

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.

Life changes over time, so do our thoughts and decisions. Return to this book to explore your feelings at different points in time.

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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Finish the first section before moving on to the rest of the tool.

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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.

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!

Reflect on what is 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 you cherish.

<p>____ / ____ / ____ mm dd yyyy</p>
<p>____ / ____ / ____ mm dd yyyy</p>

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.

<p>____ / ____ / ____ mm dd yyyy</p>
<p>____ / ____ / ____ mm dd yyyy</p>

What are your loved one's hopes and fears?

<p>Hopes These might be a short-term or long-term goals that you are aiming for.</p>	<p>Fears These might be something you always try to avoid.</p>
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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>____ / ____ / ____ mm dd yyyy</p>
<p>____ / ____ / ____ mm dd yyyy</p>

Reflect on what you and your loved one share

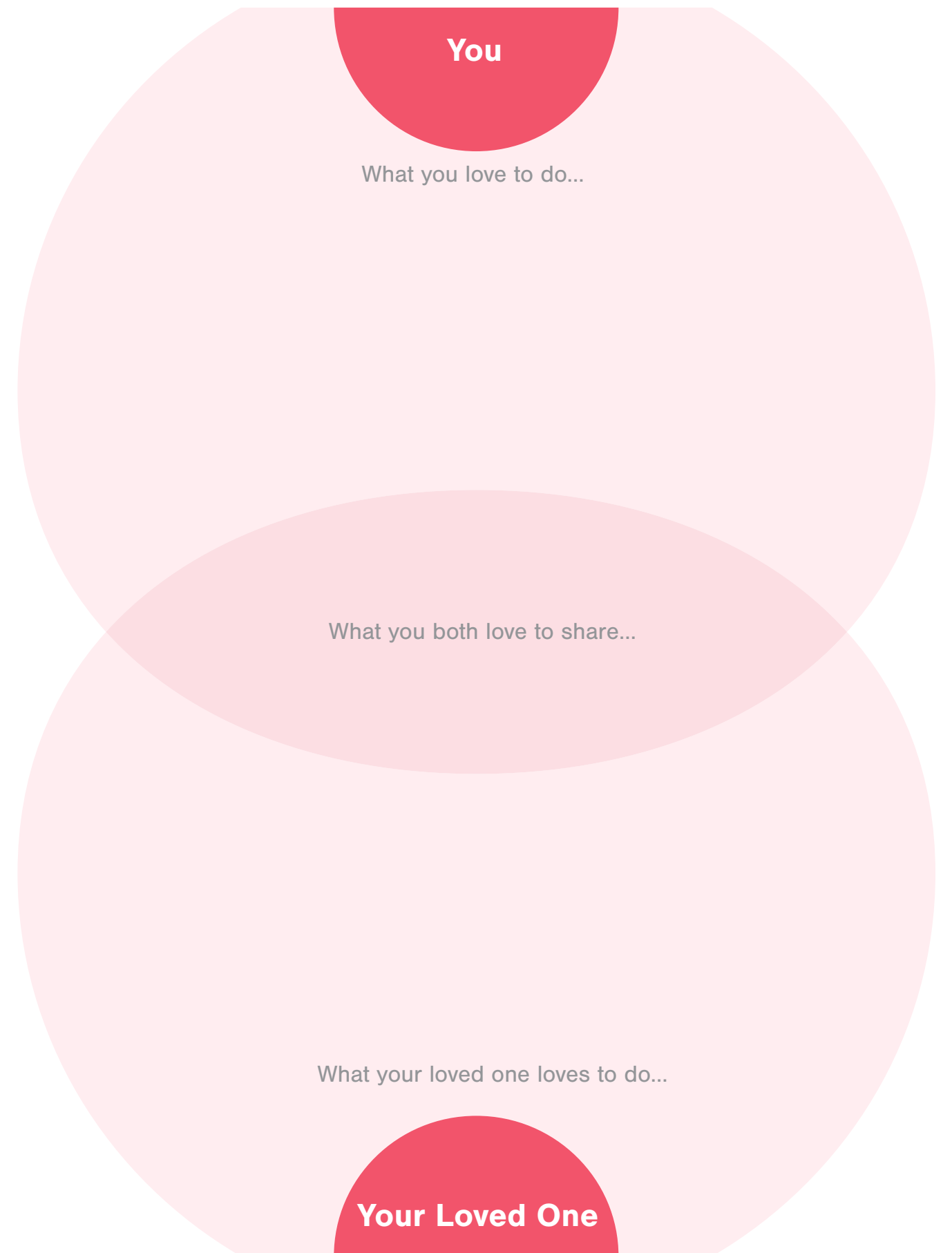
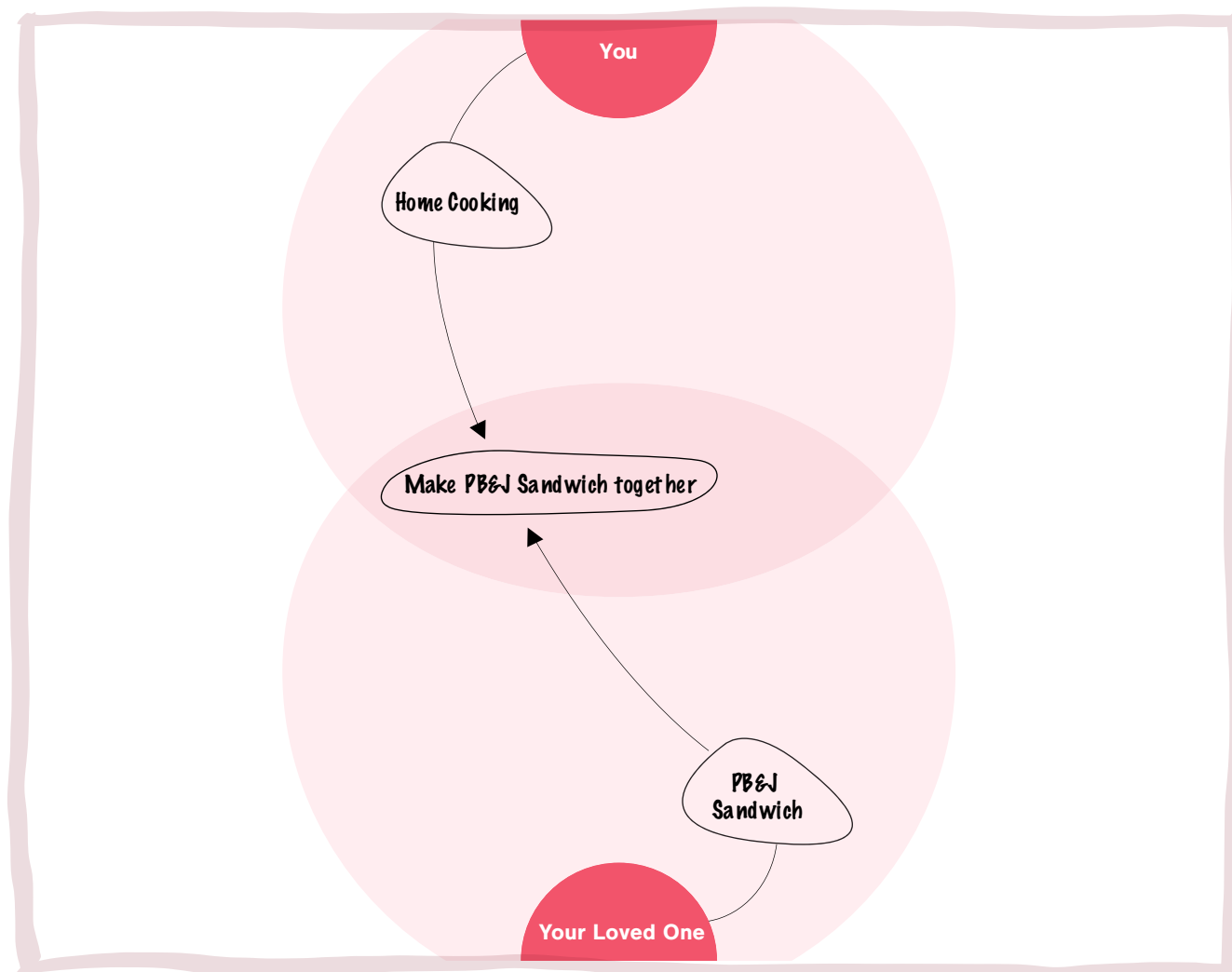
Complete this activity alongside your loved one.

