are some cards that address specific issues in that area. Would you like to pick one or two of these to talk about today?"*
Emotion Cards:	*"Living with dementia can include lots of feelings and emotions. Would you like to pick one or two cards that describe how you feel right now?"*	*"What card do you think your (person) would pick?" "Can you tell me why you picked this card?"*

FACILITATOR FEEDBACK

"Having that circle of support of people who say, 'I don't really care if you have this disease,' and who show up in ways that surprise us and touch us—is the balm to the tragedy that is dementia. *That's one of the most important aspects of dementia care. The worksheet in the toolkit works.*

[The Circle of Support] counters the experience of dementia caregivers and people with dementia who say this experience is isolating. It is a concrete visual and exercise that puts agency back into the experience.

Creating and maintaining support is also some of the balm to the deep terror of dementia, which is that if I have dementia, I may no longer be welcomed, cared about, interesting, useful."



Implementing The *Living Well* with Dementia Toolkit

Integrating the Living Well with Dementia toolkit into routine practice is optimized by applying implementation science frameworks. These frameworks give clear steps to help organizations adopt and sustain the use of the toolkit over the long term.

Using the EPIS Framework

Implementing the Living Well with Dementia Toolkit: EPIS is a helpful roadmap for making sure new programs or changes are put into practice successfully. It stands for **Exploration**, **Preparation**, **Implementation**, and **Sustainment**. First, you learn about what needs to be done (Exploration), then you get ready (Preparation), put the plan into action (Implementation), and finally, make sure it lasts (Sustainment).

Exploration

The objective of the exploration phase is to assess the organizational needs, readiness, and the fit of the Living Well with Dementia Toolkit being implemented.

Core activities in this phase include conducting an organizational needs assessment, engaging leadership, and building your team.

Preparation

The objective of the preparation phase is to equip the organization and stakeholders with the resources they need to effectively implement the Living Well with Dementia Toolkit.

Core activities in this phase include adapting the toolkit to fit the organizational context, designing implementation plans and workflows, determining a measurement plan, and conducting staff training.

Implementation

The objective of the implementation phase is to pilot the Living Well with Dementia Toolkit and refine its use.

Core activities in this phase include PDSA (Plan-Do-Study-Act) cycles to iterate on the use and implementation of the toolkit as well as engaging with stakeholders to obtain feedback.

Sustainment

The objective of the sustainment phase is to institutionalize the use of the Living Well with Dementia Toolkit within an organization's structures, workflows and processes along with considering the spread of the toolkit.

Core activities in this phase include monitoring implementation data, ensuring toolkit policy alignment, ongoing training for new staff and scaling toolkit use.

Exploration

CORE ACTIVITY

Assess your organization's readiness

Is your organization ready?

Talk with your team and community:
Explore the needs and priorities of staff, leadership, and clients to ensure the toolkit aligns with shared goals. Gather input from direct care staff, administrators, and families to identify key pain points. Aligning the toolkit with these priorities increases the chances of successful adoption.

Check readiness:
Readiness for change can be systematically evaluated using tools such as: Organizational Readiness for Implementing Change (ORIC)[3] or ATLAS Context Assessment.[4]

Map your journey:
Map existing workflows for dementia care and identify where person-centered practices emphasizing living well with dementia occur or are lacking.

List challenges and resources:
Map existing challenges and available resources to implement the toolkit. What might get in the way of using the toolkit? What strengths and resources do you have to build on?

CORE ACTIVITY

Engage leadership

Is your leadership actively engaged and committed to supporting this initiative?

Early and ongoing leadership is essential to successful implementation.
Leaders set the vision, allocate resources, and drive accountability.

Garner support and engagement of organization leaders who are critical in securing resources and ensuring the prioritization of the toolkit use and implementation.
Effective engagement may include formal endorsement, active participation in planning and involvement in regular feedback loops.

CORE ACTIVITY

Build your team

Has your organization assembled the right team to support implementation?

Define your implementation team:
The implementation team is responsible for driving adoption of the toolkit including adapting the toolkit to the context, facilitating staff training, identifying barriers and facilitators, coordinating communication across staff, monitoring progress of toolkit implementation, and ensuring organizational sustainability of toolkit implementation.

Implementation team members may or may not be direct care providers.

Identify and recruit toolkit champions: Identify clinical and support staff that can advocate for and shepherd the use and implementation of the toolkit[5]. Champions are not always formal leaders - they are often direct care staff who are passionate about quality dementia care and are early adopters of change.

Preparation

CORE ACTIVITY

Adapt Toolkit to Context

How will your organization adapt and integrate the toolkit into your practice?

Review the toolkit components:

Determine how your organization will integrate the components into your existing practice. Effective adaptation of the toolkit requires ensuring fidelity to the core components of the toolkit while ensuring the toolkit fits within the context and workflows of your organization[6].

