

Centering Our Values

A guide to making dementia care
decisions together

How to use this tool

Centering Our Values is a decision-support tool. It is for family members and caretakers of people with dementia or Alzheimer's. It is partly an educational tool and partly a workbook. It will help you

learn about what to expect as dementia progresses. It will also help you think about how to incorporate your and your loved one's values into their care.



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Use this tool to guide conversations with social workers, healthcare providers, and anyone else in your care team. It should be used over and over again as your loved one's care changes. Return to this book to remember what matters to you and your loved one.

What matters to you

A diagnosis of dementia can lead to many difficult conversations and decisions. It is important to ground these moments in your unique values and priorities. Values refer to what you believe is most important in life.

This section of the book will help you think about two sets of values: your own, and your loved one's. How might these values affect the type of care you seek? What will you do if your priorities are not the same? Who is in your "care network" that you can turn to for help?

By beginning to think and talk about these questions, you can build your own framework for making decisions that will affect your loved one's care.

Reflect on what is important to you

Take your time to reflect on the following questions by writing down or drawing to express yourself.

What makes you happy and whole?

This might be an activity, a place, a role you play, or a relationship you cherish.

What do you need to feel safe and supported?

You might find comfort and security in a relationship, a place, or even music or food.

What are your hopes and fears?

For the hopes: these might be a short-term or long-term goal that you are aiming for;
For the fears: these might be something you always try to avoid.

Hopes	Fears

What can't change in your life?

This might include where you live or work, or how you spend certain hours in a day.

Reflect on what you and your loved one share

Complete this activity alongside your loved one.

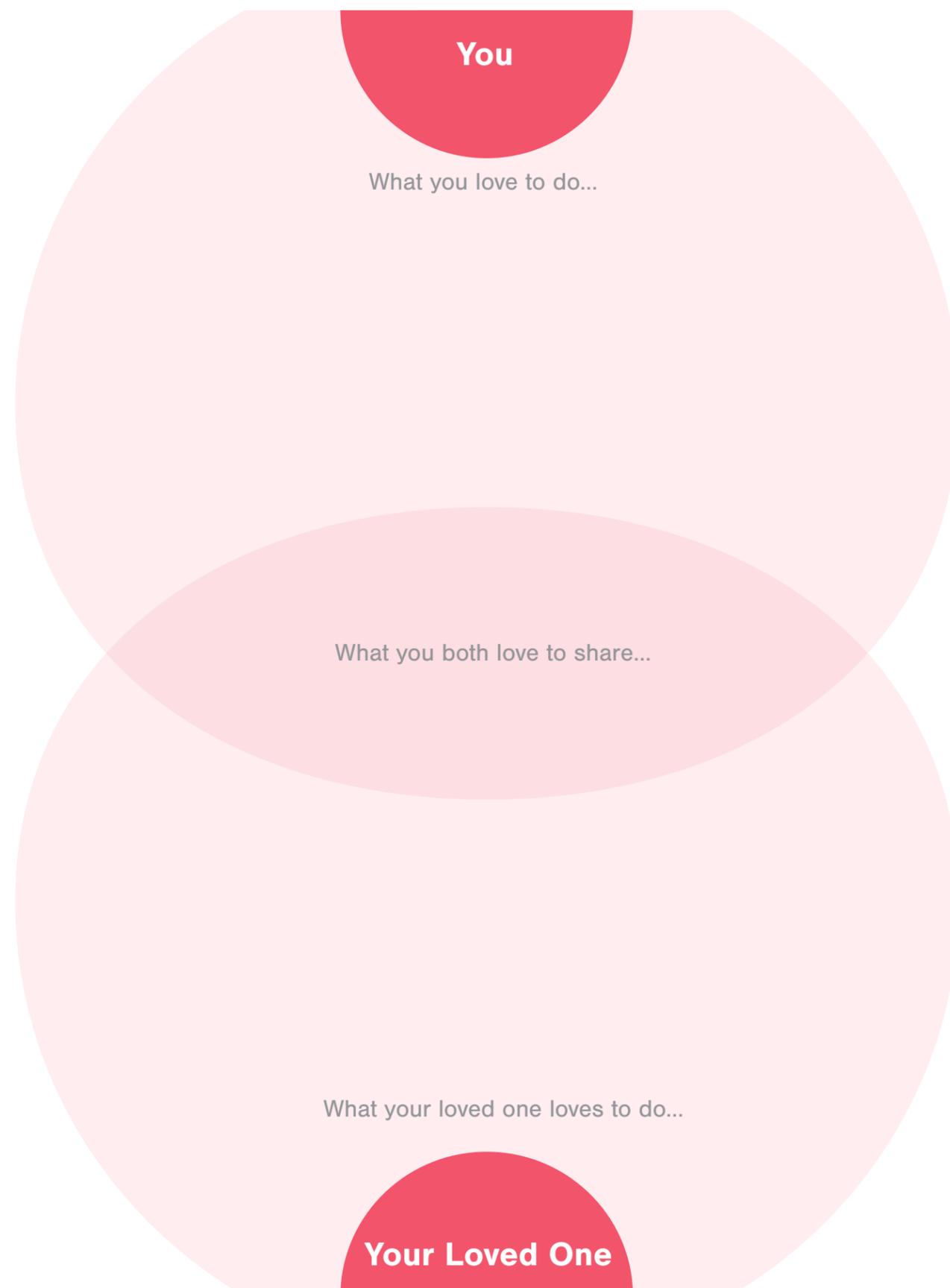
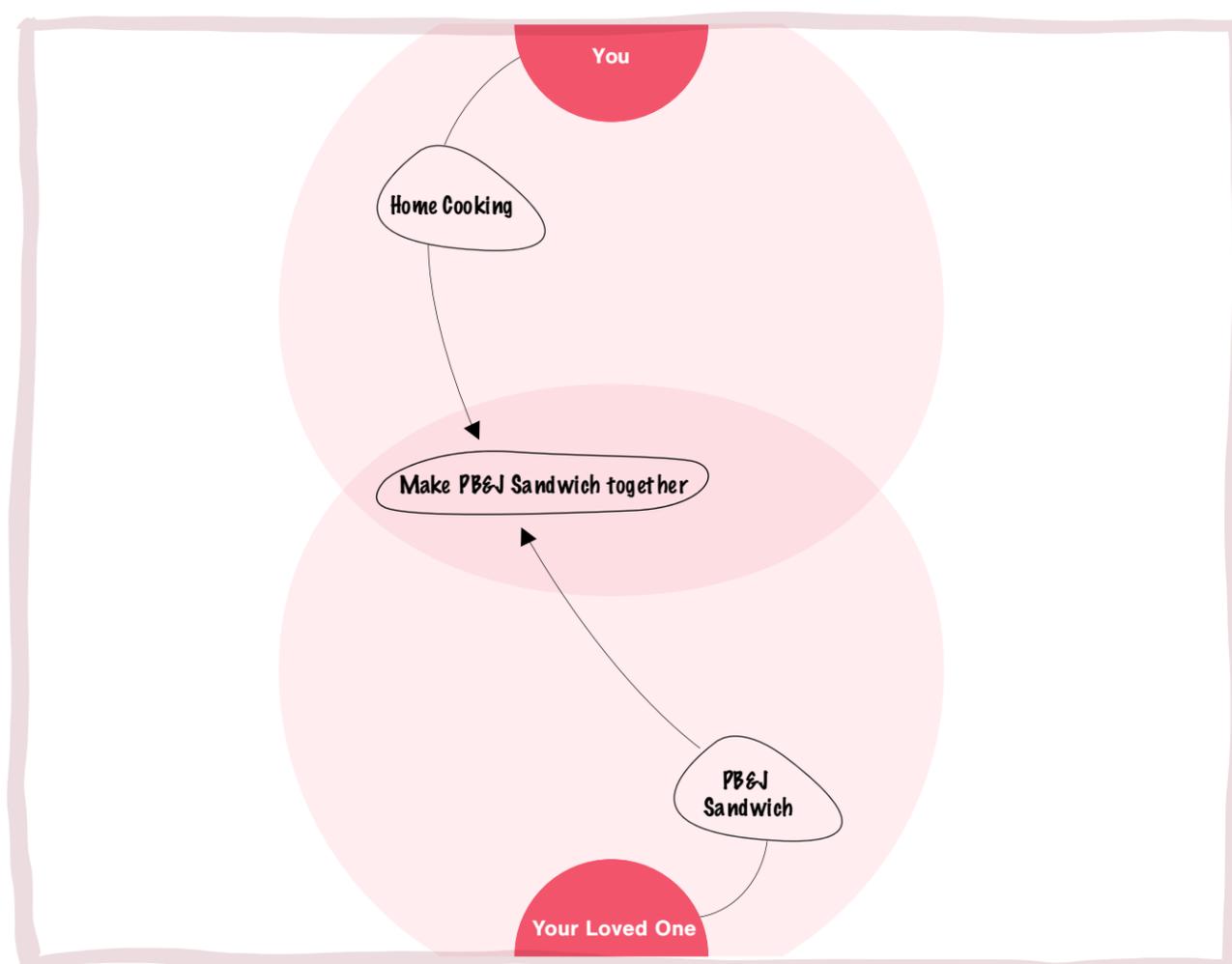
Think about what beliefs, values, or interests define who you are. On each side, draw branches to represent those ideas.

