

THE DEMENTIA DETOUR
HOW TO TURN ROADBLOCKS
INTO DETOURS

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Life's a Journey

Have you ever been on a road trip, a leisurely vacation, and come upon a roadblock: construction or an accident: something that turns into an unexpected detour? If you are like me, you might find detours to be interesting and/or exciting. They have the possibility of turning into an adventure; an unexpected chance to go a new way or discover a new place.

But sometimes, like on your morning commute or on your way to an important appointment, encountering a detour isn't fun and/or exciting; sometimes it's extremely inconvenient and difficult.

So it is with life's detours. You spend your time planning your journey. You plan to retire and travel or maybe you look forward to staying home and reading every book that you haven't had the time to get to. You carefully plan your finances so you can enjoy the retirement that you have worked so hard for. Your journey is going great...and then life throws up a roadblock.

An unexpected dementia diagnosis can create a real roadblock on your planned journey. Feelings such as grief, loss, fear, and anxiety are all too common when a diagnosis completely changes your life. Now, instead of facing retirement with excitement and anticipation all you see is a huge roadblock that is causing you dread and anxiety. Whether you have received a dementia diagnosis yourself, or your loved one is facing this roadblock, it will take adaptation, education, and lots of support to travel this new road. Those who will be most successful will identify and utilize all the resources available to them for the journey.

Detour Ahead



So, how do we face this roadblock and take this detour in a new direction without anxiety and fear being in the driver's seat? First, identify the areas that will need adaptation. The most common areas are your finances, your home environment and your support system.

Finances

Home Environment

Support System

Adaptation in response to dementia-related detours can influence the ability to *live well* for people with dementia and caregivers. Let's look at each area, one at a time: your finances, your home environment, and your support system. It is our hope, that with our suggestions and support, your unexpected roadblock can be met with adaptations that can influence your ability to live well with a dementia detour.

Finances

The Looming Cost

Your finances – the looming potential for long-term care is one of the greatest concerns of those diagnosed with Alzheimer's disease or some other form of dementia. The average cost of long-term care in the New Jersey is approximately \$14,000 a month, or \$168,000 annually. So how do you pay? There are basically three options to pay for long-term care.

The Options

1

Out of Pocket/Private Pay

The first is private pay. By my calculation \$168,000 for four to five years (the average time spent in a long-term care facility per the US Department of Health and Human Services) equal over one half to more than three quarters of a million dollars. The reality is that there are very few of us with the financial ability to shoulder that kind of expense, so other options need to be considered.



2

Long-term Care Insurance

The second financing option is long-term care insurance. Traditional long-term care insurance was more readily available a decade ago. Many of these traditional policies have life-time payout limits which are often insufficient to cover a four- to five-year stay in long-term care. Many private insurers have stopped offering these policies because they proved to be much more costly and far less profitable than projected. There are currently some hybrid long-term insurance options which can be purchased as a rider on your life insurance policy or as a one-time payment using qualified retirement funds or other assets. These vary greatly and are worth exploring with your insurance broker if you have not already done so. It is also worth noting that any of these policies must be purchased in advance of any life-altering or dementia diagnosis.



3

Medicaid

The third, and, most commonly used, option is the federally-funded Medicaid program. Unlike Medicare, which only covers short-term rehab-focused stays in a skilled nursing facility, Medicaid will cover the cost of medically necessary custodial care for those who meet the eligibility requirements.

Medicaid

Federal Funding

Medicaid is a federally-funded program that is managed by each individual state.

In New Jersey, the requirements for Medicaid eligibility are three-fold,

Meeting Eligibility



Clinical

The applicant must meet the clinical eligibility for nursing facility level of care, which means the individual requires assistance with three or more activities of daily living (eating, bathing, dressing, toileting, ambulating) or has cognitive changes which make it unsafe to remain in their own home.



Meeting Eligibility

Income

The applicant's must be under the income cap determined by the State of NJ annually, It must also be less than the cost of care. Income in excess of the annual cap can be placed into a special Qualified Income Trust.



