



How will I know when it's time to move to residential care?

The question of whether to move is one of the hardest to make and likely to be emotionally difficult for everyone involved. It is about not only the needs of the person who receives care, but also the ability and desire of the caregiver to give care.

While it's not always the first thing that comes to mind, a key concern is: what exactly are you facing? If dementia or other progressive, degenerative diseases are involved, what is their prognosis? How far has the disease progressed and what is their life expectancy?

Most dementia is progressive, meaning it gets worse over time. People in the early stages may need only minimal help. Even those with moderate dementia can receive enough support with either family help or in-home care services - as long as they are not placing themselves at risk, can manage day-to-day activities, and are able to take basic care of themselves. However, the disease will continue to progress to the point where they will need full-time care, at which point moving may be the best option.

As people become less able to manage their daily lives, that may actually worsen their condition. Especially with dementia, people benefit from a consistent, structured daily routine. They also benefit from a healthy diet, regular physical activity, and mental and social stimulation. Circumstances may make it impossible to offer your loved one a daily routine at home that supports their well-being: the primary caregiver may work long hours or have other responsibilities, other family members may not be able to commit to regular hours, and in-home care providers may not always be the same person, meaning the daily routine is frequently disrupted.

Many families make a huge effort to keep their loved one at home for as long as possible. Many people may feel guilty or anxious about placing a loved one in residential care - they may feel that they are taking the easy way out or letting their loved one down. And it's true that there are advantages to keeping someone, even with dementia, at home for as long as reasonably possible:

- Some people struggle with change and may be distressed by the move.
- Some people experience a rapid deterioration after a move.
- Facilities can be more expensive than providing the care yourself.

However, residential care doesn't have to be seen as a last resort. Today's communities have improved radically, and many offer an exceptional level of care, focused on maximizing the person's quality of life. There may come a time when moving into residential care is the best choice.

Where's the tipping point?

There's no definite answer to the question of when is the right time to move -- aging is different for every single person it affects and the resources/opinions of family members vary, too. We need to look at the challenges the person has, and also how those challenges can be met at home.

Challenges to independence and staying at home

No one knows your loved one like you do — something unusual for them may be an everyday situation at another person's home. Still, it's helpful to know common warning signs that may signal trouble. The main areas to watch are safety, functioning, and personal care.

Safety

Physical safety

- Wandering, getting lost outside of the home, even becoming disoriented inside the home. In later stages of dementia, the risk posed by wandering becomes much greater. They can wander even if you just take the time to go to the bathroom. and the probability of falls and injuries increases.
- Falls - especially if they can't get help or rely on emergency services. If your loved one has fallen and struggled to get up on more than one occasion, it is a sign of more falls to come. Nearly one third of seniors fall at least once every year, and the death rate for falls has climbed steadily in the past decade.
- Increasing injuries or bruising: Do they have more frequent bruises, scratches, or cuts, especially ones they can't recall or explain?
- Causing or failing to address other hazards, like leaving stove on.

Home security

- Leaving home unlocked
- Letting unknown people into the home
- Unable to manage alarm or security system

Personal safety

- Risk to well-being due to inability to manage functioning and personal care tasks described below
- Aggressive behaviors
- Emergency services involved

Functioning

These tasks are referred to as Instrumental Activities of Daily Living (IADL's) – life tasks that are essential to living independently: managing finances, handling transportation, shopping, preparing meals, housecleaning, maintaining the home, communication (phone/mail), and managing medications.

Cognitive impairment can hugely impact a person's functioning in these areas:

- Confusion and uncertainty with familiar tasks like laundry, vacuuming, or washing dishes
- Forgetfulness: losing or misplacing keys, phones, wallets, or other important items
- Excessive time and energy spent doing tasks or finding items means less time for more meaningful activities.

Finances

- Forgetting to pay bills – this sounds somewhat harmless because everyone forgets things from time to time. Think about it again, though: the bills come at basically the same time every month—and they have been paying bills for decades. Forgetting multiple bills might not be a series of innocent mistakes, but a sign of bigger problems.
- Financial problems: bounced checks, calls from collections, late payment notices, running out of money before the end of the month
- Forgetting to pay taxes, insurance, or community fees can put home ownership at risk.
- Managing retirement accounts and investments

Transportation

- Decreased driving competency: accidents or tickets, getting lost.
- Difficulty managing transportation that was easily used before (bus, taxi).
- Needing assistance getting into and out of a car or taxi, or to get on or off the bus.
- Unable to arrange for transportation help when needed.

