Guiding an Improved Dementia Experience (GUIDE)

EDUCATION AND SUPPORT RESOURCES

1

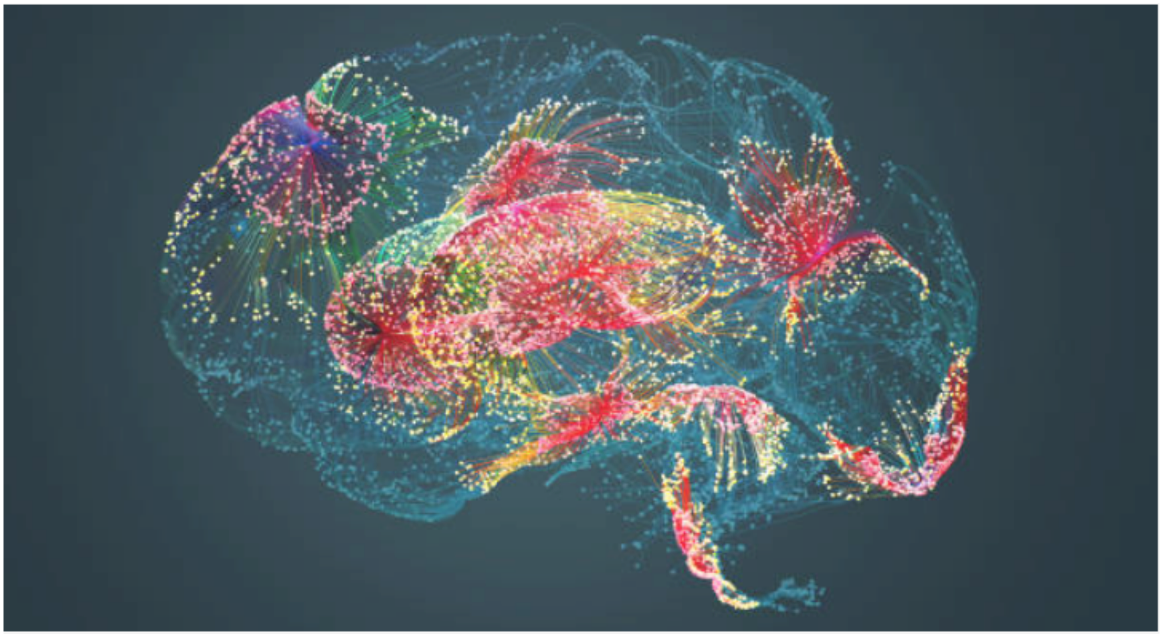
Dementia facts and expectations

Common considerations

Moving forward with preparedness planning

BAPTIST HEALTH

Table of Contents



Understanding Dementia

What is Dementia?

Diagnosis, Stages, Progression and What do I do now?

What is dementia

The brain is made up of billions of nerve cells, called neurons. These nerve cells are connected with each other in a communication network. Other cells in the brain provide the nerve cells with everything they need to survive and do perform their tasks.

Dementia is the word used to describe several different diseases of the brain. These diseases can affect: ● Memory ● Language skills ● Visual perception (the ability to see and understand what one is seeing) ● Ability to focus and pay attention ● Ability to reason, solve problems and make decisions ● Ability to understand and complete usual, everyday tasks.

What causes dementia

Dementia is caused by damage to brain cells. When brain cells are damaged, the brain cannot carry out its usual work. How and where the cell damage occurs depends on the type of dementia. The damage could be related to ●Certain types of proteins that build up and interrupt brain function. ● A blockage of blood flow to the brain or ● A head injury.

Dementia can cause loss of memory, loss of language, lost problem-solving skills and other thinking abilities that are severe enough to interfere with daily life. It can also affect behavior, feelings and relationships.

Other causes of cognitive changes

There are many other conditions that can cause symptoms of cognitive impairment but that aren't dementia, including some that are reversible, such as thyroid disease, vitamin deficiencies or other neurologic/nerve conditions.

Delirium, is a state of confusion, inattention and loss of focus. It is usually caused by an underlying issue – such as a medication side effect, an infection, high or low blood sugar levels or organ dysfunction. Delirium is usually reversible once the inciting cause is removed. While delirium is not dementia, persons with dementia are more at risk for delirium.

Types of dementia

Many think that Alzheimer's Disease and dementia are the same disease. However, Alzheimers dementia is just one type of dementia. Different types of dementia have different causes, different symptoms (though they frequently overlap) and are treated in different ways.

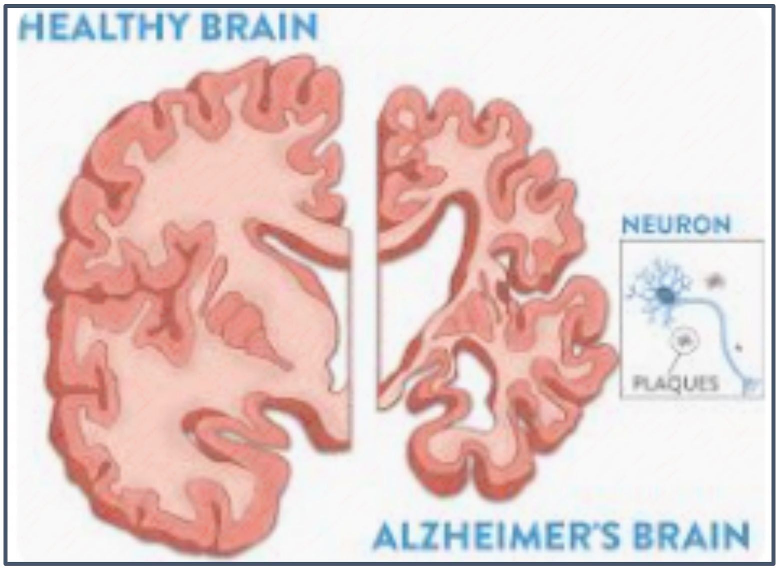
Alzheimer's Disease (AD)

Alzheimer's Disease is the most common type of dementia. As people age, protein clumps – called tangles and plaques – develop in the brain. In AD, too many tangles and plaques build up.

The nerve cells in different parts of the brain become blocked by the protein tangles and plaques. The brain cells cannot communicate with the network. In addition, these brain cells cannot receive what they need to survive. When these nerve cells die, that part of the brain shrinks.

The brain region called the hippocampus is the center of learning and memory in the brain, and the brain cells in this region are often the first to be damaged. That's why memory loss is often one of the earliest symptoms of Alzheimer's.

The symptoms of Alzheimer's Disease are mild at first but get worse (progress) over several years. AD affects memory, thinking and behavior. Not everyone experiences every symptom.



Symptoms of Alzheimer's Disease may Include

- Forgets how to use common everyday items
- Forgets how to do common everyday activities
- Misplaces items and is unable to problem-solve
- Becomes paranoid (suspicious; fearful; jealous)
- Has difficulty finding the right words to say
- Has difficulty finding the right words to write
- Repeats the same question over a short period
- Unable to remember recent events/discussions
- Poor judgment about how to behave in public
- Confused to place and time
- Has mood and personality changes

Vascular Dementia

Vascular dementia is the second most common type of dementia. It occurs when a stroke or several small (or mini) strokes blocks or reduces blood flow to the brain. This interruption of blood supply causes brain cells to lose oxygen and die. It usually damages the area of the brain responsible for learning, memory and language.

Symptoms can be sudden and severe or mild and gradual depending on the type and degree of brain damage. Often mini-strokes go unnoticed but over time can have a cumulative effect.
Here are some possible symptoms.