Assets

The applicant's assets must be limited to \$2,000. With a spouse in the community the primary home and one vehicle are exempt from this limitation along with a community spousal resource allowance (cash assets). The state has a look back period of 5 years with a penalty for people who sell assets below fair market price, transfer assets to others, or give money and property away.



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Make a Plan

Despite all these restrictions it is often possible to develop a long-term plan that helps avoid the depletion of your assets if your loved one needs long-term care. If your loved one needs nursing home care, there are special rules that allow a significant number of marital resources to be sheltered for you as a spousal resource allowance.



Hire an Expert

Our attorneys can use their expert knowledge of Medicaid rules to help you protect your assets from long-term care costs through a defined gifting plan. Each instance is different and needs its own planning technique. Such planned gifting can often be done so that Medicaid can be obtained before the 5-year look bad has been reached.

An elder law attorney is an expert in issues that affect the aging population.

There's no place like home.



Those who will be most successful will identify and utilize all the resources available to them for the journey and make many adaptations along the way. This is probably most concretely evident in the home environment.

Whether we are talking about a current family home, or eventually, a care facility, adaptations to a person's living environment can have a profound effect on a successful journey.

Many people with a dementia diagnosis want to stay in their own home for as long as possible. While this is often the preferred option, people frequently face multiple challenges due to a deterioration in their physical and cognitive abilities caused by their diagnosis. Providing services and physical modifications to the environment can help make remaining at home with a good quality of life, an achievable goal.

Home modifications can be as simple as removing clutter and putting away unnecessary items. When there is a lot of clutter around it can make it more difficult for someone with dementia to focus on the things that they need in the moment.

Home Adaptations



Keep it Simple

Use everyday household items that have good visual contrast. For example, a white plate on a dark table or placemat; a dark bathmat on a white tile floor. High contrast is easier for the brain to interpret. Conversely, busy patterns are visually confusing and harder for the brain to interpret. Too much visual stimulation can cause agitation. Keep things simple and bold.



Be Aware of Doors

Someone that is confused may not always remember where rooms are in the home. Keep interior doors open to their bedroom and areas that you would like them to have access to. Of course, if there are rooms that they should not have access to, keep the doors closed to avoid drawing attention to those areas. Consider putting simple queuing signs on doorways. For example, put a simple drawing of a toilet on the bathroom or a bed on the bedroom door. Use adaptive items like a large print calendar and/or a specialized clock that very clearly states the time, time of day (morning, evening, etc.) day and date.



The Kitchen and the Bath

In the kitchen and/or bathroom label faucets hot and cold. Put away or hide items that could be unsafe or that you don't want your loved one to find. Keeping things out of sight often is all that it takes to create a safer environment. Make sure that medications are safely stored in child-proof containers and that they are closely supervised when administered. Consider adaptive equipment such as raised toilet seats and grab bars around the toilet and in the shower.



Beware of Wandering

If your loved one tends to wander outside alone, consider putting a secondary lock higher up on a door. A simple sliding bolt is often enough to discourage someone with dementia from wandering off and getting lost or injured.



Hire Help

Home care companies can provide in-home aides to assist you during this time. They can provide direct care to your loved one, or a respite for you to leave the house for some time for yourself.

Caregiving at Home



Eventually, a person with a dementia diagnosis will need more help with activities of daily living (everyday tasks). This may include bathing, grooming, and dressing. There are a few things that can make this process easier.

