
Centering Our Values

A hands-on guide to
dementia care and decision making





Dementia is a disease which impacts not just a person, but the entire community of caregivers who know and love the person living with dementia.

Dementia affects 5.8 million Americans and occurs 2-3 times more in African American communities. African Americans living with dementia experience later diagnosis, less documentation of care wishes to guide advancing illness and more medical therapies such as hospitalizations and feeding tubes in the last month of life. Many of these variations in care continue to exist

due to limited access to dementia care resources, education and preparation.

This toolkit is intended to support African American caregivers and their loved ones with dementia knowledge, resources and support to increase dementia care choices that are guided by values.

A note about the illustrations: The examples shown in this toolkit are not recommended solutions but are representations. Each experience is unique and requires individual responses.

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What is this toolkit about?

Centering Our Values™ is a hands-on guide to help caregivers and their loved ones living with dementia make decisions that reflect their values and what is important to them. This guide includes information about dementia, care resources, as well as tools and worksheets that can help everyone reflect on what matters during this journey.

The journey of living with dementia affects everyone differently. Make this book your own!

- Take notes
- Fill out worksheets
- Make copies of the worksheets
- Share with your care team
- Skip around to the sections that support where you are

This guide is truly made to help you in whichever way works for you and your loved one.

We have put a special focus on African American caregivers for this guide (African Americans are up to 2 to 3 times more likely to have dementia) but anyone should feel welcome to use this guide.

We hope this guide will:

- Educate you on the dementia care journey
- Help you organize your thoughts, reflect, and plan
- Connect you to important resources
- Center you and your loved one's values as you make decisions together

Who is it for?

This booklet is geared for **primary caregivers** of persons living with dementia. However, we understand that some others may also be involved in making care-related choices for the person living with dementia.

This toolkit may be useful if you are:

- a primary caregiver
- a family member who is not the primary caregiver
- wanting to learn if you can be a caregiver
- a friend to a person living with dementia
- interested in learning about care for someone living with dementia

Navigating through the toolkit

SECTION 1 Being a dementia caregiver

Being a good caregiver starts with education. Learn the basics of dementia, Alzheimer's disease, and how these differ from normal aging. We'll discuss the progression of the disease as well as preparing you, the caregiver, for the journey and how to care for yourself as well.

SECTION 2 Including values in your care decisions

You'll be making decisions for the person living with dementia during their care. More compassionate, effective decisions can be made if everyone involved knows what matters to both the individual with dementia and those caregivers supporting them. This section gives you the space to express what matters so they can be useful when decision making time comes.

SECTION 3 Supporting those living through the dementia journey

Certain aspects of life change over time as one lives with dementia: managing daily care, maintaining relationships, and preparing for care as dementia progresses in the form of an Advance Care Plan. These three areas are discussed here.

SECTION 4 Providing a structure for dementia care decisions

Making decisions about dementia care are not easy. Having a structured approach in making a decision that is right for everyone involved helps. This section goes through two support tools for making decisions for dementia whether as simple as, what are the best activities to keep a loved one busy to more complex decisions of the best option for feeding a loved one who is choking with eating.

SECTION 5 Resources to help you

There are many organizations and resources available for those living with dementia. They are presented in this section in useful categories to find what you need more easily. You can also find useful worksheets here for you to make multiple copies as new decisions or changes in areas of importance come up over time.

SECTION 1

Being a dementia caregiver

Being a good caregiver starts with education. Learn the basics of Dementia, Alzheimer's disease, and how these differ from normal aging. We'll discuss the progression of the disease as well as prepare you, the caregiver, for the journey and how to care for yourself as well.

This section includes:

- Dementia Basics
- Preparing the Caregiver

Introduction to Dementia

What is Dementia?

Dementia is a general term used to describe the impaired ability to remember, think, speak or make decisions that interferes with doing everyday activities like banking, medications, shopping and eventually walking and eating.

Many causes of dementia exist and each type of dementia has subtle variation in the way it appears and progresses.

It has affected 5.8 million Americans and 30 million people world wide.

What is Alzheimer’s Disease?

- It is the most common cause of Dementia.
- 60-80% of dementia cases are Alzheimer’s Disease.
- It is caused by specific changes in the brain that damage areas of learning, memory, organization, recognition, language and information processing.
- It is a progressive type of dementia that can last for 5-13 years.

Understanding the difference between Aging and Dementia

As a caregiver, it is important to remember that dementia is a disease, not a normal part of aging. There are normal changes that happen to our brains and behavior as we get older. There are different, more severe, changes that happen to those with dementia. Here are some key differences:

| <i>Normal aging</i> | <i>Dementia</i> |
|---------------------------------------|--|
| • Forgetting the date and remembering | • Losing track of date/year |
| • Occasionally forgetting a word | • Unable to finish conversations due to forgetting words |
| • Occasionally losing items | • Regularly losing items and being unable to find |
| • Occasionally making a bad decision | • Regularly making poor decisions or judgments |
| • Hesitates more with tasks | • Can’t start tasks |

Warning Signs about Dementia

Family members are the first to notice changes. It is important to advocate for a diagnosis and a care plan when you notice any one of these signs in your loved one.



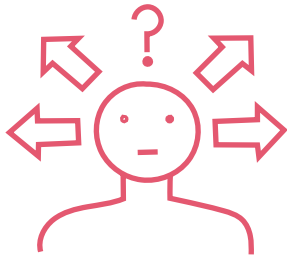
Decreasing judgment



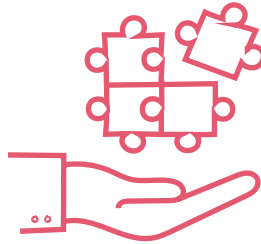
Memory loss that affects daily activity



Forgetting simple words



Loss of initiative



Trouble planning / solving problems



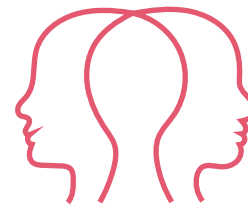
Disorientation to time and place



Difficulty performing familiar tasks



Changes in mood / behavior



Change in personality



Misplacing things

Misinformation about Dementia

False information

True facts

- | | | |
|----|---|--|
| 1 | Because someone in my family has Alzheimer's disease, I'm going to get it. | Family history of dementia carries a limited risk of developing dementia, less than 7%. |
| 2 | Dementia only affects older people. | Age is the biggest risk factor for Alzheimer's dementia. Alzheimer's is not a normal part of aging. |
| 3 | There is a cure for Alzheimer's disease or other dementia related diseases. | Currently, there is no cure for these dementia. However, there are medications that help with dementia symptoms. |
| 4 | Memory loss means Alzheimer's disease. | Many causes exist to explain memory loss. It is best to visit a doctor to find out why. |
| 5 | Aluminum causes Alzheimer's disease. | There is no conclusive evidence that aluminum causes dementia. Dementia develops from combined risk factors like age, genetics, and lifestyle. |
| 6 | Alzheimer's disease is preventable. | No single treatment can prevent Alzheimer's. However, there is evidence that healthy lifestyle choices (brain health) may reduce the risk. |
| 7 | Vitamins, supplement, and memory boosters can prevent Alzheimer's. | Studies in this area are still ongoing and findings have been mixed and inconclusive. |
| 8 | If someone is diagnosed with Alzheimer's, their life is over. | Many people still live meaningful lives. Certain measures can help maintain quality of life and decrease the progression of the disease. |
| 9 | People who have Alzheimer's become violent and aggressive. | Everyone responds differently to memory loss, which can often be frustrating and scary. This can be prevented by creating a dementia-friendly environment. |
| 10 | People with Alzheimer's can't understand what is going on around them. | Though people living with dementia may have communication issues and trouble understanding things, the degree to which they have difficulty varies. They should be treated with dignity and respect. |

Why get a diagnosis early?

Dementia can be hard to recognize early on, even for doctors. Thankfully, there are a series of tests that doctors can do to diagnose the disease in its early stages.

Early diagnosis is also important for planning the future and expressing one's wishes. It can also provide these benefits:

- Allow the person living with dementia to participate in future care choices
- Resources, supports, and medication can be used to increase safety and stability
- Optimize brain health to improve quality of life

Getting a diagnosis includes:

- Medical history
- Physical
- Blood test
- Medications
- Examples of signs
- Memory test
- Brain scan
- Genetic tests

What to bring to the initial diagnosis appointment

- A list of examples of concerns with memory and thinking, including comments from all caregiver/family members.
- Think how long the changes have existed and how they have affected daily life of the person with the changes.
- List any safety concerns.
- List any family history of memory problems and age it occurred.
- List of all active medications.

Things to prepare after the diagnosis

- **Establish the Diagnosis:** Diagnosis provides clarity. It can answer questions like: Why are these changes happening? What is normal at each stage? What therapy can support the person living with dementia?
- **Establish the Stage of the illness:** What stage of dementia is my loved one?
- **Establish plan for Medical therapy:** Creating a plan should always involve discussion with the doctor and other medical team members such as a social worker, a neuropsychologist in addition to the doctor. Ask them the above questions, the role of medications for memory, a plan for socialization, safety and support at home and in the community.
- **Start discussion of Advance care planning for future declines in health:** Start the advance care planning discussion early in the process so that your loved one with dementia can be fully involved in the process as possible (see pages 61, 66 for more on creating an Advanced Care Plan.)
- **Establish a plan for Socialization:** What activities and exercises are available to keep our loved one engaged?
- **Establish a plan for Safety:** Discuss with the medical team what support is needed for activity like taking medicine, managing finances, living alone to keep a loved one with dementia safe and happy.



We need to create an advance care plan early on, along with Dad

Stages of Alzheimer's dementia

Alzheimer's dementia is a progressive disease that eventually leads to death. In this table, 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.

The stages of dementia tend to overlap.

- Each stage represents a new levels of memory, behavior, language and decision making ability of the person living with dementia.
- A person living with dementia may show signs of two stages during one period of time; however, it may more strongly represent symptoms of one stage.
- Each stage represents new levels of symptoms which may require different levels of support, safety and resources.
- It is important to make a plan that expresses values and wishes early in the course of dementia to allow your loved ones to express their wishes while capable. Keep reading to learn how.

EARLY stage

Mild

memory

- Difficulty learning new info (taxes, new appliance)
- Short Term Memory
- Repeating information

behaviors

- Poor motivation
- Frustration with memory
- Irritable

judgement

- Limited recognition of memory decline
- Still able to state wishes

daily function

- Difficulty paying bills and keeping track of taking medicines

language

- Difficulty finding the right word or name

care needs

- Minimal assistance in managing activity like keeping track of medications, traveling to appointments, balancing checking accounts or paying bills

orientation

- Disorientation with respect to time and places

MIDDLE stage

Moderate

- Difficulty recalling recent conversations, personal events (addresses, phone numbers)
- Decreasing Short Term / Long Term Memory
- Repeating information

- Delusions (family stealing)
- Hallucinations (kids under bed)
- Agitation
- Wander from home

- Difficulty understanding positives and negatives of choices and their impact.
- Blaming others, not recognizing they forgot
- Decline in ability to state wishes

- Decline in ability to dress or bath themselves

- Unable to recall familiar items or words

- Support needed a few hours daily to 24 hours with higher level daily activity like managing daily care (e.g. medication use, financial concerns to basic daily activity like dressing, bathing, toileting)

- Increased disorientation with respect to time and places
- Forgetting or confusing names

LATE stage

Severe

- Difficulty recalling or comprehending most information, unable to recall and express needs
- Deteriorating Short Term Memory and Long Term Memory

- Agitation, grunting

- Severe verbal or memory decline, unable to express thoughts
- Unable to recall options or state decision
- Unable to state basic needs

- Unable to eat, walk, bath without assistance

- Limited ability to communicate; less than 5 words used per day

- 24-hour supervision required

- No orientation with respect to time, place and people
- Limited to no orientation with respect to time, place, people

Who is a Caregiver?

A caregiver can be a volunteer family member, friend or an individual hired from a caregiver agency to provide support to a person living with dementia.

Paid or unpaid, caregivers provide support to persons living with dementia in areas of need for safety, daily care and socialization.

Caregivers provide many different roles for the person living with dementia and others in their lives which leaves limited time for the caregiver.

Various roles of a caregivers include, but not limited to:

- Direct physical care
- Care management
- Financial resource
- Medical resource
- Social support/Advocate (reassure, encourage activity, recognize and support needs being met, communicate their needs to others when they can't)



Caregivers are at risk for stress, depression, poorer health due to the increase in time they spend directed toward others and not focusing on themselves.

Recognizing your risk for caregivers' stress is important:

Signs of caregiver stress:

- Feeling overwhelmed
- Feeling tired often
- Changes in sleep, diet
- Becoming easily irritated
- Losing interest in activities
- Feeling sad
- Having frequent physical problems
- Abusing alcohol or drugs



Increased risk for caregiver stress

- Living with the person you are caring for
- Social isolation
- Having depression
- Financial difficulties
- Higher number of hours spent caregiving
- Lack of coping skills and difficulty solving problems
- Lack of choice in being a caregiver

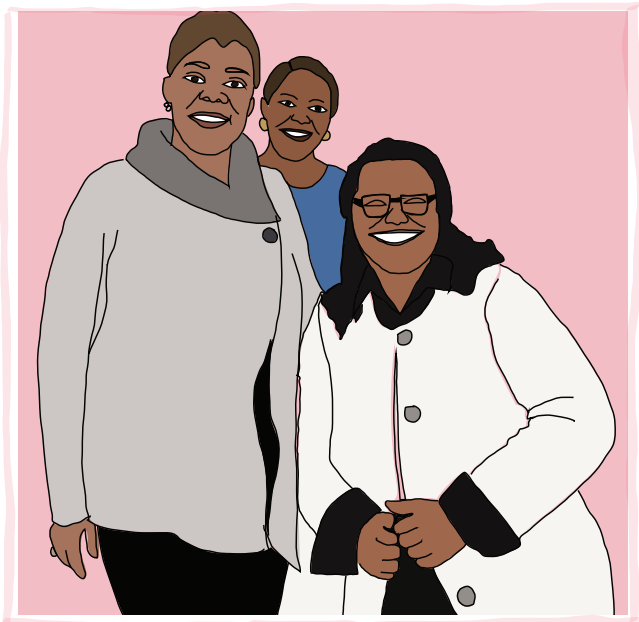
What to do if you are experiencing caregiver Stress?