Shopping

- Managing the entire process of identifying what is needed, getting to and from the store, selecting and retrieving items, paying for purchases, and putting items away at home
- Not having essentials on hand because they forgot what was needed
- Buying multiple items because they forgot what they had
- Hoarding behaviors

Meals

- Forgetting: Are they struggling to prepare well known recipes? Do they leave out important steps or ingredients? Do they get mixed up or lose track of the process during meal preparation? Are appliances being left on after the meal is prepared? Is food collecting mold on the counter or making the fridge and house smell?
- Inattention: Are meals regularly burnt or under cooked, or do they miscalculate cooking times? Are they over/under spicing or salting food? Are spoiled foods not being thrown away? Their sense of smell or taste may be fading. They may have lost their ability to use the kitchen safely.
- Changes in eating patterns: Do you notice that your family member is avoiding cooking or eating meals that do not involve many steps; for example, cereal or a sandwich, more often? Are they consuming only fast food or prepackaged snacks?

Housecleaning

- Cluttered, dirty, or disorganized house: Is the home beginning to look and feel different or unrecognizable?
- Dishes piling up in the sink – maybe they've forgotten, or maybe it's become harder to stand for long periods of time or to bend over and use the dishwasher.
- Items on the floor because mobility is more difficult.
- Garbage not getting taken out, trash piling up.
- Items blocking walkways and presenting safety hazards
- Spoiled food in the refrigerator or laying about the house
- Spills not being cleaned.
- Laundry going neglected.
- Bathrooms becoming filthy.

Maintaining the home

- Safety hazards due to condition of home.
- Broken or damaged appliances and fixtures not being fixed.
- Smoke alarms not functioning.
- Yard/grounds – grass and weeds growing uncontrollably, garden untended, trash piling up outside.

Communication

- Trouble using the phone to call out or to answer calls, or to retrieve messages.
- Difficulty with conversations: If they get confused and frustrated when talking with you, they might also misinterpret information from doctors or other important people.
- Confusion on the phone could make them easy targets for scams, which are extremely common.
- Changes in communication habits – someone who was always in touch, isn't anymore.
- Difficulty addressing and mailing letters.
- Unopened mail, especially bills.

Medications

- Are medications being taken as prescribed, at the right dosage, at the right time, with food or without? Are there full bottles of prescription pills in medicine cabinets? Is a mediset or medication dispensing device sufficient support?
- Are prescribing providers aware of supplements and vitamins, which could interact with prescribed medications? Have providers reviewed everything being taken to ensure that it is still necessary?
- Are labs needed to monitor medication effectiveness?
- Chronic or worsening health problems, taking longer to recover from illnesses or injuries – these can indicate that medications are not being taken correctly.
- Lack of medications due to missing important appointments: Are they frequently rescheduling missed appointments or simply not showing up?

Personal care

These tasks are referred to as Activities of Daily Living (ADL's): mobility/ambulation, transferring, eating, dressing, bathing, toileting, and continence. In some cases, problems in these areas can be due to physical causes (lack of mobility or strength) and/or mental (forgetting, apathy or lack of motivation, depression).

Mobility/Ambulation

- New or worsening issues with walking and moving, managing uneven surfaces, stairs or slopes.
- Decreased strength or stamina: unable to walk as far as they could prior, shortness of breath, difficulty navigating obstacles.
- Fatigue: unable to stand or walk for as long a time as they could before
- Decreased mobility – needing to use a cane, walker, or wheelchair, or refusing to use these when they can't move as well.
- Falls: Older people have the highest risk of death or serious injury arising from a fall and the risk increases with age. In the USA, 20–30% of older people who fall suffer moderate to severe injuries such as bruises, hip fractures, or head trauma.

Transferring

- Trouble getting into bed or out of bed.
- Difficulty with sitting down on a chair or the toilet, or standing up.
- Struggles getting into or out of the bath or shower, or a car.

Eating

- Changing eating habits lead to weight gain or loss without effort.
- Appetite may decrease as senses of smell and taste fade with age or due to an illness. They may be sick without knowing it. They may be clinically depressed and experiencing a reduced appetite.
- They may be forgetting whether they've eaten or not – they could forget to eat, or they could eat more than usual.
- Eating can be difficult due to mouth pain or decreased saliva (from dental problems, medication side effects, or health issues).
- They may have poorer or slower digestion, resulting in feeling full or nauseas and not eating as much.
- They may eat more sweets and snacks because these items are convenient (and often received as gifts).