Where do you differ?

What do you and your loved one share?

Connect the ideas you share.

Example



Imagine...

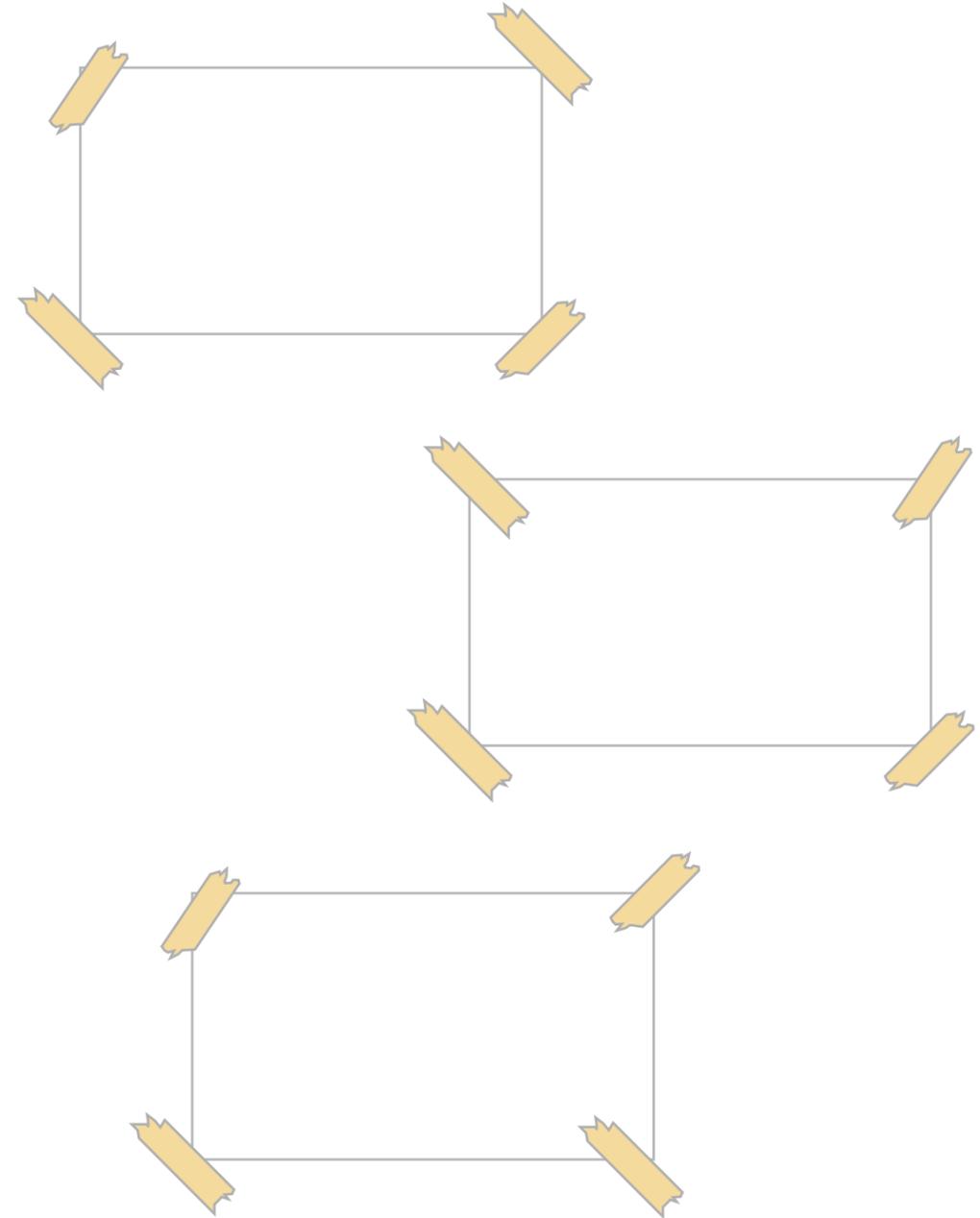
Close your eyes and imagine yourself on a relaxing day. Stick a picture, write a poem or draw something that reminds you of being relaxed.



Sitting on the bench in the park. It's a windy day and I am drinking coffee...

Close your eyes and imagine yourself doing something with your loved one. Stick a picture, write about it or draw it!

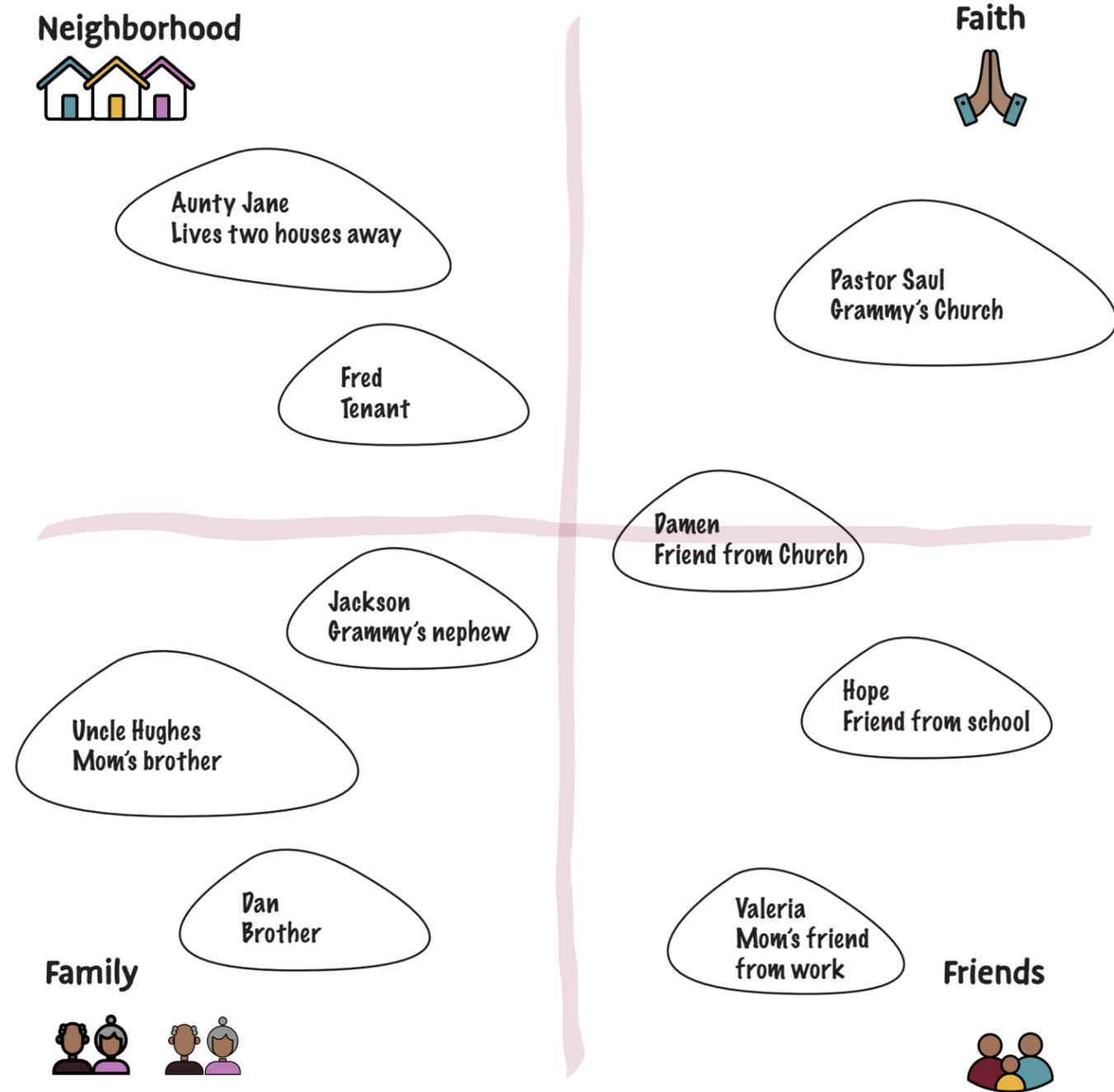
Grammy and I, cooking a meal...