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

Example



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



Nice job, let's move on!

Use what you've expressed in these pages as you move forward in this workbook.

What you've described so far will help you make choices in the future that will feel more natural and comfortable for you and your loved one.

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.

This section will help you work through areas in:

- Managing daily care
- Planning for long term care
- Maintaining relationships

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



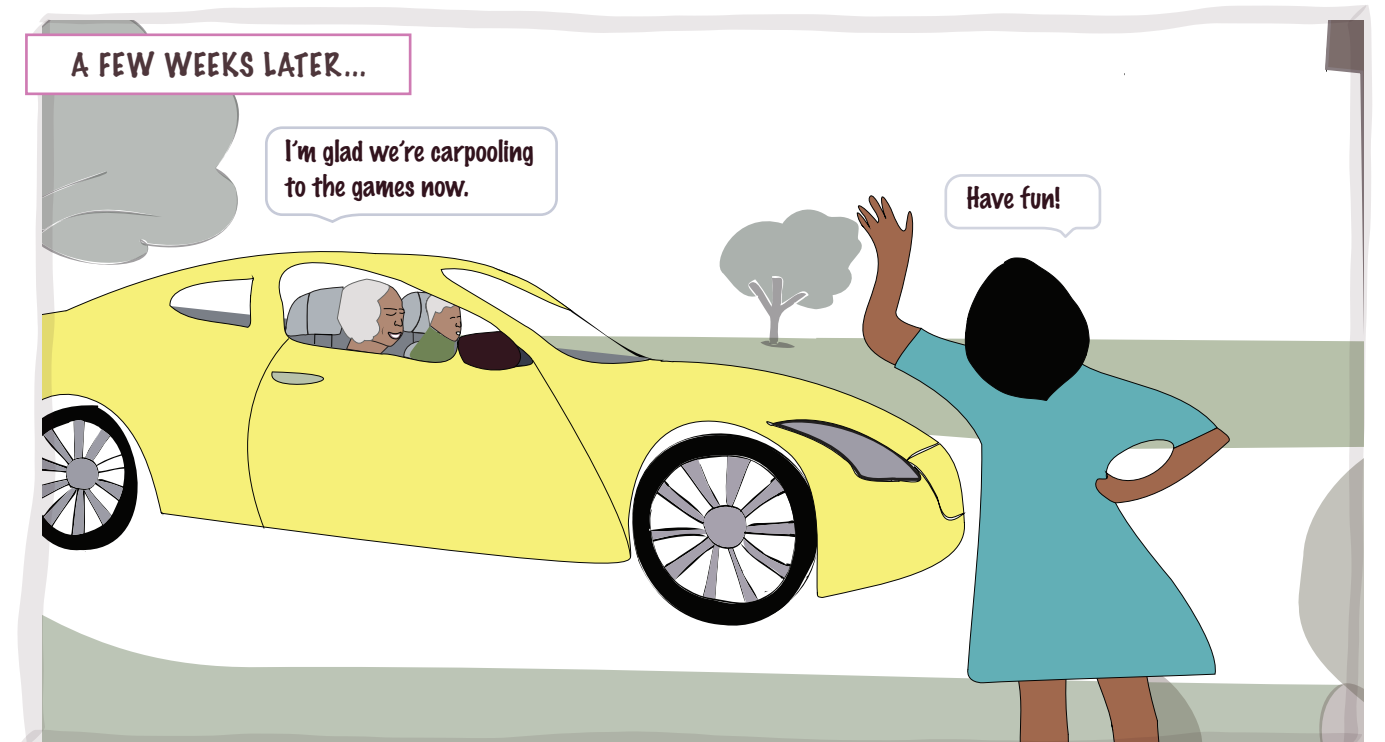
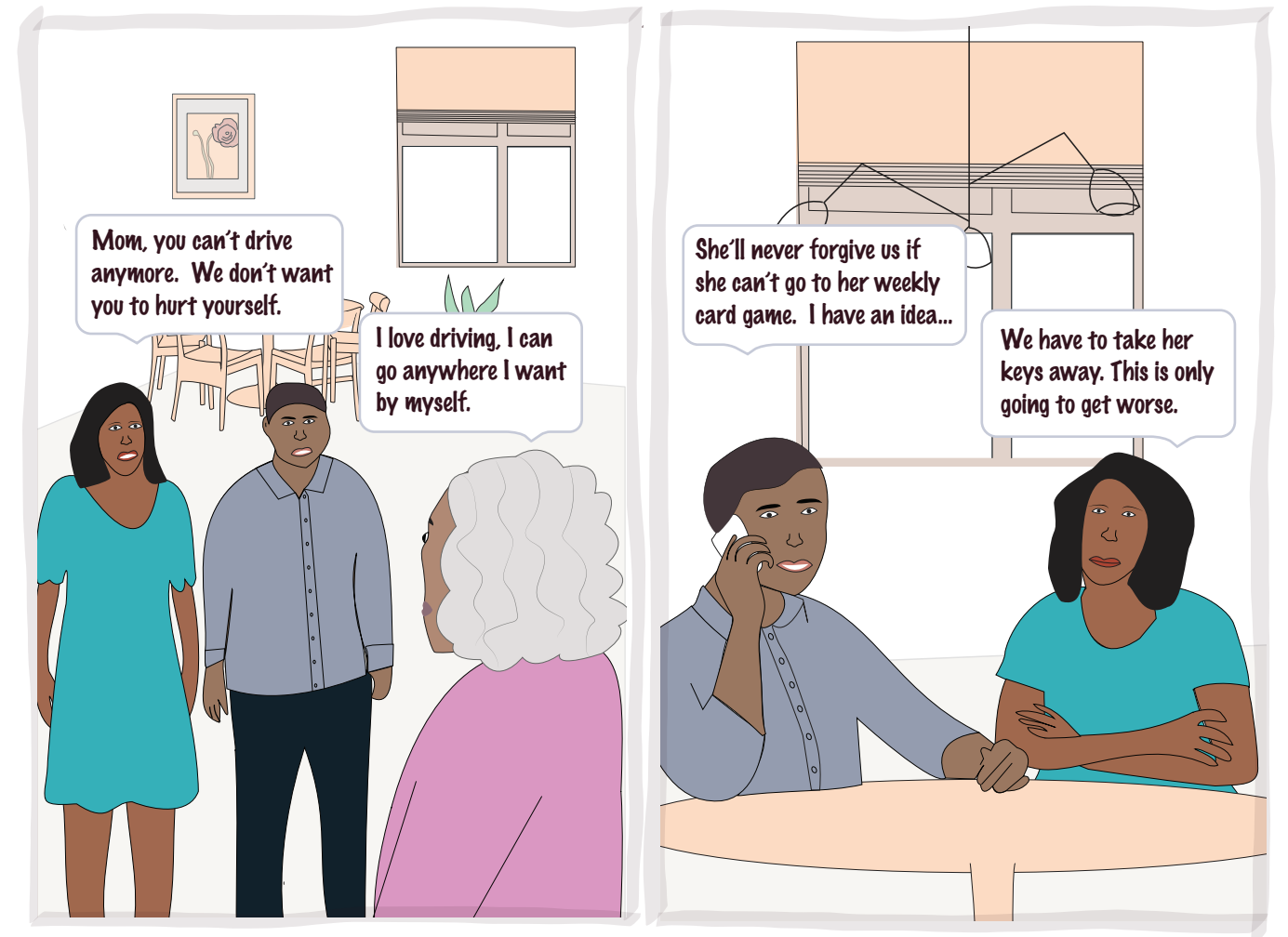
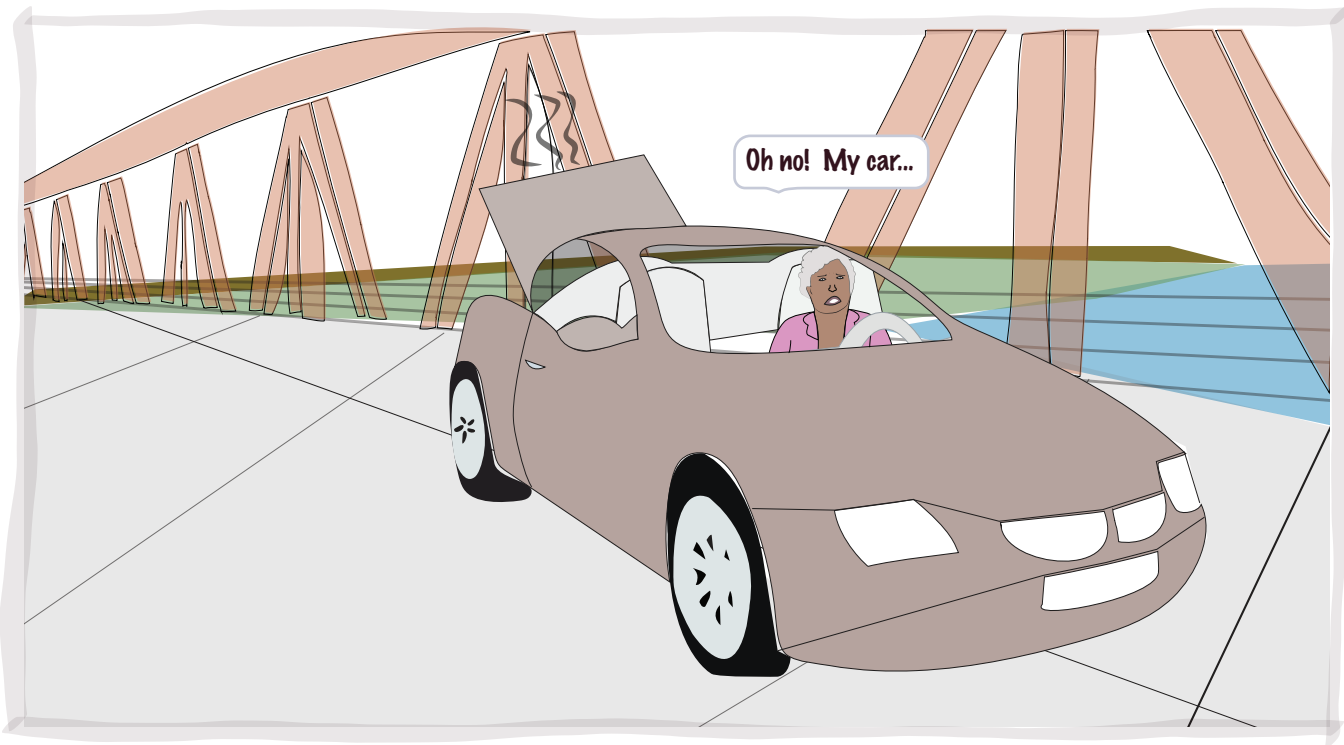
Healthy eating

