The Caregiver's Journey®

Finally! Practical Tips and Candid Conversations
for Alzheimer's and Dementia Family Caregivers

Navigating Dementia Caregiving Roadmap™

Your Resource Roadmap for Every Stage

V4.1

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The Three Stages of the Dementia Caregiving Journey

1. In the Beginning - Your loved one receives a diagnosis.

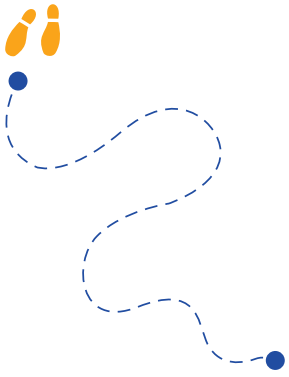
- You are the caregiver for TWO people - and you have equal responsibility to both! You instinctively know one is your loved one, but who is the second one? It's you!
- Your caregiving goal for both of you is keeping you safe and comfortable.
- For your care receiver living with dementia, keep front and center helping them maintain as much dignity and independence as possible.
- Your natural instincts will pull you to take control to protect them. This can be counter to dignity and independence. At this point, as the primary caregiver, your role is providing most of your support in the background.
- The time will come when you will need to take more control. Be patient and let it come naturally.
- You may begin grieving losses along the way - some minor, some more significant. We call this 'drip grief'. It's still grief.

2. The Messy Middle - You begin asserting control; this is when it gets messy!

- Your care receiver still thinks they can do most things while you're getting more involved, and this adds to their frustration.
- There's a lot of observing and adjusting while helping them maintain their independence.
- Your loved one is frustrated because they aren't sure what to do. Sometimes, they're also scared.
- It's important to look at things from their perspective, maintaining empathy and connection during this challenging stage.

3. Later On - You are managing all aspects of their care.

- Caregiving becomes easier in many ways at this stage - and harder in others.
- Be aware of your ongoing grief (sometimes called 'anticipatory grief').
- Prioritize self-care and reach out for support.



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In the Beginning

First Steps - Right after the diagnosis

1 Reach out for guidance

Scan to listen
TCJ Podcast Episode 42.
When To Call In Palliative Care

2 Update legal documents, end of life planning and long term care plans

Scan to listen
TCJ Podcast Episode 31.
Elder Law Attorneys

Scan to view
Legal Documents

Scan to view
End of Life
Planning Worksheet

3 Understand the financial situation

Scan to listen
TCJ Podcast Episode 53.
The Dementia Care
Financial Conversation

Scan to view
Overview of
Financial Planning

4 Find support groups

Scan to listen
TCJ Podcast Episode 57.
Finding The Right Support Group

Scan to view Dementia
Support Group Finder

5 Educate yourself on early caregiving topics

Scan to listen
TCJ Podcast Episode 2.
Memory Loss

Scan to listen
TCJ Podcast Episode 3.
Communication – in the Beginning

6 Investigate the US Medicare GUIDE program

Scan to listen TCJ Podcast
Episode 39. Is the Medicare
GUIDE program for you

Scan to view
Find a GUIDE program

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In the Beginning

First Steps - Right after the diagnosis

1. Reach out for guidance.

Investigate these organizations for valuable guidance in different ways throughout your journey.

- In addition to providing an extra layer of medical support for your loved one alongside your primary medical team, a palliative care program also supports the family caregiver throughout the journey. Palliative care is provided alongside curative treatments focusing on improving quality of life for those with a serious illness. In the US, palliative care is usually covered by insurance with a co-pay.
  - In your search engine, type 'Palliative Care' + 'the name of your country' or, in the US 'the name of your state'. Scroll down below sponsored ads and click on 'More places' to get a list with a map. Palliative care programs are not available in all areas.
    - Don't be distracted by options that say 'Hospice' in their name. Palliative care programs are usually included in organizations that also provide hospice services. Don't be scared of palliative care, educate yourself on what palliative care is:
    - 27 minute The Caregiver's Journey (TCJ) podcast: 42. When To Call In Palliative Care.
    - TCJ blog 42. When To Call In Palliative Care.
- **Area Agency on Aging (AAA)**. In the US, this is a free government service. In some states AAA provides dementia care specialists/navigators who can help guide you through your journey. Search for yours at Eldercare.acl.gov or call 1-800-677-1116.
- **A Certified Senior Advisor (CSA)** can also help guide you through your journey. Some of their services are at no cost to you. Some of their services have a fee. Find a CSA near you: https://portal.csa.us/locator.

