Making the Most of Today
A Guide to Caring for Your Loved One with Dementia
Care Dimensions Dementia Support Program

Though dementia may dim memories and make communication frustrating, the disease can never steal your loved one’s identity. At Care Dimensions, we focus on individuals – respecting their place in the world and honoring life before and after dementia took its toll.

Our Dementia Support Program tailors personalized care plans for hospice patients, whether they are experiencing moderate dementia or severe symptoms, to maximize each patient’s comfort and quality of life. We meet the needs of the whole person – physical, cognitive, spiritual and emotional – while supporting, relieving and preparing caregivers. While tomorrow may be uncertain for patients with Alzheimer’s disease and other dementias, we help you make the most of today.

MULTIDIMENSIONAL CARE

Our Dementia Support Program offers a much-needed layer of assistance to patients, reducing hospitalizations and emergency room visits and instilling calm and confidence in caregivers. Our Dementia Support Program offers:

- Pain and symptom management, providing relief even when patients cannot articulate pain
- 24/7 medical, emotional and spiritual support
- Experienced hospice aides specially trained to work with cognitively-impaired patients
- Kaplan House and the Care Dimensions Hospice House (opening January 2018) for respite care or acute symptom management to avoid hospitalizations
- Medication and equipment management
- Help transitioning from home to residential care
- Emotional and spiritual support
- Trained volunteers to provide support and companionship
- Caregiver education
- Complementary therapies, such as Reiki, art, music and pet therapy
- Grief support

OUR DEMENTIA TEAM

Care Dimensions helps patients and caregivers communicate needs, navigate the health care system and plan for the future. All Care Dimensions clinical staff receive a 13-hour training program developed by the Alzheimer’s Association of MA/NH that includes topics such as communication skills, understanding how the physical environment can make a difference, how to use activity and purposeful engagement with patients, how behavior can be a way to communicate, and understanding and working with families.
Understanding Dementia

You may feel unsure or confused about how to care for a person with dementia. You are not alone. This is a common feeling among caregivers as each person with dementia has a different set of challenges, and each day brings new difficulties as the disease progresses and the person exhibits new patterns of behavior and abilities. By learning the basics of dementia, you will be better able to understand and cope with the ongoing challenges.

Dementia is the general term for a set of diagnoses that include Alzheimer’s disease, vascular dementia, Lewy body dementia, frontotemporal lobe dementia, and Parkinson’s dementia. These diagnoses lead to gradual and progressive brain damage. Dementia also refers to the set of common symptoms for these diagnoses, such as confusion, memory changes, language difficulty, disorientation, and difficulty completing tasks, as well as changes in personality or mood.

MILD OR EARLY STAGE

The person with dementia, regardless of the actual cause, will progress through three stages of the disease. The person may have some memory loss (usually recent) and small changes in their personality. They may have difficulty solving simple math problems or balancing their checkbook. They may also have trouble planning or organizing. A simple task like making a grocery list becomes overwhelming. Most issues in the early stages can be covered up by the person.

MIDDLE OR MODERATE STAGE

This stage is where the memory loss and confusion become obvious. Planning, organizing, and following instructions becomes challenging. The person may have some memory loss (usually recent) and small changes in their personality. They may have difficulty solving simple math problems or balancing their checkbook. They may also have trouble planning or organizing. A simple task like making a grocery list becomes overwhelming. Most issues in the early stages can be covered up by the person.

SEVERE OR LATE STAGE

Dementia is a terminal disease. People with this stage of the disease will be dependent on others for care, and may or may not be able to walk or sit up. They may not be able to talk or will jumble their words, and often do not recognize family members. Difficulty swallowing can become an issue and they will refuse to eat. It is important to remember that every person is different and that each stage can blur into the next, but the general pattern is the same.

AN EXTRA LAYER OF SUPPORT

Our Dementia Support Program is designed to provide additional support to family or professional caregivers. To facilitate communication and ease the transition of care, the social worker on your hospice team will complete a comprehensive assessment with the family to inform the clinical team and volunteers about how best to communicate and work with the patient. Questions include:

- What are the most effective communication techniques?
- What does he/she find calming and relaxing?
- What does he/she find upsetting?
- Does he/she have favorite books or music?
- Are there special subjects he/she likes to discuss?