- Check in with your primary care physician
- Increase support and resources for your loved one with dementia
- Discuss arranging respite for your loved one in the form of a few hours to few days of care for them. This allows you time to care for yourself.
- Contact the Alzheimer's Association helpline:

24/7 Helpline 800.272.3900

Supporting the Caregiver

As the saying goes, you need to care for the caregiver. There are activities and resources to support the caregiver. It is natural to experience stress, but knowing when to reach out is important.



Having a social network for yourself is one way to prevent caregiver stress.

Preventing Caregiver stress is important

- Save time for yourself and things that make you happy everyday
- Have you asked for help or said yes when others offer help?
- Have you optimized use of resources for your loved one outside of yourself?
- Develop a team of resources (social, professional, spiritual, emotional)
- Are you sleeping enough to feel energy to do normal tasks the next day?
- Are you maintaining a heart healthy diet?
- Is exercise that you enjoy a regular part of your life?
- When was the last time you had a check up with your doctor?

How to support brain health in the caregiver and persons living with dementia



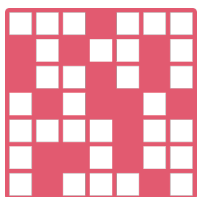
Regular exercise



Heart healthy diet



Address mental health



Stimulation of the brain (puzzles, reading, coloring)



Regular social interaction



Regular sleep to allow for rest and energy saving

Visit the resource pages (pg. 80-83) for more information

Behavior changes across the three stages of dementia

Behavioral changes in a person living with dementia can disrupt the relationship with caregivers and make the role of caregiver very challenging.

It is important to accept these changes are related to dementia and do not change the love and respect you share with one another.

This section is intended to introduce many of the behavioral changes that occur as dementia progresses and how caregivers can approach these behaviors in a healthy and loving manner.

Tips on managing behaviors

In general, there are some tips to help you manage behavior changes, regardless of what stage the person living with dementia may be in.

Ways to prevent negative behaviors

Routine: Having some regular activity in the world of dementia may feel less chaotic.

Respect: That this is an adult with opinions. Engage and involve them.

Relationship: Know that things may change as a parent becomes reliant on an adult child. Try to allow independence.

Ways to respond to unfavorable behaviors

Repeat: Try to offer again

Reassess: 'What do you need?' 'How can I support you?'

Reassure: 'I love you.' 'You are ok.'

Redirect: 'Let's do this...' 'Let's change the topic.'

Managing unsafe behaviors

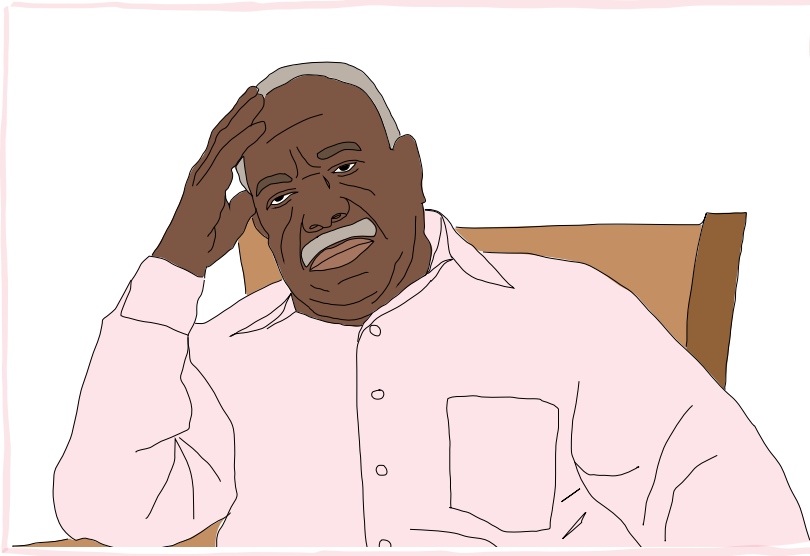
In some cases, the behaviors may be unsafe to you or to the individual. In such cases, consider these:

- Contacting a medical provider (Primary physician, Geriatric or Psychiatry) may be needed for medication support.
- Considering a care consultation with Department of Aging or Alzheimer's Association.
- Calling 911, if behavior is an immediate threat to self or others.

EARLY stage

Mild

1 - 3 years



Common EARLY-stage behaviors

- Depression
- Complaints about memory
- Lack of motivation
- Frustration due to changes

Managing EARLY-stage behaviors

Prevent by...

- Providing a routine schedule
- Knowing behavior triggers
- Providing written reminders
- Giving regular positive reinforcement

Respond by...

- Providing reassurance
- Involving them in decisions
- Treating depression, if present
- Avoiding challenging them

MIDDLE stage

Moderate

2 - 9 years



Common MODERATE-stage behaviors

- Hallucinations
- Wandering
- Delusions (false beliefs)
- Sleep disturbances
- Agitation, hitting, biting
- Forgetting where they are
- Frustration with words

Managing MODERATE-stage behaviors

Prevent by...

- Breaking tasks into small steps
- Providing verbal reminders
- Joining them where they are in timeframe or location

Respond by...

- Providing reassurance
- Providing easy answers
- Letting go of little things
- Using community-based services
- Avoiding corrections

LATE stage

Severe

10 - 13 years



Common LATE-stage behaviors

- Biting, spitting
- Repeating the same few words
- Becoming agitated
- Sleeping majority of the day

Managing LATE-stage behaviors

Prevent by...

- Paying attention to non-verbal signs (grunting, yelling, hitting).
- Anticipating needs (Are they hungry, wet, in pain?)

Respond by...

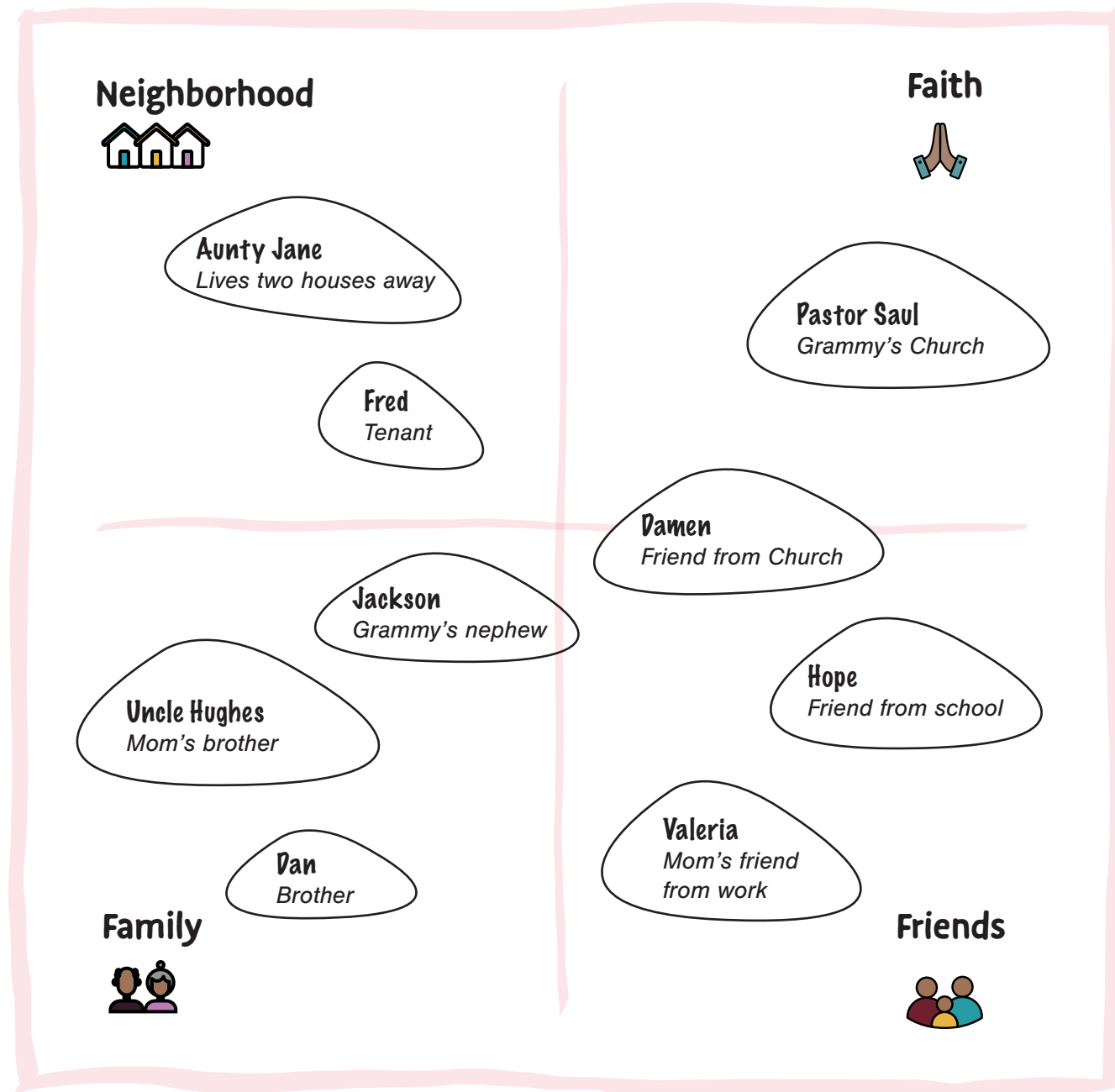
- Learning what the emotion is (associate behavior with need)
- Refocusing and making connections
- Speaking calmly
- Touching gently

It's important to engage a network of support to care for people living with dementia. The next pages are worksheets to help you gather that information.

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**.

Example



Now you try.

Neighborhood



Faith



Family



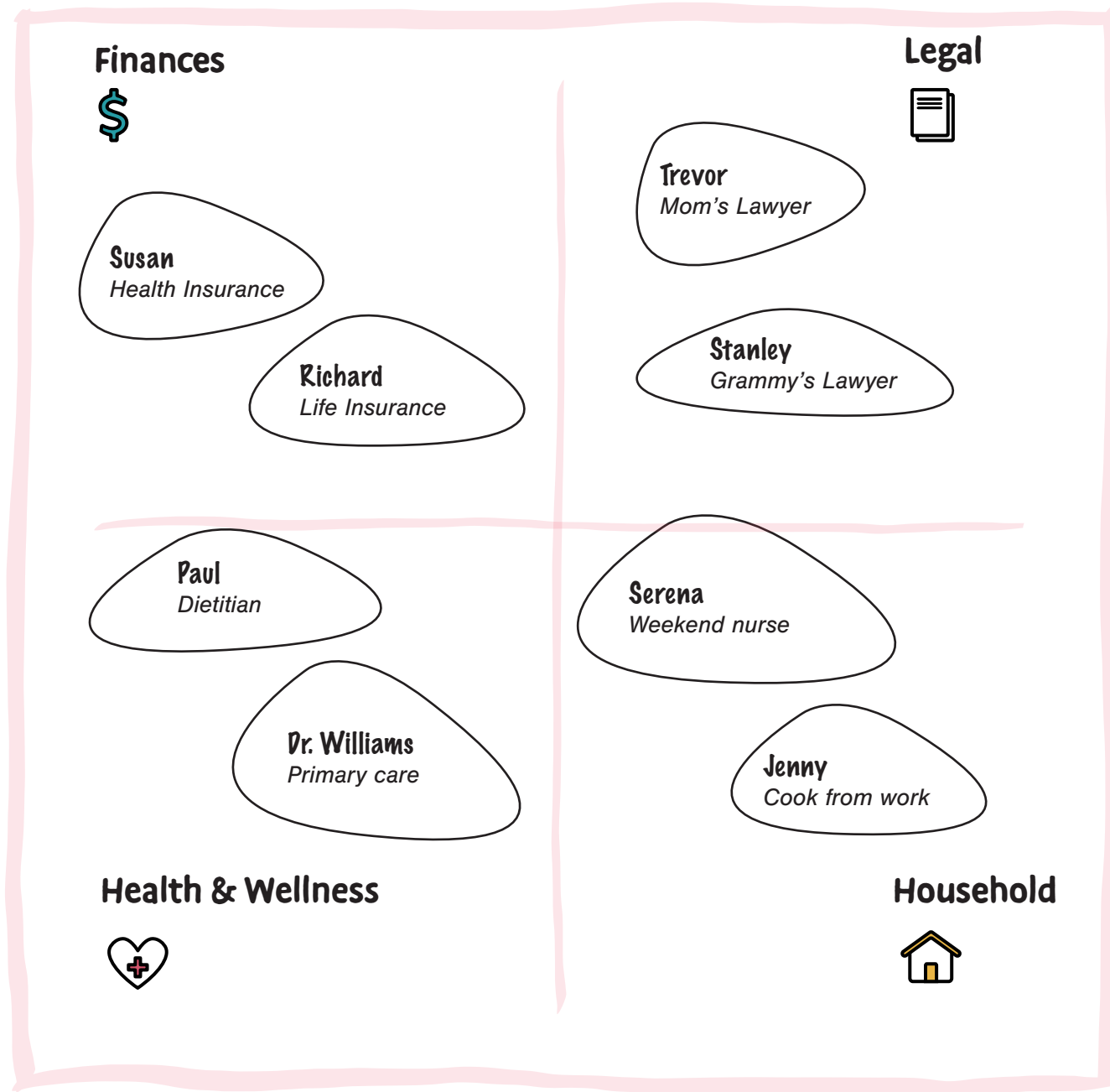
Friends



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**.