Considerations

❏ Map how each toolkit component (e.g., emotion cards, action plan) interfaces with existing practices and workflows and consult with toolkit users to co-design workflow integration.

❏ Documentation: Determine if, and how, you will integrate use of the toolkit into documentation/EMR.

❏ Digital access: Establish plans for training and use of virtual toolkit; adapting virtual encounter flow to incorporate toolkit use.

❏ Resource linkage: Prepare staff with referral and resource information to support prompts on conversation card

❏ Note: Not every part of the toolkit needs to be utilized during every client encounter - adapt the tool use to context and need.

CORE ACTIVITY

Design implementation plans and workflows

How will your organization integrate the toolkit into workflows and processes?

Develop workflow processes that identify where and by whom the toolkit will be used:

❏ Choose pilot settings such as visit/encounter types or selected clients where you will initially pilot the toolkit.

❏ Consider how you will implement across encounter types (e.g., initial visit vs follow-up visit), encounter visit lengths, and clients (e.g., persons living with dementia vs caregivers, different stages of dementia severity). (See case studies for examples)

❏ Identify triggers for toolkit use.

❏ Consider adding reminders in workflows and processes to help prompt facilitators to utilize the toolkit.

❏ Determine documentation requirements.

CORE ACTIVITY

Train Staff

Is your team ready?

Provide thorough, hands-on training that incorporates didactics, modeling and role-play with the toolkit

Provide didactic training to orient staff to the toolkit and the components. Didactic training materials are available on the Ariadne Labs website: https://www.ariadnelabs.org/dementia-solutions/

❏ Reference and utilize the training slidedeck

❏ Share and discuss training didactic videos detailing use of each toolkit component

❏ Utilize scenario-based training with real-life case examples relevant to trainees

❏ Provide training on how to use each tool incorporating role-playing to build confidence in toolkit use

Utilizing the emotion and conversation cards can be challenging for staff at first as this style of communication and engagement with clients is not part of routine care and can take time to adjust to. Provide ample opportunities for staff to practice and get comfortable with introducing and using the emotion and conversation cards to support better integration into practical application.

Implementation

CORE ACTIVITY

Pilot the toolkit

Have you planned a small-scale pilot of the toolkit to test, gather feedback, and make improvements before a full rollout?

Begin implementation of the toolkit in one setting or with a selected group before a full rollout of the toolkit. These pilots allow for early learnings, iterations and feedback from staff that can inform a more successful larger scale implementation of the toolkit. Phased implementation utilizing PDSA cycles supports teams learning how to utilize the toolkit and adapt toolkit implementation to better fit organization needs, goals, and context. Early successes and lessons should be documented, shared, and used to inform broader implementation efforts.

CORE ACTIVITY

Implementation meetings and peer learning

Have you scheduled regular implementation meetings and peer learning dessions?

Discuss successes and challenges:
Throughout implementation of the toolkit, it is critical to regularly meet as an implementation team to: discuss successes and challenges, facilitate peer learning/debrief, and engage in PDSA cycles to iterate on the process of implementing the toolkit.

Encourage early implementation peer shadowing by champions and debriefs.

CORE ACTIVITY

Plan-Do-Study-Act (PDSA) Cycles

What challenges are you facing implementing the toolkit, have you engaged in a PDSA cycle to iterate your impementation efforts?

PDSA Cycles are utilized in the implementation and sustainment phases of the EPIS framework to test a change, iterate and improve the implementation efforts of the Living Well with Dementia Toolkit to better fit the specific context needs and resources. These test of change cycles are particularly useful in the early pilot period to iterate prior to larger implementation, however they can be utilized throughout implementation as adaptation and improvement are needed[9].

Plan: Plan the change test including plan for collecting data on the result of the change

Do: Implement the plan

Study: Examine the data and the results of the change

Act: Iterate the change based on the results from the test

During implementation, hold brief, regular meetings with champions and staff to discuss what worked well and where staff/clients struggled to inform opportunities to test a change with PDSA cycles.

Implementation

EXAMPLE

Plan-Do-Study-Act (PDSA) Cycles In Practice

- **Plan**: Facilitators plan to introduce emotion cards earlier in dementia coaching visits, with the goal of encouraging clients to identify both challenging and positive emotions. Facilitators also intend to use a positive emotion card when collaboratively developing the action plan, hoping this will foster a sense of hope and balanced discussion.
- **Do**: Facilitators integrate the new approach with five families over the next two weeks, documenting which emotion cards clients select (including at least one positive emotion), and noting any changes in client engagement or conversation flow.
- **Study**: After each visit, facilitators reflect together in a debrief, comparing client responses and gathering feedback from both people living with dementia and their care partners. They assess whether the new approach leads to more balanced emotional discussions and whether it helps set a collaborative agenda for the visit.
- **Act**: Based on the feedback and observations, the team decides to update their standard coaching workflow: they will introduce action planning earlier in visits and always encourage the inclusion of a positive emotion card when co-creating next steps. Additional training and role-playing will be provided for staff to build comfort with this technique, and results will be reviewed again in the next

FACILITATOR FEEDBACK

"Emotion cards allowed more exploration on topics that may not have been covered by a medical appointment. It felt like an expansion of the social determinants of health, presented in a conversational way."