Emotional ● Hallucinations ● Unusual changes in mood or attitude ● Slower thinking/processing ● General forgetfulness and confusion ● Loss of social skills

Physical ● Walking with rapid shuffling steps ● Loss of bowel and bladder control ● Weakness in the arms or legs ● Dizziness and problems with balance

Behaviors ● Getting lost in familiar surroundings ● Laughing or crying at inappropriate times ● Inability to plan, organize or follow instruction ● Difficulty word-finding

The most important treatment of vascular dementia is to reduce the risk of more strokes. This includes the treatment of high blood pressure, diabetes and high cholesterol. Exercising, smoking cessation, limiting alcohol, reducing salts and saturated fats and maintaining a healthy weight can decrease the risks for vascular dementia.

Dementia with Lewy Bodies (DLB)

Dementia from Lewy Bodies shares symptoms similar to Alzheimer's and Parkinson's Disease. This can make diagnosis more difficult, however, treatment is different. DLB patients can do poorly with medications that are prescribed to control body movements or behaviors.

This type of dementia is caused by the build-up of tiny protein deposits (Lewy Bodies) in the brain. This damage can affect behavior, sleep, body movements and the ability to reason and make decisions.
Symptoms of LBD ● Visual hallucinations that repeat and can be very detailed ● Depression ● Excessive sleepiness during the day and insomnia, which can proceed the diagnosis by years ● Acting out dreams physically by talking, walking, kicking ● Staring off into space for long periods of time ● Difficulty moving such as trembles, jerks and shuffles ● Sudden changes in blood pressure, body temperature and an inability to swallow

Frontotemporal Dementia (FTD)

FTD is caused by protein build-up in two areas of the brain: the frontal and temporal lobes. Damage to the frontal lobe (located in the area just above your eyes) affects the ability to reason, make decisions, prioritize and multi-task, act appropriately and control movement. Damage to the temporal lobes (located in the areas close to your ears) affects the ability to hear and understand what is heard.

Symptoms of FTD ● Changes in behavior (acting inappropriately in public; acting impulsively; changing from an active lifestyle and outgoing personality to quiet and withdrawn; acting without regard to others; unable to start an activity)
● Difficulty making sense when speaking, difficulty understanding what others are saying, difficulty reading

Mixed Dementia

Mixed dementia has the signs and symptoms of more than one type of dementia. The most common form occurs when the brain is damaged by the protein plaques and tangles of Alzheimer’s Disease and by the blocked blood vessels of vascular dementia.

Diagnosing Dementia

There is no one test to determine if someone has dementia. Doctors diagnose dementia based on careful medical history, a physical examination, laboratory tests, and the characteristic changes associated with each type.

Doctors can determine that a person has dementia with a high level of certainty. But it's harder to determine the exact type of dementia because the symptoms and brain changes of different dementias can overlap. In some cases, a doctor may diagnose "dementia" and not specify a type. If this occurs, it may be necessary to see a specialist such as a neurologist, psychiatrist, psychologist or geriatrician.

The future is likely to bring more definitive testing. These include blood tests and imaging.

Treatment of Dementia

Treatment depends on cause. In most progressive dementias, including Alzheimer's disease, there is no cure, but one treatment — lecanemab (Leqembi®) — demonstrated that removing protein plaques can reduce cognitive and functional decline in people living with early Alzheimer’s. Other medications can temporarily slow the worsening of dementia symptoms and improve quality of life for those living with Alzheimer's Disease and their caregivers. The same medications used to treat Alzheimer's are among the drugs sometimes prescribed to help with symptoms of other types of dementias. Non-drug therapies can also alleviate the symptoms of dementia.

Ultimately, the path to effective new treatments for dementia is through increased research funding and participation in clinical studies.

Treating Compounding Conditions

While most changes in the brain that cause dementia are permanent and worsen over time, thinking and memory problems can be caused or worsened by other conditions. These can include: depression, medication side effects, excess use of alcohol, thyroid problems and low vitamin levels. Your care team will work to determine any contributing factors that may be reversible.

Stages of Dementia

Dementia is a progressive disease. It is also a terminal disease. This means it will lead to death. Dementia is predictable in terms of symptoms and time course but it is also very variable. Additionally, new medical events - such as a new stroke or decline from another chronic illness like COPD or heart failure or kidney disease can impact outcomes. Your loved one is unique and will experience the disease in their own way. This includes symptoms and time to progression.

However, dementia tends to move through three stages: Early-Stage (mild), Mid-Stage (moderate) and Late-Stage (severe). These stages may overlap. Understanding these stages will help you know what to expect so you will know what to do.

Early-stage (mild)

In the early stage, a person may function independently. He or she may still drive, work and be part of social activities. Despite this, the person may feel as if he or she is having memory lapses, such as forgetting familiar words or the location of everyday objects.

Symptoms may not be widely apparent at this stage, but family and close friends may take notice and a doctor would be able to identify symptoms using certain diagnostic tools.

You may be wondering

- Are there any medications, treatment or lifestyle changes that could help my loved one's memory and thinking?
- How can we help our loved one stay active and connected?
- Should my loved one still be driving?

What to Expect - Common difficulties include

- Coming up with the right word or name.
- Remembering names when introduced to new people.
- Having difficulty performing tasks in social or work settings.
- Forgetting material that was just read.
- Losing or misplacing a valuable object.
- Writing reminders and losing them.
- Experiencing increased trouble with planning or organizing.
- Have more trouble driving safely

At the same time, you may find some memories are more present: they will likely remember stories from long ago and remember how to do things they were familiar with – like playing an instrument. They may be able to focus more on the present moment, enjoy a sense of humor and a growing ability to be creative.

During the early stage, it's possible for people with dementia to live well by taking control of their health and wellness, and focusing their energy on things that matter most to them. This is the best time to put legal, financial and end-of-life plans in place because the person with dementia will be able to participate in decision-making.

Action Steps

☐ **Make sure your loved one** either carries ID or wears a medical alert necklace or band.

☐ **Promote the best function** possible. Get hearing loss and vision tests regularly. Make sure hearing aids and glasses are in good shape and are used.

☐ **Review options** to make your home safer. Page ______.

☐ **Have a family meeting** to discuss what is happening and next steps, such as ways the family can support you.

☐ **Make a care plan** with your GUIDE Care Navigator or Baptist Care Coordinator. Discuss support networks and respite options.

☐ **Make a back-up plan** to be used if something happens to you.

☐ **Discuss and document** your financial plan and your preparedness plan. Preparedness planning helps understand the goals of care, your loved one's wishes for end-of-life care and begins discussions on resources if the goal is to age-in-place.

☐ **If your loved one is still driving**, review the plan. Page ___ .

Mid-stage (moderate)

Mid-stage dementia is typically the longest stage and can last for many years. As the disease progresses, the person with dementia will require a greater level of care.

Your loved one may have a harder time remembering things that happened a few hours – or even minutes – ago. They may confuse words, get frustrated or angry, and act in unexpected ways, such as refusing to bathe. Damage to nerve cells in the brain can also make it difficult for the person to express thoughts and perform routine tasks without assistance. You may see changes in their personality. Your kind and outgoing loved one may become angry or suspicious. To avoid embarrassment, they may withdraw from social activities. Friends may not be sure what to do with these changes and may drift away.

In the middle stage, one can still participate in daily activities with assistance. It's important to find out what the person can still do or find ways to simplify tasks. As the need for more intensive care increases, caregivers may want to consider respite care or an adult day center so they can have a temporary break from caregiving.