2. Update legal documents, end of life planning and long term care plans.

- With your loved ones input, get their legal documents in order, do some initial end of life planning, and discuss other issues such as who they would like to have take over their finances when they are no longer able and what their long term living preferences are.
  - Contact your attorney or an elder law attorney NAELA.org.
  - Listen to this podcast or read this blog on elder law attorneys:
    - 32 minute TCJ podcast: 31. Elder Law Attorneys.
    - TCJ blog: 31. Elder Law Attorneys.
  - In the United States, look for free legal help here.
  - Alzheimer's Association legal documents overview:
    - While named Alzheimer's Association, this group focuses on all types of dementia.
    - Medical Power of Attorney (POA), Financial POA, Will, Advance Directive/Living Will, end of life preplanning with your loved ones input.
  - Leverage this End of Life Planning Worksheet.

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3. Understand the financial situation.

- Listen to this podcast or read this blog on the financial conversation:
  - 22 minute TCJ podcast: 53. The Dementia Care Financial Conversation.
  - TCJ blog: 53. The Dementia Care Financial Conversation.
- Work with a financial advisor - especially those who focus on seniors. Elder law attorneys can also advise in this area.
- Alzheimer's Association overview of financial planning:
  - Long term care insurance, when and how to leverage
  - US Social Security Administration - Disability
  - US Medicaid eligibility and options
  - US Veterans Affairs (VA) eligibility
  - Other forms of income.

4. Find support groups.

- First and foremost for you. If possible, find a support group you can attend in person:
  - For a support group focused on a specific type of dementia, in your search engine, type 'name of dementia type' + 'support group'.
  - The Alzheimer's Association support group finder has support groups for a variety of types of dementia.
- Listen to this podcast or read this blog on finding the right support group:
  - 18 minute TCJ podcast: 57. Finding The Right Support Group.
  - TCJ blog: 57. Finding The Right Support Group.
- If your loved one is interested a support group:
  - Dementia minds online groups for people living with dementia.
  - Many local senior centers have support groups for your loved one to increase socialization:
    - In the US, go to your 'countyname'.gov website and search for a senior center.
- If you need someone to talk you through how to find a support group for any type of dementia, call this free 24/7 helpline from The Alzheimer's Association. You will be connected directly to someone you can talk with:
  - The Alzheimer's Association 24/7 helpline in the US: 1.800.272.3900.
  - Talk with your support group about what self-care means and ways to incorporate it in your daily plans.
  - Self-care is NOT selfish; it's important for you throughout your entire caregiving journey.
  - The most important thing is to continuously prioritize caring for you.

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5. Educate yourself on early caregiving journey topics.

- Listen to these two podcasts or read these two blogs:
  - Memory Loss:
    - 29 minute TCJ podcast: 2. Memory Loss.
    - TCJ Blog: 2. Memory Loss.
  - Communication:
    - 20 minute TCJ podcast: 3. Communication – in the Beginning.
    - TCJ Blog: 3. Communication - in the Beginning.