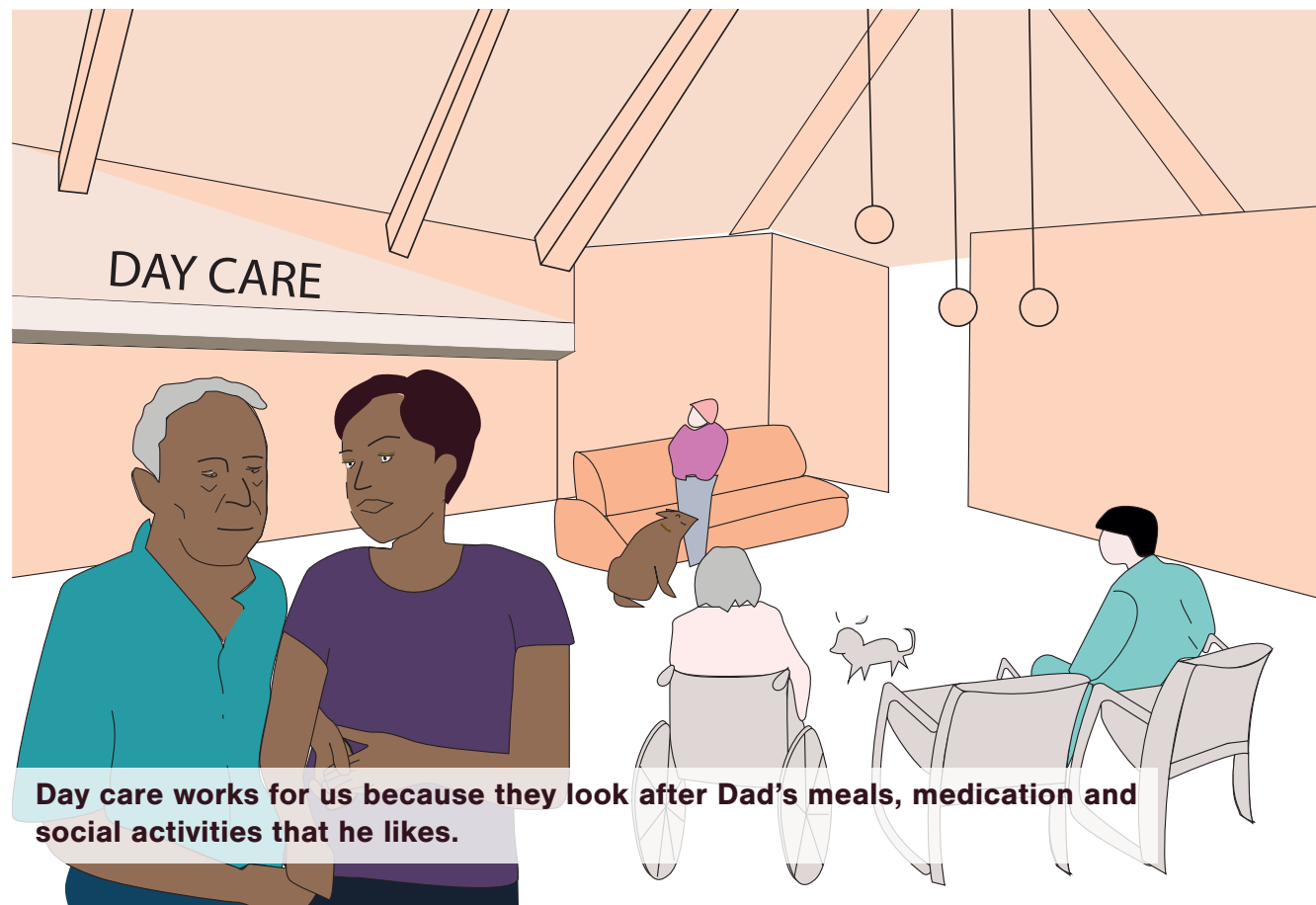
Cooking, eating, managing groceries, and considering food preferences