Example



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

Finances



Legal



Health & Wellness



Household

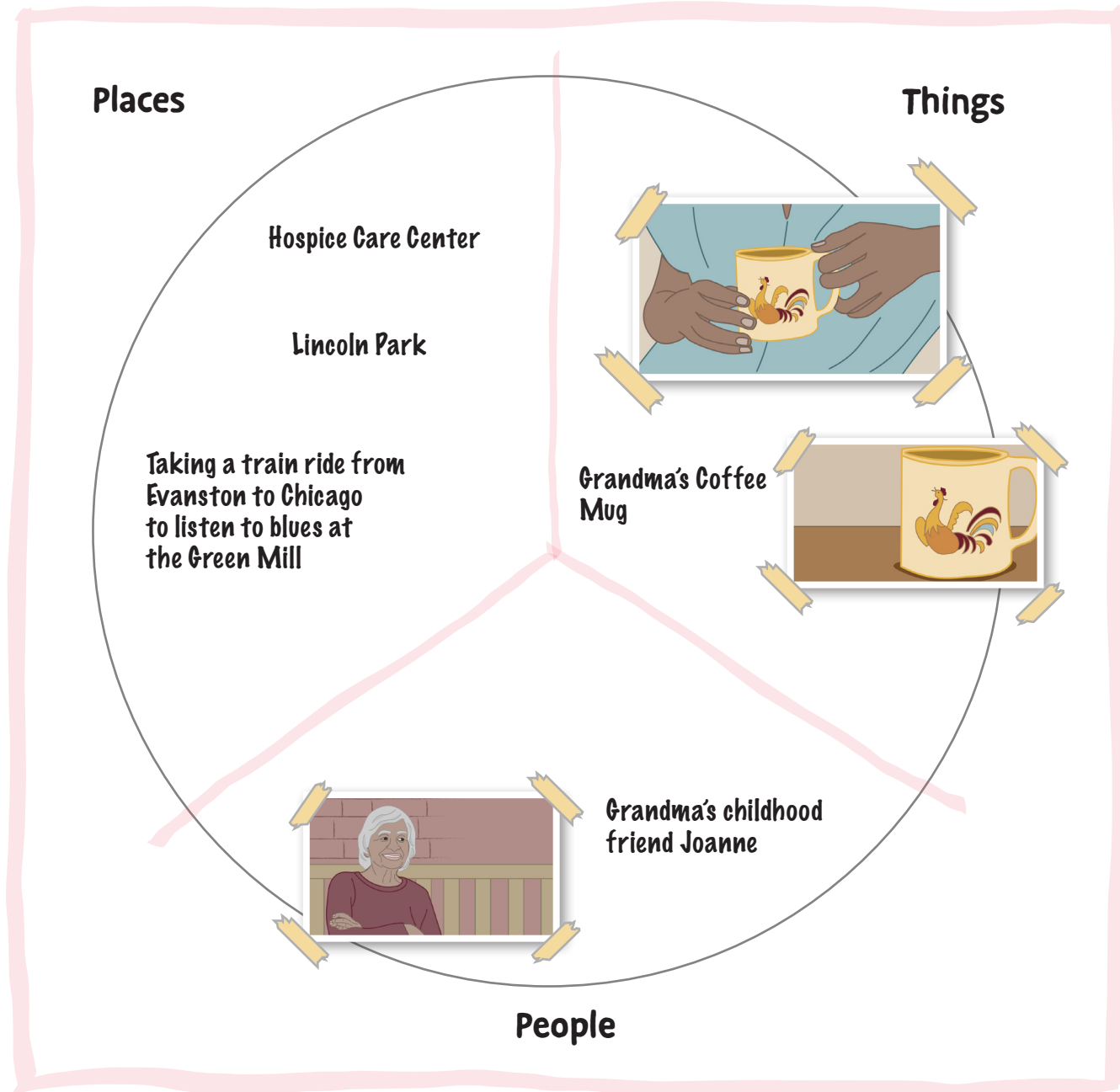


Visit the resource pages (pg. 80-83) for more information

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.

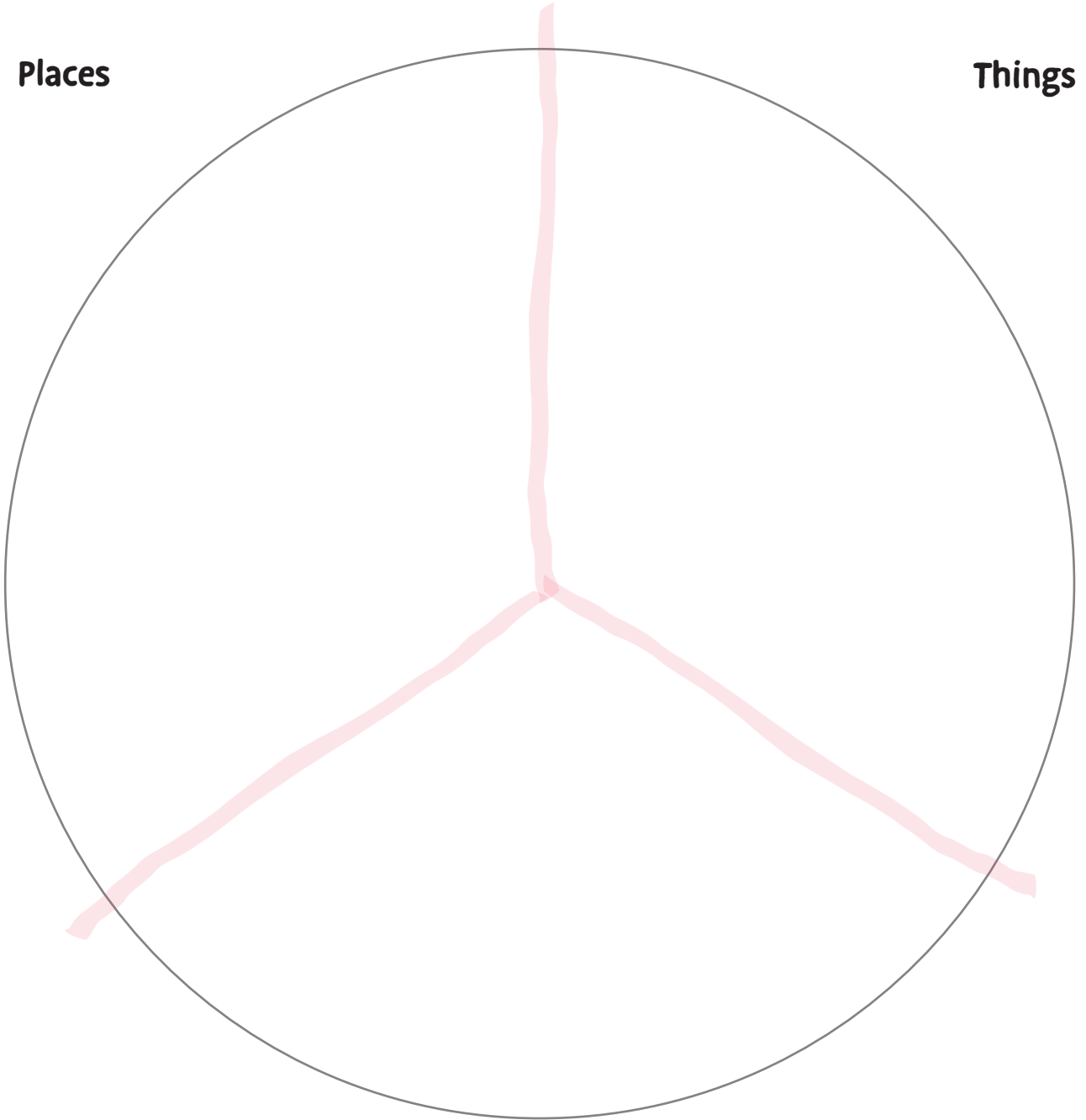
Example



It's your turn.

Places

Things



People

Visit the resource pages (pg. 80-83) for more information

SECTION 2

Including values in your care

You'll be making decisions for the Person Living with Dementia during their care. More compassionate, effective decisions can be made if everyone involved knows what matters to both the individual with dementia and these caregivers supporting them. This section gives you the space to express what matters so they can be useful when decision making time comes.

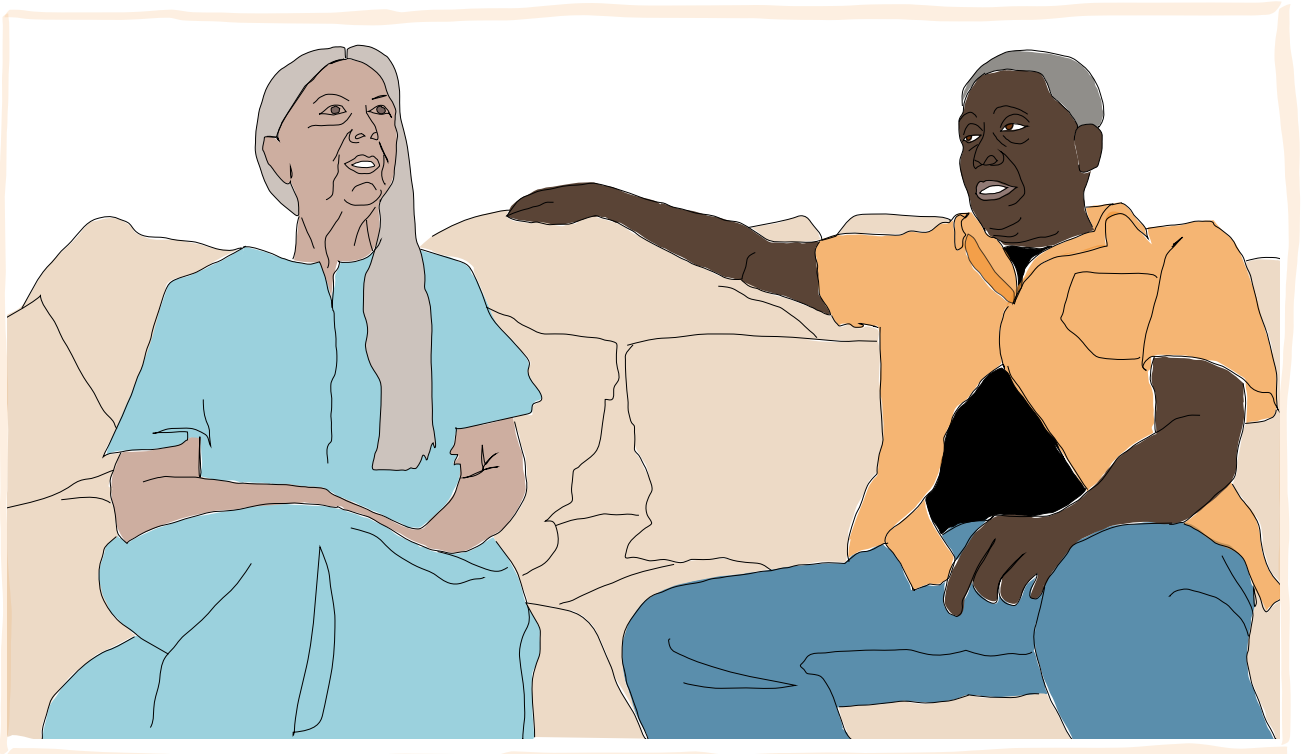
This section includes:

- What matters to you?
- What matters to your loved one?
- What you and your loved one share

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.



Knowing what's important to your loved one in everyday life can be valuable when decisions need to be made about his/her care.

Imagine for yourself...

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**.

This exercise may be sensitive and emotional.

Example



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!



Reflect on what's important to you

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

What makes your loved one **happy and whole**?

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

mm / *dd* / *yyyy*

mm / *dd* / *yyyy*

What does your loved one need to feel **safe and supported**?

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

mm / *dd* / *yyyy*

mm / *dd* / *yyyy*

What are your loved one's **hopes and fears**?

Hopes

These might be a short-term or long-term goals that you are aiming for.

Fears

These might be something you always try to avoid.

What **can't change** in your life?

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

____ / ____ / ____
mm dd yyyy

____ / ____ / ____
mm dd yyyy

Imagine with your loved one...

Now let's do the same thing for your loved one! Tell him/her to close their eyes and imagine himself/herself on a relaxing day, what would it look like?

Help your loved one to write or draw something that **reminds him/her of being relaxed.**

This exercise may be sensitive and emotional.

Example



Mom likes to go to the beach to enjoy sunset...

Help your loved one to imagine **him/her doing something with you.**

What are the activities that you both enjoyed? Go write about it or draw it!

A large, empty rectangular box with a light orange border, intended for writing or drawing. The box is centered on the page and occupies most of the lower half of the page.

Reflect on what's important to your loved one

Now let's consider your loved one. There are two ways to use these pages.

- Sit with your loved one and have a conversation.
- You may be at a point in time where your loved one can't express his or her feelings. Think back to 5 years or 10 years ago, what would they say or think?

What makes your loved one **happy and whole**?

This might be an activity, a place, a role you play, or a relationship he/she cherishes.

____ / ____ / ____
mm dd yyyy

____ / ____ / ____
mm dd yyyy

What does your loved one need to feel **safe and supported**?

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

____ / ____ / ____
mm dd yyyy

____ / ____ / ____
mm dd yyyy

What are your loved one's **hopes and fears**?

| Hopes | Fears |
|---|---|
| These might be a short-term or long-term goals that you are aiming for. | These might be something you always try to avoid. |

What **can't change** in your loved one's life?