Build your social support network

This map is where you can put down the names of everyone you can count on when you need help, These people could be from your **neighborhood**, your **faith circles**, your **family** or your **friend circle**.

On this page we have an example for your reference.



Now you try!

Neighborhood



Faith



Family



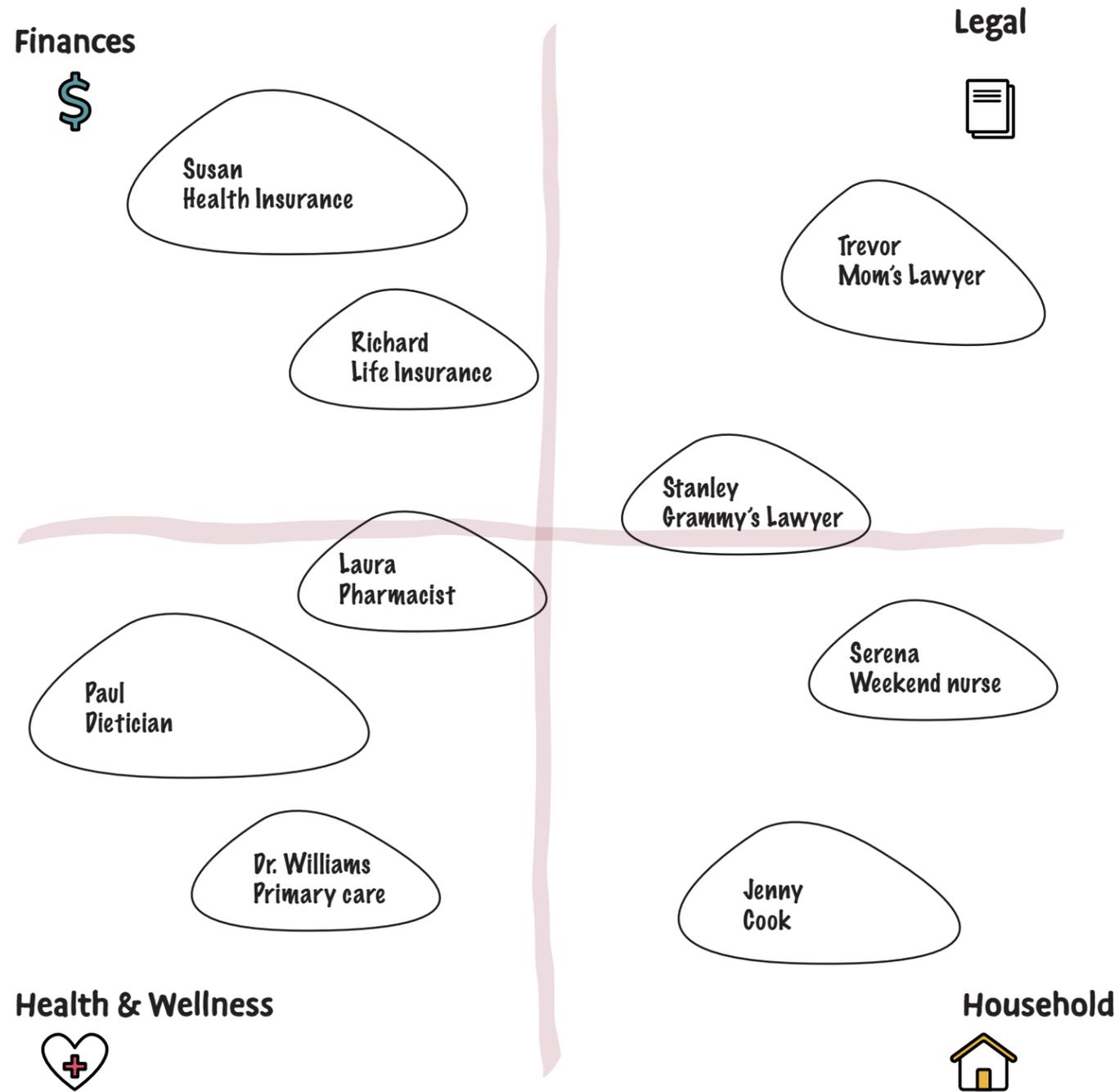
Friends



Build your professional care team

This map is where you can put down the names of the people you can look to for help. These are your professional assistants who may help you with **finances, health & wellness, legal** or **household**.

On this page we have an example for your reference.



Here is a copy of the map for you to give it a go...