Dressing

- Choosing appropriate clothing, shoes and outerwear for the situation, activity, and weather.
- Difficulty getting clothing on and off.
- Appearing disheveled or sloppy, not zipping or fastening clothing correctly.
- Wearing the same thing for multiple days – are they forgetting to change or do laundry?
- Unable to determine if clothing is soiled and needs to be laundered, or is damaged and needs repair.

Bathing

- With aging comes greater susceptibility to illness, so cleanliness is important to overall health.
- Do they have bad breath, unkempt hair, dirty nails or a bad odor more often?
- Infrequent bathing or showering: Sometimes people forget or lose track of taking care of themselves.
- They may feel less strong or have physical difficulty getting into and out of the shower.
- They may have difficulty reaching to wash everywhere or shampoo their hair.
- Many older adults are afraid to bathe without assistance as 80% of falls happen in the bathroom.
- Feelings of depression and lack of motivation can affect self-care.

Toileting

- Decreasing mobility and strength make the entire process of using the toilet more challenging.
- The physical processes of getting to the bathroom, opening or taking off clothing and sitting down.
- Cleaning afterward and being able to flush
- Properly rearranging clothing and washing hands

Continence

- Having sensory awareness of the need to use the toilet in order to get there in time.
- Physical challenges in elimination: urinary retention or leakage, constipation, diarrhea, uncontrolled bladder and/or bowels.
- Ability to manage incontinence supplies or disposable undergarments.
- Awareness of need to change oneself.

Other issues

Some things are important but don't exactly fall into the categories discussed above: health and medical issues, sleep, animals, mental health and emotional wellbeing.

Health and medical issues

- As people age, their health declines and they become more frail. This results in their needing more medical attention, taking more medications, and often managing multiple chronic conditions.
- With later-stage dementia, a person may need access to medically-trained staff full-time to help with feeding, changing, bathing and moving them.
- If the person has medical condition that is difficult to manage at home, they may benefit from residential care -- for example, uncontrolled diabetes or diseases that require support devices like oxygen.
- Medical conditions in addition to dementia may require around-the-clock medical care.
- There are more frequent accidents and injuries at home, even with your vigilance and care. This isn't your fault; may simply mean that it's time for 24/7 professional help.

Sleep

- Getting up a lot at night for care needs, or disruption of sleep/wake or day/night cycle.
- Sundowning – doing worse later in the day. Often this appears as very agitated behavior that becomes more pronounced as the day goes on. It is common with dementia, with one theory being that the person becomes increasingly fatigued and is unable to manage themselves over the course of the day. This can take a heavy toll on caregivers, and when it begins to severely disrupt family routines, this may be a sign that the caregiving burden is too hard to handle.

Animals

- Pets seem unhappy or neglected.
- Physical abilities to care for an interact with animals decreases.
- Remembering to feed and water pets becomes difficult.
- Challenges in being aware of and giving attention to a pet's difficulties can result in neglect or even abuse.

Mental health and emotional wellness

- Friends or neighbors have expressed concerns.
- Changes in mood or extreme mood swings: Are they acting differently toward you, friends, or even strangers?
- Depression: Has their demeanor noticeably changed? Do they no longer smile or do they seem unhappy? Do they say things that indicate they feel helpless, less optimistic, or hopeless?
- Having little to no energy: are they less active, or do they not talk or laugh like they used to?
- Loss of interest in activities or hobbies they once enjoyed: When was the last time they did something they loved?
- They don't have access to a supportive community or regular visits from loved ones. Isolation can affect older adults' overall health and wellness: decreasing participation in hobbies and social interactions with family and friends results in more serious psycho-social conditions such as depression, unhealthy habits, poorer health, and ultimately mortality.
- Aggression. Verbal, physical, and even sexual aggression frequently happen in those with dementia, and caregivers and other family members may suffer or begin to feel resentful.

Challenges to providing care at home

As discussed above, the need to move depends on not only the needs of the person who receives care, but the ability and desire of the caregiver(s) to give care. It is crucial to frequently re-evaluate on a regular basis. Stress and other caregiver symptoms can be just as telling a sign as the care challenges described above. Key areas to look at are the physical demands of care, logistical issues, and emotional capacity.