This might include where he/she lives or works, or how he/she spends certain hours in a day.

| |
|--|
| <u> </u> / <u> </u> / <u> </u> <i>mm</i> <i>dd</i> <i>yyyy</i> |
| <u> </u> / <u> </u> / <u> </u> <i>mm</i> <i>dd</i> <i>yyyy</i> |

Reflect on what you and your loved one share

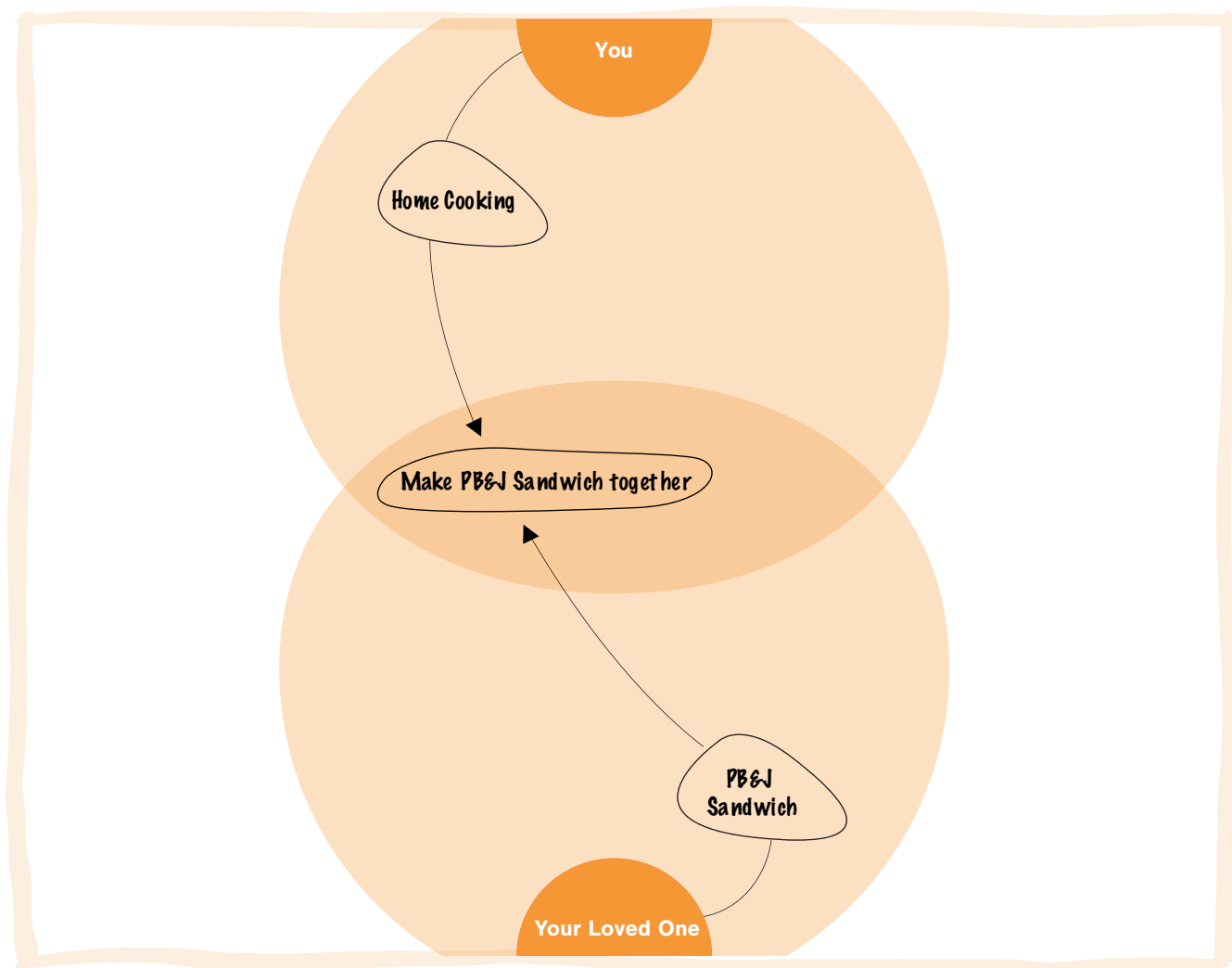
Complete this activity alongside your loved one. You may want to repeat this with others who are involved in the care.

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 love one share?
- Connect the ideas you share.
- Continue to think of other things you and your loved one shares.

Example



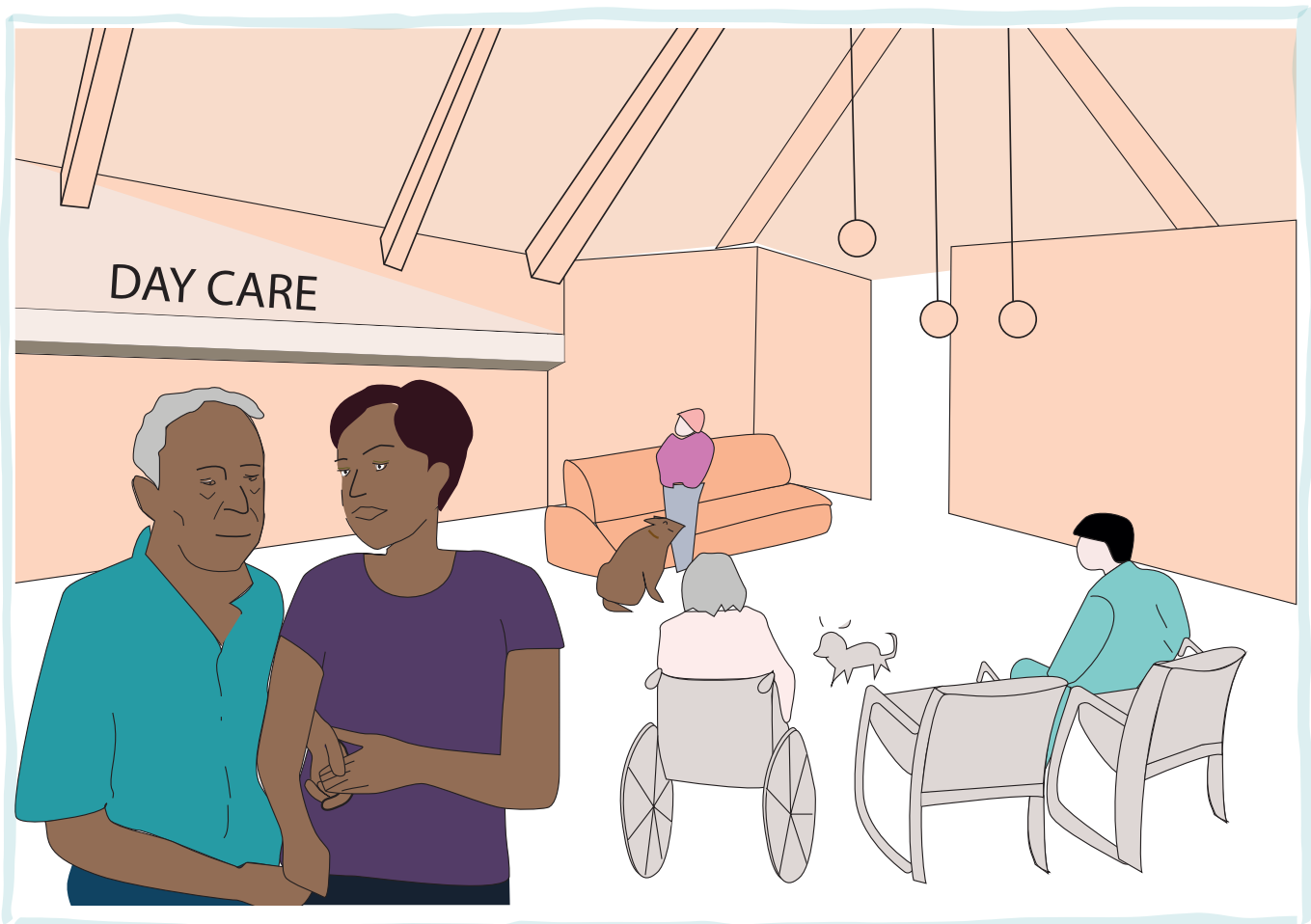
You

What you love to do...

What you both love to share...

What your loved one loves to do...

Your Loved One



We need to plan for Dad's long term care that looks after his daily needs as well as his love for being around people.

SECTION 3

Supporting someone who lives with dementia

Many aspects of everyday life change over time as one lives with dementia: from simple things like preparing food and eating, getting dressed, socializing with people, to more involved tasks like planning for care as dementia progresses in the form of an Advance Care plan.

This section helps you make a plan that works for everyone through each step of the journey by focusing on:

- Managing the changes in daily care needs
- Maintaining relationships over time
- Planning for long term

Changes in daily care needs

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

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.



Healthy eating

Cooking, eating, managing groceries, and considering food preferences

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.



We need to ensure Mom eats healthy meals regularly that can include foods she likes.



Hygiene

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

People with dementia may have difficulties with some personal hygiene 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.

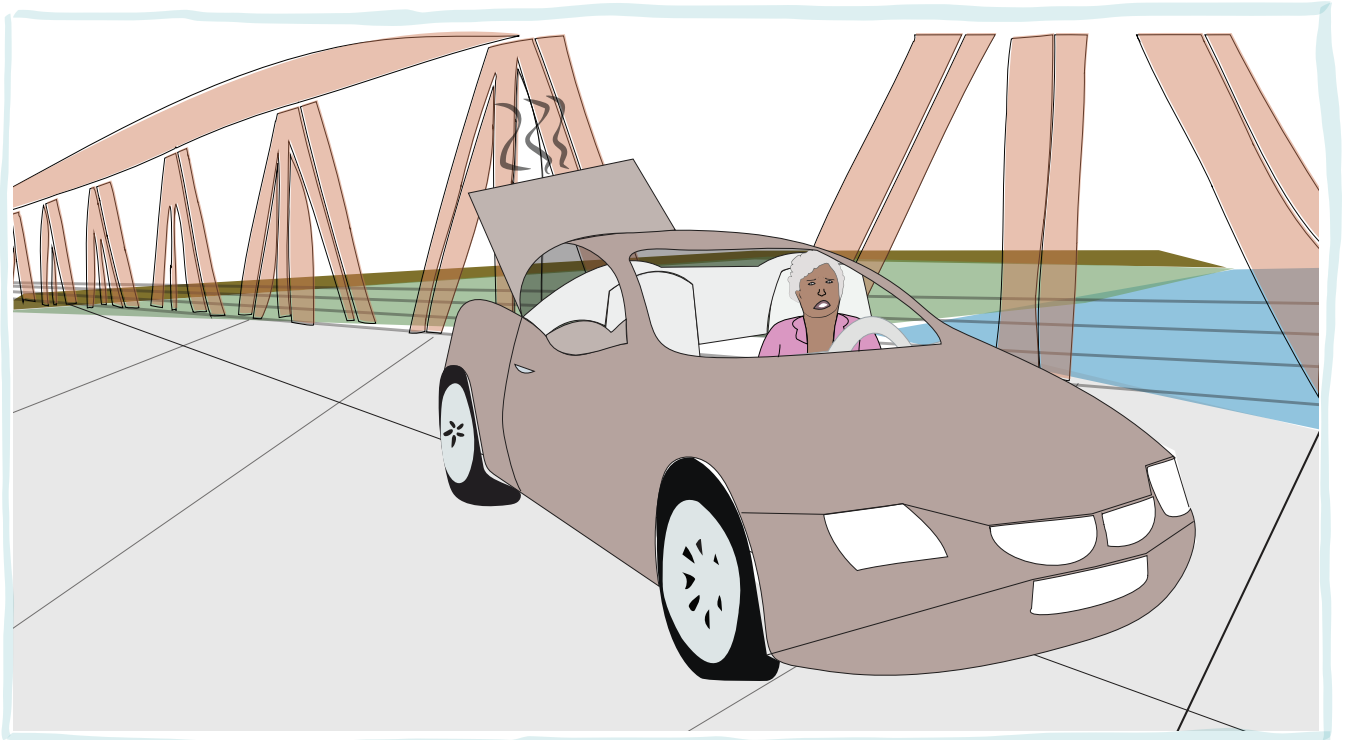


Mobility

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

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.



Discuss driving and alternative transportation options with family.

Changes in daily care behavior for loved ones with dementia

| | EARLY stage |
|---------------------------|---|
| | <i>Mild</i> |
| Medical Management | <ul style="list-style-type: none">• Forgetting to take medications or taking the wrong dosage• Forgetting doctor appointments |
| Hygiene | <ul style="list-style-type: none">• Wearing soiled or unkept clothing |
| Healthy Eating | <ul style="list-style-type: none">• Leaving food out and letting it spoil• Spoiled food in refrigerator |
| Mobility | <ul style="list-style-type: none">• Getting in minor or major car accidents (safety risk)• Getting lost in unfamiliar environments |
| Behaviors | <ul style="list-style-type: none">• Apathy, depression |

MIDDLE stage

Moderate

- Resistant to physical activity, especially physical therapy exercises
- Resistant to following their doctors' directions
- Resistant to getting dressed in the morning
- Not able to make it to the bathroom in time
- Forgetting to eat meals, or forgetting when they last ate
- Leaving the stove on (safety risk)
- Getting lost in familiar environments
- Getting lost or wandering (safety risk)
- Unable to get around using public transit
- Slower or unsteady walking
- Hallucination / delusions

LATE stage

Severe

- Relies on others for medication and appointments
- Not able to trim their own fingernails and toenails
- Bedbound
- Having difficulty swallowing or are losing weight
- Unable to walk without help or falling (safety risk)
- Screaming out

Changes in daily care behavior for loved ones with dementia

Use this to jot down the behavior changes you notice. You can discuss these on your next doctor's visit.

| | DATE / / | DATE / / |
|---------------------------|-------------|-------------|
| Medical Management | | |
| Hygiene | | |
| Healthy Eating | | |
| Mobility | | |
| Behaviors | | |

DATE

/ /

DATE

/ /

DATE

/ /

Changes in daily care needs

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** have you noticed in your loved one related to daily care?

____ / ____ / ____
mm dd yyyy

____ / ____ / ____
mm dd yyyy

What **options** have you considered to support daily care challenges?

____ / ____ / ____
mm dd yyyy

____ / ____ / ____
mm dd yyyy

Connecting to your network

____/____/____
mm dd yyyy

Refer back to your **support network**.

Who can help you manage both yours and your loved one's daily care? Revisit page 25.

Write down contact information



Neighborhood



Family



Faith



Friends

There are also many **professionals** you can turn to for help and expertise.