Finances



Legal



Health & Wellness



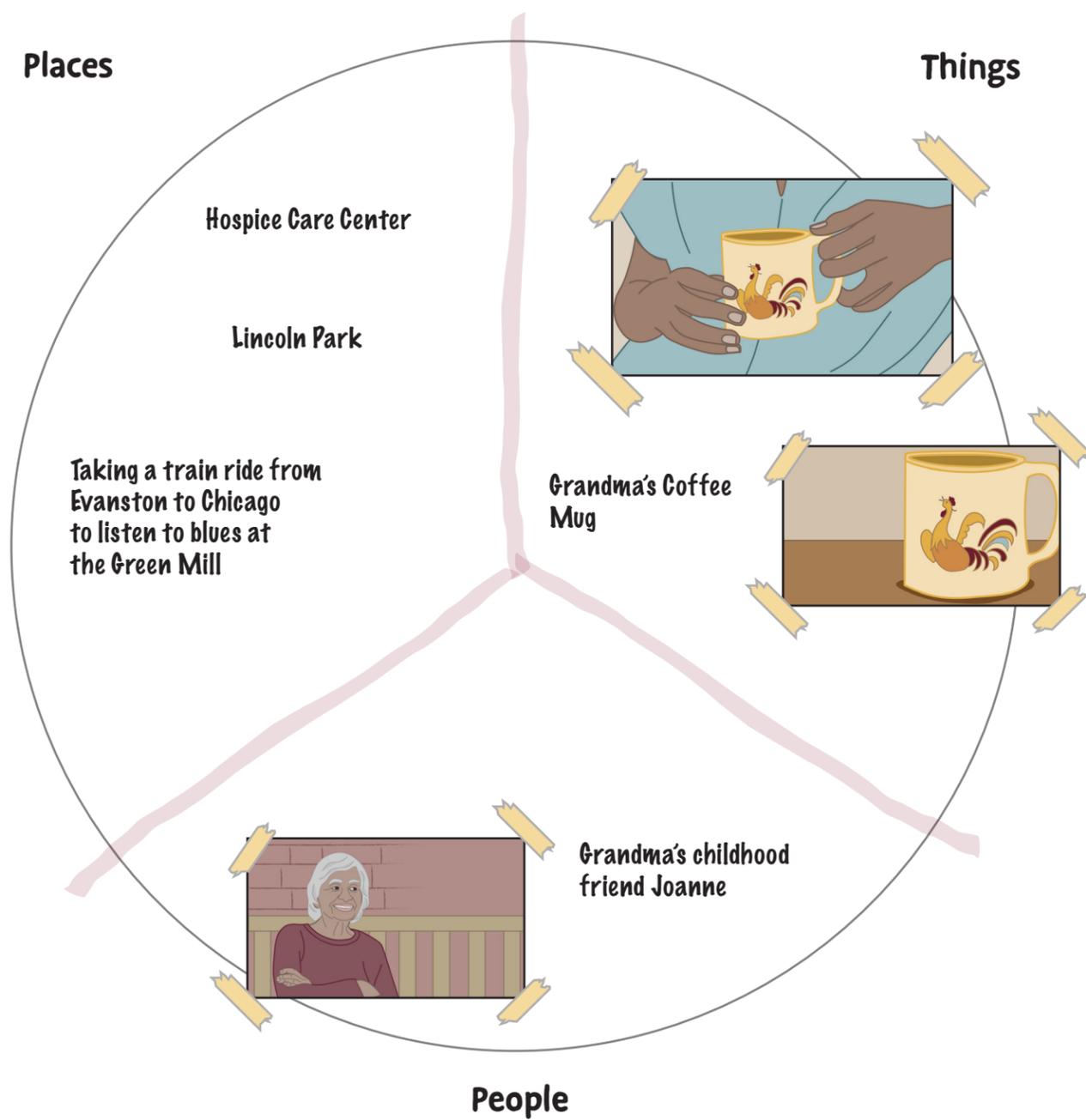
Household



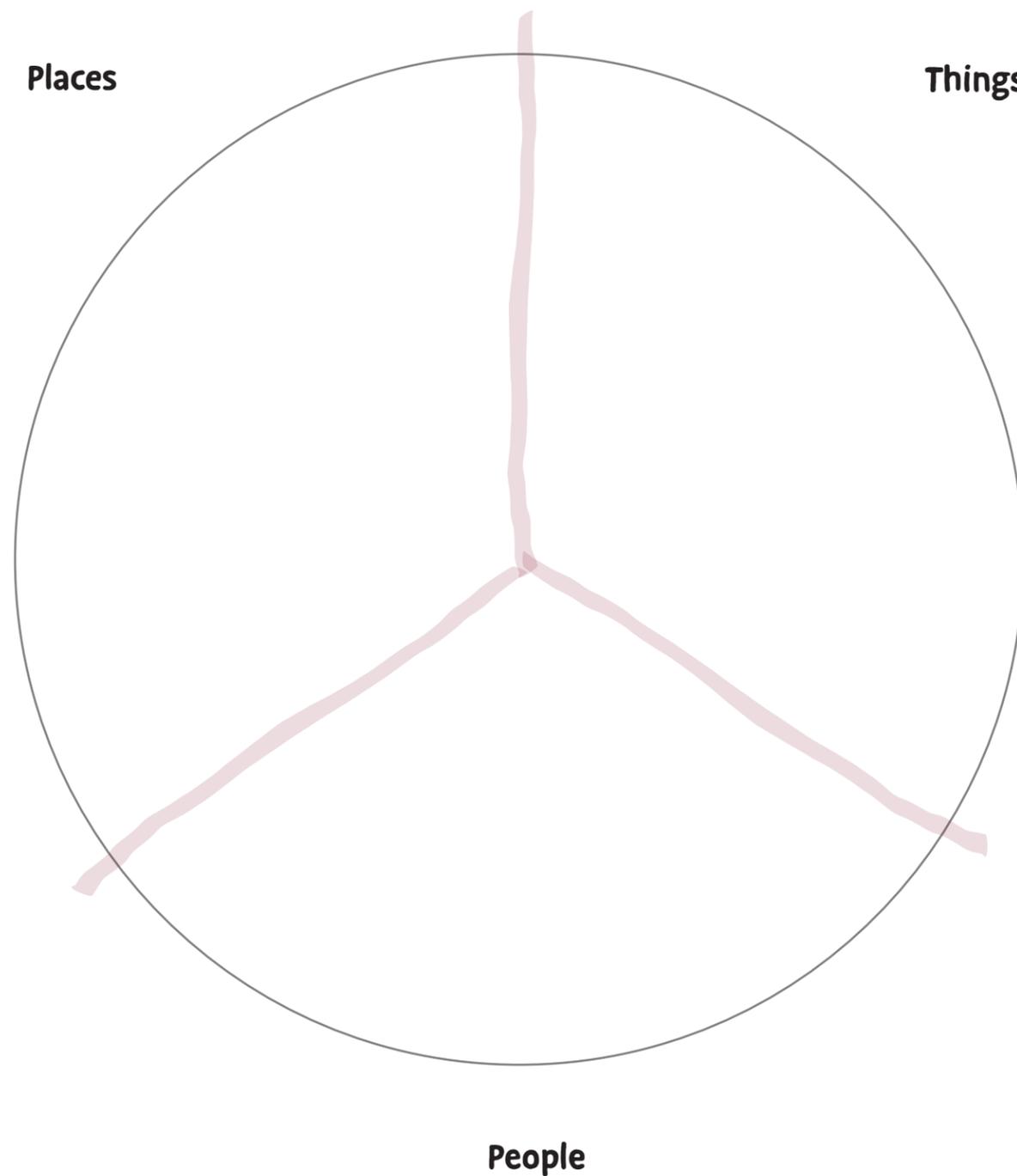
Support in times of sadness

This is not a simple journey and there will be many moments when you will feel very hurt, confused or sad. On this map, you can make a list of things, people and places that you can turn to in these moments of emotional stress.

On this page we have an example for your reference.



It's your turn!



Moments and decisions

Making a plan that works for you

Families and caretakers often struggle with making decisions about their loved one's care. It is important to know what to expect as dementia progresses so you can make informed choices.

This section will address challenges you might encounter as you manage daily care, plan for long term care, and maintain relationships. The worksheets in this section will also help you think through how to make the best decision for your circumstances.

Managing daily care

Many times, the first signs of dementia are seen in people's daily habits. Dementia can make every day activities difficult. As the disease advances, your loved one may need more support in their daily care.

Some daily care activities your loved one may need help with include:



Medical management:

