Leading the Team

A Legal and Financial Guide and Workbook for Caregivers of Someone with Dementia





Attorney Mark T. Johnson has prepared this guide and workbook for general informational purposes. Please consult an attorney for legal advice for your particular situation.



2924 Marketplace Drive, Suite 102 Fitchburg, WI 53719

> Phone: 608-273-8609 Website: jtlawwi.com

Disclaimer: The information in this guide is not legal advice. Do not act on this information without the advice of professional legal counsel, who must discuss with you your specific circumstances and wishes before giving you legal advice.

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Leading the Team

Introduction



You are reading this guide because someone you know has dementia. Perhaps you are a family member of someone with dementia—their spouse, child, sibling, or parent. Perhaps you are a friend or neighbor. You may be a professional caregiver, like a doctor or nurse; or you may be a trusted advisor, like an attorney or financial advisor.

This guide may be particularly important to you if you have primary responsibility for providing or coordinating care for your loved one with dementia. You may be the leader of several personal and professional helpers who form a team of support. A companion guide—Building Your Team—has been prepared to assist individuals living with dementia.

This guide covers the following topics:

- Identifying the various team members
- The team for personal decisions
- The team for health decisions
- The team for financial decisions
- The team for final wishes
- Autonomy and protection
- Decision makers appointed by a court
- Capacity to make decisions
- Resources

This guide describes topics for support and assistance. However, in nearly all cases, the individual with dementia will be the one making their own choices and plans. With early planning, the individual with dementia and their team can consider the options, discuss, plan, and revisit as needed.

This guide is written with references to Wisconsin law, so please keep in mind that there may be numerous ways it will not apply in other states.

Identifying the Various Team Members



Who is the team?

- Who is currently helping with various decisions and tasks?
- Are additional helpers needed now?
- As dementia advances, who will help?

Team requirements:

- Skills for particular tasks or assistance
- Time to help as the need arises
- Will payment be necessary?
- How will team members communicate and coordinate their efforts?

Recruiting the team:

- Personal relationships:
 - o Family
 - o Friends
 - Neighbors
- Professional relationships:
 - Financial Advisor
 - Accountant
 - Lawyer
 - o Doctor
 - Care provider

And, one more valuable team member: Time

- Time allows for planning and updates to the plan.
- Phases of dementia—mild, moderate, and advanced—determine the individual's ability to make decisions and plans.

The Team for Personal Decisions

Who will help with personal decisions?

- What is the most suitable living arrangement?
 - Single-family dwelling
 - Apartment or condo
 - Assisted living facility
 - o Is help needed for moving or down-sizing?
- Who will help with pet care?
 - Feeding
 - Veterinary care
 - Walking and exercise
- Who will help maintain social activities?
 - Relatives and friends
 - Religious community
 - Clubs, senior centers, and community centers
- Who will assure safety at home and when traveling?

Legal advice and documents for personal decisions

- A. Trusted advisors—family, friends, clergy, attorney, financial planner, daily money manager
- B. Supported decision-making agreement
- C. Durable power of attorney for finances

A supported decision-making agreement is a formal document to designate someone to help with gathering information, making a decision based on that information, and communicating the decision. A supporter is not a substitute decision maker, power of attorney, or guardian. For more information, the website for the Wisconsin state form for a Supported Decision-Making Agreement is listed in the Resources on page 12.



The Team for Health Decisions

Who will help with health care decisions?

- Participating in care and medical needs
- Dealing with health insurance—Medicare, supplemental insurance
- Arranging help at home
 - Home modifications for accessibility and safety
 - In-home care or services
- Dealing with insurance or programs that help pay for care
 - Long-term care insurance
 - Medicare and Medicaid benefits
 - Veterans Affairs benefits
- Working with staff at a care facility
- Advocating for appropriate medical treatment or services
- Making end-of-life decisions

Legal advice and documents for health care

- A. Supported decision-making agreement
- B. Health care power of attorney
- C. Living Will
- D. Contracts or applications for admission to facilities or care programs
- E. Authorization for release of protected health information (HIPAA release)

A health care power of attorney can take a variety of forms. Some popular versions are the Wisconsin state form, Five Wishes, and Honoring Choices. For more information, the websites for each of these options are listed in the Resources on page 12.

The Team for Financial Decisions

Who will help with financial decisions?

- Shopping
- Paying bills
- Banking
- Investing
- Tax planning
- Dealing with insurance companies
- Managing property—arranging for repairs, paying taxes, hiring lawn care
- Managing income—Social Security, pension, investment income
- Paying for living expenses and care needs:
 - O What can income and assets pay for?
 - o Is there insurance that will cover some of the cost?
 - O Does a reverse mortgage make sense?
 - Are government programs available, such as Medicaid or Veterans Affairs programs?

Legal advice and documents for finances

- A. Durable power of attorney for finances
- B. Revocable living trust
- C. Representative payee (for Social Security payments)
- D. Care contracts with caregivers or service providers, even if they are family members

A financial power of attorney is a legal document to name one or more people or entities to manage finances and property. It can be effective right away for convenience or become effective only upon incapacity. It can cover one or two specific topics or cover all general financial matters. Advice from an attorney is strongly recommended if you wish to include power to make gifts or change how property is owned.

The Team for Final Wishes

Who will help with carrying out final wishes?