Who can you reach out to? Revisit page 27.

Write down contact information



Finances



Legal



Health & Wellness



Household

Applying your values to the decision

How can you manage your loved one's daily care? Revisit page 36 to 39.

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

You might consider medical dietary restrictions, or exercise.

____ / ____ / ____
mm dd yyyy

____ / ____ / ____
mm dd yyyy



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.

____ / ____ / ____
mm dd yyyy

____ / ____ / ____
mm dd yyyy



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

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

 / /
mm *dd* *yyyy*

 / /
mm *dd* *yyyy*



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).

 / /
mm *dd* *yyyy*

 / /
mm *dd* *yyyy*



Maintaining relationships over time

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

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

See pages 20-23 for techniques to support communication behaviors.



Social engagement

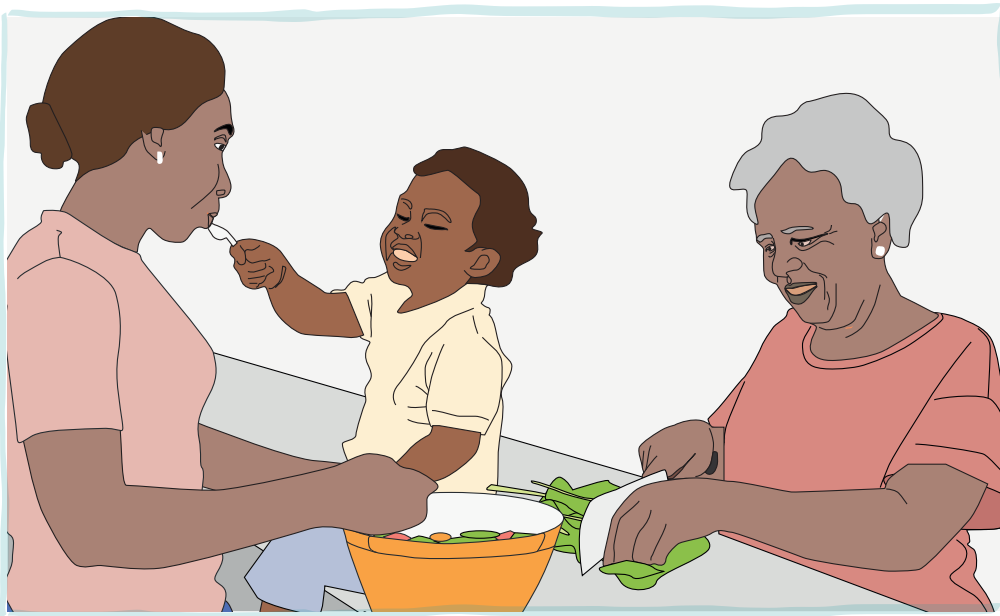
Combating social isolation, connecting to community, and maintaining friendships

Dementia, as well as the stigma surrounding it, often makes it hard for a person to socialize, leading to 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

Refer to local/national resources for socialization on pages 80-83.



Cooking together encourages bonding and can trigger happy memories.



Strengthening bonds

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

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



Caregiver well-being

Building a care team, making yourself a priority, combating caregiver fatigue, and seeking help

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

See pages 16-19 for ways to support the caregiver.

WORKSHEET

Maintaining relationships over time

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 have you noticed in your loved one's **behavior and social interactions**?

| | | | | |
|--------------------|---|--------------------|---|----------------------|
| _____ <i>mm</i> | / | _____ <i>dd</i> | / | _____ <i>yyyy</i> |
| _____ <i>mm</i> | / | _____ <i>dd</i> | / | _____ <i>yyyy</i> |

What **options** have you considered to support your loved one through these changes?

| | | | | |
|--------------------|---|--------------------|---|----------------------|
| _____ <i>mm</i> | / | _____ <i>dd</i> | / | _____ <i>yyyy</i> |
| _____ <i>mm</i> | / | _____ <i>dd</i> | / | _____ <i>yyyy</i> |

Connecting to your network

____/____/____
mm dd yyyy

Refer back to your **support network**.

Who can help you maintain relationships with your loved one? Revisit page 25.

Write down contact information



Neighborhood



Family



Faith



Friends

There are also many **professionals** you can turn to for help and expertise.

Who can you reach out to? Revisit page 27.

Write down contact information



Finances



Legal



Health & Wellness



Household

Applying your values to the decision

Refer back to **What matters to you.**

How can you help your loved one maintain social relationships?
Revisit pages 36-39 or see resources section on pages 80-83.

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.

____ / ____ / ____
mm dd yyyy

____ / ____ / ____
mm dd yyyy



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.

____ / ____ / ____
mm dd yyyy

____ / ____ / ____
mm dd yyyy



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

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

____ / ____ / ____
mm *dd* *yyyy*

____ / ____ / ____
mm *dd* *yyyy*



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.

____ / ____ / ____
mm *dd* *yyyy*

____ / ____ / ____
mm *dd* *yyyy*



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

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
- Unsafe (wandering, leaving stove on, opening door for strangers)
- Recurring illness
- Requiring increased supervision



Finances

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

It is important to think about finances as you plan for your loved one's long term care. These could be a range of involvement based on your need. It could mean managing the cost of care. It could mean talking about or monitoring your loved one's finances. 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 one early on 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...

- Forgetting to pay bills
- Concerned about what will happen to their assets and property in the future
- Making irregular purchases
- Unable to navigate insurance or state benefits

It's also important to separate who will assist with **financial** power of attorney, in addition to **healthcare** power of attorney.



We need to sit together as a family to plan for Mom's long term care to ensure her wishes are fulfilled and values are taken into consideration while making decisions.



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)

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, 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

See pages 66-71 for more detailed information on Advanced Care Planning.

WORKSHEET

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 have you noticed with your loved one in terms of **their ability to live independently, manage finances, and plan for advanced medical care?**

____ / ____ / ____
mm dd yyyy

____ / ____ / ____
mm dd yyyy

What **options** have you considered to help you and your loved one through these changes?

____ / ____ / ____
mm dd yyyy

____ / ____ / ____
mm dd yyyy

Connecting to your network

____ / ____ / ____
mm dd yyyy

Refer back to your **support network**.

Who can help you plan for your loved one's long term care? Revisit page 25.

Write down contact information



Neighborhood



Family



Faith



Friends

There are also many **professionals** you can turn to for help and expertise.

Who can you reach out to? Revisit page 27.

Write down contact information



Finances



Legal



Health & Wellness



Household

Applying your values to the decision

Refer back to **What matters to you**.

How can you manage your loved one's daily care? Revisit pages 36-39.

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.

____ / ____ / ____
mm dd yyyy

____ / ____ / ____
mm dd yyyy



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.

____ / ____ / ____
mm dd yyyy

____ / ____ / ____
mm dd yyyy



What matters to your loved one in terms of care as **their illness progresses or if death is near**?

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

____ / ____ / ____
mm dd yyyy

____ / ____ / ____
mm dd yyyy



What is Advance Care Planning (ACP)?

Advanced Care Planning (ACP) involves planning for future care and choices when health changes occur (severe illness, terminal stages) or functional changes (walking, eating, decision making).

Why is Advance Care Planning important?

Early discussion of ACP in dementia is important to empower the person living with dementia to express their preferences and values **in their own voice** while they can.

ACP can be used as a **road map for care** during early/middle/late stages of dementia. However, having the person with dementia to express their preferences for care, acceptable levels of changes and care providers/locations is important while they are best able to participate fully in the discussion.

An early discussion between the person living with dementia and the caregiver gives the caregiver the opportunity to become an **advocate** for the person living with dementia. Caregivers can also limit guilt, confusion, or loneliness of making decisions for another by knowing their loved one's wishes early.

It is important to review the documented discussions in the future to provide better clarity as new changes develop.

What types of choices are in an Advance Care Plan?

- *Living Will*: Preferences for end-of-life care: breathing/heart resuscitation, feeding tubes

- *Concerns and hopes for the future-setting of care*: level of function acceptable or not, thoughts regarding medical therapies
- *Financial Power of Attorney*: Establishing who should manage finances
- *Healthcare Power of Attorney*: Appointing a substitute decision maker for health

Establishing an Advance Care Plan

What you need: A copy of your state's **advance directive for health** document. Clarify with the medical team if your loved one is able to clearly state who they trust as a decision maker and what their choice is for care if their condition is considered "terminal" (life expectancy of months-days.)

Who you need: Your loved one, a witness, the person trusted as decision maker; make sure the decision maker understand the wishes.

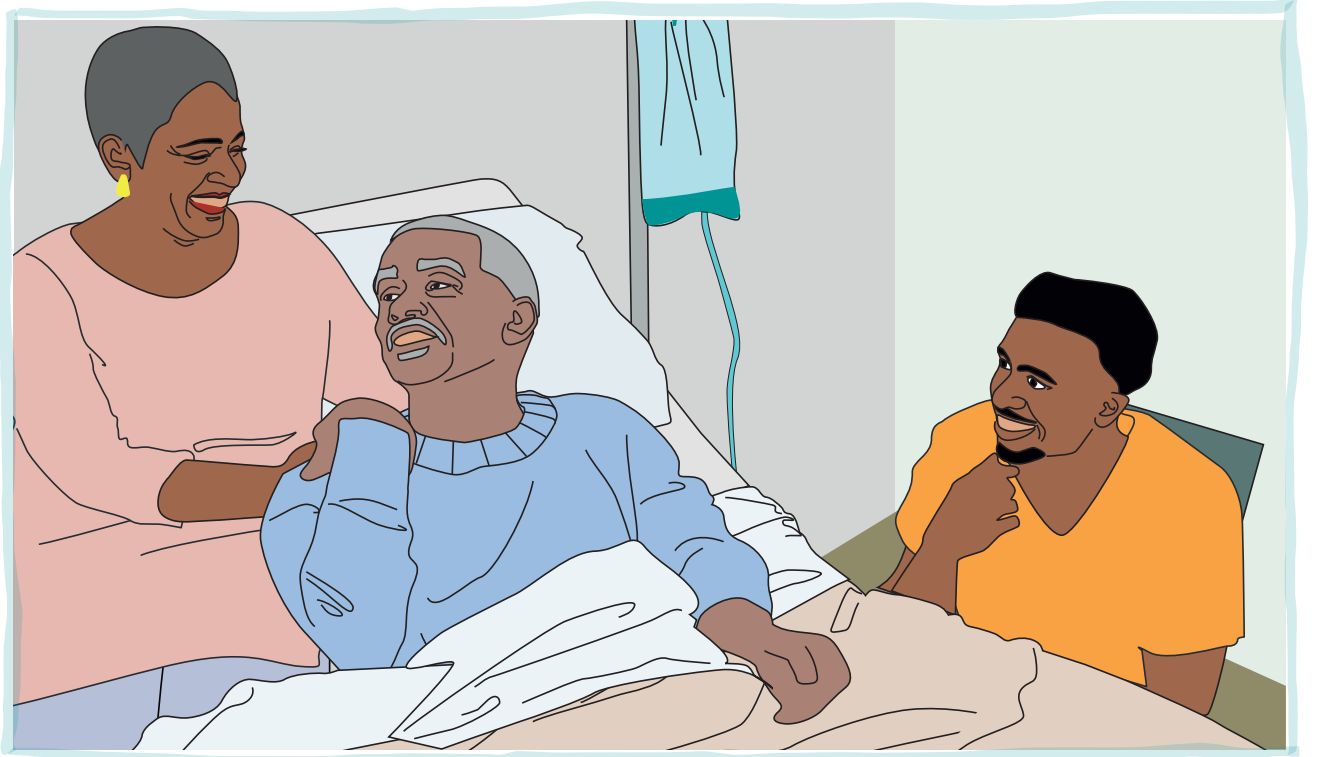
You do not need an attorney to establish the healthcare power of attorney portion. You do need one to create the financial power of attorney or a property will.

When: Do this early while your loved one can still state their choices. If your loved one cannot, an appointed decision maker will create the plan. This person is often decided by closeness in family relation or court appointment.

Where: You can establish in your doctor's office, hospital, notary, bank.

How: Keep a copy for the healthcare power of attorney (trusted decision maker), give a copy to the doctor, store the original in a safe place.

See page 81 for Advanced Care Planning resources.



Having an Advance Care Plan will help plan for Dad's future care and better prepare for unexpected circumstances

Advanced Care Planning topics

Living situation

- Whether to remain in home versus relocate to a nursing facility as 24-hour care becomes necessary with dementia progression.
- Enlisting hired caregivers, called homemakers or home aides to provide personal care to increase safety and support for persons living with dementia to keep them safe and engaged in their homes.

Feeding Tubes (FT) vs. Slow Hand Feeding

- Feeding tube is provided when a person is not swallowing/eating. However, use of feeding tubes does not correct swallowing problems, increases risk of infection,

increases fluid congestion, does not extend life and limits physical interaction of the person living with dementia.

- Slow hand feeding allows the person to take small volumes of fluids and solids for pleasure, with a caregiver feeding them increasing human interaction.

Respirator / Ventilator

- If a person can no longer breathe on their own, ventilators can breathe for them. However, it may cause greater discomfort and stress.
- When the burdens of this device is too much and not consistent with values, an order for DNI (do not intubate with breathing tube) care is appropriate.

Advanced Care Planning: Early discussion worksheet *with your loved one*

Discuss with your loved ones the following questions and bring responses to discuss in the next doctor visit.

What does your loved one **value now**? What would they **value if things changed**?

____ / ____ / ____
mm dd yyyy

____ / ____ / ____
mm dd yyyy

What is your loved ones' **biggest fear or hope** as dementia progresses?