Mobility

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





Day care works for us because they look after Dad's meals, medication and social activities that he likes.

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



I call Mom every morning to remind her to take her medicine.

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?

mm / dd / yyyy

mm / dd / yyyy

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

mm / dd / yyyy

mm / dd / yyyy

Connecting to your network

Refer back to your **support network**.

mm / dd / yyyy

Who can help you manage your loved one's daily care? Revisit page 17.

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 19.

Write down contact information

 Finances

 Legal

 Health & Wellness

 Household

Applying your values

How can you manage your loved one's daily care? Revisit page 18 to 19.

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



Additional Resources

This section will help you with additional information:

- Steps to help you make decisions with purpose
- National-level resources
- Stages of Alzheimer's and dementia

An example of making decisions with purpose

Here's a scenario where the family needs to find a new living arrangement for Mom. Let's walk through the steps.

1. What problem are you trying to solve?

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

2. What options do you have?...

Explore both the positives and negatives

a Live at home with hired caregivers coming to her house

positive	negative
- familiar	- stranger coming into home
- home is paid for	- feels like a prisoner
	- limited socialization

b Relocate to an assisted living facility

positive	negative
- support with meals & meds	- needs to move from home
- more social interaction	- limited friends initially
- independence in own apartment	- downsize possessions

c

positive	negative

3. Reflect these against your loved one's values

Jot down important values that will help to navigate your solution (see pg 12-13)

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

4. What specific resources are available?

Consider what makes this option possible (see pg 54-55 for more info.)

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 determine 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.

National-level resources

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

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 and jot their numbers down. Also, go back to page 12-15 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

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.thewhpc.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

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.

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Team Members

Harini Balu
Yuan Feng
Xuning Guo
Rachel Huvad
Cagla Kuzu
Goeun Lee
Adithya Ravi
R. McKinley Sherrod
Andriya Veintimilla
Catherine Wieczorek
Yueyue Yang
Jianing Zhong

Instructor

Tomoko Ichikawa

Project Sponsor/Advisor

Shellie Williams, M.D.

Research Consultant

Jeffrey Graupner

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