Sustainment

CORE ACTIVITY

Monitoring implementation data

Is ongoing monitoring in place to keep the toolkit effective and identify any challenges?

Sustainment relies on ongoing processes to ensure continued high-quality use of the toolkit[10].

Design and implement a monitoring plan with regular assessment of key process and outcome data to assess ongoing fidelity, identify emerging barriers and ensure the toolkit remains relevant and effective.

CORE ACTIVITY

Ensuring toolkit alignment with organizational policies and procedures

Have you aligned the toolkit with your organization's policies and procedures?

To ensure sustainability of the toolkit it is critical to embed the toolkit into existing policies and procedures.

This institutionalization secures leadership support overtime and ensures new staff adopt the toolkit as part of the organizational practice culture.

Update clinical protocols, documentation requirements, and standard operating procedures to include the toolkit as a required element for relevant visits.

Update workflows and internal quality improvement processes to include the toolkit as the standard of care for dementia-related visits.

CORE ACTIVITY

Ongoing staff training

Have you included the toolkit in staff training?

Maintain fidelity of toolkit use by embedding the toolkit into new staff orientation and ongoing training for staff.

Incorporate toolkit use into annual staff competency and onboarding.

Offer practical scenario-based training that reflects challenging cases and evolving needs (e.g. telehealth adaptations).

Create job aids or brief tip sheets.

Use train-the-trainer models to build internal capacity for coaching. mentoring, and peer support.

FACILITATOR FEEDBACK

"I think the more practice, the better, the more confident that we feel with utilizing the tools.
I recommend practicing with your peers. Because I think across the board from the larger group [of implementers] when we met, these aren't typical ways that we interact with clients. It was kind of a new skill set for all of the practitioners."

Implementation Checklist

Exploration

- ❏ Conduct organizational needs assessment (using both qualitative and quantitative methods, e.g., staff interviews, surveys, readiness tools)
- ❏ Map alignment between toolkit and current dementia care practices/workflows
- ❏ Identify and engage leadership
- ❏ Build an implementation team and identify direct-care provider champions
- ❏ Establish team roles/responsibilities for communication, feedback collection, and data management

Preparation

- ❏ Adapt toolkit components to fit organizational context, co-designing with end-users
- ❏ Map toolkit to workflows/processes; determine how the toolkit will be integrated into different visit types and lengths and with different clients.
- ❏ Plan integration with digital systems
- ❏ Determine documentation requirements
- ❏ Prepare resource materials
- ❏ Design detailed implementation workflows
- ❏ Develop processes specifying toolkit use cases/triggers
- ❏ Pilot workflows with staff for feasibility
- ❏ Define SMART aims and a comprehensive measurement plan
- ❏ Specify process and outcome metrics
- ❏ Assign data collection/monitoring responsibilities
- ❏ Develop a feedback schedule for ongoing learning/improvement
- ❏ Develop and provide comprehensive staff training
- ❏ Scenario-based, hands-on, and role-play training sessions
- ❏ Prepare job aids, e-learning modules, tip-sheets

Implementation Checklist

Implementation

- ❑ Formal roll-out in pilot settings with select clients/visits.
- ❑ Engage in PDSA cycles to iterate toolkit use and implementation.
- ❑ Track toolkit use, feedback, and adaptations.
- ❑ Collect process and outcome measures and use data to inform adaptations to toolkit use or implementation.
- ❑ Identify areas where staff encounter barriers and respond with workflow changes.
- ❑ Regularly meet as an implementation team or add toolkit implementation to existing meeting agendas to facilitate ongoing communication and debrief of toolkit implementation

Sustainment

- ❑ Develop and implement a monitoring plan for ongoing toolkit use
- ❑ Add toolkit implementation/utilization to internal meeting agendas
- ❑ Schedule regular assessments of key process and outcome measures
- ❑ Identify and address emerging barriers through continuous quality improvement cycles
- ❑ Institutionalize toolkit use in organizational policies and procedures
- ❑ Secure ongoing leadership endorsement and support
- ❑ Update clinical protocols, workflows, and standard operating procedures to include toolkit use as an expected standard for relevant encounters
- ❑ Ensure toolkit materials (physical and digital) are maintained, accessible, and updated as needed
- ❑ Embed toolkit into ongoing staff training and support
- ❑ Incorporate toolkit into onboarding and orientation for new staff
- ❑ Provide periodic refresher trainings
- ❑ Develop processes for peer mentoring and support
- ❑ Plan for scale-up of toolkit
- ❑ Conduct structured readiness and context assessments before spreading
- ❑ Use data and lessons from initial sustainment sites to inform phased expansion to additional settings or populations

Implementation Tips

From Facilitators

PREPARATION

"I would definitely have other people for the institution or the department get involved early on, including if you have a social worker or care navigator or even the medical assistants to all be on the same page so it's more streamlined."