A critical component of the dementia program is our cadre of specially trained volunteers. Volunteers receive additional training and complete a Dementia Live training, in which they wear apparatus to simulate the experience of a person with dementia while they try to do tasks and follow directions. This training helps them understand and become sensitive to the physical and mental challenges that a patient with dementia experiences. They also carry a bag of supplies to help them engage with patients in non-verbal ways.

To request a specially trained volunteer, please speak with your social worker or nurse.
Communication Tips

A person with dementia has difficulty remembering things and struggles to find words to express what they want to say. They also have difficulty understanding what you are saying. This often makes communication challenging and frustrating for caregivers. Communication problems you may see are:

- Trouble finding the right word
- Difficulty understanding what words mean
- Unable to pay attention
- Losing train of thought in a conversation
- Trouble remembering steps in common activities such as getting dressed
- Becoming distracted by background noises such as the television
- Sensitivity to touch or tone and loudness of voice
- Frustration if their communication is not working or being understood
- Using another language if English was learned as their second language

Try these simple tips to help you communicate with your loved one.

**DO:**

- Call the person by name.
- Tell the person who you are, if there is any doubt.
- Remain calm and pay attention to your posture, facial expressions, eye contact, and tone of voice. If you seem impatient or upset when giving directions, your loved one may think you are angry and refuse to cooperate.
- Try to remember that the person can’t help their condition or control their behavior.
- Make the person feel safe rather than stressed.
- Take a short break if you feel your fuse getting short.
- Try to remember that the person can’t help their condition or control their behavior.
- Keep communication short, simple and clear. Give one direction or ask one question at a time.
- Speak slowly. The person may need more time to process what you said.
- Use closed-ended questions, that are easier to process and answer with yes or no. For example, ask, “Did you enjoy the beef at dinner?” instead of “What did you have for dinner?”
- Find a different way to say the same thing if it wasn’t understood. Try a simpler statement with fewer words. Add gestures to match your words like eating or brushing teeth.
- Use distraction or “fiblets” if telling the whole truth will upset the person. For example, to answer the question “Where is my Mother?” it may be better to say, “she’s not here right now,” instead of “she died 20 years ago.”
- Use repetition as much as necessary. Be prepared to say the same thing over and over as the person may not recall things for more than a few minutes at a time.
- Minimize distractions and noise – such as the television or radio – to help the person focus on what you are saying.

**DO NOT:**

- Say things like: “Do you remember?”, “Try to remember!”, “Did you forget?”, “How could you not know that?”
- Ask questions that challenge short-term memory such as, “Do you remember what we did last night?” The answer will likely be “No,” which may be humiliating for the person with dementia.
- Talk in paragraphs. Instead, offer one idea at a time.
- Point out the person’s memory difficulty. Avoid remarks such as, “I just told you that.” Instead, just repeat it over and over.
- Talk in front of the person as if they were not present. Always include them in a conversation if they are physically present.
- Use vague directions. For example, instead of “sit there” try “sit in the blue chair.”
- Talk to the person like a baby or continually correct them.
AROMATHERAPY: USING SCENTS TO IMPROVE WELL BEING

Pleasant fragrances may subtly trigger the release of natural hormones in the brain, enabling people to feel uplifted. Below are oils that may be effective in treating and controlling different symptoms of dementia:

1. **Lavender**
   - Lavender is thought to be calming and help to balance strong emotions. It can be used to help with depression, anger and irritability, and insomnia. Lavender can be directly inhaled, used as a massage oil or sprayed on linens.

2. **Peppermint**
   - Peppermint is an energizer and can be used to stimulate the mind and calm nerves at the same time. Best used in the morning, peppermint oil can be inhaled directly, diffused in a room, used as a massage oil, sprayed in the air or even placed in a bath.

3. **Rosemary**
   - Similar to peppermint, rosemary is an uplifting oil used to stimulate the mind and body. Rosemary may ease constipation and symptoms of depression, reinvigorate appetite, and improve mood. Rosemary oil can be directly inhaled, diffused through a room, or used as a spray.

4. **Bergamot**
   - Bergamot can be used to relieve anxiety, agitation, mild depression and stress. This mood elevating and calming oil can also be used to relieve insomnia. To use bergamot oil, place a few drops in a bath, use as a massage oil, diffuse through a room, or spray on clothing or linens.