You may be wondering

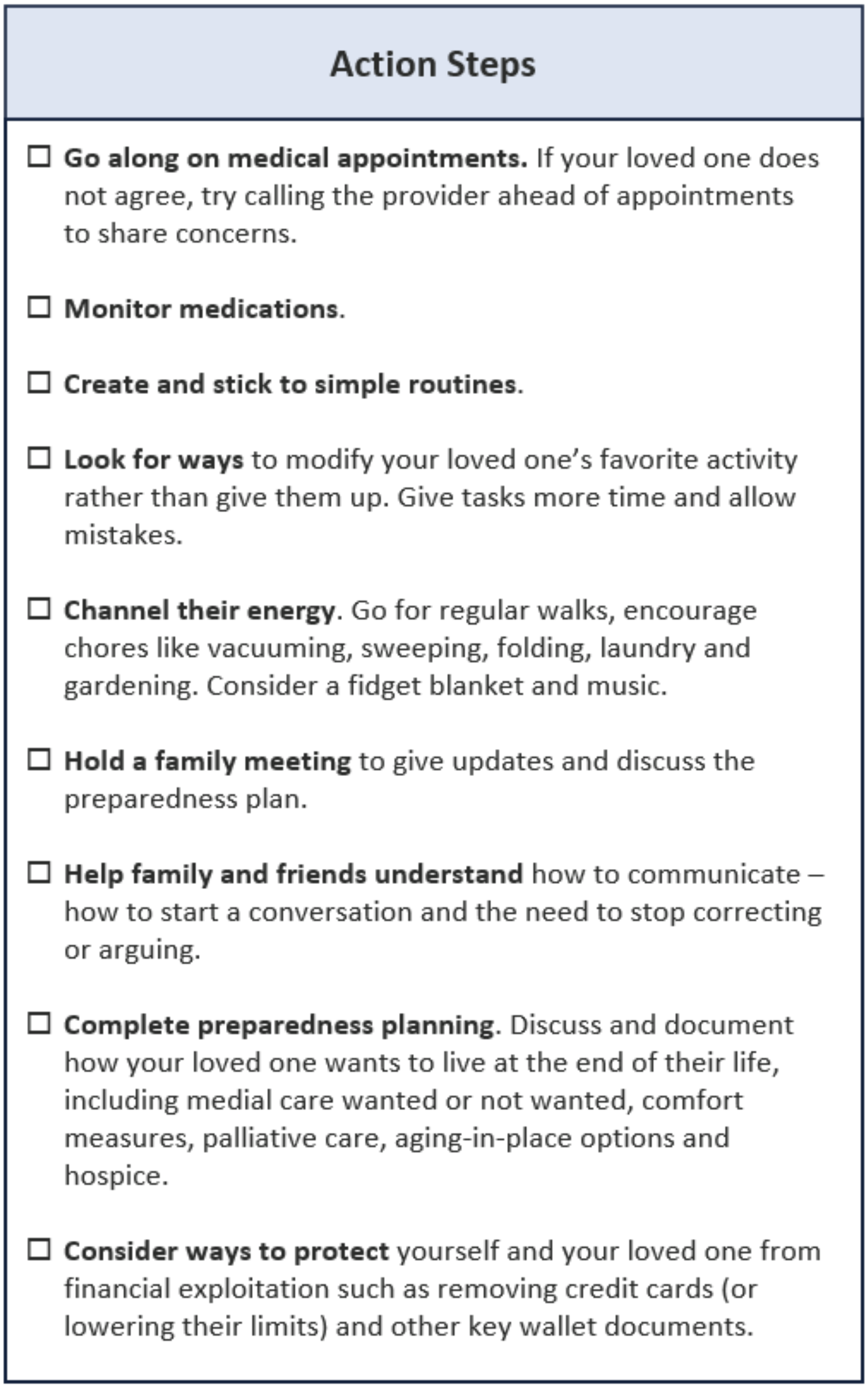
- Where do we get help to cope with behaviors?
- What services might help and where do I find them?
- What do we do if our loved one won't stop driving?
- How can I make my loved one's life more enjoyable?

What to Expect

- Having more trouble with memory – such as recalling their address
- Have problems organizing, planning and following instructions.
- Not recognize familiar people.
- Forget how to start routine tasks – like brushing their teeth.
- Resisting bathing or other personal care; may have incontinence.
- Have delusions (false beliefs) or hallucinations.
- Have more problems with balance; increasing the risk for falls.

- Lack judgement and have the following behaviors: trouble sleeping, irritability, aggressive talk and actions, clinging, repetitive questioning, wandering

At the same time, they may be increasingly present in the moment, continue to use their five sense to enjoy the world around them, discover new ways of communicating (nonverbal, touch) and can be quite creative.



Action Steps

☐ **Go along on medical appointments.** If your loved one does not agree, try calling the provider ahead of appointments to share concerns.

☐ **Monitor medications.**

☐ **Create and stick to simple routines**.

☐ **Look for ways** to modify your loved one's favorite activity rather than give them up. Give tasks more time and allow mistakes.

☐ **Channel their energy**. Go for regular walks, encourage chores like vacuuming, sweeping, folding, laundry and gardening. Consider a fidget blanket and music.

☐ **Hold a family meeting** to give updates and discuss the preparedness plan.

☐ **Help family and friends understand** how to communicate – how to start a conversation and the need to stop correcting or arguing.

☐ **Complete preparedness planning.** Discuss and document how your loved one wants to live at the end of their life, including medial care wanted or not wanted, comfort measures, palliative care, aging-in-place options and hospice.

☐ **Consider ways to protect** yourself and your loved one from financial exploitation such as removing credit cards (or lowering their limits) and other key wallet documents.

Late-stage (severe)
In the final stage of the disease, dementia symptoms are severe. Individuals lose the ability to respond to their environment, to carry on a conversation and, eventually, to control movement. They may still say words or phrases, but communicating pain becomes difficult. As memory and thinking continue to worsen, significant personality changes may take place.

At this stage, individuals may: ● Require around-the-clock assistance with daily personal care ● Lose awareness of recent experiences as well as of their surroundings. ● Experience changes in physical abilities, including walking, sitting and, eventually, swallowing. ● Have difficulty communicating. ● Become vulnerable to infections, especially pneumonia.

The person living with Alzheimer's may not be able to initiate engagement as much during the late stage, but they can still benefit from interaction. During this stage, caregivers may want to use support services, such as hospice care, which focus on providing comfort and dignity at the end of life.

You may be wondering
- What can we do to promote quality of life?
- What kind of care is best for my loved one?

What to Expect
- Not recognizing you or others.
- More difficulty with communication – may use "word salad" or be speechless.
- Be frequently or totally incontinent.
- Have rigidity, immobility, jerks or seizures.
- Be more vulnerable to infections.

At the same time, you may notice that they are still attuned to the emotions of others, enjoy companionship, respond to physical touch or music, and can encourage others to slow down and focus on the present.

What do I do Now?

Learning that someone you care about has been diagnosed with dementia can be life changing. Coming to terms with the diagnosis takes time. Feelings of denial and fear are normal and may help you and the person diagnosed process the grief you are feeling.

The process of acceptance

Perhaps you tried to encourage the person living with dementia to learn about their diagnosis, only to be told “nothing is wrong.” Perhaps you may have been hesitant to learn more yourself for fear of the future. Whatever the circumstance, accepting a diagnosis of dementia requires time to absorb information about the disease before you might be ready to learn more.

It is not unusual for care partners to be the first people to seek information about the disease soon after diagnosis. Knowing what to expect and having access to the resources and support available can be empowering and lead to an increased commitment to your partner and determination to get through this together.

Allowing time to process the diagnosis is an important first step to adjust to this “new normal.” The process of acceptance is just as important for the care partner as it is for the newly diagnosed person. No two people deal with the diagnosis in exactly the same way. There is no right approach and some days may be more difficult than others, but don’t be discouraged.