TRAINING

"Do a little bit of role-playing with people so that they can practice using the tools in different ways with different people and getting different responses about that. I know that our staff, once they did that a couple of times, felt a little bit more comfortable."

- ❏ Staff flexibility, willingness to experiment, and commitment to regular feedback leads to enhanced implementation success.
- ❏ When using Emotion Cards, ensure facilitators are experienced enough to be able to navigate "high emotion" situations with clients/ patients or provide more training to improve skills for less experienced facilitators.

USE

"There's a lot of different things, and so you have to work it in over time. You can't expect you're going to do the whole thing all at once."

- ❏ Don't rush—allow teams to go slow and embrace "not knowing."
- ❏ Create opportunities for practice, role-play, and shared debrief. Provide additional opportunities to practice particular pain points, such as emotion/conversation cards and digital application of tools.
- ❏ Use emotion and conversation cards as touchpoints to deepen exploration and patient/caregiver-driven agendas.

Case Studies

Area Agency on Aging

Academic Affiliated Medical Center

Psychiatric Hospital/CMS GUIDE Site

Area Agency on Aging

Setting and Context:

A non-profit Area Agency on Aging (AAA) organization providing dementia coaching and support groups for persons living with dementia and their caregivers. The toolkit facilitators at this site included a dementia coach, program manager of the day program and a Licensed Clinical Social Worker.

"Having a specific card like 'Joy & Pleasure' helped us have a productive conversation about what the care partner was struggling with, that was otherwise overlooked at first."

"Filling out the circle together was really helpful—highlighted some supports the person forgot they had… when we finished, they were amazed at how many people could help."

How the Toolkit was Used:

At this site, staff implemented the toolkit in dementia coaching visits along with a support group with persons living with dementia and their caregivers. Dementia coaching visits were primarily conducted with caregivers but a minority of visits included the person living with dementia along with their caregiver. All components were used by coaches during dementia coaching visits, primarily with caregivers but also including people living with dementia. Coaches decided when to use each tool depending on the needs of the individual and context of the visit.

In the support group, the toolkit's conversation cards were successfully integrated into an eight-week support group for people living with dementia and their caregivers. Each week, facilitators selected one conversation card to guide the topic and structure of that session's discussion.

During the support group meetings, participants engaged in both joint and separate sessions: sometimes people living with dementia and their caregivers met together as one large group, and at other times, they broke into separate groups to discuss the cards' prompts independently.

Facilitators used the conversation prompts and accompanying resource suggestions from the cards to prepare activities and materials for each week's session. Other components of the toolkit were also incorporated throughout the eight weeks, enhancing the content and engagement of the support group. The Circle of Support was utilized during the week focusing on the Relationships topic to foster discussion around participants' support network.

Main Challenges & Adaptation

Although staff were initially hesitant with the emotion and conversation cards, they noticed a shift towards a more client-driven encounter when they used them in practice. Facilitators stated that including peer discussion and debriefing with each other about how they used the toolkit reduced anxiety and built facilitator skills. Ultimately, the cards were seen as a significantly impactful component of the toolkit.

"Do a little role-playing so people can practice using the tools in different ways. Our staff felt more comfortable after doing this a couple of times."

Sharing Successes

Staff used the Circle of Support worksheet with a recently-diagnosed client, who initially reported feeling "very alone." As they listed faith community, old friends, and neighbors together, both client and care partner felt more supported. They shared, "Filling out the circle together was really helpful—highlighted some supports the person forgot they had…when we finished, they were amazed at how many people could help."

Staff reported improved confidence, especially in facilitating complex and emotionally charged conversations.

Academic Affiliated Medical Clinic

Setting and Context:

An academic-affiliated medical clinic providing comprehensive dementia care to persons living with dementia. The toolkit was utilized in the clinic by a physician and medical residents. The clinic setting includes an interdisciplinary team of physicians, nurse practitioners, social workers, and care navigators, and scale-up efforts have been considered for additional clinical roles outside the pilot physician and resident facilitators.

"Emotion cards gave me courage to ask tougher questions—I noticed clients shared stories they hadn't mentioned before."

How the Toolkit was Used:

The toolkit was used in a cognitive clinic dedicated to dementia care and in a geriatric clinic. The use of the toolkit was most consistent during cognitive clinic visits, which allowed focused time for discussion of living with dementia. The geriatric clinic provided primary care for older adults with diverse medical needs. In this clinic, the toolkit was utiltized for patients with dementia-related diagnoses.