Organizing medication, medical recommendations, and regular activity



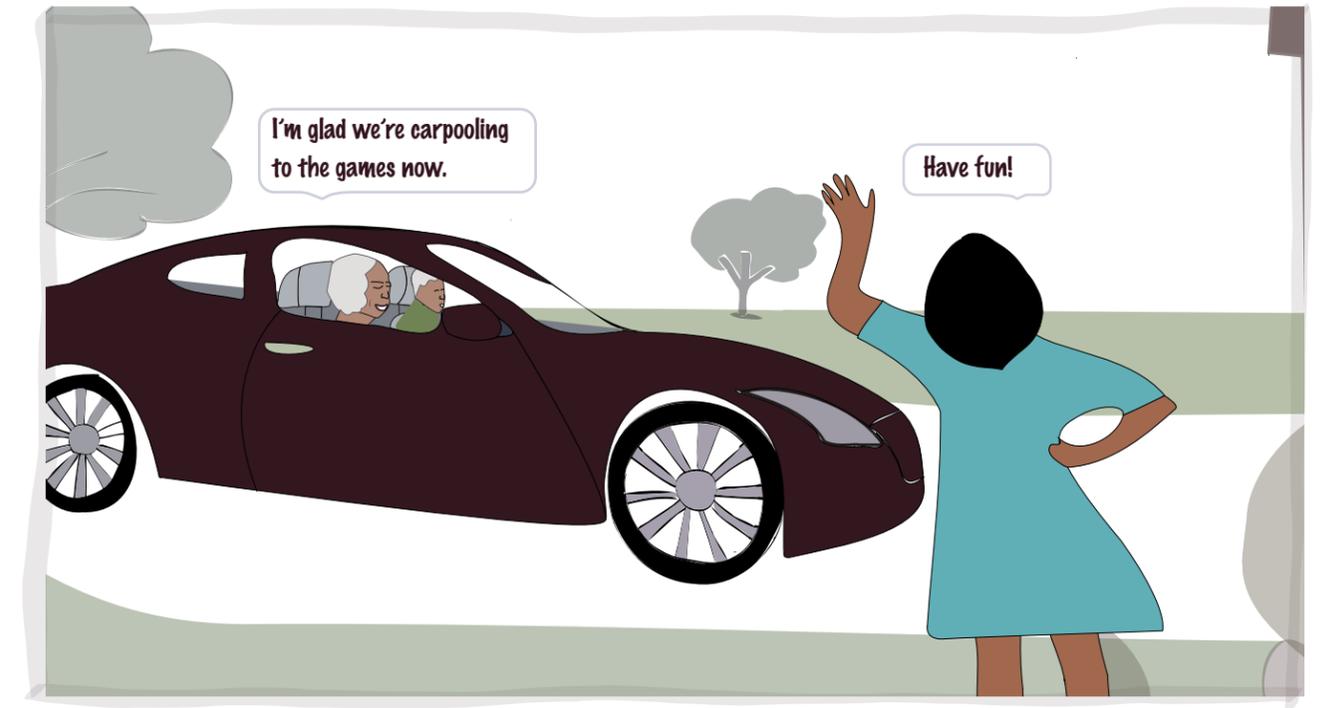
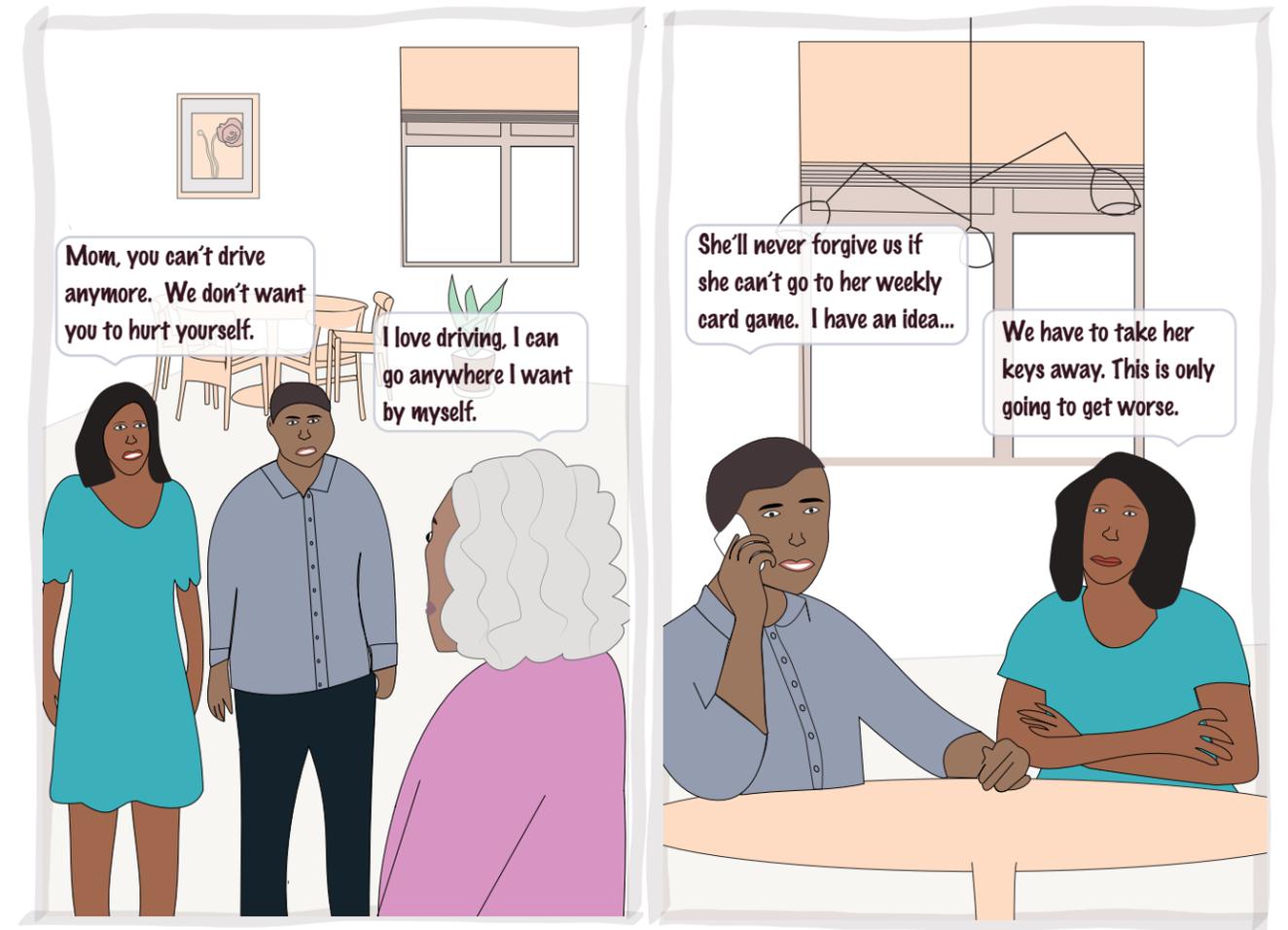
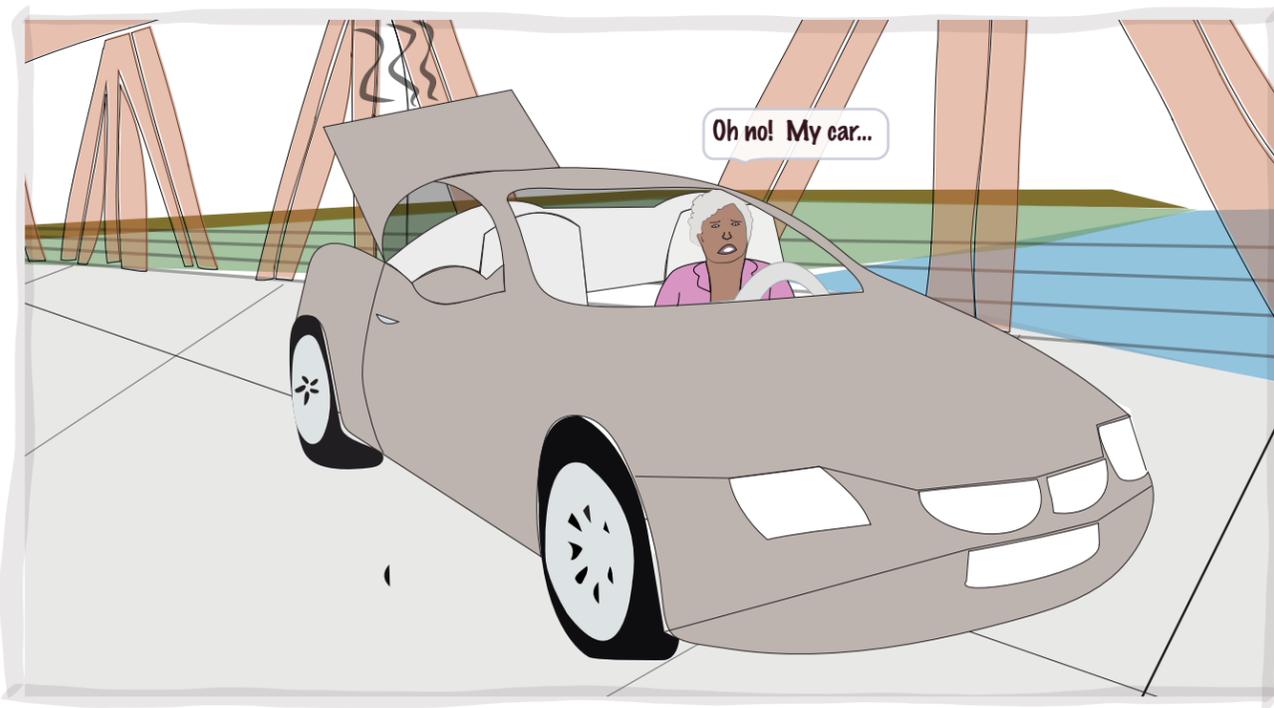
Hygiene: Dressing, bathing, grooming, dental care, and going to the bathroom



Healthy Eating: Cooking, eating, managing groceries, and considering food preferences



Mobility: Arranging transportation, safely walking with or without a cane, walker, or wheelchair





Hygiene

People with dementia may have difficulties with some tasks. An example could be bathing or changing their clothes. Helping a loved one with these tasks can be an intimate experience. However, Proper hygiene can help improve self-esteem and avoid health risks.

It may be time to consider your strategy for your loved one's hygiene if they are...

- Resistant to getting dressed in the morning
- Not able to make it to the bathroom in time
- Not able to trim their own fingernails and toenails

Healthy eating

Eating regular, healthy meals may be difficult for people with dementia. As a person's cognitive function becomes worse, their eating habits might change. They may get confused by food choices, forget to eat, or have trouble using utensils.