Allowing yourself time to grieve and mourn over the current and future losses you and the diagnosed person may experience can be healthy. The sooner you are able to accept the diagnosis, the better suited you will be to help the person living with dementia move closer to acceptance too.

Individuals with the disease acknowledge that while it often takes time to accept their diagnosis, specific actions initiated by the care partner help in this process. Patience, flexibility and open communication can provide reassurance that the person with the disease does not have to face their diagnosis alone. For many, the simple reinforcement from their care partner that “we are in this together” is the most memorable act of support.

Consider these tips to help the person in the early stage of the disease come to terms with their diagnosis:

- Provide time for the individual to feel sad about how his or her identity is changing as a result of the diagnosis.
- Emphasize the roles that are still significant to their identity, i.e. grandfather, mother, daughter, etc.
- Encourage the person to speak with a trusted friend, minister or even a professional counselor, to talk through difficult emotions.

Telling others about a diagnosis of dementia can be one of the most difficult steps. There may be anxiety surrounding who to tell.

Sharing the diagnosis with others can open up new relationships and connections to people you did not realize were willing to support you. For others, hearing the diagnosis may test relationships and some friends and family may react with denial, or pull away in ways that reflect their misunderstanding of dementia.

Yet, it can be empowering to share the diagnosis with others. Be open with friends and family about the changes that are taking place. **Remind them that changes they see are because of the disease not the person.** Educate them on the disease and tell them how they can be supportive.

Maintaining a sense of self and finding purpose

A diagnosis of dementia is often accompanied by uncertainty around one's identity and life purpose. New challenges presented by living with the disease can cause the person to question their capabilities and identity. It's not uncommon for a person living in the early stage to ask the question "Who am I?"

One way to move beyond the loss of identity is to find ways to engage in activities that bring meaning and purpose to their life. Finding a new purpose can help confirm that dementia does not have to define a person; it only becomes a part of who they are.

Consider these tips to help the person in early stage find meaning and purpose:

- Discuss what brings meaning and purpose to his or her life.
- Encourage the person to stay involved in activities he or she enjoys.
- Consider activities you can do together.

- Work together to identify opportunities at home or in the community that can leverage his or her strengths and interests.
- Discuss what new activities the person may be interested in trying.
- Encourage the individual to get connected with others who are living with the disease to learn what they are doing to remain active and engaged in life.

Getting support

A diagnosis of Alzheimer’s or other dementia is life-changing for both the person living with the disease and family and friends. You play an important part in providing support to the person who has been diagnosed. Along the way, you will need the support of others, too.

Often times, care partners look to family and friends first. Once you’ve identified trusted friends or family members, be specific about how you would like to engage their support. This can be assistance with transportation to or from medical appointments, help with social outings or simply having someone to talk with.

There are also community programs, support groups and online social networks that provide the opportunity to learn from others who have a friend or family member with dementia.

We often hear care partners say that they are looking for support from people who "really understand because they've been there, too."

Common Considerations

The Care Team

Begin to think of yourself as the leader of a care team. As the disease progresses, it is inhumanly possible to do all you need to do for your loved one, your family and yourself.

The idea of putting together a care team may sound impossible. Asking for help may cause anxiety. Perhaps you are afraid something bad would happen if someone else looked out for your loved one.

The care team includes you, your loved one. It may also include family members, friends, community support systems, health care professionals (primary care providers, social workers, dentists, pharmacists, therapists, respite staff, local aging service providers, support groups, meal delivery services, local law and fire agencies, and hospice providers in end-stage disease. You are not alone.

Care Team tips

- Consider a tasks list, the time the task may take and who may be able to help.
- Think ahead about needs that may come up in the future.
- Guide the team but show them appreciation and respect.
- Listen to the team's input while showing confidence in making decisions.
- Be flexible when someone says "no". It is not personal.
- Remember team members may be experts in the area but you are the expert about your loved one.

Problem Solving

Dementia may cause your loved one to behave in unexpected ways. As the disease progresses, you may experience these behaviors. Your loved one may demand to go home even though they are home, pretend to take medicine and then hide it under the pillow or follow you around the house like a shadow. These types of unusual behaviors are common among people with dementia. Once you know these new and unusual events are symptom of the disease, you can use preplanning and creativity to solve the problem.

Dealing with dementia requires patience, paying close attention and being a bit of a detective. For example, your loved one may pick up the juice glass next to the bed and throw it on the floor. You may think they are "acting crazy". Instead, they may be trying to tell you the television is too loud or that they want something different to drink.

Problem-solving requires an organized process of finding answers. Here is one problem-solving model that may help.

1. **Define the problem**. What exactly is the behavior that is troubling you? Take a few minutes to break the situation down into smaller parts.

Consider this statement: “My husband drives me crazy when I am preparing dinner every evening.”

And now this: “Several evenings a week my husband comes into the kitchen while I prepare dinner asking me to stop and watch TV with him. Each time, I say I must get dinner ready. After about 10 minutes of this, we both become agitated. He begins pulling things off the counter and throwing them on the floor. At this point, I have to decide whether to continue arguing with him or give in. If I give in, then we will have cereal for dinner.”

Why is this behavior a problem? What effect does it have?: “This is a problem for me because cooking is something I enjoy and take pride in. It provides stress relief for me and I need this time for myself.” Or “I get very upset when he begins to throw things on the floor. Sometimes he breaks things that I care about. I resent having to clean up the mess on top of all the other things I must do around the house."

How would you like this behavior to change? Most caregivers would say , “I want it to stop.” But this is rarely possible. Think about smaller changes: “I do not mind him asking me over and over to come with him. I really wish the situation would not escalate to the point of throwing thing son the floor.”

Ask yourself these questions and answer them in as much detail as possible.

- When does the behavior happen?
- Where does the behavior happen?
- Who is around when the behavior occurs?
- What lifelong routines or personal/work experiences may be triggers?
- How often does the problem occur?

2. Think about what you have tried in the past.

- What were the different ways in which you tried to manage the behavior?
- Did any of your ideas help?
- Which ideas made things worse?
- What can you learn from your loved one's reactions?
- Consider other stories you have heard in support groups.

3. Set a goal for the problem.

Depending on the problem is and how it affects you, the solution may be unrelated to your loved one's behavior. It may be about how you respond. Set realistic goals that you can achieve.

Ask yourself: When would you consider the problem to be completely solved? What would make it seem better or okay to you?

Consider: "My goal is for my husband not to make such demands on my time and leave me alone more often." **And now**: "We will have cereal for dinner only once a week due to my husband's interruption" **or** "I will not argue and escalate my husband's agitation to the point where he throws things off the counter" **or** "I will keep my husband busy with something else so he will not need my attention when I prepare dinner."

4. Consider the possible solutions.

- Review the strategies in the GUIDE caregiver manuals.
- Select some strategies you would like to try.
- Think through the strategies – write pluses and minuses for each.
- Select 1-2 strategies with more plusses than minuses.
- Make a plan to try the strategy.
- And remember: could pain, fear, noise or light avoidance or bathroom needs be driving the behavior. Target that possible feeling.

Communication

General Strategies for Communication

- Before you begin speaking make sure your loved one can see you.
- Speak face to face. Stand or sit at or just below eye level.
- Make eye contact without staring and avoid closing in.
- Speak clearly and slowly.
- Keep each sentence to 10 or fewer words.
- Count to 5 before saying the next sentence.
- After you ask a question, give them a minute or so to think about it.
- Avoid sentences that begin with "Do you remember".
- Use sentences without adding a question at the end.
- Be specific – use names instead of pronouns, avoid words with multiple meanings.

Consider using the "Best Friend's Strategy"
The Best Friends Approach was developed in the 1990's by researchers at the university of Kentucky Alzheimer's Disease Research center. There are several pillars of this approach. These include:

Understanding what it's like to have dementia. Behaviors seem less strange or unreasonable when you understand that dementia impacts the brain.