During visits that were primary care focused, the toolkit was sometimes referenced as a conversation framework, with more in-depth toolkit work scheduled for annual visits.

All toolkit components—check-in, action plan, emotion cards, conversation cards, dementia journey visual, and circle of support—were employed. The selection of specific components was tailored by the facilitator based on the purpose and flow of each visit, though the check-in tool was utilized with every visit to anchor the visits and guide discussion.

Main Challenges & Adaptation

Primary care visits were often time-limited and focused on acute or chronic health issues, leaving less room to fully utilize the toolkit. Therefore, this site chose to utilize the toolkit at annual wellness visits in the geriatric clinic and at every visit in the cognitive clinic visits.

Sharing Successes

"Emotion cards gave me courage to ask tougher questions—I noticed clients shared stories they hadn't mentioned before."

" I was able to use [the emotion cards] with different severity of patients with dementia along with their caregivers. Even with the most severe, were able to pick out cards and make a story out of it"

"Action Plan was useful for breaking bigger goals into attainable steps. Families saw that we weren't losing track of their priorities."

Psychiatric Hospital/ CMS GUIDE Site

Setting and Context:

A psychiatric hospital and CMS GUIDE pilot site with care providers that specialize in dementia care. The multidisciplinary toolkit facilitator team included a Licensed Clinical Social Worker, a Social Work intern, and a GUIDE Care Navigator providing primarily virtual care for persons living with dementia and their caregivers.

"It definitely gives a structure that we can always lean on as facilitators, but also for the people that work under me it gives a unified vision that I know we hold together. Especially when I'm supervising very new staff, I have a lot of confidence that they're not out there just on their own."

How the Toolkit was Used:

The toolkit was implemented in virtual GUIDE care planning meetings. Visits were structured around the toolkit's core components including: the Check-in, Action Plan, Emotion Cards, Conversation Cards, Dementia Journey, and Circle of Support. All components of the toolkit were utilized in a systematic manner during each visit.

The Check-in and Action Plan components were embedded in the Epic EMR, making person-centered goals accessible and trackable for all team members.

The toolkit was also used in support groups that were held separately for caregivers and for persons living with dementia. Emotion and Conversation cards were utilized for the caregiver support groups with facilitators prompting caregivers to select emotion or conversation cards to set the agenda for the group discussion, resulting in more client-directed and focused encounters.

Main Challenges & Adaptation

EMR Integration: Translating the action plan worksheet into the EMR care plan templates required dedicated IT support and iteration. The team developed "smart phrases" to standardize documentation.

"The toolkit is naturally interwoven with care plan meetings. Emotion cards help people say what really affects them right now, and focus the action plan."

Sharing Successes

"The Circle of support helps families expand their own perspective of support. Once they see Community Systems of Support, they mention providers or care workers they're connecting with—and smile."

"Looking at cards and worksheets together makes it more conversational, less like a script."

"Having a more client-driven encounter with clients selecting topic cards to set the agenda changed the dynamic of the visits and conversations in a positive, patient-centered way."

"Workflow wise, the action plan actually changed my way of doing things in a good way. I tend more towards, as a therapist, the psychodynamic and emotional. But to have that kind of reminder prompt in the action plan has been helpful for me and changed how I work for the better."

What We Heard:

"I was meeting with a caregiver to speak about her experience with her loved one who has dementia. She is one of those caregivers who seem like she has everything together, which is very admirable. We went through the daily Check-In, and that was helpful for her to see everything laid out. Then, I went to the Circle of Support and we went through all the people who could maybe help her loved one, but also herself. And that led into being like, 'How are you?' I pulled up the six category cards, and I said, 'Is there anything in these categories that you want to touch on that I can even show you some more subtopics?' Just having a visual space for her to really dive into one of those topics rather than the logistics of dementia allowed her to share the stress she was feeling, and that it's okay for her to lean on those people that she put in the circle of support."

"It has been a shift from what I was originally trained in, which was habilitation therapy, which seems to be much more focused on managing behaviors and safety and anticipating. I feel like the toolkit is a lot more person-centered as far as the person with dementia and identifying what's important to them and just bringing them into the conversation more."

"Filling out the circle together was really helpful—highlighted some supports the person forgot they had…when we finished, they were amazed at how many people could help."

"Having a more client-driven encounter with clients selecting topic cards to set the agenda changed the dynamic of the visits and conversations in a positive, patient-centered way."

"Prior to utilizing the toolkit, we had a basic assessment that we would utilize, but it wasn't nearly as structured. … It [was] harder to pinpoint "what do we want to work on? What are the next steps going to be." and then the rest the same"

Outcomes & Lessons Learned:

The Living Well with Dementia Toolkit puts person-centered care at its core, surrounding it with practical structure and supportive tools—ensuring that person-centered dementia care is both the foundation and the focus of every step.