It may be time to consider your strategy for your loved one's eating and diet if they are...

- Leaving food out and letting it spoil
- Forgetting to eat meals, or forgetting when they last ate
- Leaving the stove on (safety risk)
- Experiencing changes in taste
- Having difficulty swallowing or are losing weight



Medical management

Managing medications. Refilling prescriptions. Attending doctor's appointments. These are all key factors to staying healthy. But, people with dementia may forget to take their medication or may not follow directions from their doctor.

It may be time to consider your strategy for your loved one's medical management if they are...

- Forgetting to take medications or taking the wrong dosage
- Resistant to physical activity, especially physical therapy exercises
- Resistant to following their doctors' directions
- Forgetting doctor appointments

Mobility

We all move around. By foot, car or public transit. The ability to move is linked to independence. As a person's cognitive function becomes worse, they start to react slower. Or they may have difficulty with directions. This could lead to a person with dementia losing their ability to move on their own.

It may be time to consider your strategy for your loved one's mobility if they are...

- Getting lost or wandering (safety risk)
- Getting in minor or major car accidents (safety risk)
- Unable to navigate public transit
- Unable to walk without help or falling (safety risk)

Managing daily care

This worksheet will help you think about the changes you see in your loved one that affect their daily activities and help you build ways to manage these changes.

Taking your **loved one's values and wishes** into account, use this worksheet in a way that works best for you, refer back to them from time to time, and make additions as you see fit.

Noticing changes

What changes are you noticing with your loved one in terms of daily care?

What decisions do you need to make to help your loved one through these changes?

Connecting to your network

Refer back to your **support network**. Who can help you manage your loved one's daily care? Revisit page 11.

There are also many **professionals** you can turn to for help and expertise. Who can you reach out to? Revisit page 13.

	_____
Neighborhood	
	_____
Faith	
	_____
Family	
	_____
Friends	
Write down contact information	

	_____
Finances	
	_____
Health & Wellness	
	_____
Legal	
	_____
Household	
Write down contact information	

Applying your values

What matters to you and your loved one in terms of medical management?

You might consider medical dietary restrictions, or exercise.



What matters to you and your loved one in terms of healthy eating?

You might consider favorite recipe and dish, or preparing soft and easy to swallow foods.



What matters to you and your loved one in terms of hygiene?

You might consider favorite outfit, or name of barber or beautician.



What matters to you and your loved one in terms of mobility?

You might consider trusted drivers, or use of a walking aid (walker or wheelchair).



Planning for long term care

As dementia progresses, people begin to lose their ability to make reliable decisions. You may find yourself making or contributing to decisions about your loved one's life.

We have already discussed some decisions about your loved one's daily care above. You will also need to start thinking about their long term needs. These can relate to financial, legal and healthcare matters.

Talking to your loved one about their wishes is important. It may help you make these difficult decisions when the time comes. Knowing what is coming before it does will make you a powerful decision-maker.

Some long term care items you may want to consider include:



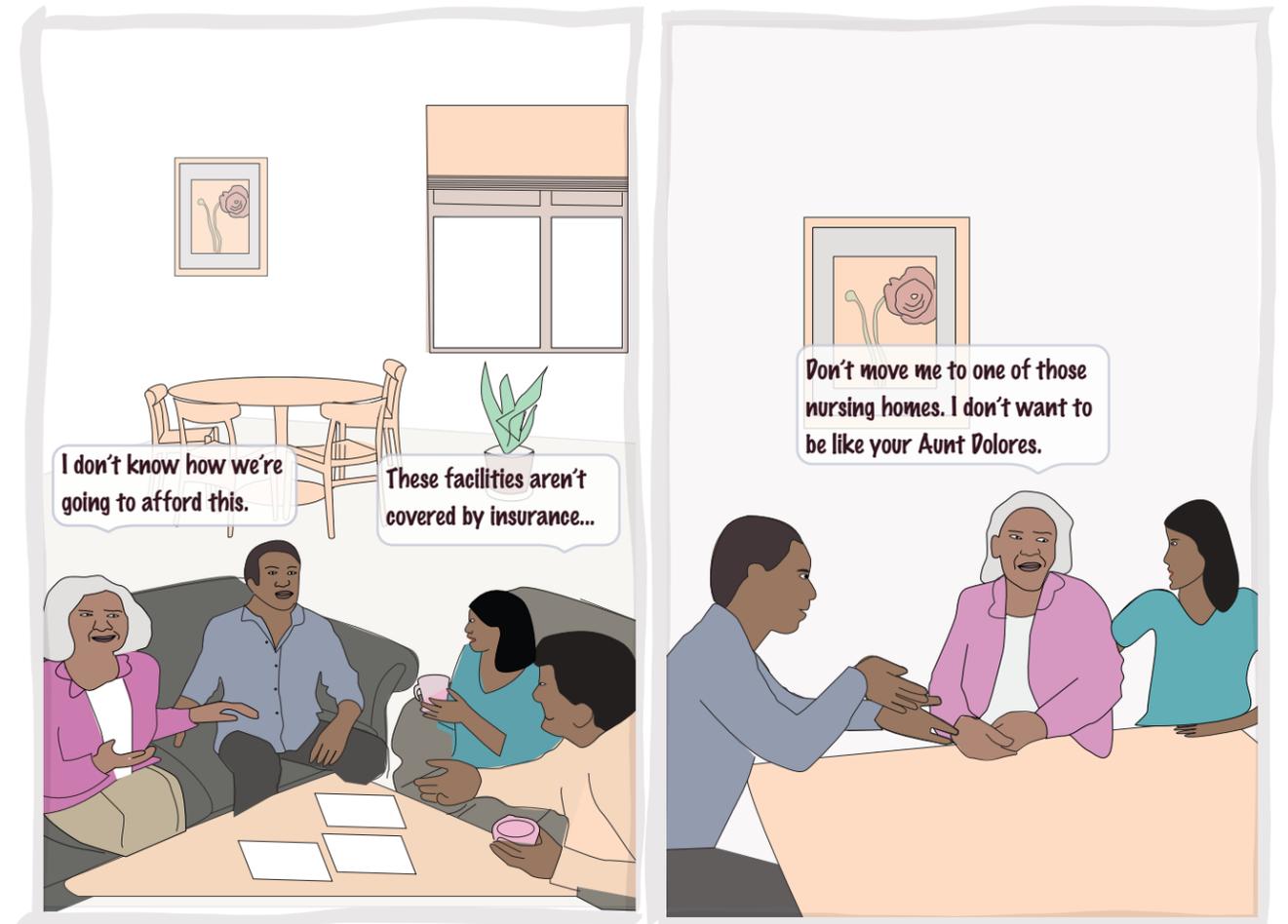
Care setting: Hiring in-home support, considering a nursing home, and hospice care

