



DEMENTIA CONVERSATIONS

Conversation Cards



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 create concrete action plans that build the knowledge, skills and support needed to live well with dementia.

The cards are not intended to be used all at once. We suggest using a few at a time in order to prioritize what matters most as the experience of living with dementia changes over time.

Learn more at:

<http://go.ariadnelabs.org/living-with-dementia>



About Ariadne Labs

Ariadne Labs is a joint center for health systems innovation at Brigham and Women's Hospital and the Harvard T.H. Chan School of Public Health. With a mission to save lives and reduce suffering, our vision is for health systems to equitably deliver the best possible care for every patient, everywhere, every time. A single principle guides our work: innovations must work in the real world of healthcare.

AriadneLabs.org



Brigham and Women's Hospital
Founding Member, Mass General Brigham



HARVARD T.H. CHAN
SCHOOL OF PUBLIC HEALTH

Learn more about the cards:

<http://go.ariadnelabs.org/living-with-dementia>

AriadneLabs.org

For the Facilitator

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 Dementia right now.

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

Worries: Ask, "What are your worries about this topic?"

Hopes: Ask "What can you hope for at this time?"

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

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

Topics

Topics



Relationships



Daily Life



**Quality of
Life**



**Planning for
the Future**



Health



**Dementia
Support**



Emotions



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

Subtopics



Community



Family



Friends



Pets



RELATIONSHIPS

Community

How is dementia affecting your participation in community?

Conversation Prompts:

- Who is in your community
- Sharing the diagnosis
- Stigma
- Transportation or access issues
- Ways to contribute or engage

CONSIDER: Support groups; Scripts or cards to share diagnosis; Dementia advocacy organizations; Dementia-friendly communities; Resources for people with disabilities



RELATIONSHIPS

Family

How is dementia affecting your **family**?

Conversation Prompts:

- Who is in your family
- Intimate or romantic relationships
- Family activities
- Traditions
- Family conflict and relationships
- Communication and staying in touch
- Changing roles and dynamics
- Household tasks

CONSIDER: Family meeting; Therapy;
Support groups; Mediation;
Communication books or tools



RELATIONSHIPS

Friends

How is dementia affecting your **friendships**?

Conversation Prompts:

- Who is in your friend circle
- For the person with dementia
- For the care partner
- Activities
- Communication
- Loneliness

CONSIDER: Adapt old activities to new abilities; Share ideas with friends for visits; Explore new activities and communities



RELATIONSHIPS

Pets

Are **pets** part of your life?

Conversation Prompts:

- Pet history
- Likes and dislikes
- Past routines with pets
- Spending time with animals in other settings

CONSIDER: Care for pets; Friends or neighbors to help with current pets or bring visiting pets; Electronic pets; Exploring if a pet would bring comfort or routine into a household



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

Subtopics



Transportation



Housing



Routine



Personal Care



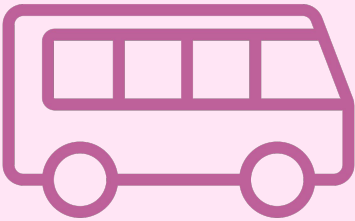
Food



Hobbies



Communication



DAILY LIFE

Transportation

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

Housing

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



DAILY LIFE

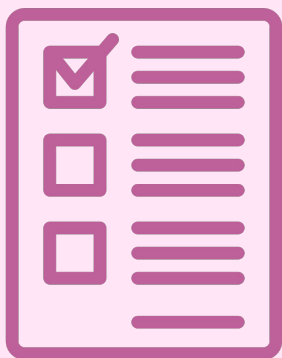
Food

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



DAILY LIFE

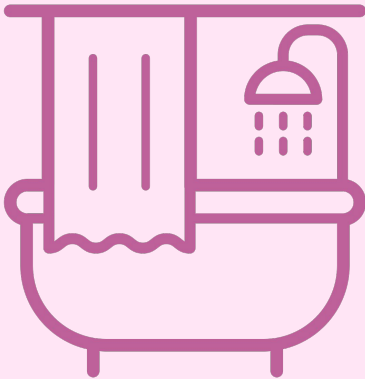
Routine

How has dementia impacted your **daily routine**?

Conversation Prompts:

- Schedule
- Tasks
- Roles and responsibilities
- Sense of comfort
- Meals, sleep, exercise

CONSIDER: Self care; Who can help; Building routine and structure to ground the person with dementia; Discuss how to balance the needs of the person with dementia and the primary care partner



DAILY LIFE

Personal Care

What is **personal care**?