6. Investigate the US Medicare GUIDE program.

- Listen to this podcast or read this blog:
  - 23 minute TCJ podcast: 39. Is the Medicare GUIDE program for you.
  - TCJ blog: 39. Is the Medicare GUIDE program for you.
- Understand if your loved one may be eligible:
  - https://www.cms.gov/priorities/innovation/guide/faqs#ben-cgs.
- If you think you might be eligible, find a US Medicare GUIDE program provider near you:
  - There may be several who cover your zip code so explore options.
  - Go here to find a GUIDE program:
    - Enter your state.
    - Under models select 'Guiding an Improved Dementia Experience (GUIDE) Model'.
    - Click 'Display selected'.
    - You can use the plus and minus signs in the upper right corner to zoom in closer to your area.
    - When you find the location you want, click on the blue dot and detailed contact information will show.

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In the Beginning – continued

Next Steps - You are ready for more

7 Continue your education

Scan to view
Savvy Caregiver Course

Scan to view
Virtual Dementia Tour

Scan to view
Mayo Clinic Living with Dementia

8 Start planning for the next stage of care

Scan to listen
TCJ Podcast Episode 40. Create Your Personal Support Network

Scan to view
Memory Cafe Finder

Scan to view
Dementia/Respite (adult) Day Programs Finder

Scan to view
Home Safety Assessment

9 Investigate your government community support

Scan to view
Area Agency on Aging Eldercare.acl.gov

10 Evaluate driving risks

Scan to listen
TCJ Podcast Episode 5. Taking Away the Keys

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In the Beginning – continued

Next Steps - You are ready for more

7. Continue your education.

- Take the Savvy Caregiver course in person or online.
- Read this magazine:
  - Mayo Clinic Living with dementia: A guide to caregiving and support.
- Find and take a virtual dementia tour near you. In the United States, in your search engine, type 'virtual dementia tour' + 'your state'. For example: 'virtual dementia tour Florida' or, outside the US, replace your state with your country.

8. Start planning for the next stage of care.

- Build your personal support network:
  - 21 minute TCJ podcast: 40. Create Your Personal Support Network.
  - TCJ Blog: 40. Create Your Personal Support Network.
- Find and try a memory cafe (Caregivers and care receivers go together).
- Investigate dementia/respite day centers (also known as adult day centers that include dementia care programs) for your care receiver. Community resource finder:
  - Select Community Services and choose Adult Day Centers for your search.
- Ask your loved one's medical team for a home safety assessment:
  - The goal is to have someone evaluate your home for safety and dementia care needs.
  - This is usually available through palliative care, GUIDE program, or an order from a physician.
  - You can get a free assessment from social services with this order, or you can pay for an independent assessment from a private organization.

9. Investigate your local government community support.

- In the US, contact your local Area Agency on Aging. Search for yours at Eldercare.acl.gov or call 1-800-677-1116.
- Call and set up a screening for eligibility:
  - They will point you to any free government services where you are eligible.
  - Be sure to find out if you are eligible to get paid to be a caregiver.

10. Evaluate driving risks.

- Some US states have specific requirements for individuals with dementia to report their diagnosis and potentially undergo driving evaluations.
- Listen to this podcast or read this blog:
  - 21 minute TCJ podcast: 5. Taking Away The Keys.
  - TCJ Blog: 5. Taking Away The Keys.