Knowing and using the person's Life Story. When persons with dementia forget their past, their Best Friend can remember. **Collecting key social and personal history** can help the person to recall happy times and successes and give us tools for **redirection** when the person is having a bad day.

Knowing just what to say when communication is breaking down. Dementia damages a person's ability to "make conversation," express their wishes verbally, understand requests, or remember directions. Best Friends understand the importance of slowing down and being present for the person with dementia, using good communication skills.

Developing the 'Knack' of great dementia care. Knack is the "art of doing difficult things with ease," or "clever tricks and strategies." Acting as a Best Friend, our world view changes. We can practice patience and understanding. If the person says that she likes the current President, Abraham Lincoln, we don't correct her. Instead, we could say, "I really like him too." **Don't fight or argue. Agree and diffuse the situation.**

Experiencing meaningful engagement throughout the day. Persons with dementia who no longer can take part in favorite activities or initiate new ones can easily become isolated, bored, and frustrated. See if taking a short walk, chatting, offering hand massages or doing simple chores together might help.

Managing Medications

You may find it challenging to keep up with what medications to take and when. Managing medications includes understanding what your loved one is taking and why. As we age and/or more medications are added, side effects can occur. These can manifest also as behaviors in persons with dementia. Here are some common side effects: tremors, falling, difficulty walking, dry mouth, confusion, constipation and drowsiness.

1. **Keep an active medication list at all times**. Make a few copies. This includes over the counter medicines and supplements. Track the dose and how often the pill is given.

2. **Understand why**. Don’t be afraid to ask your physician, provider or pharmacist why a medication has been prescribed.

3. **Give the medicine.** Keep it simple and give it time. Check to see if they are hiding medicine in their mouth. You can give something small to eat right after taking the medicine(s). If they suddenly have a hard time chewing the food, it is possible they have not swallowed the medication.

   What if they have problems swallowing pills or spit them out? Crushing pills may be an option but **not all medications are safe to crush**. **Check with your doctor or pharmacist** before crushing pills. There are pill crushers you can buy if needed. Once crushed, you can mix them into soft foods such as applesauce, cottage cheese or pudding.

   Some medications come in liquid form and others in capsule. You can pull apart the capsule and dissolve the contents in a small amount of liquid or mix into a soft food. Again, it is important to clear this with your doctor or pharmacist.

   What if they argue or refuse to take the medication? Drop the issue for a while. Refocus your loved one’s attention on something else. Try again at a later time.

Safety

The home in which your loved lives may become a safety challenge. Common everyday items may become a fall hazard or even frighten your loved one if they no longer recognize them. On the other hand, removing familiar items may cause anxiety. Other safety challenges for your loved one may include driving, wandering inside or outside the home, smoking, and guns.

Think about assistive devices. These can be “low tech” like plates with bumper guards so your loved one does not get frustrated accidentally pushing food off the plate) or “high-tech” like a talking alarm clock.

One important safety step is to register your loved one with the **MedicAlert Alzheimer’s Associations Safe Return program**. This is a 24-hour nationwide emergency response system for those with dementia who wander or have a medical emergency. Call 1-888-572-8566 to register. Local law enforcement and community agencies are also vital member of a safety plan; ask your GUIDE team or contact your local support agency for detailed enrollment information.

Making the Home Safer

Clearing Clutter

Clutter can be things that are not used daily or weekly. They are things your loved one does not touch frequently. Too many things in the house may make it hard to move around. Clutter may also distract or confuse your loved one. Keeping the house free of clutter may reduce the risk of agitation ad help them make choices more quickly. As memory changes, your loved one may forget where he or she put things. They may even accuse another person of stealing. Clearing clutter makes it easier to find misplaced items.

But don’t remove everything at once. Remove just a few items at a time. If your loved one asks for a particular item? Stretch the truth. Try saying that another family member or friend is borrowing and fixing it.

Environmental Changes

As dementia progress, your loved one may have problems telling the difference between items. Use light against dark. An example: if the walls are a light color, consider painting the handrails, baseboards and doors a darker color.

Use low-glare light bulbs or dimmers. They are less agitating for those with low vision.

Put reflective (glow in the dark) tape in the hallways and around the bathroom doors. Add automatic night lights in these areas.

Use chairs with arms to make it easier for your loved one to get up and down.

Put signs and arrows around the house to find rooms and objects. Use 1-2 words and drawings for each room or item.

Use STOP signs on doors that lead outside and safety gates on stairs.

Consider alarms on outside doors and windows. Consider a bed alarm or room monitor.

Cover electrical outlets with safety caps. Tape down power cords.

Put items your loved one uses every day on shelves within easy reach.

As the disease progresses, your loved one may mistake their reflection for a burglar. You can cover all mirrors when not in use or use mini blinds over mirrors that are used frequently.

Avoid loose rugs, which increase the risk of trips and falls.

In the Kitchen

Use kitchen appliances that have automatic shut-off timers.

Use kitchen gadgets that have danger alerts (such as boil alerts that rattle in the pot).

Use plastic covers to hide knobs of the hot water heater, stove and oven. Use cozies to hide small appliances such as blenders or juicers.

Put **poisonous items** such as medicines, first aid supplies, cleaning supplies, laundry detergents, paint . . . in cabinets that have safety latches or containers.

Preventing Falls

People with dementia have a higher risk of falling and fall-related injuries.
● Encourage exercises that improve strength and balance. ● Keep up with annual vision testing. ● Remove loose rugs and clutter. ● Install shower bars, rails and grab bars.

Bathroom Safety

Consider a manual buzzer or bell. Place one near the toilet and the shower/tub. Being using it early so it becomes a routine.

Use an automatic night light or leave the bathroom light on at night.

Remove door locks to prevent a lock-in and allow access when help is needed.

Use hand-held shower head, grab bars, rubber slip mat and a padded shower bench or chair.

Install raised toilet seats and grab bars near the toilet to help your loved one sit down and stand up.

Use a dressing chair/bench or the toilet seat for dressing or undressing.

Use soap bars and baby no-tear shampoo. These are less slippery. Consider putting the soap in pantyhose to make it easier to grab. Be sure to remove it after use. Consider putting the shampoo into trial-sized bottles. These are lighter and easier to grab.

Declutter. This includes potted plants. They may be mistaken for toilets.

Fire Safety

Let your fire department know your loved one has dementia. Remember to call their office number, not the emergency line. Have an escape plan. Put fire extinguishers on each floor, the kitchen and garage. Practice using them. Put a smoke alarm with a carbon monoxide detector on each floor and in each bedroom. IF your loved one smokes, decide whether he or she can be home alone. Smoking is the most frequent case of house fires. Create a smoking schedule or set up a smoking area **away** from upholstered furniture, oxygen tanks, bedroom and use large deep ashtrays.

Safe Driving

Here are some common symptoms of unsafe driving to watch for: ● Becomes angry, frustrated or confused while driving. ● Has several minor accidents or a major one. ● Gets lost while driving in familiar places. ● Makes slow or poor driving decisions. ● Stops in traffic for no apparent reason. ● Has big scrapes or dents in the car. ● Drives too fast or too slowly. ● Does not follow traffic signs. ● Becomes confused at exits. ● Signals incorrectly. ● Has near misses. ● Hits curbs.

Because of the dementia, your loved one may not realize that his or her current driving practices are unsafe. Plan ahead and keep it simple. Decide when and how the issue should be raised. Decide who should talk to your loved one – limit it to 1-2 people.