Conversation Prompts:

- Trouble getting dressed or washing up
- Trouble walking or moving around the home
- Trouble with toileting
- Trouble getting in and out of bed

CONSIDER: Home care/personal care aides; Care partner training; State options for paying the care partner for care work; Educational videos by Teepa Snow; Discussing risks and worries; Emphasizing autonomy for the person with dementia to do as much for themselves as possible



DAILY LIFE

Hobbies & Activities

How is dementia affecting your usual **hobbies or activities**?

Conversation Prompts:

- Past work or jobs
- Past social roles
- Personal interests and strengths
- Adapting prior hobbies/activities
- Recreation

CONSIDER: Adapting activities to current abilities; Music; Dance; Arts; Nature; Walking and other movement; Identifying others who can participate in activities; New sources of roles and jobs; Adult day programs; Senior centers; Programs for people with disabilities



DAILY LIFE

Communication

How is dementia affecting communication?

Conversation Prompts:

- Misunderstandings and frustration
- “Behaviors” or neuropsychiatric symptoms
- Lack of insight (anosognosia)

CONSIDER: Care partner education; Dementia coaching; Allowing more time; Short simple phrases; Low stimulation environments; Non-verbal communication; Communicating with a person within their lived experience; Addressing emotions rather than facts



Quality of Life

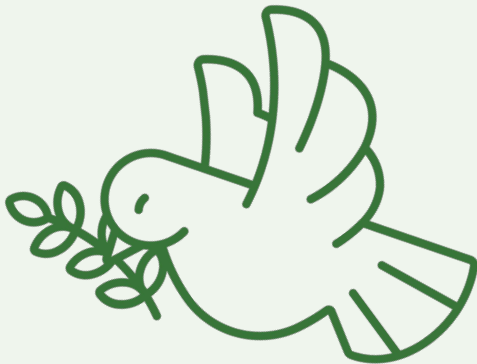
Quality of life is critical for everyone living with dementia. Daily attention to quality of life can improve clinical outcomes and wellbeing.

Quality of Life



Subtopics

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



QUALITY OF LIFE

Spirituality & Faith

Is **spirituality or faith** important to you?

Conversation Prompts:

- Effects of faith on living with dementia
- Source of strength
- Transportation, access to services
- Faith or spiritual community of support

CONSIDER: Ability to get to services or community events; Home visits; Televised or online services; Adapting practice for this moment; Identifying other practitioners in this community



QUALITY OF LIFE

Building Hope

What do you **hope** for at this moment?

Conversation Prompts:

- Effects of dementia on hope
- Effects of grief on hope
- Changing what is hoped for as the disease changes
- Finding hope with others in the family or community

CONSIDER: Start small; Seeing hope through others' eyes; Increasing social connection (family, friends, support group, Alzheimer's Helpline)



QUALITY OF LIFE

Meaning & Purpose

How is dementia affecting your sense of **purpose**?

Conversation Prompts:

- Past sources of meaning and purpose, personally or professionally
- Meaning from relationships
- Pride in living well
- Identifying role played in social situations

CONSIDER: Redefining meaning now;
Redefining contributions at home;
Identifying new (or old) jobs for the person with dementia; Using art, music, nature, and the senses to create meaningful experiences



QUALITY OF LIFE

Autonomy

Do you wish you were **in charge of** your routine, activities or body?

Conversation Prompts:

- Offer the opportunity for:
 - Choice
 - Control or responsibility
- Identify frustrations from lack of control or agency
- Identify when the person with dementia is happiest

CONSIDER: Increasing choices; Increasing responsibility in daily tasks; Simplifying tasks into smaller steps; Respite and adult day programs, Exploring worries about safety and ways to maintain autonomy; New opportunities for autonomy, control and agency



QUALITY OF LIFE

Growth

How do you **make sense** of the challenges brought by dementia?

Conversation Prompts:

- Learning or growing from past challenges in your life
- Spiritual growth or shift
- Learning new skills
- Human developmental task(s) related to living with dementia or caring for someone with dementia

CONSIDER: Seeking out new things to learn or improve; Therapy; Self-help tools; Journaling; Creative expression



QUALITY OF LIFE

Belonging

How is dementia affecting your feeling of **belonging**?