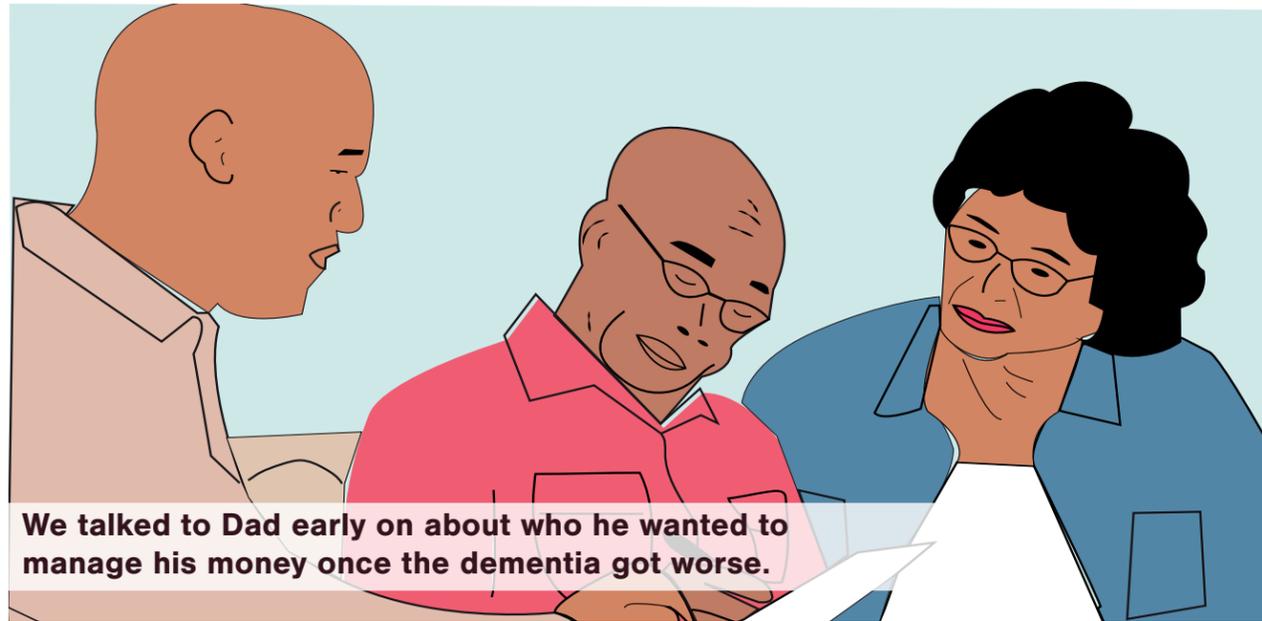


Finances: Tracking daily spending, managing bills, and assuming financial power of attorney



Advanced care plan: Managing medical decisions, conveying your loved one's wishes, and assuming advanced care decision maker (power of attorney or surrogate decision maker)





Care setting

Your loved one's daily needs will change as their disease progresses. This will need you to change how you think about their care situation. You and your loved one's care team may decide to provide care at home for as long as possible. This may be with or without support from in-home nurses or homemakers. Or, moving to a community living environment or nursing home may be the right choice for your situation.

It may be time to consider your strategy for your loved one's care setting if they are...

- Becoming isolated or showing signs of boredom
- Opening the door to strangers (safety risk)
- Requiring you to take more time away from work to help
- Showing more decline in health; being unable to communicate, decline in eating or walking
- In need of recurrent illnesses or repeated hospitalization
- In need of constant supervision or assistance

Finances

It is important to think about finances as you plan for your loved one's long term care. It helps to build a strong foundation for caregiving. These considerations could be, assessing and monitoring your loved one's resources. It could also be about planning for future expenses. You may also need the legal appointment of someone to make decisions for your loved one. Talk to your loved early on one about who they want to give decision-making power.

It may be time to consider your strategy for your loved one's care finances if they are...

- Losing track of their finances or forgetting to pay bills
- Concerned about what will happen to their assets and property in the future
- Making irrational purchases
- Unable to navigate insurance or state benefits
- Having trouble making clear decisions



Day care works for us because Mom likes to socialize, and it gives me time to take care of myself.

Advanced care plan

As dementia progresses, people may start to lose their ability to reason and speak. Towards the end of this progression, they might also lose their abilities in moving, feeding, toileting, moving; needing 24/7 care and medical assistance. When your loved one reaches this stage, someone else will need to become your loved one's decision maker. This is a power of attorney or surrogate. It is important to do Advance Care Planning early. This should happen when your loved one is able to contribute and express wishes about what matters to them the most. It could be their spiritual beliefs, and who they trust to make decisions for them.

It may be time to consider your strategy for your loved one's advanced medical care if they are...

- Concerned about medical treatments they might receive in the future
- Interested in incorporating their spiritual or religious beliefs into their end-of-life plans
- Having more trouble making clear decisions
- Worried about hospice or palliative care

Planning for long term care

This worksheet will help you think about planning for your loved one's long term care.

Taking your **loved one's values and wishes** into account, use these pages in a way that works best for you, refer back to them from time to time, and make additions as you see fit.

Noticing changes

What changes are you noticing with your loved one in terms of their ability to live independently, manage finances, and plan for advanced medical care?

What decisions do you need to make to help you and your loved one through these changes?

Connecting to your network

Refer back to your **support network**. Who can help you manage your loved one's daily care? Revisit page 11.

There are also many **professionals** you can turn to for help and expertise. Who can you reach out to? Revisit page 13.

	_____
Neighborhood	
	_____
Faith	
	_____
Family	
	_____
Friends	

Write down contact information

	_____
Finances	
	_____
Health & Wellness	
	_____
Legal	
	_____
Household	

Write down contact information

Applying your values

What matters to your loved one in terms of their care setting?

You might consider loved one's views on in-home care versus outside home (assisted living or nursing home), amount of time you are able to spend caring for your loved one.



What matters to your loved one in terms of financial decision making?

You might consider responsibility for your loved one's finances and assets, or estate planning.



What matters to your loved one in terms of advanced medical care?

You might consider spiritual or religious views, or views on quality of life.



Maintaining relationships

As dementia advances, your loved one's ability to process information gets weaker. Their responses can become delayed. This can make participating in conversation and maintaining relationships difficult. But, finding ways to continue communicating and opportunities for social engagement is important. This will help your and your loved one's quality of life.

Some elements of maintaining relationships you may want to consider include:



Communication tactics: conflict-coping methods, managing aggression and non-verbal communication



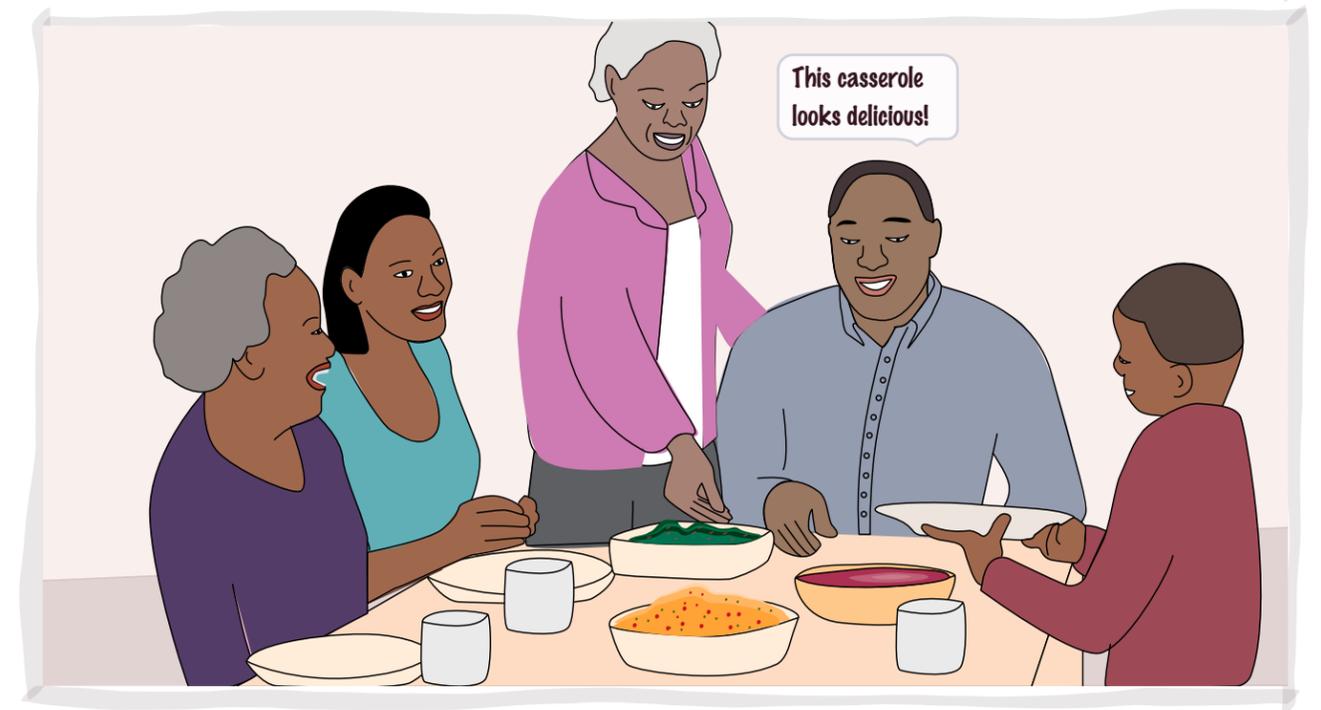
Social engagement: Combating social isolation, connecting to community, and maintaining friendships



Strengthening bonds: Sharing activities, maintaining bonds, sharing information, and building resilience



Caregiver well-being: Building a care team, making yourself a priority, combating caregiver fatigue, and seeking help





We had to find new ways to communicate once dad stopped speaking

Communication tactics

Communicating with your loved one may need more patience and understanding due to dementia symptoms. You may not be able to communicate with your loved one in the same way you used to. But, having communication strategies in place can help you maintain your bond.