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Messy Middle

First Steps - You are asserting more control

11 Focus on safety

Scan to listen
TCJ Podcast Episode 6.
Home Alone

Scan to listen
TCJ Podcast Episode 20.
Medication Management

Scan to listen
TCJ Podcast Episode 7.
Home Safety

Scan to listen
TCJ Podcast Episode 4.
Wandering

12 Focus on your self-care

Scan to listen
TCJ Podcast Episode 27.
The Realities of
Caregiver Self-Care

13 Educate yourself on activities of daily living (ADL's)

Scan to listen
TCJ Podcast Episode 9.
Preparing for Incontinence

Scan to listen
TCJ Podcast Episode 14.
Bathing and Dressing

Scan to listen
TCJ Podcast Episode 15.
Personal Care

Scan to listen
TCJ Podcast Episode 16.
Eating and Drinking

14 Create a Care Plan - at minimum a Family Emergency Plan

Scan to listen
TCJ Podcast Episode 33.
How to Create a Care Plan

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Messy Middle

First Steps - You are asserting more control

11. Focus on safety.

- Listen to these podcasts or read these blogs:
  - Home Alone - Hear about the deal breakers for living home alone:
    - 21 minute TCJ podcast: 6. Home Alone.
    - TCJ Blog: 6. Home Alone.
  - Medication - Understand strategies to safely manage medication:
    - 20 minute TCJ podcast: 20. Medication Management.
    - TCJ Blog: 20. Medication Management.
  - Home Safety - Find approaches to the basics of home safety:
    - 25 minute TCJ podcast: 7. Home Safety.
    - TCJ Blog: 7. Home Safety.
  - Wandering - Learn ways to manage three types of wandering: outside, inside and during the night:
    - 20 minute TCJ podcast: 4. Wandering.
    - TCJ Blog: 4. Wandering.

12. Continue to prioritize your self-care.

- Understand how to approach the realities of self-care:
  - 23 minute TCJ podcast: 27. The Realities of Caregiver Self-Care.
  - TCJ Blog: 27. The Reality of Caregiver Self-Care.

13. Educate yourself on activities of daily living (ADLs).

- Prepare for changes in your loved ones ability to manage their ADLs.
- Listen to podcasts or read these blogs on activities of daily living:
  - 26 minute TCJ podcast: 9. Preparing for Incontinence.
  - TCJ blog: 9. Preparing for Incontinence.
  - 21 minute TCJ podcast: 14. Bathing and Dressing.
  - TCJ blog: 14. Bathing and Dressing.
  - 21 minute TCJ podcast: 15. Personal Care e.g. brushing teeth, trimming hair
  - TCJ blog: 15. Personal Care.
  - 21 minute TCJ podcast: 16. Eating and Drinking.
  - TCJ blog: 16. Eating and Drinking.

14. Create a Care Plan - at minimum a Family Emergency Plan.

- 25 minute TCJ podcast: 33. How to Create a Care Plan.
- TCJ blog: 33. Creating a Care Plan.

Messy Middle – continued

Next Steps - It's time for more support

15 **Start leveraging dementia/respite (adult) day programs**

Scan to view Community Resource Finder

16 **Start thinking about professional help**

Scan to listen TCJ Podcast Episode 28. Home and Community Living Options

Scan to view Potentially Leverage a Senior Care Advisor

Scan to listen TCJ Podcast Episode 32. Hiring a Paid Caregiver

Scan to view Home Care and Communities Finder

Scan to listen TCJ Podcast Episode 70. Choosing the Right Memory Care Community

Scan to view Memory Care Community Checklist

17 **Continue your education**

Scan to view Savvy Caregiver Advanced Course

Scan to listen TCJ Podcast Episode 23. Delusions

Scan to listen TCJ Podcast Episode 10. Incontinence Begins

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Messy Middle – continued

Next Steps - It's time for more support

15. Start or increase leveraging dementia/respite (adult) day programs.

- Community Resource Finder:
  - Select Community Services and choose Adult Day Centers for your search.

16. Start thinking about professional help.

- Educate yourself:
  - Evaluate communities (even if you never plan to use one) just in case:
    - 33 minute TCJ podcast: 28. Home and Community Living Options.
    - TCJ blog: 28. Home and Community Living Options.
    - 22 minute TCJ podcast: 70. Choosing the Right Memory Care Community.
    - TCJ blog: 70. Choosing the Right Memory Care Community.
    - Leverage this Memory Care Community Checklist.
  - Understand the types of paid caregivers:
    - 26 minute TCJ podcast: 32. Hiring a Paid Caregiver.
    - TCJ blog: 32. Hiring a Paid Caregiver.
- Find an organization to help. Search online: 'Senior Care Advisor' + 'your area'.
- Look for options yourself. Go to the Community Resource Finder sponsored by the Alzheimer's Association and AARP.