Conversation Prompts:

- Past experiences of belonging
- Roles and identities
- Family traditions, customs, rituals
- Barriers to belonging now

CONSIDER: Adaptations or supports that enhance a sense of belonging (e.g. hearing aids, plan on more time to do things); Day programs; Early onset dementia groups; Dementia advocacy programs (Dementia Action Alliance); Language and cultural supports that might enhance belonging



QUALITY OF LIFE

Joy & Pleasure

What do you **enjoy** doing now?

Conversation Prompts:

- Activities, relationships that bring happiness or enjoyment
- Activities, relationships that bring laughter
- New ways of experiencing joy or pleasure as the disease progresses

CONSIDER: Starting with small joys; Listing 5 things that bring you pleasure or joy; Exploring how to increase these moments in your life; People; Sensory stimulation; Music; Nature; Physical activity and movement



QUALITY OF LIFE

Behavioral Health

How is your **mood**?

Conversation Prompts:

- Moods of others
- Activities, relationships that help when you are feeling down
- Worries about anyone's moods
- Challenges of managing emotions
- Coping with difficult emotions

CONSIDER: Faith or spiritual practices; Medications; Counseling; Exercise; Time with loved ones; Hobbies; Dementia education and coaching; Dementia support groups



QUALITY OF LIFE

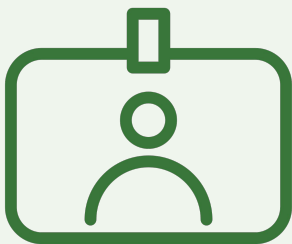
Dignity of Risk

How do you balance **safety** and **quality of life**?

Conversation Prompts:

- Worries or dangers associated with activities that improve quality of life
- Minimizing risks while preserving quality of life
- What is acceptable risk
- Family conflict about quality of life and safety
- Alternative ways to support quality of life

CONSIDER: Increasing autonomy, meaning, joy, pleasure to balance limits required to reduce risk; Clarifying what risks are too much for all involved; Family meeting



QUALITY OF LIFE

Identity

How are different aspects of your **identity** affecting your experience with dementia?

Conversation Prompts:

- Race, ethnicity, culture
- Language
- Gender
- Personal information to share to help others provide better care and support

CONSIDER: Exploring how these parts of identity can be a source of support, community, or hope; Language supports; Cultural navigators; Culturally relevant support groups; Dementia communities; www.portraitsofdementia.com



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

Subtopics



Crisis
Planning



Housing



Finances



Legal



Palliative &
Hospice Care



Medical
Wishes



Decision-
Making



PLANNING FOR THE FUTURE

Crisis Planning

Do you have a plan in place for an unexpected **crisis** or **change**?

Conversation Prompts:

- Identifying people to call in the middle of the night
- Identifying the next change likely to occur
- Identifying partners in complex decision-making
- Role of emergency services

CONSIDER: Breaking down crises into smaller pieces; Identifying a next step rather than an answer; Identifying a task for tomorrow; Identifying the biggest worry



PLANNING FOR THE FUTURE

Housing

How is your current **housing** situation?

Conversation Prompts:

- Accessibility and affordability
- Upkeep and management
- Access to needed services and supports
- Signs that the current situation needs to change
- Understanding what is needed to age in place here
- Isolation and connection

CONSIDER: Nursing homes; CCRCs or assisted living facilities; Shared homes; Adult foster care; Intergenerational housemates (nursing students); Accessing local housing authority; Council on Aging and Area Agency on Aging; Home safety evaluation by physical or occupational therapist



PLANNING FOR THE FUTURE

Finances

What **financial** concerns do you have?

Conversation Prompts:

- Power of attorney
- Managing renewing services such as rent, household utilities, health insurance including Medicare and Medicaid
- Financial planning for a change in residence (moving to a nursing home or assisted living facility)

CONSIDER: Elder care attorneys; Financial planners; Staff at local banks; Area Agencies on Aging often have a counselor for Medicare/Medicaid Support



PLANNING FOR THE FUTURE

Legal

Would you like any help with **legal** issues?

Conversation Prompts:

- Power of attorney
- Health care proxy
- Wills

CONSIDER: Elder care attorneys; Templates on the internet such as The Conversation Project and https://www.va.gov/geriatrics/pages/advance_care_planning_topics.asp; Family meetings; Local resources from Area Agencies on Aging



PLANNING FOR THE FUTURE

Palliative & Hospice Care

What have you heard about **palliative care** and about **hospice**?

Conversation Prompts:

- Difference between palliative care and hospice
- When is the timing right for these services
- Worries and fears
- Past experiences with palliative care or hospice

CONSIDER: Making an appointment with a palliative care provider to learn about symptom management; Contacting a local hospice for information; PCP guidance when palliative care or hospice might be appropriate; Talking to family about their hopes and fears with palliative and hospice care



PLANNING FOR THE FUTURE

Medical Wishes

Have you talked about your wishes for **future medical care** with anyone?