Person-Centered

The toolkit fostered more patient-centered, values-driven client and caregiver encounters by encouraging a holistic approach that addressed emotional and social wellbeing alongside practical care needs. Both staff and families appreciated this broader focus, finding that sessions became more conversational and less scripted. As a result, clients and families felt increasingly comfortable discussing previously unspoken topics, especially with the aid of the emotion cards--- “what was unspeakable in the first visit became speakable in the second visit [using the emotion cards].”

Effective Tools

The toolkit improved clarity and coordination in care planning and documentation, serving as a “north star” for staff. Staff found that visits became more concise and effective without adding time, and action plans were more meaningful and actionable, offering clients and care partners clear next steps. Tools like the “Circle of Support” and emotion cards also deepened discussions around support networks and unmet needs.

Structured Approach

Using the toolkit provides a unified vision of dementia care and a structure for providing that care that all team members can use. Even when physical toolkit components were not utilized during a visit, the facilitator felt that they were now approaching care with the toolkit in mind and serving as a mental model for conducting a dementia-related care visit.

Conclusion

Implementing the *Living Well* With Dementia Toolkit is both achievable and transformative when approached with thoughtful planning, collaborative teamwork, and a commitment to continuous learning.

By using evidence-based implementation strategies and frameworks such as EPIS, organizations can systematically explore their needs, prepare their teams, adapt toolkit components, and rigorously test and refine their implementation efforts. Effective implementation is further strengthened by clear measurement plans, leadership engagement, and active involvement of frontline staff, caregivers, and people living with dementia.

Sustaining this work requires embedding the toolkit into everyday practice—through integration in policies and workflows, ongoing monitoring and feedback, and regular investments in staff training and support. Drawing on implementation science principles and lessons from real-world pilot sites, teams can anticipate challenges and capitalize on facilitators to drive meaningful change.

Above all, the Toolkit offers not just a set of tools but a pathway toward more person-centered, responsive, and empowering dementia care. As organizations adapt and scale these practices, they build lasting capacity to help people living with dementia and their care partners truly live well.

The journey to better dementia care is ongoing—rooted in partnership, reflection, and purposeful action. By leveraging this implementation guide and its strategies, your team is well-equipped to create positive impact and model excellence in dementia care delivery.

Local Resources

Here are a list of resources and supports that may exist in your community that can be part of a plan of care for the families you are working with. We recommend researching the local services and supports in your community for each of the items on the list so you can share them with your patients and clients when appropriate and personalize to your local and geographic context.

Supports for Dementia

Dementia support groups for people with dementia and for caregivers
Dementia coaches
Adult and social day programs
Respite opportunities
Dementia-Friendly organizations
Dementia advocacy groups
Memory Cafes
Teepa Snow videos

National Organizations

Alzheimer's Association - hotline, coaching, community linkages, education
Dementia Action Alliance - advocacy group
Disease-based websites (Frontotemporal dementia, Lewy Body disease, etc)

Organizations on Aging

Senior Centers
Councils on Aging
Area Agency on Aging or Aging Service Access Point
Meals on Wheels and other food delivery services
Housing authority and community action agencies
Geriatric Care Managers or Aging Life Care Professionals (care navigators)
Eldercare attorneys and financial planners
Health insurance counselors (Area Agencies on Aging)
Nursing homes, assisted living facilities, adult foster programs, shared living opportunities
Programs through local Emergency Services (Fire and EMS)
Local Village or Neighbor volunteer organizations
Caregiver support groups
Public transportation, volunteer rides and Rides for Health

Clinical Resources

Home physical therapy, occupational therapy and home safety assessments (VNA)
Personal and home care aides and services
Driving assessment facilities
Palliative care providers
Hospice programs
Geriatricians and Geriatric Psychiatrists
Neurologists
PACE programs

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Appendix

Check-In

Action Plan

Sample of Conversation Cards

Sample of Emotion Cards

Dementia Journey

Circle of Support

Session Date: _____

Check-In

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

Topic:	Notes:	Going Well	Needs Support
Daily Life		☐	☐
Quality of Life		☐	☐
Health		☐	☐
Relationships		☐	☐
Planning for the Future		☐	☐
Dementia Support		☐	☐

Session Date: _____

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

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?

DEMENTIA CONVERSATIONS

Conversation Cards

Facilitator Framework

Topics

Facilitator Framework

Consider using these or similar questions in your conversation.

Emotion Card: Ask the person to draw an Emotion Card to express how they feel about this topic.

Ask Why: Be curious about what people are saying; Ask "why" or say "tell me more about..." often.

Worries: What are your worries about this topic?

Hopes: What can you hope for about this?

Reflect back what you've heard. Ask if they would like to talk about solutions or **next steps**.

Brainstorm: Use care plan to document notes and next steps.

About the Conversation Cards

The cards are designed to 1) promote *meaningful conversations* about important topics for *people and families living with dementia* and 2) to help lead to solutions to issues families may be struggling with.