Strategies to Discuss Driving

- Keep the conversation relaxed and non-confrontational.
- Share your observations.
- Share your concerns about your loved one's safety and the safety of others.
- Offer other options: Household members, family members, friend and neighbors, church members, in-home care workers, public transportation, Call on demand services.

Strategies for Dealing with Continued Driving

- Discuss with your loved one's primary care provider privately.
- Discuss the option of a Do Not Drive prescription.
- Discuss options with your GUIDE Care Navigator, who can refer to a social worker.
- Keep in mind that your loved one may not remember the driver's license has been cancelled. They may not remember that they agreed to stop driving.
- Keep the car keys out of sight – remember this is a lifelong routine. If needed, consider a locking bar on the steering wheels. Keep an eye on bank statements and credit cards. You loved one may not remember what happened to the car and try to buy another one.

Guns and Other Firearms

Whether to keep guns and other firearms in the home can be a very sensitive issue, much like driving. Discuss it with you loved one as well as all members of the care team, including family and friends.

Until a decision has been made, here are some steps to make the home safer. Ask an experienced firearm user to unload all firearms and put the trigger lock on. Remove all ammunition from the house. Lock all firearms and all weapons in a cabinet, gun safe or vault; hide the keys or change the code.

Progression of Disease

Skills Training: Disease Progression and What to Expect

The late stage of dementia may last from several weeks to several years. As the disease progresses, intensive, around-the-clock care is usually required.

What to expect

Get support. Late-stage care decisions can be some of the hardest time that a family can face. Connecting with other caregivers who have been through the process may help.

As the disease advances, the needs of the person living with Alzheimer's will change and deepen. A person with late-stage dementia usually:

- Has difficulty eating and swallowing
- Needs assistance walking and eventually is unable to walk
- Needs full-time help with personal care
- Is vulnerable to infections, especially pneumonia

Your role as caregiver

During the late stages, your role as a caregiver focuses on preserving quality of life and dignity. Although a person in the late stage of dementia typically loses the ability to talk and express needs, research tells us that some core of the person's self may remain. You may be able to continue to connect throughout the late stage of the disease.

At this point in the disease, the world is primarily experienced through the senses. You can express your caring through touch, sound, sight, taste and smell. For example, try: ● Playing his or her favorite music ● Reading portions of books that have meaning for the person ● Looking at old photos together ● Preparing a favorite food ● Rubbing lotion with a favorite scent into the skin ● Brushing hair ● Sitting outside together on a nice day

Late-Stage Care Options

Since care needs are extensive during the late stage, they may exceed what you can provide. This may mean additional help in the home or moving into a facility.

Deciding on late-stage care can be one of the most difficult decisions families face. Families that have been through the process tell us that it is best to gather information and move forward, rather than second guessing decisions after the fact. There are many good ways to provide quality care. Remember, regardless of where the care takes place, the decision is about making sure the person receives the care needed.

At the end of life, another option is hospice. The underlying philosophy of hospice focuses on quality and dignity by providing comfort, care and support services for people with terminal illnesses and their families. To qualify for hospice benefits under Medicare, a physician must diagnosis the person with dementia as having less than six months to live.

Ideally, discussions about end-of-life care wishes should take place while your loved one still has the ability to make decisions and share wishes about life-sustaining or life-prolonging treatment. We will discuss this later in the booklet.

Food and fluids

One of the most important daily caregiving tasks during late-stage dementia is monitoring eating. As a person becomes less active, he or she will require less food. However, a person in this stage of the disease also may forget to eat or lose his or her appetite. Adding sugar to food and serving favorite foods may encourage eating; the doctor may even suggest supplements between meals to add calories if weight loss is a problem.

To help the person in late-stage dementia stay nourished, allow plenty of time for eating and try these tips:

- Make sure the person is in a comfortable, upright position.
- To aid digestion, keep the person upright for 30 minutes after eating.
- Adapt foods if swallowing is a problem. Choose soft foods that can be chewed and swallowed easily. You can try pudding or ice cream, or substitute milk with plain yogurt.
- Encourage self-feeding. Sometimes a person needs cues to get started. Begin by putting food on a spoon, gently putting his or her hand on the spoon, and guiding it to the person's mouth. Serve finger foods if the person has difficulty using utensils.
- Assist the person with feeding, if needed. Alternate small bites with fluids. You may need to remind the person to chew or swallow. Make sure all food and fluid is swallowed before continuing on with the next bite.

- Encourage fluids. The person may not always realize that he or she is thirsty and may forget to drink, which could lead to dehydration. If the person has trouble swallowing water, try fruit juice, gelatin, sherbet or soup. Always check the temperature of warm or hot liquids before serving them.

Bowel and bladder function

Difficulty with toileting is very common at this stage. Your loved one may need to be walked to the restroom and guided through the process. Incontinence is also common during late-stage dementia.

To maintain bowel and bladder function:

- Set a toileting schedule. Keep a written record of when the person goes to the bathroom, and when and how much the person eats and drinks. This will help you track the person's natural routine, and then you can plan a schedule. If the person is not able to get to the toilet, use a bedside commode.
- Limit liquids before bedtime. Limit — but do not eliminate — liquids at least two hours before bedtime. Be sure to provide adequate fluids for the person throughout the day to avoid dehydration.
- Use absorbent and protective products. Adult disposable briefs and bed pads can serve as a backup at night.
- Monitor bowel movements. It is not necessary for the person to have a bowel movement every day, but if there are three consecutive days without a bowel movement, he or she may be constipated. In such instances, it may help to add natural laxatives to the diet, such as prunes or fiber-rich foods (bran or whole-grain bread). Consult with the doctor if the constipation continues.

Skin and body health

A person with late-stage dementia can become bedridden or chair-bound. This inability to move around can cause skin breakdown, pressure sores and "freezing" joints.

To keep skin and body healthy:

- Relieve body pressure and improve circulation. Change position at least every two hours to relieve pressure and improve blood circulation. Make sure they are comfortable and properly aligned. Use pillows to support arms and legs.

- Learn how to lift. A care provider, such as a nurse or physical therapist, can provide instructions on how to properly lift and turn without causing injury. Make sure not to ever lift by pulling on the person's arms or shoulders.
- Keep skin clean and dry. Since skin can tear or bruise easily, use gentle motions and avoid friction when cleaning. Wash with mild soap and blot dry. Check daily for rashes, sores or breakdowns.
- Protect bony areas. Use pillows or pads to protect elbows, heels, hips and other bony areas. If you use skin moisturizer on these areas, apply it gently and do not massage it in.
- Prevent "freezing" of joints. Joint "freezing" (limb contractures) can occur when a person is confined to a chair or bed. It's sometimes helpful to do range-of-motion exercises, such as carefully moving the arms and legs two to three times a day while the skin and muscles are warm, like right after bathing.