____ / ____ / ____
mm dd yyyy

____ / ____ / ____
mm dd yyyy

How have changes brought about by dementia **changed the day-to-day life** of your loved one?

| |
|--|
| <p><u> </u> / <u> </u> / <u> </u> <i>mm</i> / <i>dd</i> / <i>yyyy</i></p> |
| <p><u> </u> / <u> </u> / <u> </u> <i>mm</i> / <i>dd</i> / <i>yyyy</i></p> |

Who will your loved one **trust to support them in future decisions** if they are unable to fully express their wishes?

| |
|--|
| <p><u> </u> / <u> </u> / <u> </u> <i>mm</i> / <i>dd</i> / <i>yyyy</i></p> |
| <p><u> </u> / <u> </u> / <u> </u> <i>mm</i> / <i>dd</i> / <i>yyyy</i></p> |

Advanced Care Planning: 5-step approach when a loved one cannot participate

Consider your loved ones' responses to these questions and what is in their best interest given the current condition. Refer back to their values (pages 36-39) and your network (pages 25-27) to help answer these questions.

What is the **problem / issue** that stands before you?

_____ / _____ / _____
mm dd yyyy

What are **potential options** for care and the **risks/benefits of the options**?

_____ / _____ / _____
mm dd yyyy

How do **my loved ones' values impact the appropriateness** of these options?

 / /
mm *dd* *yyyy*

What are **resources for support** (social, professional, spiritual)?

 / /
mm *dd* *yyyy*

What is the **best decision for us?**

 / /
mm *dd* *yyyy*

SECTION 4

Providing a structure for dementia decisions

Why support decision making for those living with dementia?

As a person lives with dementia over time, they may have a harder time grasping their health issues, and the care they need. The potential risks and benefits of their choices and actions may also become hard to grasp. This decline in breaking down information can make things unsafe without the support for daily decisions. These can be in areas like driving, eating, taking medicines, or managing their money.

Caregivers, be it a single person or a group, often support to help make decisions for their loved ones with little guidance.

How do I know when to help with decisions?

Use your loved ones' healthcare team by asking if they think your loved one is able to make care decisions with a full understanding. Ask yourself if your loved one is able to analyze the decision by knowing:

- 1 What is the **problem/decision**?
- 2 What are **potential options**, and the negatives or positives of each?
- 3 What things are **most important to my loved one or our care team**?
- 4 What are **additional resources** (social, professional, spiritual) to help with this problem/decision?
- 5 What **choice best fits** my loved one and our care team based on answers to questions 1-4?

How can these decision tools be used?

These two tools are intended to support the caregivers in communicating with the healthcare team the care decisions in the best interest of the person living with dementia. These tools will help you process the best options as you communicate and decide the best plan in discussion with the medical team.

1. **The 5 step decision tree** on page 74 is intended to help support many of the complex care issues like decisions about surgery, hiring a caregiver, relocating to a new living situation, enrolling in hospice care, continuing to manage finances.
2. The **daily care decision worksheets** starting on page 50 is intended to help support safe daily care choices that are focused on values. These worksheets are time stamped because the care challenges and values which are most important will change over time. The choices focused in these worksheets will always help you to recognize:
 1. What has **changed** in your loved one?
 2. What **options** are you considering to help you and your loved one?
 3. What is **available in your network** to support daily care decisions?
 4. What are **important values** of your loved one or care team that should be considered in care decisions?

You may already have filled these out. Continue to use them throughout your journey as your needs and decisions change.

5-steps to help you make decisions with purpose

When faced with big decisions, it's easy to let emotions take over. Instead, include the values of your loved one to ground the choices in meaningful ways. These pages help you walk through a purposeful, considered 5-step process. Discuss and weigh your options with others involved in the care.

Here's one example:

1. What problem or decision are we facing?

Mom's no longer able to function in her home alone.

2. What choices are available?

Explore the positives and negatives of these choices.

a Live at home with hired caregivers coming to her house

positive

- familiar
- house is paid for

negative

- stranger coming into home
- feels like a prisoner
- limited socialization

b Relocate to an assisted living facility

positive

- support with meals & meds
- more social interaction
- independence in own apartment

negative

- needs to move from home
- limited friends initially
- downsize possessions

c

positive

negative

3. What are important values of my loved one and our care team that will help us in deciding?
(see pages 32-39)

Mom is:
Fiercely independent
Loves to socialize
Wants ability to choose options

4. What resources are available to support our decision?

Consider what makes this option possible
(see pages 81-83 for more information.)

Department on Aging

A Place for Mom
Visiting senior communities and having lunch to get a feel

5. Have you weighed your options?

Once you've worked through this, take time to document and discuss your decision.

Mom visited 3 senior communities, we involved her by giving a list of 3 important questions she'd ask to see what felt right. We chose the facility with the most extensive activities list and let her choose the unit that was closest to the activities area.

5-steps to help you make decisions with purpose

Follow these steps to help walk you through a purposeful, considered process that includes your loved one's values. Discuss and weigh your options with others involved. Blank copies are provided in the Resources section.

1. What problem or decision are we facing?



2. What choices are available?

Explore the positives and negatives of these choices.

a

positive

negative

b

positive

negative

c

positive

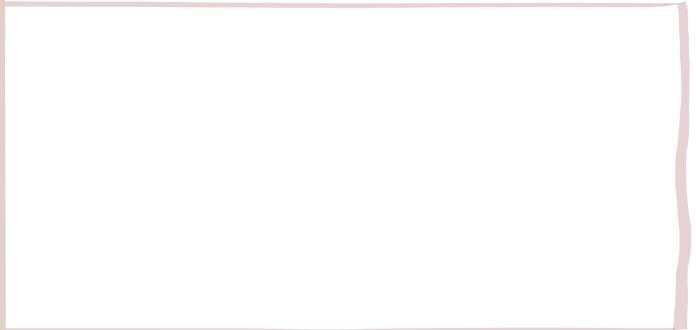
negative

3. What are important values of my loved one and our care team that will help us in deciding?
(see pages 32-39)



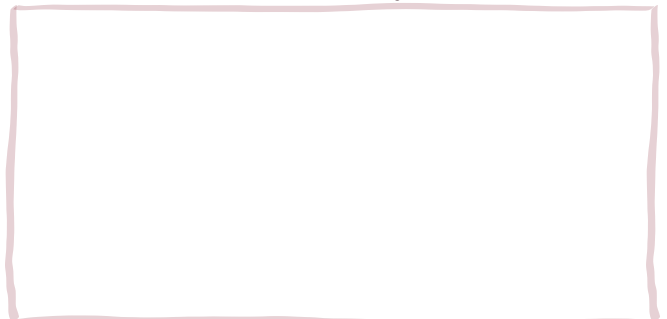
4. What resources are available to support our decision?

Consider what makes this option possible
(see pages 81-83 for more information.)



5. Have you weighed your options?

Once you've worked through this, take time to document and discuss your decision.



SECTION 5

Resources

There are many organizations and resources available for those living with dementia. They are presented in this section in useful categories to find what you need more easily. You can also find useful worksheets here for you to make multiple copies as new decisions or changes in areas of importance come up over time.

Resources are grouped into these areas:

- Managing behaviors
 - Education
 - Socialization
 - Caregiver support
 - Daily care
 - Late stage
 - Advanced Care Planning
 - National-level organizations
-
- Blank worksheets

Your personal resources

There may 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 and jot their numbers down. Also, go back to pages 25-27 for the social, professional care teams you've thought about.

Local resources

Department of Aging

() - _____

Alzheimer's Association

() - _____

A Place for Mom

() - _____

Caregiver support

() - _____

() - _____

Other

Resources by categories

Managing Behaviors

NIH's National Institute on Aging: Alzheimer's Disease and Related Dementias

<https://www.nia.nih.gov/health/alzheimers>

Alzheimer's Association's Alzheimer's and Dementia Caregiver Center

<https://www.alz.org/help-support/caregiving>

Education

National Institute on Aging

<https://www.nia.nih.gov/health/what-are-signs-alzheimers-disease>

UIC Dementia Expert App

https://play.google.com/store/apps/details?id=edu.uic.nursing.dg&hl=en_US

Alzheimer's Association

<https://www.alz.org/alzheimers-dementia/stages>

SHARE Network Resource Guide

www.sharenetworkchicago.org/resources

Socialization

Social support options online via the Alzheimer's Association

<https://www.alzconnected.org/>
24/7 Helpline: 1-800-272-3900

Chicago Hyde Park Village healthy aging programming

www.chpv.org

Senior Centers

https://www.cityofchicago.org/city/en/depts./fss/provdrs/senior/svcs/regional_senior_centers.html

Supporting Healthy Aging Resources & Education (SHARE) Network

<https://sharenetworkchicago.org/>

Gold Mind Arts provide art activities for those with memory loss

Email: info@goldmindartsandaging.com
(312) 405-6672

Senior services in the community (Adult day health, hired caregivers)

<https://www.Illinois.gov/aging>
IL Department on Aging (Chicago)
(312) 744-4016

Adult Day Health Programs provide care and socialization daily

(773) 373-5055 Chicago Commons
(800) 252-8966 Illinois Dept on Aging helps provide referrals

Next Steps in care (planning for daily care)

<https://www.nextstepincare.org/>

Caregiver Support

Caregiver Counseling & Support Services (Center for New Horizons)

(773) 357-4112

Alzheimer's Association: Caregiving

24/7 Helpline: 1-800-272-3900
<https://www.alz.org/help-support/caregiving>

Classes/Training for Caregivers

<https://www.powerfultoolsforcaregivers.org/>

Care Smart Illinois (Workshops on Memory care)

www.caresmart.org

AARP Caregiving resources

<https://www.aarp.org/home-family/caregiving/?cmp=RDRCT-CRGVER>
[APR12_012](#)

Alzheimer's Association:

24/7 Helpline (Person living with dementia, Caregivers, Family, etc)
1-800-272-3900

IL Senior Helpline

1 -800-206-1327

SHARE Network Resource Guide

Online: www.sharenetworkchicago.org/resources

Also in print

Daily Care

Senior services in the community (Adult day health, hired caregivers)

<https://www.Illinois.gov/aging>

Department on Aging

312-744-4016

Alzheimer's Association 24/7 Helpline

<http://www.alz.org>

800-272-3900

Adult Day Health Programs provide care and socialization daily

(773) 373-5055 Chicago Commons
(800) 252-8966 Illinois Dept on Aging helps provide referrals

Next Steps in care (planning for daily care)

<https://www.nextstepincare.org/>

Late Stage

National Respite Network Phone

(703) 256-2084

Salvation Army Chicago Community & Family services

(773) 382-4601

Palliative Care and Hospice for loved ones with advancing dementia and increasing care needs

Ingall's Homecare, Palliative and hospice

(708) 331-0226

Vitas Healthcare

(855) 791-6375

More about end-of-life decisions and how to honor the wishes of a person living with Alzheimer's disease

https://www.alz.org/national/documents/brochure_endoflifedecisions.pdf

End-of-life care for people with dementia

<https://www.nia.nih.gov/health/end-life-care-people-dementia>

Coping with late-stage dementia

<https://www.nia.nih.gov/health/coping-late-stage-alzheimers-disease>

Advanced Care Planning

Prepare for Your Care

<https://prepareforyourcare.org/faq>

Five Wishes

<https://fivewishes.org/shop/order/product/five-wishes-advance-directive>

Illinois Advance Care Plan

Who I trust to make decisions:

<https://www.dph.illinois.gov/sites/default/files/forms/powerofattorneyhealthcareform.pdf>

What I want to make the focus of my care when I am this stage:

<https://www.dph.illinois.gov/sites/default/files/forms/living-will-040416.pdf>

National-level resources

Alzheimer's Association

www.alz.org

The leading voluntary health organization in Alzheimer's care, support and research.
24/7 Helpline, 1-800-272-3900

SHARE Network Aging Resource Guide

www.sharenetworkchicago.org/resources

Chicago's hub for resources related to healthy aging, caregiving, memory loss, socialization, and much more.

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.

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.

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.

Community Resource Finder

www.communityresourcefinder.org

Your local caregiver support group

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

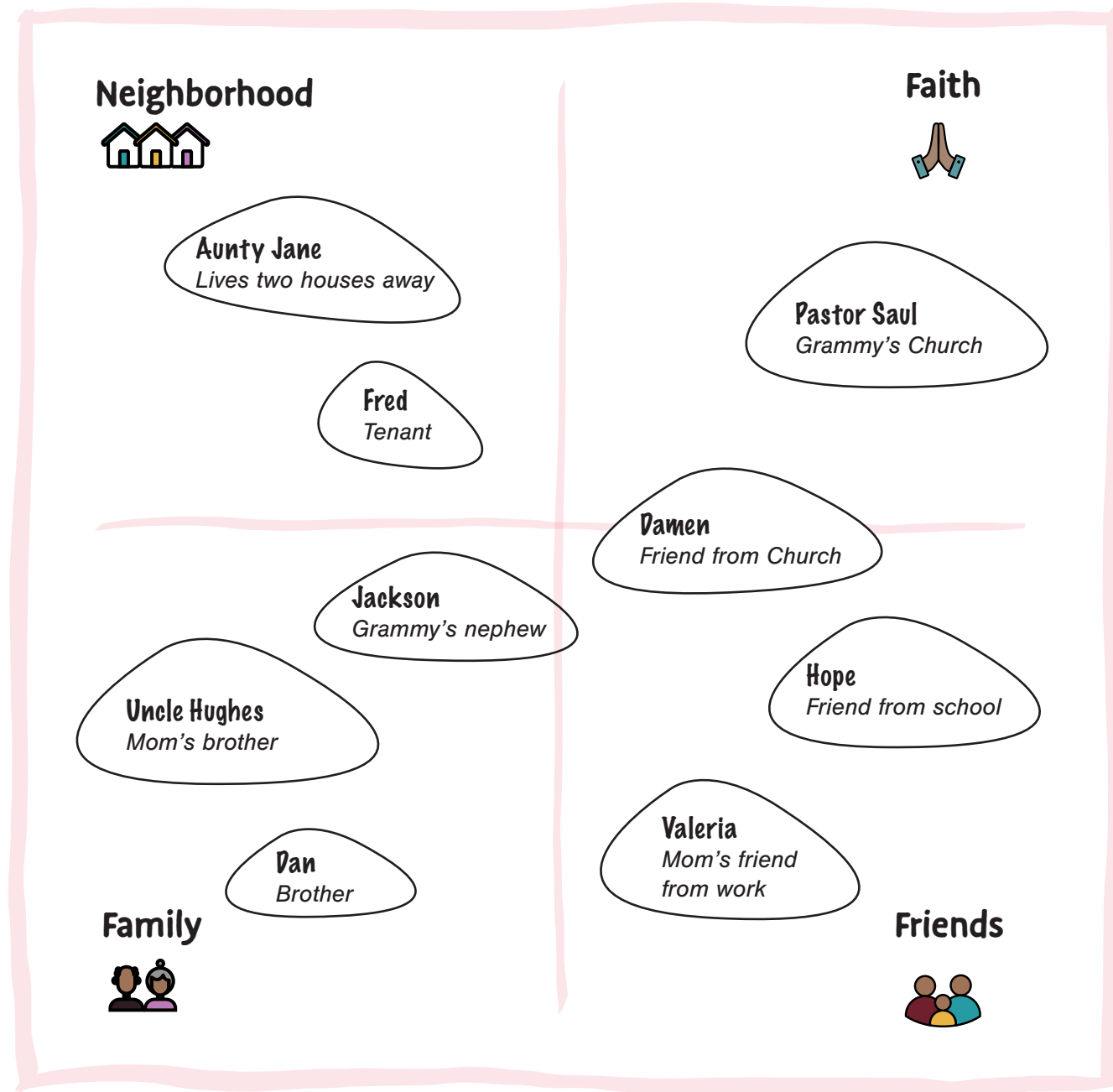
www.benefitscheckup.org

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

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**.