It may be time to consider your strategy for communicating with your loved one if they are...

- Speaking less often or losing their train of thought frequently
- Repeating themselves over and over
- Argumentative, irritable, or aggressive
- Having trouble finding the right words or relying on gestures

Strengthening bonds

Changes in your loved one's behavior may trigger changes in your relationship over time. Some behaviors caused by dementia may cause frustration, stress, and conflict between your loved one and their care team. Learning how to respond to these behaviors may help you and your loved one maintain a strong relationship.

It may be time to consider your strategy for strengthening bonds with your loved one if they are...

- Withdrawing from relationships
- Causing you to feel frustrated or angry toward them
- No longer able to participate in activities you used to do together



Dad and I have always gone to church on Sundays, and our community here has been really supportive.

Social engagement

Dementia, as well as the stigma surrounding it, often inhibits a person's ability to socialize, resulting in a higher risk of being socially isolated and lonely. Staying engaged with your community and seeking out social support can increase the quality of life for you and your loved one.

It may be time to consider your strategy for your loved one's social engagement if they are...

- Exhibiting signs of loneliness, depression, or boredom
- Unable to spend time with friends in the way they used to
- Uninterested or less engaged in activities they used to enjoy

Caregiver well-being

Caring for a loved one with dementia is not an easy task – it takes a lot of hard work, patience, and determination. You may find yourself with so many responsibilities toward your loved one that you lose sight of your own needs. However, it is important to maintain your own physical and emotional health for yourself and those around you.

It may be time to consider your strategy for your own well-being if you...

- Haven't visited your doctor recently
- Are losing touch with friends or activities you once enjoyed
- Feel hopeless, overwhelmed, or tired all the time
- Overwhelmed by treatment options for your loved one

Maintaining relationships

This worksheet will help you think about the changes you see in your and your loved one's behavior and relationships, and build ways to manage these changes.

Taking your **loved one's values and wishes** into account, use these pages in a way that works best for you, refer back to them from time to time, and make additions as you see fit.

Noticing changes

What changes are you noticing in your loved one's behavior and social interactions?

What decisions do you need to make to help your loved one through these changes?

Connecting to your network

Refer back to your **support network**. Who can help you manage your loved one's daily care? Revisit page 11.

There are also many **professionals** you can turn to for help and expertise. Who can you reach out to? Revisit page 13.



Neighborhood



Faith



Family



Friends

Write down contact information



Finances



Health & Wellness



Legal



Household

Write down contact information

Applying your values

What matters to you and your loved one in terms of communication?

You might consider staying calm in the face of conflict, or possible strategies for non-verbal communication.



What matters to you and your loved one in terms of personal relationships?

You might consider accepting your loved one's alternate reality, or recalling memories from the past.



What matters to you and your loved one in terms of social engagement?

You might consider staying connected to communities, or finding enjoyable activities.



What matters to you and your loved one in terms of your own wellbeing as a caregiver?

You might consider hobbies and activities you enjoy, or accepting help from friends and family.



Further Resources

There are many resources available for people living with dementia and those who care for them. You can find some of them on the next page.

There may also be resources in your neighborhood or city that can help. Talk to your doctor or social worker to find out more about resources close to you.

HelpGuide

www.helpguide.org

Caregiver support resources and care strategies.

Family Caregiver Alliance

www.caregiver.org

Caregiver support resources and care strategies.

Caregiver Action Network

caregiveraction.org

Caregiver support resources and care strategies.

Alzheimer's Association

www.alz.org

The leading voluntary health organization in Alzheimer's care, support and research.

Alzheimer's Society

www.alzheimers.org.uk

Alzheimer's Foundation of America

alzfdn.org

Providing support, services and education to individuals, families and caregivers affected by Alzheimer's disease and related dementias nationwide.

Alzheimer's Navigator

www.alzheimersnavigator.org

Helping guide Caregivers to answers by creating a personalized action plan and linking you to information, support and local resources.

ALZConnected®

www.alzconnected.org

A free online community for everyone affected by Alzheimer's or another dementia.

Parent Giving

www.parentgiving.com

Source for affordable care products such as adult diapers, walkers, meal supplements, etc.

Meals on Wheels Association of America

www.mealsonwheelsamerica.org

Provides information on local meal delivery and group meal locations for seniors.

National Center for Assisted Living

www.ncal.org

Represents long-term care providers; contains information for consumers on assisted living.

Your local Little Brothers of the Elderly - Friends of the Elderly

littlebrothers.org

Volunteer-based elderly companionship.

US Department of Health and Human Services

www.hhs.gov/aging/index.html

Government resources and programs for the elderly and caregivers.

National Care Planning Council

www.longtermcarelink.net

A comprehensive source for senior care services.

National Academy of Elder Law Attorneys

www.naela.org

Source for legal services.

Medicare.gov

www.medicare.gov

The official US government site for Medicare healthcare and health insurance.

National Hospice and Palliative Care Organization

www.nhpco.org

Resources and strategies for holistic health and quality of life based care.

Worldwide Hospice Palliative Care Alliance (WHPCA)

www.thewhpca.org

International network of national and regional hospice and palliative care organizations.

Family Caregiver Alliance (FCA)

www.caregiver.org

Source for care planning, direct care skills, wellness programs, and legal/financial consultation vouchers.

Hospice Foundation of America(HFA)

hospicefoundation.org

Source of information on end of life, hospice care and grief.

National Hospice and Palliative Care Organization

www.caringinfo.org

Provides free resources to help people make decisions about end-of-life care and services before a crisis.

BenefitsCheckUp

www.benefitscheckup.org

Service of the National Council on Aging (NCOA) that helps people to understand benefits available from federal, state, and local programs.

Community Resource Finder

www.communityresourcefinder.org

Your local caregiver support group

24/7 Helpline, 1-800-272-3900

Stages of Alzheimer's and dementia

Alzheimer's/dementia is a progressive disease that eventually leads to death. Below, we outline some of the signs and symptoms you might see as the disease progresses. However, each person's journey with Alzheimer's/dementia is unique, and may not follow a "typical" timeline.

1-3 years

Mild Impairment

- Disoriented by dates
- Difficulty with names
- Mild difficulty copying figures
- Problems managing finances
- Difficulty recalling recent events
- Decreased insight
- Irritability, mood change
- Social withdrawal
- Impaired functioning at work (noticeable to coworkers)
- Difficulty with traveling to new locations
- Impaired ability to perform complex tasks

2-7 years

Moderate Impairment

- Disoriented by dates, places
- Difficulty with comprehension
- Impaired calculating skills
- Getting lost in familiar places
- Difficulty with dressing and grooming
- Not performing daily activities like cooking, shopping, or banking
- Restless, anxious, depressed
- Delusions, agitation, aggression
- Unable to bathe properly
- Unable to use the bathroom properly (e.g., forgets to flush, does not wipe properly)
- Urinary incontinence

1-3 years

Severe Impairment

- Unable to remember events in the distant past
- Verbal communication is impossible to understand
- Unable to copy or write
- No longer grooming or dressing
- Motor or verbal agitation
- Limited ability to speak (1-5 words per day)
- Loss of speech, movement, and/or consciousness
- Unable to smile
- Unable to hold up head
- Complete incontinence

The *Centering Our Values: A guide to making dementia care decisions together* project is part of a 16-week Communication Design Workshop at the Institute of Design/ Illinois Institute of Technology during the Fall 2019 semester. The project resulted in the creation of a toolkit of exercises and resources that would support the decision making process of caregivers of dementia patients, specifically pertaining to the African-American cultural context.

This work was supported in part by the University of Chicago Bucksbaum Institute for Clinical Excellence and the SHARE Network. For more information: Dr. Shellie Williams, swillia2@medicine.bsd.uchicago.edu

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