The cards are **not** intended to be used **all at once** but instead to be used a few at a time, as the situation evolves and the dementia changes.

Topics

Relationships

Daily Life

Quality of Life

Planning for the Future

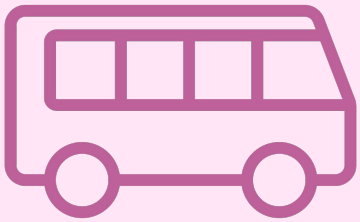
Health

Dementia Support

Emotions

Daily Life

Dementia shows up in every part of our daily lives. Living well with dementia requires adapting routines and daily life to your new normal.



DAILY LIFE

Transportation

DAILY LIFE

Housing

DAILY LIFE

Food

How is dementia affecting your ability **to get where you want to go**?

Conversation Prompts:

- Current modes of transportation
- Driving ability and safety
- Community options
- Getting to medical appointments, activities, communities
- Changing transportation needs over time

CONSIDER: Public transportation; Walking; Biking; Volunteer rides; Carpooling; Driving Assessment; Exploring other ways to provide someone with a sense of control or autonomy in their daily routine

Daily Life

Subtopics

Transportation

Housing

Routine

Personal Care

Food

Hobbies

Communication

What concerns do you have about **food** at this time?

Conversation Prompts:

- Food insecurity
- Food prep ability
- Cooking safety
- Food shopping

CONSIDER: Assisted cooking; Safety-proofing; Meals on Wheels; Other food delivery options, Community resources; Farmers' markets; Shared meals; Explore how the person with dementia can help with food prep

What concerns do you have about **housing**?

Conversation Prompts:

- Housing stability
- Safety and accessibility
- Who lives in the home currently
- Household chores and upkeep
- Future housing worries
- Future options and plans

CONSIDER: Occupational or physical therapy home safety evaluation; Home care services; Local funding for accessibility repairs (ASAPs or Council on Aging); Others in your family or community who could help with household management

Relationships

Dementia can affect our relationships with those around us. Dementia also makes the need for these relationships even greater. Explore common challenges as well as ways to build relationships while living with dementia.

RELATIONSHIPS

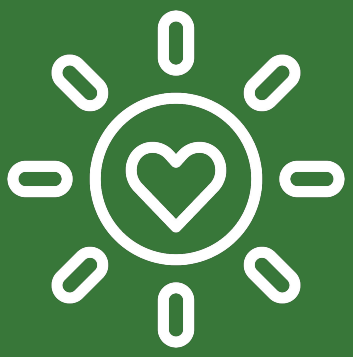
Community

RELATIONSHIPS

Family

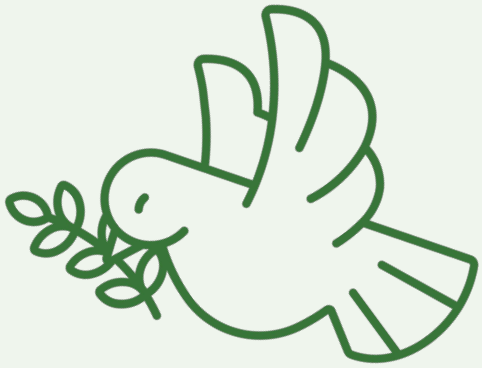
RELATIONSHIPS

Friends



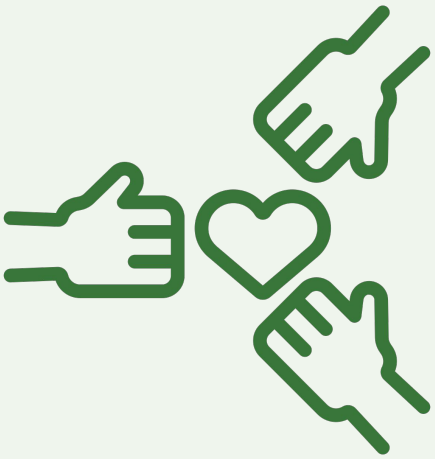
Quality of Life

Quality of life is critical for everyone living with dementia. Daily attention to quality of life can improve clinical outcomes and wellbeing.



QUALITY OF LIFE

Spirituality & Faith



QUALITY OF LIFE

Building Hope

QUALITY OF LIFE

Meaning & Purpose

Planning for the Future

While we don't know what the future holds, discussing goals and planning for the future can create some security for everyone.

PLANNING FOR THE FUTURE

Crisis Planning

PLANNING FOR THE FUTURE

Housing

PLANNING FOR THE FUTURE

Finances

Health

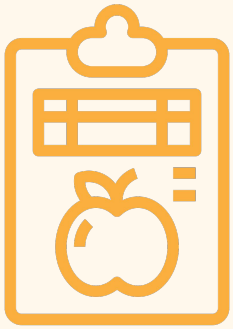
Staying healthy is good for the mind as well as the body. Also, dementia often occurs alongside other chronic conditions. Managing dementia may require addressing other health issues as well.