- End-of-life wishes
 - setting for final days
 - visitors
 - o feeding tube and life support
 - extraordinary measures
 - o religious observances
- Wishes for burial, cremation, or funeral
 - O What needs to be done?
 - O Who will decide?
 - O Who will do it?
- Plans to distribute the estate after death
 - o Will
 - Revocable living trust
 - Other non-probate transfers:
 - beneficiary designations
 - joint ownership
 - transfer-on-death
 - pay-on-death

Legal advice and documents for final wishes

- A. Living will for end-of-life medical decisions
- B. Authorization for Final Disposition for burial, cremation, or funeral wishes
- C. One or more of the following: will, trust, non-probate transfers



Autonomy and Protection

- Personal autonomy is highly valued—We all want our personal choices, preferences, and independence to be respected.
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- However, an individual may become vulnerable to other people taking advantage of them or abusing them.
 - o Scams
 - Stealing
 - Physical or sexual abuse
 - o Bullying, threats, or verbal abuse
- Having a good team in place and complete legal documents can help preserve an individual's autonomy and protect them from abuse.
- Planning early gives the individual maximum input for expressing their wishes.
- Unforeseen circumstances or a lack of planning may lead to intervention by family members, medical providers, government agencies, or courts to protect the individual's wellbeing.

Legal advice and documents for autonomy and protection

Listed from most autonomy/least protective to least autonomy/most protective

- A. Supported decision-making agreement
- B. Health care power of attorney
- C. Durable power of attorney for finances
- D. Revocable living trust
- E. Trusted contact person for financial institutions
- F. Conservatorship (voluntary court proceeding)
- G. Guardianship (involuntary court proceeding)

Decision Makers Appointed by a Court

Voluntary—Conservatorship

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Wisconsin law allows an individual to voluntarily request a court to appoint a financial decision maker. If someone believes they cannot manage their own financial affairs, the individual can petition the county court to appoint a **conservator** for their finances. The court does not declare the person incompetent, which is the main distinction from guardianship. The conservator will have power similar to a guardian of the estate. A conservatorship can only be ended with court approval.

A conservator is not authorized to make healthcare decisions, so the individual will need a healthcare power of attorney to name someone to make health care decisions if the person becomes unable to make their own health care decisions.

Involuntary—Guardianship

If a person does not have powers of attorney, and then becomes incapacitated, a guardianship may be necessary for a court to appoint a guardian to make decisions.

Guardian of the estate is a person appointed to manage financial matters, and **guardian of the person** is a person appointed to manage health and personal decisions. The person under guardianship is the **ward**. If the court determines that an individual is incompetent (based largely on the report or testimony of the examining doctor), the court appoints the guardian to make decisions on the ward's behalf.

In most guardianships, the court restricts or removes the ward's rights to act independently. The court gives the guardian most of those rights to exercise in the ward's best interest. The guardian may exercise only those powers authorized by the court. The guardian is under ongoing court supervision and must file annual reports regarding the ward's well-being and financial accounts. If anyone wishes to modify or terminate the guardianship, court approval is required.

Guardianship has pros and cons for those seeking this type of court-appointed authority. Pros include protecting the ward from serious mistakes or financial exploitation and providing certainty that decisions are made by a suitable substitute decision-maker. Cons include the expense of fees for obtaining a guardianship, plus the additional cost in time and energy to appear in court and file annual reports.

Capacity to Make Decisions

 An individual with a cognitive impairment may ask, "Will my doctor or a judge declare me incompetent?"



- Capacity is a fluid concept. It can diminish over time and can have ups and downs at certain stages of dementia.
- Time is a powerful component of making decisions and signing legal documents.
 A person with mild dementia usually has the capacity to make decisions and to understand and sign legal documents to prepare for future incapacity.
- In some cases, the additional input from medical professionals will help an attorney or other advisor determine whether an individual has the necessary capacity to make legal or financial decisions.

Legal definitions:

- A. In general, **incapacity** is defined as the inability to receive and evaluate information effectively or to communicate decisions.

 Incapacity for health care decisions and for financial decisions may be separate determinations.
- B. A health care power of attorney takes effect upon a finding of incapacity by two physicians or by a physician and a psychologist, who personally examine the individual and sign a statement specifying that the individual has incapacity. For a financial power of attorney, one physician or psychologist may determine incapacity. Alternatively, a power of attorney document may state a different event or occurrence to establish incapacity.
- C. For purposes of guardianship, a person must be incapacitated, plus the incapacity must cause the individual's personal or financial wellbeing to be at risk. This is the basis for a judge to determine a person is **incompetent**.
- D. Further details regarding legal incapacity and incompetency are specifically spelled out in the Wisconsin Statutes related to these subjects.

Resources



- 1. The Wisconsin Department of Health Services provides state forms for health care power of attorney, financial power of attorney, declaration to physicians (living will), and authorization for final disposition: https://www.dhs.wisconsin.gov/forms/advdirectives/adformspoa.htm
- The Wisconsin Department of Health Services provides a state form for supported decision-making agreements: https://www.dhs.wisconsin.gov/library/f-02377.htm
- 3. The website for Five Wishes (for health care advance directives) is www.fivewishes.org
- 4. The website for Honoring Choices Wisconsin (for health care advance directives) is www.wisconsinmedicalsociety.org/professional/hcw/
- 5. The National Academy of Elder Law Attorneys (NAELA) provides information about attorneys who practice in the areas of elder law and special needs planning: www.naela.org.
- 6. The Alzheimer's Association provides information for individuals with dementia and their families and caregivers, including publications and events for financial and legal matters: www.alz.org.
- 7. The Alzheimer's & Dementia Alliance of Wisconsin has numerous resources and event available throughout Wisconsin: www.alzwisc.org.
- 8. The Eldercare Locator, a service of the U.S. Administration on Aging, provides information about local agencies that can assist senior citizens, plus has numerous brochures and factsheets under its "Consumer Publications" section: https://eldercare.acl.gov/Public/Index.aspx.