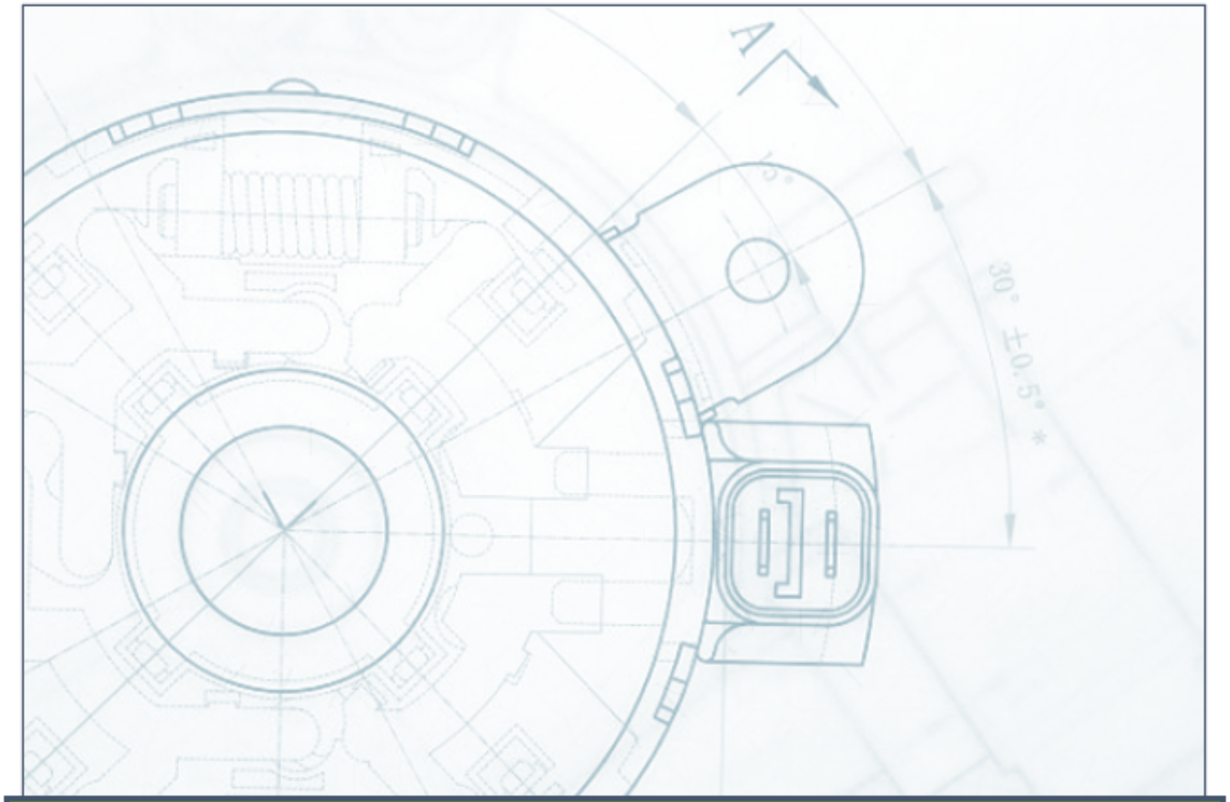
Infections and pneumonia
The inability to move around during late-stage dementia can make a person more vulnerable to infections.

To help prevent infections:
- Keep teeth and mouth clean. Good oral hygiene reduces the risk of bacteria in the mouth that can lead to pneumonia. Brush the person's teeth after each meal. If the person wears dentures, remove them and clean them every night. Also, use a soft toothbrush or moistened gauze pad to clean the gums, tongue and other soft mouth tissues.
- Treat cuts and scrapes immediately. Clean cuts with warm soapy water and apply an antibiotic ointment. If the cut is deep, seek professional medical help.
- Protect against flu and pneumonia. The flu (influenza) and COVID can lead to pneumonia (infection in the lungs). It's vital for your loved one and his or her caregiver to get vaccines every year to help reduce the risk. A person can also receive a vaccine every five years to guard against pneumococcal pneumonia (a severe lung infection caused by bacteria).

Pain and illness
Communicating pain becomes difficult in the late stages. If you suspect pain or illness, see a doctor as soon as possible to find the cause. In some cases, pain medication may be prescribed.

To recognize pain and illness:

- Look for physical signs. Signs of pain and illness include pale skin tone; flushed skin tone; dry, pale gums; mouth sores; vomiting; feverish skin; or swelling of any part of the body.
- Pay attention to nonverbal signs. Gestures, spoken sounds and facial expressions (wincing, for example) may signal pain or discomfort.
- Be alert to changes in behavior. Anxiety, agitation, trembling, shouting and sleeping problems can all be signs of pain.



Moving forward with Preparedness Planning

Preparedness Planning for Anticipated Decline

We know the path dementia is likely to take. Thankfully not all people will experience all outcomes. However, issues of mobility, feeding – including being fed through a feeding tube and infections – including pneumonia, urinary tract infections and pressure ulcers (often know as bedsores) are common occurrences of end-stage dementia.

Not talking about them does not prevent them, it just leaves us unprepared. Preparedness planning for anticipated decline restores some of the power a diagnosis like dementia can seem to strip away. Living without the disease would be best, but being prepared and acting in a way that best honors your loved one has power.

Preparedness Planning addresses

- Potential complications and a plan to address them if they occur.
- Advance Care Planning; naming a healthcare surrogate to speak for you if you lost the ability to speak for yourself and telling them what to say.
- Discussing options and resources for aging-in-place or placement if needed.
- Discussing when and if the resource of Hospice is right.

Potential complications and a plan to address them if they occur

When discussing goals of care, it is important to know how a person wants to live. What brings them joy, comfort and meaning. When a decision needs to be made, if it provides joy, comfort and meaning, it is likely a good idea. When a decision needs to be made for a loved one with end-stage dementia, it can be more difficult. All treatments have a benefit and a burden. If the benefit is much greater than the burden, we tend to say yes. Alternatively, if the burden is much greater than the benefit, we tend to say no.

With end-stage dementia, loved ones are often bed-bound and not able to consistently engage with the people or things in their environment. They often do not know themselves or their families. Often, they can no longer reliably do those things that brought them joy, comfort and meaning. Medical treatments can often prolong this stage of illness – through feeding tubes, hospitalizations for recurring infections, attempts at resuscitation in the case of a natural death.

However, if prolongation cannot return quality of life because it cannot cure the underlying disease, it is important to discuss these benefits and burdens.

Preparedness Planning for Anticipated Decline acknowledges potential outcomes, during a time when both the person with dementia and their loved one's can discuss, debate and come to decision that best honors their quality of life. Below is some additional information regarding tube feeding, attempts at resuscitation (CPR) and Advance Care Planning. We cannot plan for every eventuality but we can be prepared. Plans may change but starting the discussion is important. It is often what brings the greatest comfort to those faced with making decisions in a medical crisis. They may have a heavy heart from the illness and what it has done but as long as they follow the wishes of those they loved, they are not burdened by feeling they made a mistake.

Tube Feeding

What is tube feeding?

- Some illnesses make it difficult or even unsafe to eat. This happens when food, fluids or saliva go down the windpipe (trachea) instead of the food pipe (esophagus). This can make the lung irritated or even cause a lung infection like pneumonia. This is called aspiration. Some illnesses like dementia cause anorexia (when we eat less than our body needs). Aspiration and anorexia common and expected side effects of dementia.

What are the benefits of tube feeding?

- Tube feeding gives your body nutrients and fluids. It is also a way to get many medications. If your provider thinks your illness will get better (such as getting medicines for a cancer), the tube feeds may help with your nutrition, strength and recovery. If you get a feeding tube for an illness that will not get better and cannot be cured, like dementia, research shows tube feeding does not make you live better or longer.

Are there risks of tube feeding?

- Most people do okay but there are risks of placing the tube into your body, like infection and pain at the tube site. There have been rare cases of serious problems. You may have diarrhea or bloating which often gets better. You may feel nauseous or get short of breath with your daily feeding(s). You may get infections around the tube and the tube may fall out. Sometimes people are put in arm or hand restraints to stop them from pulling out the tube. The risk of aspiration is lower but it is not gone.

- At the end of life, tube feeding can have additional risks. As the body shuts down, it does not need extra food or fluid. If tube feeding continues, it can cause nausea, bloating, swelling (usually in the arms and legs) and even skin weeping. Keeping the dialogue open between you, your loved ones and your providers is an important way to address these risks with a plan of compassion and action.

What are my other choices aside from tube feeding?