Physical demands of care

Being a caregiver is physically hard work. Are their care needs escalating beyond what you can manage? Do you have physical limitations, fatigue, less strength, or mobility issues of your own that make it difficult to cope with the physical demands of care? This can put both you and your loved one at risk. As a caregiver, it can be difficult to find time to care for your senior loved one, let alone yourself, but staying healthy is one of the best things you can do to provide the support your loved one needs.

Logistical issues

Adult children are often struggling with other responsibilities, such as their own children to care for, a full-time job, or their own health issues. Providing care is time-consuming, and may therefore limit your ability to socialize or enjoy leisure time, spend time with other family members, or commit fully to your work. If only one person is able to provide care, it probably isn't enough. It usually takes at least two people to manage care of someone at the end of life, especially if they have dementia.

Even if multiple family members or care providers are involved, it can be hard to coordinate and share the load. Pre-existing family patterns may be exacerbated, or old issues can come back. Financial concerns around reimbursement and compensation can cause conflict.

Emotional capacity

Caregiving is hard emotional work as well. While it can be immensely rewarding, it is also demanding, stressful, and unrelenting. Taking care of your mental health is critical, and there are many benefits to seeking out a circle of support to bolster you when times are difficult. Counseling, therapy, and support groups all exist to help family members going through similar challenges.

The psychological costs of caregiving and of making difficult care decisions are said to be similar to the effects of post-traumatic stress disorder. Caregivers may experience symptoms such as

- Intrusive thoughts
- Disabling anxiety
- Hyper-vigilance
- Social withdrawal from friends and activities that used to bring you pleasure
- Denial about the disease and how it's affecting the person diagnosed.
- Anger at or resentment of the person who is ill.
- Exhaustion and fatigue.
- Sleeplessness or insomnia.
- Irritability that triggers moodiness and negative actions.
- Difficult concentrating and remembering details.
- Being unable to remember the last time you felt good.

Everyone in a caregiver role may feel have some of the above signs at some point. In some cases, it might be clear immediately when the demands of care become too great. In other cases, it might not be so obvious. It's important to consider if a lot of these signs are occurring, for ongoing periods of time, and affecting your ability to provide appropriate care. Looking after a loved one puts you at serious risk of caregiver depression. Severe depression may impede your ability to care for your loved one in the way that you'd like -- burnout is real.

It may get to the point where you're afraid for the health and safety of your loved one and feel incapable of caring for them anymore. If you can't go to the bathroom without worrying about their safety, it may be time to consider alternative care options.

At-home care services may not be enough

Professional at-home care is one way that families try to share the effort of caring for a loved one. This can help keep the person at home for longer, but it doesn't always solve everything. You've likely noticed this first-hand if the at-home care your loved one has agreed to isn't working. This isn't to say it's the caregiver's fault, rather, that your loved one just needs more support.

A temporary respite stay can help

Arranging a short stint in respite care is one way to get some time to rest and recuperate, especially if you are caring for someone at home. Most assisted living and memory care communities have furnished rooms set aside for respite – this allows people to “try it out” and see if it's a good fit.

Making the move from home

It's common to feel guilty and sad when moving a loved one into care, even if you made plans in advance. It may feel like you're abandoning them or taking away a piece of their freedom. Caregivers may wonder if they could or should have done more; they may feel separation anxiety in moving their loved one to another location. If family dynamics are difficult, that may further complicate the decision process.

In many cultures, people don't want to talk about those things, but planning ahead is so important. Discussing concerns and preferences and making decisions – before an emergency (like a bad fall) happens, or before dementia significantly affects your loved one's cognitive health – allows you to make choices and have options. It's important to have the right legal and financial paperwork in place, as well as advance care directives. Being informed, planning ahead, and involving the appropriate people will ultimately help ease the process when it's time to move your loved one into care.

Benefits of moving into care – for your loved one and YOU:

Many times, the best way to care for your loved one is to have them in the proper place for getting the care and support that they need. It's important to recognize when you're making the best decision for your loved one's health and safety — and yours.

For the person moving into care, living in a residential community with support provides many benefits. When they don't have to worry about cleaning or cooking anymore, enjoying themselves becomes much easier and they can relax more. Not having to do difficult tasks puts much less strain on the body and reduces risk of falls. Exercise programs, medication management, and monitoring help to maintain health and wellbeing. Greater social interaction with peers and participating in activities planned by the facility can help them live more positively and meaningfully.

For the caregiver and family, you'll worry less about their physical and cognitive abilities to do everything because you can be comfortable knowing they have the care they need. Family members don't have as much of a burden to provide direct care and instead can focus on spending quality time together and having meaningful relationships.