Example



Now you try.

Neighborhood



Faith



Family



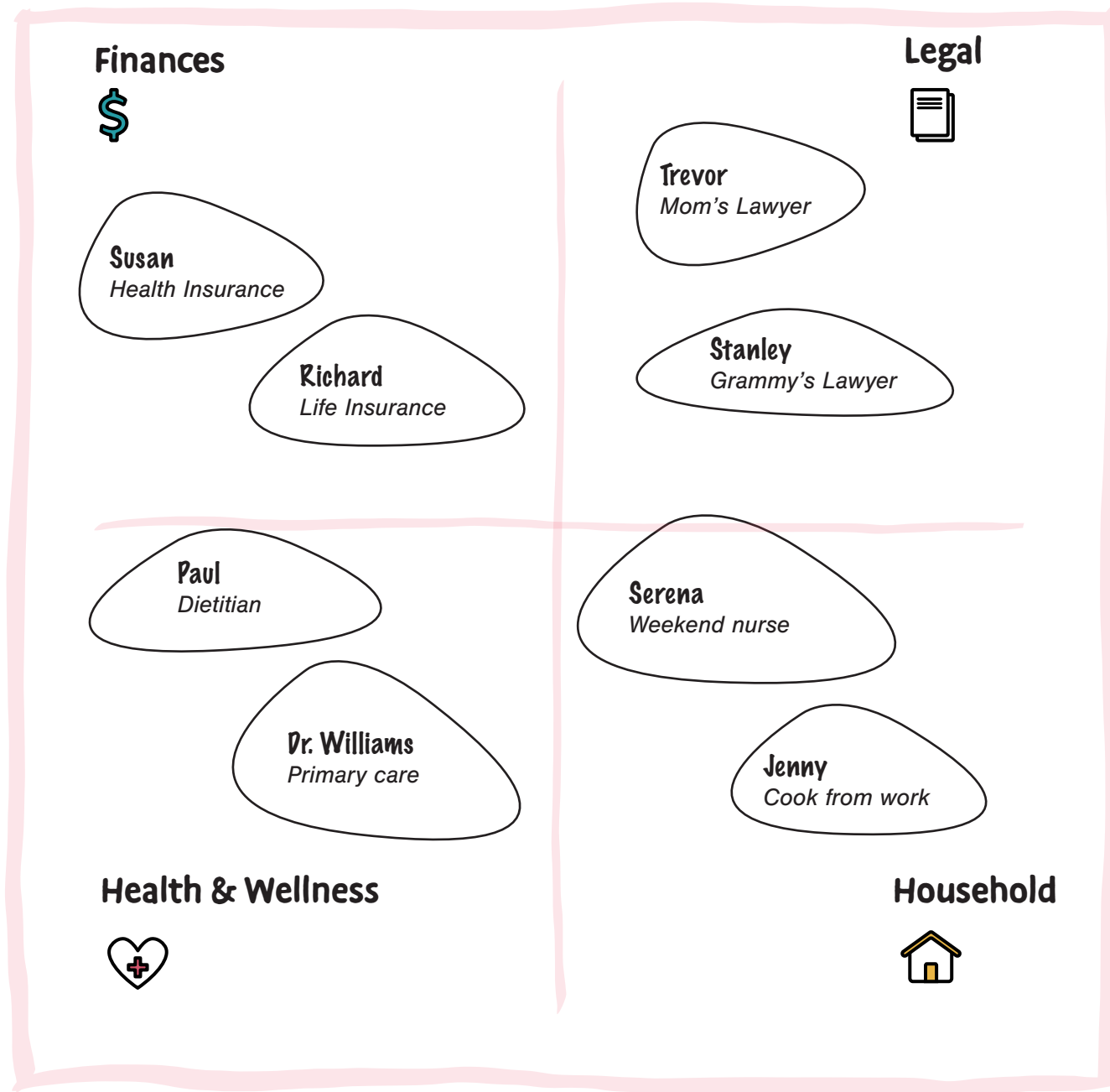
Friends



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**.

Example



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

Finances



Legal



Health & Wellness



Household

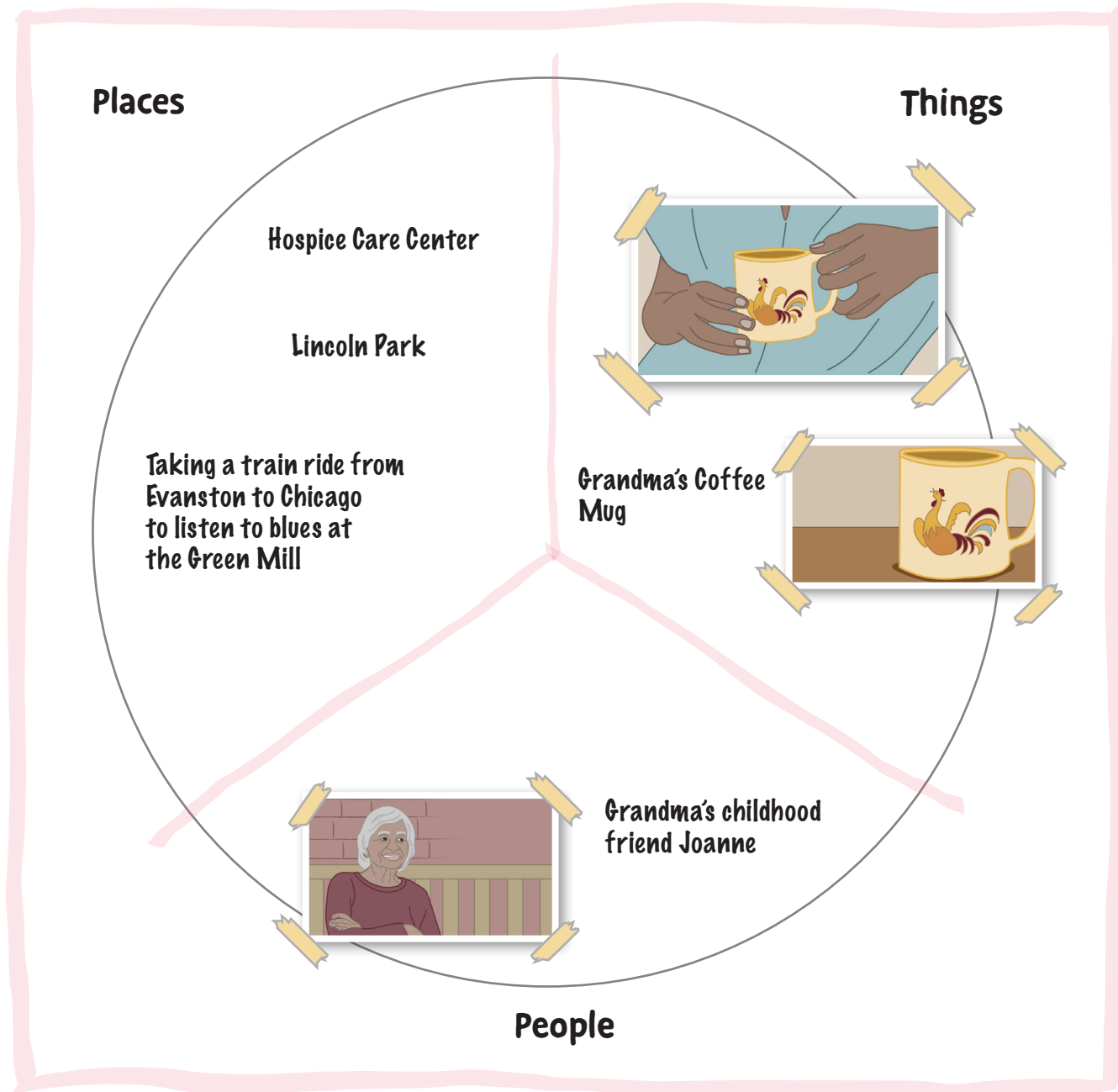


Visit the resource pages (pg. 80-83) for more information

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.

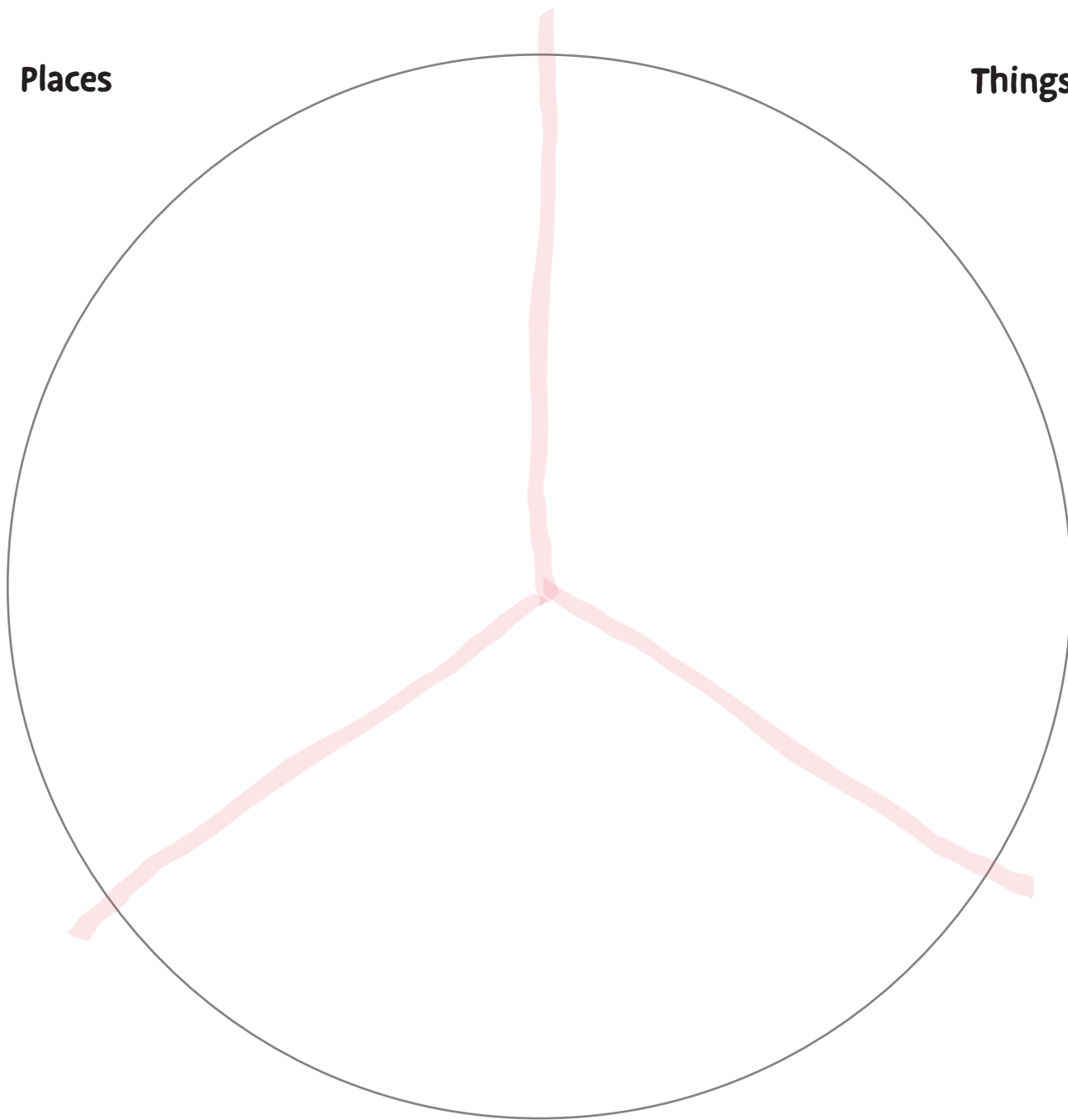
Example



It's your turn.

Places

Things



People

Visit the resource pages (pg. 80-83) for more information

Imagine for yourself...

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**.

This exercise may be sensitive and emotional.

Example



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!



Reflect on what's important to you

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

What makes your loved one **happy and whole**?

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

mm / *dd* / *yyyy*

mm / *dd* / *yyyy*

What does your loved one need to feel **safe and supported**?

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

mm / *dd* / *yyyy*

mm / *dd* / *yyyy*

What are your loved one's **hopes and fears**?

Hopes

These might be a short-term or long-term goals that you are aiming for.

Fears

These might be something you always try to avoid.

What **can't change** in your life?