HEALTH

Dementia

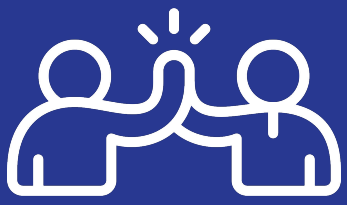
HEALTH

Medications



HEALTH

Staying Healthy

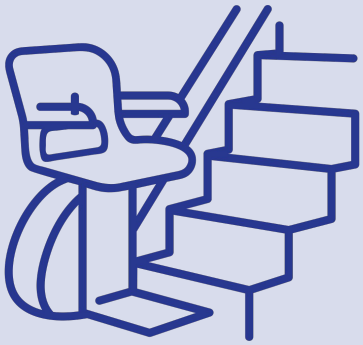


Dementia Support

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

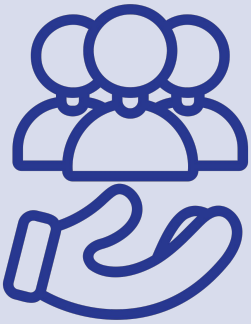
DEMENTIA SUPPORT

Care Coordination



DEMENTIA SUPPORTS

Adaptive Supports & Technology

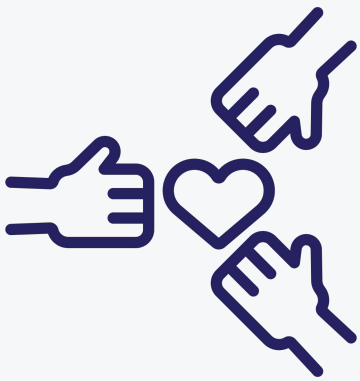


DEMENTIA SUPPORT

Care Partners

Emotions

Guilt



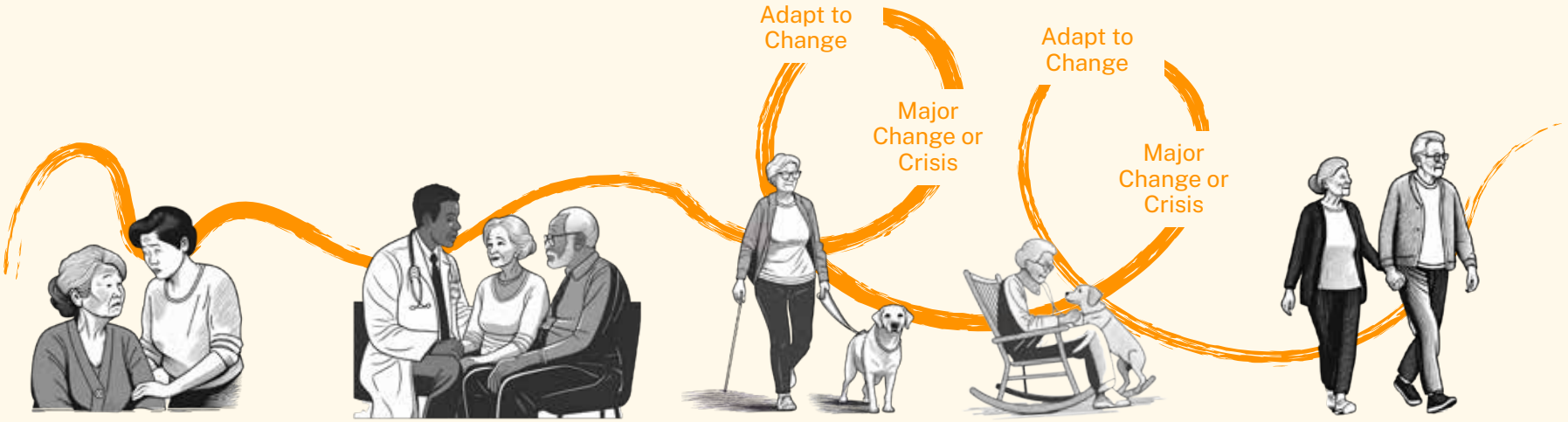
Hope

Grief

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 the relevant **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

When Beth was diagnosed with dementia, her friend Sue quickly stepped in to support her by finding new ways for them to connect. As Beth's dementia progressed, they adapted and found new ways to spend time together.

Having Dinner Together

Beth and Sue used to go out for dinner once a month before Beth's diagnosis. When that became too overstimulating for Beth, they had dinner together at Beth's home.

Listening to Music Together

They transitioned from having dinner together to enjoying quiet evenings listening to music creating a more comforting environment.

Playing with Beth's Dog Together

To further simplify their interactions, they began spending time playing with Beth's dog, which provided a gentle and joyful way to bond.

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

- ❑
- ❑