Conversation Prompts:

- Family conversations
- Wishes as the disease progresses
- Values/beliefs that might affect the care you want at the end of your life
- People who can partner with you in making complex medical decisions

CONSIDER: Talking to your PCP about POLST forms; Using the Five Wishes Tool; Using the What Matters to Me workbook and other resources from the Conversation Project; Talking to your PCP about your goals, hopes and worries



PLANNING FOR THE FUTURE

Decision-Making

How do you approach making big **decisions** related to dementia?

Conversation Prompts:

- Housing/medical/safety
- How does your family make medical decisions?
- Ethical issues underlying the decision
- The voice of the person with dementia
- Navigating conflicting opinions

CONSIDER: Pro-con lists; Emotion cards; Supported decision making; Identifying goals and impact of decision for all involved; Breaking decisions into smaller issues; Past methods of decision making



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

Subtopics



Dementia



Medications



Hospitals



Staying
Healthy



Medical
Providers



HEALTH

Dementia

What questions do you have about **dementia**?

Conversation Prompts:

- Diagnosis
- Personal meaning of dementia
- Stages:: Early, Middle, Late
- Activities of Daily Living (ADLs) needs
- Deciding to see a specialist
- Treatment options
- Symptoms (e.g., sleep, mood, delirium, sexuality, communication, neuropsychiatric)
- Good days and bad days

CONSIDER: FAST Scale; Getting help with personal care; Meeting with a PCP/ geriatrician/ neurologist; Managing symptoms with medication and other supportive interventions



HEALTH

Medications

Do you have concerns about your **medications**?

Conversation Prompts:

- Side effects and effects on brain function
- Trouble taking medications
- Cost
- Knowing purpose of each medication
- Accessible, updated medication list
-

CONSIDER: Reviewing all medications with your PCP for side effects, purpose, effect on symptoms, longevity; Considering effects of medication on cognition or brain health; Asking for generic versions of medication; Discussing a simpler medication schedule



HEALTH

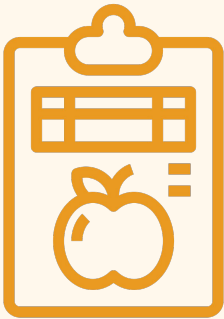
Hospitals

What about going to the **hospital** for non-dementia medical issues?

Conversation Prompts:

- Risks and benefits of going to the hospital with dementia
- Risks and benefits of surgery with dementia
- Brain health while in the hospital
- After the hospitalization
- Other options to prevent hospitalization

CONSIDER: Requesting a geriatric or palliative care consultation as an inpatient; Keeping glasses, hearing aids, dentures, other assistive devices with you in the hospital; “Rescue medications” at home to prevent rehospitalization



HEALTH

Staying Healthy

What can you do to stay healthy?

Conversation Prompts:

- Exercise
- Nutrition
- Brain Health
- Social Engagement
- Complementary or traditional therapies

CONSIDER: Finding a partner for walks or exercise; Mediterranean diet; Staying intellectually and socially active in projects, communities, activities important to you



HEALTH

Medical Providers

How do you navigate the healthcare system?

Conversation Prompts:

- Ensuring each provider has a current medication list
- Ensuring all providers know about your dementia
- Identifying best communication strategies for each office
- Identifying which clinician to see for which problem
- Preparing for appointments

CONSIDER: Writing a list of questions or topics to bring to each appointment; Telling each clinician about your dementia; Bringing a support person to all appointments; Recording visits on a phone to listen to later; Asking about medications and brain health



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



DEMENTIA SUPPORT

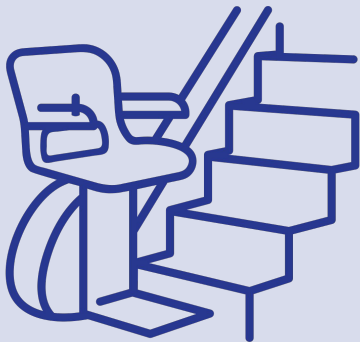
Care Coordination

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



DEMENTIA SUPPORT

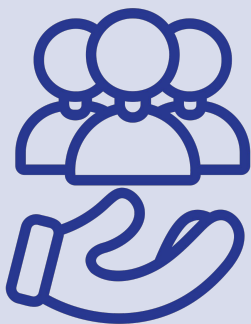
Adaptive Supports & Technology

Can **technology** or **adaptive equipment** help?