5. **Lemon Balm**
   - Lemon balm is one of the most studied and effective oils. It has been shown to help calm and relax those with anxiety and insomnia, improve

Sensory Experiences for Relaxation and Connection

HAND MASSAGE TECHNIQUES

Many people suffering from dementia also experience sensory deprivation. Touch is the first sense to develop and the last to fade. A touch of any kind can lower heart rate and blood pressure and stimulate the release of endorphins (the body's natural pain killers). A gentle hand massage given during light conversation has shown to improve appetite within an hour. It can also provide relief from anxiety, depression and pain. Massage serves as a way to remain connected and encourages feelings of tenderness and closeness for those who may not otherwise be able to communicate.

Below are simple hand massage instructions. Using hand lotion with a pleasing scent can also enhance the sensory experience.

1. **Hand and Arm Massage**
   - Start by placing your thumbs, one above the other, at the base of the fingers. Move upwards in circular movements with the cushions of your thumbs. Using a continuous action, move slowly towards the elbow, sliding back hands firmly down to the base of fingers. Repeat 3 or 4 times.

2. **Wrist Twisting**
   - Grip the wrist with both hands in opposite direction, one above the other. With light pressure, move hands firmly back and forth around the wrist in opposite directions. Repeat several times on both hands.

3. **Hand Relaxation**
   - Starting at the base of the little finger, rotate with small movements continually upward along the bone from the knuckles to the wrist. Maintain contact and slide back down to the next finger, continuing to the thumb.

4. **Elbow Circles**
   - Hold right hands together and rest elbow in opposite hand. While firmly gripping hands, rotate the elbow without any discomfort as far as possible. Repeat several times with both arms.

5. **Wrist Circles**
   - Holding the hand the same as the previous technique, hold the lower arm with the opposite hand. Rotate the wrist one way several times, and then in the opposite direction. Repeat several times with both hands.

6. **Finger Circles**
   - Holding the wrist in your opposite hand, hold the fingers, one at a time, at the tip and rotate 6 or 7 times. Rotate all fingers 2 or 3 times each.

7. **Finger Massage**
   - Starting at the base of the thumb, rotate with firm movements slowly towards the finger tip end. Repeat the same movement on each finger 3 or 4 times.
memory and ease indigestion. Lemon balm can be dropped into a bath, inhaled directly, diffused, sprayed or applied directly to the skin as a massage oil.

6. **Ylang Ylang** - Ylang Ylang oil can help ease depression while also promoting good sleep. Ylang Ylang is often combined with lemon balm and can be placed in a bath, inhaled, diffused or sprayed.

7. **Ginger** - Ginger oil is helpful for anyone struggling with digestion issues. Commonly used to treat a loss of appetite and constipation, ginger can help promote good eating habits. Ginger oil can be applied directly to the skin as an abdominal massage, inhaled, diffused, sprayed, or placed on a compress.

8. **Sweet Orange** - Sweet orange oil has an uplifting, cheerful and refreshing effect. It is used to relieve anxiety, moodiness, nervousness and frustration. It can also aid in digestion, stimulate appetite and help with water retention. It can be inhaled, placed in a bath or sprayed in a room.

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**Keeping Active and Engaged**

Finding activities that a person with dementia can do and is interested in can be challenging. Activities can help maintain functional skills, enhance feelings of personal control and allow the person to feel busy and involved. Simple activities are best, especially when they use current skills. Below are 101 ideas to get you started.