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

____ / ____ / ____
mm dd yyyy

____ / ____ / ____
mm dd yyyy

Imagine with your loved one...

Now let's do the same thing for your loved one! Tell him/her to close their eyes and imagine himself/herself on a relaxing day, what would it look like?

Help your loved one to write or draw something that **reminds him/her of being relaxed.**

This exercise may be sensitive and emotional.

Example



Mom likes to go to the beach to enjoy sunset...

Help your loved one to imagine **him/her doing something with you.**

What are the activities that you both enjoyed? Go write about it or draw it!

A large, empty rectangular box with a light orange border, intended for writing or drawing. The box is centered on the page and occupies most of the middle section.

Reflect on what's important to your loved one

Now let's consider your loved one. There are two ways to use these pages.

- Sit with your loved one and have a conversation.
- You may be at a point in time where your loved one can't express his or her feelings. Think back to 5 years or 10 years ago, what would they say or think?

What makes your loved one **happy and whole**?

This might be an activity, a place, a role you play, or a relationship he/she cherishes.

____ / ____ / ____
mm dd yyyy

____ / ____ / ____
mm dd yyyy

What does your loved one need to feel **safe and supported**?

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

____ / ____ / ____
mm dd yyyy

____ / ____ / ____
mm dd yyyy

What are your loved one's **hopes and fears**?

| Hopes | Fears |
|---|---|
| These might be a short-term or long-term goals that you are aiming for. | These might be something you always try to avoid. |

What **can't change** in your loved one's life?

This might include where he/she lives or works, or how he/she spends certain hours in a day.

| |
|--|
| <p>_____ / _____ / _____ <i>mm dd yyyy</i></p> |
| <p>_____ / _____ / _____ <i>mm dd yyyy</i></p> |

Reflect on what you and your loved one share

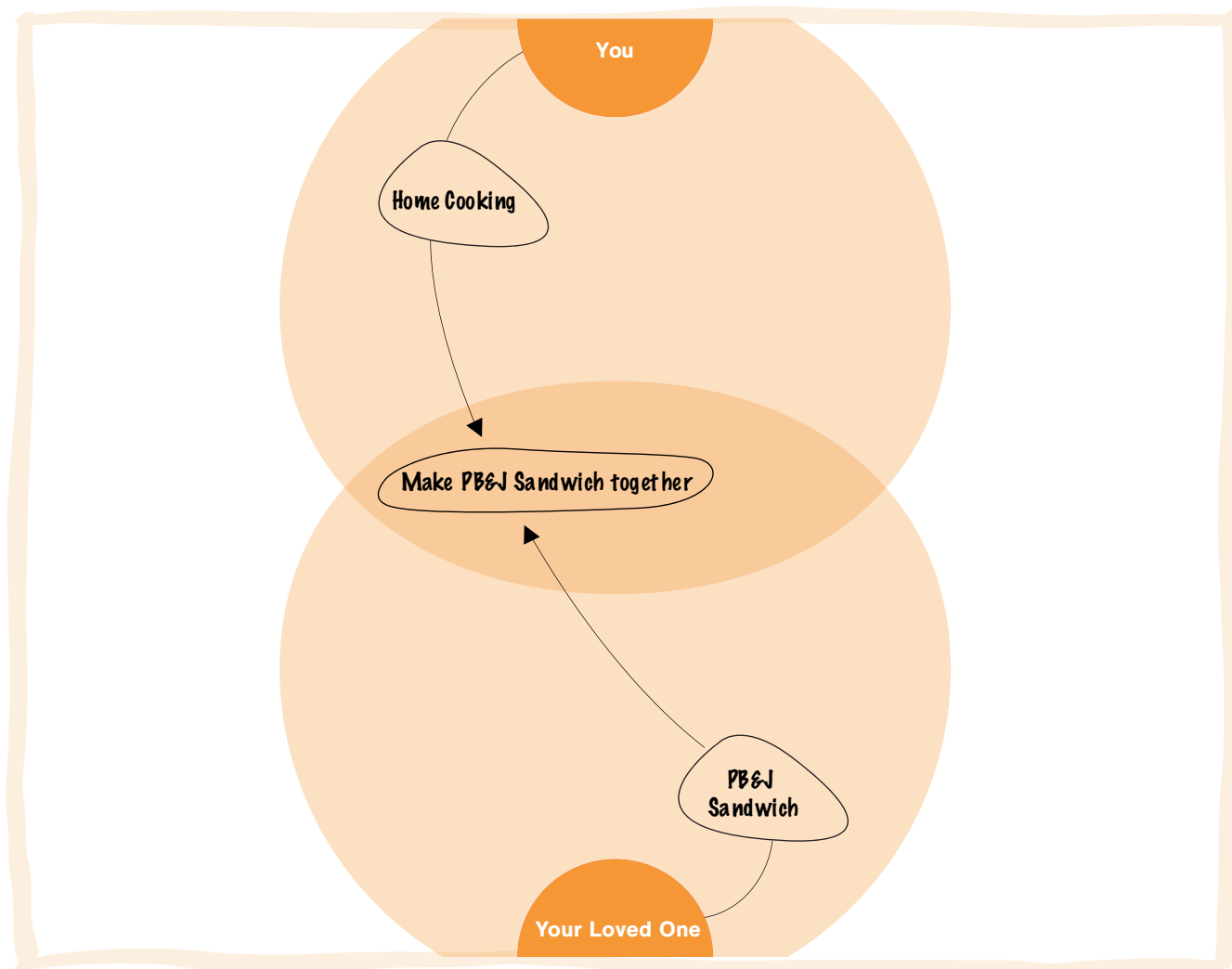
Complete this activity alongside your loved one. You may want to repeat this with others who are involved in the care.

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 love one share?
- Connect the ideas you share.
- Continue to think of other things you and your loved one shares.

Example



You

What you love to do...

What you both love to share...

What your loved one loves to do...

Your Loved One

Changes in daily care behavior for loved ones with dementia

Use this to jot down the behavior changes you notice. You can discuss these on your next doctor's visit.

| | DATE / / | DATE / / |
|---------------------------|-------------|-------------|
| Medical Management | | |
| Hygiene | | |
| Healthy Eating | | |
| Mobility | | |
| Behaviors | | |

DATE

/ /

DATE

/ /

DATE

/ /

Changes in daily care needs

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** have you noticed in your loved one related to daily care?

____ / ____ / ____
mm dd yyyy

____ / ____ / ____
mm dd yyyy

What **options** have you considered to support daily care challenges?

____ / ____ / ____
mm dd yyyy

____ / ____ / ____
mm dd yyyy

Connecting to your network

____ / ____ / ____
mm dd yyyy

Refer back to your **support network**.

Who can help you manage both yours and your loved one's daily care? Revisit page 25.

Write down contact information



Neighborhood



Family



Faith



Friends

There are also many **professionals** you can turn to for help and expertise.

Who can you reach out to? Revisit page 27.

Write down contact information



Finances



Legal



Health & Wellness



Household

Applying your values to the decision

How can you manage your loved one's daily care? Revisit page 36 to 39.

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

You might consider medical dietary restrictions, or exercise.

____ / ____ / ____
mm dd yyyy

____ / ____ / ____
mm dd yyyy



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.

____ / ____ / ____
mm dd yyyy

____ / ____ / ____
mm dd yyyy



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

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

 / /
mm *dd* *yyyy*

 / /
mm *dd* *yyyy*



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).

 / /
mm *dd* *yyyy*

 / /
mm *dd* *yyyy*



WORKSHEET

Maintaining relationships over time

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 have you noticed in your loved one's **behavior and social interactions**?

____ / ____ / ____
mm dd yyyy

____ / ____ / ____
mm dd yyyy

What **options** have you considered to support your loved one through these changes?

____ / ____ / ____
mm dd yyyy

____ / ____ / ____
mm dd yyyy

Connecting to your network

____ / ____ / ____
mm dd yyyy

Refer back to your **support network**.

Who can help you maintain relationships with your loved one? Revisit page 25.

Write down contact information



Neighborhood



Family



Faith



Friends

There are also many **professionals** you can turn to for help and expertise.

Who can you reach out to? Revisit page 27.

Write down contact information



Finances



Legal



Health & Wellness



Household

Applying your values to the decision

Refer back to **What matters to you.**

How can you help your loved one maintain social relationships?
Revisit pages 36-39 or see resources section on pages 80-83.

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.

____ / ____ / ____
mm dd yyyy

____ / ____ / ____
mm dd yyyy



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.

____ / ____ / ____
mm dd yyyy

____ / ____ / ____
mm dd yyyy



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

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

____ / ____ / ____
mm *dd* *yyyy*

____ / ____ / ____
mm *dd* *yyyy*



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.

____ / ____ / ____
mm *dd* *yyyy*

____ / ____ / ____
mm *dd* *yyyy*



WORKSHEET

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 have you noticed with your loved one in terms of **their ability to live independently, manage finances, and plan for advanced medical care?**

____ / ____ / ____
mm dd yyyy

____ / ____ / ____
mm dd yyyy

What **options** have you considered to help you and your loved one through these changes?

____ / ____ / ____
mm dd yyyy

____ / ____ / ____
mm dd yyyy

Connecting to your network

____/____/____
mm dd yyyy

Refer back to your **support network**.

Who can help you plan for your loved one's long term care? Revisit page 25.

Write down contact information



Neighborhood



Family



Faith



Friends

There are also many **professionals** you can turn to for help and expertise.

Who can you reach out to? Revisit page 27.

Write down contact information



Finances



Legal



Health & Wellness



Household

Applying your values to the decision

Refer back to **What matters to you**.

How can you manage your loved one's daily care? Revisit pages 36-39.

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.

____ / ____ / ____
mm dd yyyy

____ / ____ / ____
mm dd yyyy



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.

____ / ____ / ____
mm dd yyyy

____ / ____ / ____
mm dd yyyy



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.

____ / ____ / ____
mm dd yyyy

____ / ____ / ____
mm dd yyyy



Advanced Care Planning: Early discussion worksheet *with your loved one*

Discuss with your loved ones the following questions and bring responses to discuss in the next doctor visit.

What does your loved one **value now**? What would they **value if things changed**?

____ / ____ / ____
mm dd yyyy

____ / ____ / ____
mm dd yyyy

What is your loved ones' **biggest fear or hope** as dementia progresses?

____ / ____ / ____
mm dd yyyy

____ / ____ / ____
mm dd yyyy

How have changes brought about by dementia **changed the day-to-day life** of your loved one?

____ / ____ / ____
mm dd yyyy

____ / ____ / ____
mm dd yyyy

Who will your loved one **trust to support them in future decisions** if they are unable to fully express their wishes?

____ / ____ / ____
mm dd yyyy

____ / ____ / ____
mm dd yyyy

Advanced Care Planning: 5-step approach when a loved one cannot participate

Consider your loved ones' responses to these questions and what is in their best interest given the current condition. Refer back to their values (pages 36-39) and your network (pages 25-27) to help answer these questions.

What is the **problem / issue** that stands before you?

_____ / _____ / _____
mm dd yyyy

What are **potential options** for care and the **risks/benefits of the options**?

_____ / _____ / _____
mm dd yyyy

How do **my loved ones' values impact the appropriateness** of these options?

 / /
mm *dd* *yyyy*

What are **resources for support** (social, professional, spiritual)?

 / /
mm *dd* *yyyy*

What is the **best decision for us?**

 / /
mm *dd* *yyyy*

5-steps to help you make decisions with purpose

Follow these steps to help walk you through a purposeful, considered process that includes your loved one's values. Discuss and weigh your options with others involved. Blank copies are provided in the Resources section.

1. What problem or decision are we facing?



2. What choices are available?

Explore the positives and negatives of these choices.

a

positive

negative

b

positive

negative

c

positive

negative

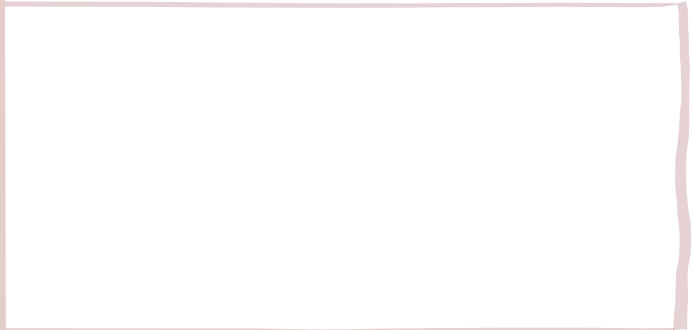
3. What are important values of my loved one and our care team that will help us in deciding?

(see pages 32-39)



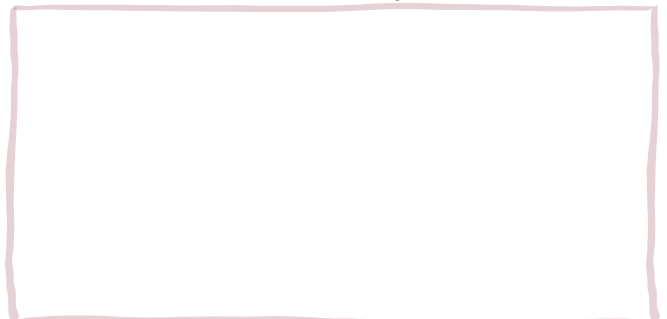
4. What resources are available to support our decision?

Consider what makes this option possible (see pages 81-83 for more information.)



5. Have you weighed your options?

Once you've worked through this, take time to document and discuss your decision.



Sources

Alzheimer's Association

Centers for Disease Control (CDC)

National Institute on Aging (NIA) –National
Institutes of Health (NIH)

Health Resource Services Administration
(HRSA)

SHARE Network

Caregiving.com

PrepareForYourCare.org

PlanYourLifespan.org

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The *Centering Our Values™: A hands-on guide to dementia care and decision making* project originated from a 16-week Communication Design Workshop at the Institute of Design/Illinois Institute of Technology during the Fall of 2019. 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. Subsequent user testing and revisions were conducted in 2020-2021, resulting in this more comprehensive version of the toolkit.

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