17. Continue your education.

- Take the Savvy Caregiver Advanced training (this can be taken in-person or virtually).
- Delusions:
  - 38 minute TCJ podcast: 23. Delusions.
  - TCJ blog: 23. Delusions.
- Incontinence:
  - 26 minute TCJ podcast: 10. Incontinence Begins.
  - TCJ blog: 10. Incontinence Begins.

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Later On

You are now managing all aspects of their care

18 Pre-plan for end of life

Scan to listen
TCJ Podcast Episode 30.
End of Life Service Preplanning

Scan to view
End of Life Service
Planning Worksheet

Learn about Anticipatory Grief

Scan to read
How To Manage Mourning
a Loss Before It Happens

19 Engage hospice

Scan to listen
TCJ Podcast Episode 29.
When To Call In Hospice

20 Honor Your Grief and Navigate Death-Related Responsibilities

Scan to listen
TCJ Podcast Episode 47.
Navigating Grief Throughout Caregiving

Scan to listen
TCJ Podcast Episode 49.
Navigating Death-Related Responsibilities

Scan to view
TCJ Death-Related
Responsibilities Worksheet

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Later On

You are now managing all aspects of their care

18. Pre-plan for end of life.

- You may have pre-planned an end of life service with your loved one just after their diagnosis. If not, do this without them now.
  - 26 minute TCJ podcast: 30. End of Life Service Preplanning.
  - TCJ blog: 30. End of Life Service Preplanning.
  - Leverage this End of Life Service Worksheet.
- Learn about Anticipatory Grief.
  - Read this AARP article:
    - How To Manage Mourning a Loss Before It Happens.

19. Engage hospice.

- If you are not working with palliative care or a US Medicare GUIDE program organization (both of these are able to tell you when it's time to call in hospice):
  - Find a hospice organization.
  - Get a doctor's referral.
  - Schedule an initial evaluation. It's almost never too early to get the initial evaluation, so don't wait.
- Search 'hospice' + 'your country' - or in the US - 'your state'. Scroll down until you get below the sponsored links where it says 'Places':
  - Click on 'More places' to get a list with a map.
  - Notice rating stars and those located around your area.
  - Schedule an initial consultation with two so you can compare.
- Educate yourself on when to call in hospice:
  - 26 minute TCJ podcast: 29. When To Call In Hospice.
  - TCJ blog: 29. When To Call In Hospice.

20. Honor your grief and navigate death-related responsibilities.

- Honor your grief, be compassionate with yourself, reach out for support:
  - Each of us navigates the loss of our loved one in our own time and way.
- If you feel lost, reach out to your family, support group, faith community, friends, professionals. Most importantly - reach out!
  - 25 minute TCJ podcast: 47. Navigating Grief Throughout Caregiving
  - TCJ Blog: 47. Navigating Grief Throughout Caregiving
- Navigate death-related responsibilities:
  - 27 minute TCJ podcast: 49. Navigating Death-Related Responsibilities
  - TCJ blog: 49. Navigating Death-Related Responsibilities
  - Leverage this Death-Related Responsibilities Worksheet.

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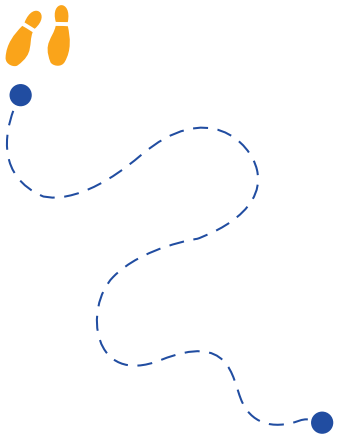
The Caregiver's Journey®

Finally! Practical Tips and Candid Conversations
for Alzheimer's and Dementia Family Caregivers

Free resources at
www.thecaregiversjourney.org

Interactive webpage
and downloadable guide at



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