1. Clip coupons
2. Sort poker chips
3. Count tickets
4. Rake leaves
5. Use the carpet sweeper
6. Read out loud
7. Bake cookies
8. Look up names in the phone book
9. Read the daily paper out loud
10. Ask someone with a child to visit
11. Listen to music
12. Plant seeds indoors or out
13. Look at family photographs
14. Toss a ball
15. Color pictures
16. Make homemade lemonade
17. Wipe off the table
18. Weed the flower bed
19. Set the table with silverware
20. Have a spelling bee
21. Put away the dishes
22. Fold clothes
23. Have a friend visit with a calm pet
24. Cut pictures out of greeting cards or calendars
25. Wash silverware
26. Bake homemade bread
27. Sort objects by shape or color
28. Sing old songs
29. “Tell me more” memory review
30. Put silverware away
31. Make a Valentine collage
32. Play favorite songs and sing
33. Take a ride
34. Bake a favorite dessert
35. Read aloud from a magazine
36. Play checkers
37. Match and roll socks
38. Take a walk
39. Reminisce about 1st day of school
40. String Cheerios to hang outside for birds
41. Make a fresh fruit salad
42. Sweep the patio
43. Color paper shamrocks green
44. Fold towels
45. Have afternoon tea
46. Remember great inventions
47. Play Pictionary
48. Paint with watercolors
49. Cut out paper dolls
50. Identify states and capitals
51. Make a family tree poster
52. Color a picture of our flag
53. Use a fidget quilt to keep hands busy
54. Watch a travel video of a favorite place
55. Water house plants
56. Reminisce about the first kiss
57. Play horse shoes
58. Dance
59. Sing favorite hymns
60. Make homemade ice cream
61. Force bulbs for winter blooming
62. Make Christmas cards
63. Sort playing cards by their color
64. Write a letter to a family member
65. Dress in your favorite football team’s color
66. Pop popcorn
67. Name the Presidents
68. Give a manicure
69. Make paper butterflies
70. Plant a tree
71. Write down favorite family stories
72. Make homemade applesauce
73. Finish famous sayings
74. Feed the ducks
75. Mold with Play Dough
76. Look at pictures in National Geographic
77. Put a puzzle together
78. Sand wood
79. Rub in hand lotion
80. Decorate paper placemats
81. Arrange fresh flowers
82. Remember famous people
83. Straighten out underwear drawer
84. Finish nursery rhymes
85. Make peanut butter sandwiches
86. Wipe off patio furniture
87. Cut up used paper for scratch paper
88. Look at a picture book of a favorite topic (animals, travel)
89. Trace and cut out leaves
90. Ask simple trivia questions
91. Finish Bible quotes
92. Finger paint
93. Cut out pictures from magazines
94. Read classic short stories
95. Put coins in a jar
96. Sew buttons on fabric
97. Put bird feed out for the birds
98. Clean out a pumpkin
99. Reminisce about a favorite summer
100. Roll yarn into a ball
101. Make a birthday cake
Safety Precautions

WHAT DO I NEED TO KNOW ABOUT HOME SAFETY?
As a caregiver, you face the challenge of making the environment inside and outside safe for your loved one. To complicate matters, the symptoms of dementia vary from person to person. As the disease progresses, your loved one will have increasing difficulty remembering, thinking, processing and reasoning. These changing symptoms require families to adjust the living situation to meet their loved one’s current needs and abilities.

Generally, have a plan with emergency numbers close at hand, assure the home is well lit, remove trip hazards such as scatter rugs, have working fire extinguishers and smoke detectors, and adjust water temperatures that may be too hot or cold.

TOP SAFETY CONCERNS

Burn and Fire Safety
Your loved one may experience a loss of or decreased sense of touch. They may not be able to feel heat, cold, and even discomfort. They also may have a decreased ability to remember what to do in case of a fire.

Driving
Many individuals in the early stages of memory loss can and do drive. However, as dementia and memory loss progresses, the person’s ability to react and make appropriate decisions decreases and they lose the ability to drive a vehicle safely. Develop a proactive plan to gradually retire a person’s driving (dependent on their current abilities).

Falls and Slips
Falls are the number one safety concern among the elderly. Falls are even more of a concern for people with dementia or memory impairment because of decreased spatial perception. Keep the living environment clutter-free, remove throw rugs, and secure electrical cords.

Guns and Knives
It is strongly advised that guns, knives and other weapons be removed from the home of anyone with dementia. Having access to a gun or knife may increase the chances of the person with dementia harming himself/herself or causing a tragic accident if a friend or family member is mistaken for an intruder.