- Some illnesses get better and the feeding tube may come out. Dementia does not. Tube feeding does not make a dementia better. It is a sign that the illness is getting worse.
- When we face this decision, it helps to know your goals for health care. If the goal is living longer, tube feeding may give that chance. If the goal is comfort and quality of life, tube feeding may not be the right choice.
- Comfort or pleasure feeding is an alternative to tube feeding. It can mean eating what and when you want while accepting there may be risks. This decision can feel overwhelming. Knowing your values and goals can help you chose what is best for you.

CPR

What is CPR (cardiopulmonary resuscitation)?

- When your heart stops, this is called cardiac arrest. Cardiac arrest is a normal part of the dying process. It can be expected or unexpected.
- During a cardiac arrest, blood stops flowing to your brain, heart, liver and kidneys. CPR tries to act like your heart and lungs to pump blood and oxygen. CPR may include chest compressions, electric shocks, artificial breathing and/or specialized medicines.
- During chest compressions, someone forcefully pushes on your chest around 100 times per minute. Electric shocks or defibrillations may be needed once or many times. Artificial breathing is given by mouth-to-mouth, a specialized bag or a breathing tube that can be hooked to a machine.

Am I awake?

- No. In a cardiac arrest you lose consciousness. You are not awake.

What happens after CPR? What are the risks?

- If you survive CPR, you will be taken to the Intensive Care Unit and put on life support. It often takes several days to know how successful CPR was. During this time, some people remain unconscious. Sometimes brain damage can occur. Sometimes medications that keep you sleepy are used to control pain or discomfort from the breathing tube. Sometimes there is damage to the liver and kidneys, which requires other artificial treatments.
- There are risks from the cardiac arrest and there are risks from CPR itself. The force needed during chest compressions can cause your ribs and breastbone (sternum) to break and your lungs to collapse. There can be deep bruising and sometimes burns from the defibrillator pads.
- During the cardiac arrest, if you do not get enough blood to the brain, heart, liver and kidneys, you may face additional problems. You may recover or you may be dependent on a breathing machine, have brain damage or need others to care for you. You may or may not be able to live at home again.

Does CPR work? What is the benefit?

- CPR does save lives. It is most useful in young and healthy persons who have a sudden event such as trauma, drowning or poisoning. It is most successful when started right after the heart stops. Sadly, even in these cases, CPR does not always work.
- Several studies estimate around 10% of adults survive an out-of-hospital cardiac arrest. This can increase two to three times if CPR is started immediately and there are few or no chronic health problems.
- If you have a cardiac arrest in the hospital, several studies estimate the chances of survival are less than 20% and the chances of death are greater than 80%.

I have specific questions about my health conditions that may change what I think is best.

- Health problems like dementia, heart disease, COPD, liver disease, kidney disease or cancer, functional limitations (how well you are able to move around and care for yourself), and age can all decrease the success of CPR. Some conditions can lower the chances of living after CPR to less than 1-2%. No matter your choice, it is important to remember that CPR will not improve your current health problems.

Is CPR right for me?

- You will make the right decision for yourself as long as it is based on good information and your goals and values. CPR may not be the best choice for someone with chronic illness who sees independence and comfort as most important. It may be the best choice for someone who sees having a longer life as most important and who accepts the possibility of brain damage or loss of function.

How do I make these difficult decisions?

- It is important to consider what matters most to you. Things to consider: What makes a good day? Who would you be with? What would you do? What does quality of life mean to you?
- Consider how you make other important decisions: With family? With friends? With spiritual support?
- Most of us want to live a long life in good health. Sometimes, illness or injury force people to make difficult decisions. This can be especially true when your goals of care do not align with your illness or injury. Sometimes, what we wish for must change, but knowing your goals and having the support of your loved ones and your providers can help prepare for the unexpected.

Is a Living Will the same as a Do Not Resuscitate (DNR) or Do Not Attempt Resuscitation (DNAR) order?

- No. The Living Will is a guideline. It is not a doctor's order. It is legally recognized but not legally binding. It serves as a guideline for your family and your providers for a time when you may not be able to make health care decisions for yourself.
- An AND (Allow Natural Death) order, a DNR (Do Not Resuscitate) order, and a Do Not Attempt Resuscitation (DNAR) order all mean the same thing. If you feel confident in your decision for a natural death in its time, you should discuss a Florida DNR order with your provider. This is a medical order that directs Emergency Medical Technicians and other First Responders to respect the care you want and do not want at end of life.

Advance Care Planning

Advance Care Planning (ACP) is a process of understanding, reflecting on and discussing your experiences, values and beliefs in an effort to identify how you want to live if faced with a serious or life-limiting illness. It may include your care preferences if a chronic illness gets worse. It may include identifying the care you would want at the end of your life. It is also important to choose someone to speak on your behalf if you are unable to make your own decisions.

ACP is a discussion.
It is a conversation to understand your beliefs, values and experiences. This helps us know how to best treat you in case of a sudden injury (like a car accident) or a sudden illness (like a stroke) if you could not speak for yourself.

ACP means being prepared.
It is for every adult. A serious injury or sudden change in your health can cause a medical crisis. Advance Care Planning can prevent a crisis of medical decision-making for you or your family.

ACP is limited.
It speaks for you during circumstances you define, such as when you cannot speak for yourself.

ACP can involve filling out documents.
They are called advance directives. It can be added to your medical record so your care providers can understand and honor your wishes.

ACP is a part of good care.
You can decide when completing an advance directive is right for you.

For additional information or to schedule a Virtual Introduction to Advanced Care Planning Class, visit **https://www.baptistjax.com/patient-info/advance-care-planning**.

What is a Health Care Advance Directive?

Having a living will and naming a health care surrogate are ways to ensure you have control over your treatment even when you cannot speak for yourself.

Health Care Advance Directives are a set of documents that help define your goals for care and name medical decision makers. At Baptist Health, we ask all of our patients to think about two types of Advance Directive documents:

- **Health Care Surrogate (HCS):** A document that identifies a person to speak for you and make decisions about your treatment based on your desires, values and beliefs.
- **Living Will (LW):** A document for writing down your goals, values and care preferences.

Choosing your Health Care Surrogate (HCS)

Who would be the best Health Care Surrogate (HCS)?

A HCS is the person you choose to speak for you. They make decisions about your treatments based on your desires, values and beliefs – not theirs. Consider naming someone: Who is willing. Who understands your goals and values. Who will follow your preferences, even if they are different from their own. Who can make decisions in sometimes difficult or emotional situations.

Who can be an HCS? How do I name an HCS?

A HCS needs to be an adult (age 18 years or older). Your HCS can be any person of your choice, including an unmarried partner. They do not need to be a family member.

Do I need a witness, notary, or lawyer?

Fill out a HCS form and have it signed by two witnesses – only one witness can be a spouse or blood relative. Your HCS cannot be your witness. You do not need a lawyer to complete an HCS form. In the state of Florida, it does not need to be notarized. As long as you complete a HCS form in another state under their law, it is valid in Florida.

What if I don’t choose an HCS?

If you do not choose an HCS, the State of Florida has laws in place to determine who will make your medical decisions. This person is called your health care proxy. Florida law names people in this order to make decisions for you:

- legal guardian
- legally married spouse (even if you are separated)
- majority of adult children
- a parent
- majority of adult siblings
- an adult relative that shows care and concern
- a close friend who shows care and concern
- a licensed clinical social worker
- Florida law does not use “next of kin”

Can a HCS be changed?

Yes. You can change it at any time. In fact, it should be reviewed and updated regularly. You should review it each decade, with a change in diagnosis (illness), a decline, a divorce or the death of a loved one.

In summary, Preparedness Planning cannot prevent a medical crisis but it can prevent a crisis of medical decision-making. It is a powerful ally on the care team.