Conversation Prompts:

- Home safety
- Getting lost
- Social isolation
- Tools for daily activities

CONSIDER: Home safety and occupational therapy evaluation; Adaptive tools to help with eating, sleeping, dressing, bathing; Reviewing risks and benefits of new technology



DEMENTIA SUPPORT

Care Partners

How to support your primary **care partner**?

Conversation Prompts:

- Staying connected with the person with dementia
- Building competence and confidence in dementia caregiving
- Focus on and value of care partner quality of life
- Humor, improvisation
- Spiritual practice or faith
- Social connections

CONSIDER: Finding pleasure in small moments; Taking time for self; Finding meaning or pleasure in caregiving; Asking for help or support



DEMENTIA SUPPORT

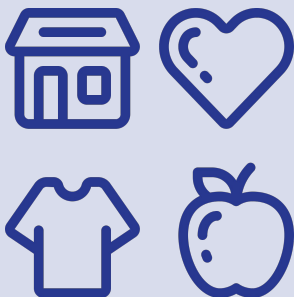
Mapping Your Support

Who can help **support** your needs?

Conversation Prompts:

- Building a team
- Asking for help
- Identifying who to ask for help
- Help with personal care

CONSIDER: Identifying specific tasks for others to help with (ex. driving, shopping, pet visits, check-in calls, 30 minutes of reading together); Identifying improvements to quality of life; Use of emergency services



DEMENTIA SUPPORT

Community Resources

What other **resources** are out there?

Conversation Prompts:

- What have you tried already?
- What worked?
- What's missing?

CONSIDER: Caregiver support groups; Memory cafes; Alzheimer's Association; Dementia Action Alliance; Councils on Aging and Area Agencies on Aging; Dementia Coaches; Village or Neighbor Networks; Personal care or Home care aides; Adult day programs; Possible role of hospitalization to manage symptoms of dementia; Psychiatric or neurology specialists



DEMENTIA SUPPORT

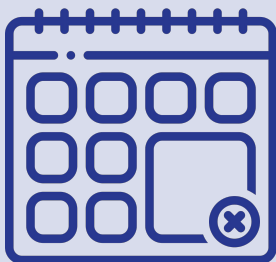
Coaching

What is **dementia coaching**?

Conversation Prompts:

- Building care partner confidence and skills
- Communication skills
- Managing emotions
- Understanding “behaviors” as responses

CONSIDER: Dementia classes; Alzheimer’s Association; Youtube videos; Teepa Snow for neuropsychiatric symptoms and communication; Community-based organizations; Area Agencies on Aging



DEMENTIA SUPPORT

Respite

What is **respite**?

Conversation Prompts:

- Creating time for the care partner
- Offering new activities
- Offering new relationships and roles
- Cognitive stimulation
- Preparing for travel

CONSIDER: Formal and informal respite;
Planning activities for the person with dementia and other friends or family;
Adult day health or social day programs;
Overnight in-home care; Short nursing home stays; Shared care with another care partner



Emotions

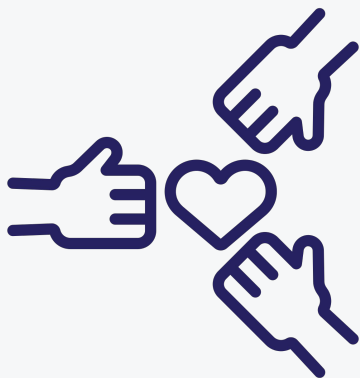
Use the **emotion cards** to check-in on how you are feeling about dementia right now.



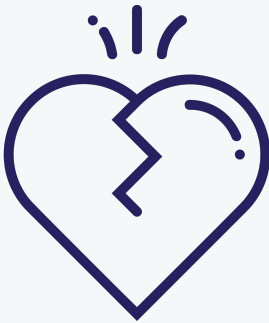
Anxieties



Guilt



Hope



Grief



Contentment



Wishes & Worries



Joy



Pleasure



Frustration



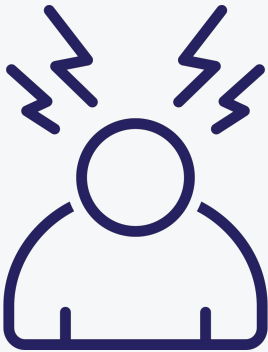
Isolation



Love



Confidence



Stress



Overwhelm



Fears