Medications
People with dementia are at an increased risk of making medication errors. As the caregiver, your role in managing medications will increase significantly as the dementia symptoms progress. Some tips to help you:

- Use a pill organizer box, medication list or calendar to assure all medications are taken
- Develop a daily routine or ritual to taking medications, such as with breakfast or at bedtime
- Give simple instructions such as, “Here is your medicine for high blood pressure.”
- If the person refuses to take the medication, try again later
- If swallowing is an issue, ask if the medication is available in another form
- Keep medications locked up and destroy unused medications to avoid accidental overdose
- Keep emergency numbers easily accessible

Poisons and Hazardous Material
As dementia progresses, memory loss increases and judgment is impaired. Your loved one could mistake a poisonous or hazardous product, such as everyday cleaning materials, for something to eat or drink. Keep cleaning materials stored in a separate area from food and beverages and consider locking or installing alarms on cabinets with such materials. Refrigerators can also pose potential threats, including glass jars or raw meat. Consider installing latches out of view to limit access.

Scams, Fraud, Crime
Because of memory loss and impaired judgment, people are at a higher risk for being victims of scams, fraud and crime. Although you may not be able to protect your loved one from all scams or intruders, you can take some basic precautions:

- Put up a “no solicitation” sign on the outside entrance
- Register your loved one’s phone number with the national “Do Not Call” Registry (1-888-382-1222)
- Remove the person’s name from the credit bureau’s mailing list. Call the Consumer Credit and Reporting Industry at (1-888-567-8688)
- Monitor or limit access to mail, credit cards and bank accounts

Wandering (Getting Lost)
The majority of people with dementia will wander or become lost at some point. Most individuals who wander have an increased risk of wandering more than once. Prevent wandering by:

- Maintaining a daily routine to provide structure
- Identifying the time the individual is most likely to wander and plan activities for that time
Reassuring the person if they feel lost or abandoned. Use phrases such as “We are safe and I am staying with you,” or “We can go home in the morning after a good night’s rest.”

Ensuring basic needs are met, so they don’t go in search of a bathroom or food

Avoiding busy confusing places like a grocery store or a mall

Installing locks or bolts high or low on exterior doors to prevent exit

Hiding doors and cabinets by painting them the same color as the walls or covering them with curtains and using child-proof locks

Keeping car keys out of sight

Ensuring good lighting to the bathroom at night

Maintaining constant supervision at home and out in the community

If your loved one does wander and becomes lost, have a plan in place.

Keep a list of people you can call for help.

Call neighbors, friends and family to have them on the lookout for the person and to call you if they see them.

Know your neighborhood and its hazards, such as bodies of water, dense trees and bushes, stairwells, tunnels and bus stops.

Is the person right- or left-handed? Wandering generally follows the direction of the dominant hand.

Know and keep a list of favorite places: parks, restaurants, churches, work places and friends’ homes.

Consider having the person wear an alert or GPS device.

If the person does wander, search the immediate area for no more than 15 minutes and then call the police (911). Give the police any helpful information such as height, weight, hair and eye color and what they were last wearing. A photograph would also be helpful.

LEAVING YOUR LOVED ONE ALONE

Leaving your loved one alone is a difficult decision that needs careful thought. Consider the following:

Does the person with dementia:

- Become confused or unpredictable under stress?
- Recognize a dangerous situation such as fire?
- Know how to use a telephone in an emergency?
- Know how to get help?
- Stay content within the home?

- Show signs of agitation, depression or withdrawal when left alone for any period of time?
- Attempt to do any former interests or hobbies that might now require supervision, such as cooking, woodworking or electronics/appliance repair?

Ask your Care Dimensions’ nurse or social worker and your doctor to assist you in your decision and review it often based on your loved one’s changing condition and needs.

Taking Care of Yourself

Caring for a person with dementia comes with many responsibilities and can be overwhelming. The best thing you can do for the person you care for is to stay physically and emotionally strong and manage your stress level.

THE 10 SIGNS OF CAREGIVER STRESS:

1. Denial about the disease and its effect on the person who has been diagnosed
2. Anger at the person with dementia, that no cure exists, that people don’t understand what’s happening
3. Social withdrawal from friends and activities that brought pleasure in the past
4. Anxiety about the future
5. Depression that begins to break your spirit and affects your ability to cope
6. Exhaustion that makes it impossible to complete daily tasks
7. Sleeplessness brought on by your endless list of concerns and tasks
8. Irritability that leads to moodiness and triggers negative responses
9. Inability to concentrate or focus making every task an effort
10. Health problems beginning to become worse and making you feel unhealthy

CARING FOR YOURSELF

1. See your doctor. Visit your physician at least annually and listen to what your body is telling you. Any exhaustion, stress, sleeplessness or changes in your appetite or behavior should be taken seriously. Report these symptoms to your physician immediately. If you ignore these symptoms your physical and mental health could begin to decline.

2. Get Moving. Exercise can help relieve stress, prevent disease and make you feel good, but finding the time for it while caring for a loved one may be difficult.

Try these tips: Take family and friends up on their offers to help. Just 30 minutes will give you a good workout whether it’s a walk or something more.
Start small - even 10 minutes a day helps. Fit in what you can and work towards a goal. Yoga and stretching, a stationary bike or exercise tapes are all a good beginning.

There are things you can do with your loved one with dementia that will keep you both active. Take a walk outside together and enjoy the fresh air. Try seated exercises at home or dance to favorite music. Gardening in the good weather is great exercise for you both and will produce results you can both watch.

3. **Eat well.** Good eating habits will keep both of you healthy! A diet balanced in whole grains, fruits, vegetables, fish, nuts, olive oil and healthy fats such as the Mediterranean Diet is good for overall health.

4. **Make time for yourself.** Stay connected to family, friends and activities that you love. Even 30 minutes a week set aside for yourself will improve your well-being.

5. **Learn and use relaxation techniques.** Visualization, massage, meditation and breathing exercises are just a few ways to help you relax. Talk with your team nurse and social worker for more suggestions.

6. **Get Help!** You can’t do this alone; seek support from friends, family and caregivers who are going through similar situations. Tell others exactly how they can help you. Locate a local support group; many adult day health centers, local hospitals and nursing homes have them.

7. **Become an educated caregiver.** As time progresses, your loved one’s condition will change, making it necessary for you to learn new caregiver skills. Your Care Dimensions hospice team can help you to better understand and cope with the personality, behavior and functional changes that happen with dementia. Care Dimensions offers a caregiver support group the second Monday of every month.

8. **Know what resources are available.** Services like adult day health programs, private duty assistance or Meals on Wheels can help you manage daily tasks or give you a break from caregiving.

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**Resources**

- Care Dimensions 888-283-1722 or CareDimensions.org
- Alzheimer’s Association alz.org
- Alzheimer’s Association - Massachusetts Chapter alz.org/manh
- Medicare 800-772-1213 or medicare.gov
- Medicaid 800-252-8263 or medicaid.gov
- Massachusetts Medicaid mass.gov/eohhs/gov/departments/masshealth
- National Institute on Aging nia.nih.gov
- National Institutes of Health nih.gov
- Elder Abuse Hotline 1-800-677-1116
- Centers for Disease Control & Prevention cdc.gov
- Commonwealth of Massachusetts mass.gov/elders
- Executive Office of Elder Affairs
- MBTA’s “The Ride” Program mbta.com/riding_the_t/accessible_services
- Massachusetts Assisted Living Facilities Association massalfa.org
- Massachusetts Extended Care Federation mecf.org
- Nursing Home Compare medicare.gov/nursinghomecompare
- Meals on Wheels mealsonwheelsamerica.org

The materials in this booklet were developed in part with resources from:

- Alzheimer’s Association
- Columbia, Missouri Chapter of the Alzheimer’s Association
- “Caring for a Person with Alzheimer’s Disease”, National Institute on Aging, US Department of Health and Human Services
- Hand Massage Techniques by Jane Ellwood, www.aromacaring.co.uk
Compassionate Expertise for Advanced Illness

Care Dimensions, one of the nation’s first hospice programs and the region’s largest, provides services in more than 90 communities in Eastern Massachusetts. As a non-profit, community-based leader in advanced illness care, our services include:

- Hospice
- Palliative care
- Specialized care programs: *Dementia, Cardiac and Lung Diseases, Pediatrics, Developmentally disabled adults*
- Meeting the unique needs of: *Veterans and the LGBTQ community*
- Kaplan Family Hospice House and Care Dimensions Hospice House
- Grief support
- Education and training

Main: 888-283-1722
Referrals: 888-287-1255
Referral Fax: 978-774-4389

CareDimensions.org

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