Try to keep a routine, doing things such as bathing, dressing, and eating at the same time each day. Serve meals in a consistent, familiar place and give the person enough time to eat. Allow the person that you are caring for to do as much for themselves as possible. Small things such as using clothing with elastic waist bands and shoes with Velcro closures encourage independence in your loved one. Tell the person that you are helping what to expect every step of the way (“I am going to help you with your shoes now” “Here is the washcloth for you to wash your face”). These kind respectful narrations will help to foster trust and should make routines more predictable and less stressful. Allow a person to make as many choices and decisions for themselves as safely possible. Build quiet times into the day, along with activities

Caregiving at Home

Communication can become difficult with dementia. Memory difficulties can cause your loved one to perseverate (repeat themselves endlessly) or have difficulty finding words or speaking. As this happens more frequently, they also can become agitated and anxious, even angry. This may leave you feeling frustrated or impatient. There are a few things that can help make communication easier in these instances. Speak calmly and show that you are truly listening. Try not to speak for your loved one, rather wait for them to find a word or indicate that they need help. .



If the dementia patient doesn't remember you, or calls you by the wrong name, try not to correct them or say, "Don't you remember me?" Encourage a two-way conversation for as long as possible, even if the conversations don't make complete sense, the feeling of connection is very real and reassuring to a dementia patient. If you have trouble communicating with words hold their hand or look at a familiar book or photo album. When the time comes that your loved one does not remember your name, or who exactly you are in their life, they do know how you make them feel. Your love is clear, even if your name is not.

Remember to take
care of yourself.



Follow the advice of the airline attendant and “put your own oxygen mask on first”. A caregiver that is completely depleted cannot give anything to anyone.

Care at Home Just Isn't Working



Very likely a time will come when the increasing needs of a loved one with dementia will exceed your capabilities to provide care in the home. It might be time for another detour along the way. You may well have to consider moving your loved one into an assisted living community or a long-term facility. But how will you know when you reach this roadblock, this new detour? Every situation is different. There is rarely an exact moment in which you will know. However, there are some common indications that it may be time for assisted living or nursing home care.

It may be that you are caring for a parent. Your job, your family and your own health are suffering. You just don't have enough time in the week to handle everything effectively. Or you may be an aging spouse that is at risk of being injured physically and emotionally. Your health may be suffering.

Perhaps your loved one is falling frequently. Loved one with dementia are very prone to falling. They can have diminished depth perception and frequently have less strength as the disease progresses. Decreased mobility at home can be risky for a dementia patient and for their caregiver. For example, a 75-year-old woman can easily hurt herself showering her 180-pound husband. It is not uncommon for a caregiver to become injured moving a dementia patient.



Their cognitive impairment and inability to perform activities of daily living can take a toll on caregivers, both physically and emotionally. Often caregivers sacrifice their own wellbeing to keep the dementia patient at home.

Wandering is a very common symptom as dementia progresses. They might be looking for something from their past that seems like it is happening right now, like going to work on the bus, and walk outside looking for the bus. Unfortunately, a person with dementia often no longer has directionality, or the ability to find their way back and are at a great risk of becoming lost or put in a life-threatening situation.

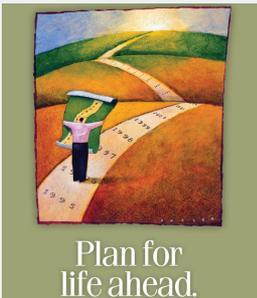
“Sundowning” is common with dementia. Sundowning often occurs late in the afternoon or early evening. While its exact cause is still unknown, sundowning can cause persons with dementia to pace, be confused, anxious, or violent. A person with dementia can sometimes display aggression for other reasons also. Fear and frustration can cause some persons with dementia to bite, hit, or kick a caregiver. A caregiver can be badly injured in these instances.

Difficult Decisions

If your loved one is creating an unsafe situation either for them or you by: exceeding your physical ability to care for them; displaying physical or violent aggression; wandering outside; it is time to consider placement.

It is hard to move our loved ones into a care facility. Not only do we consider the emotional toll it creates, but financial considerations can also weigh heavily on our minds.

If you are facing the roadblock of a dementia diagnosis, no matter how far ahead the actual detour may be, it is crucial that you identify your resources. Although this is all uncharted territory for you, Van Dyck Law Group is very familiar with the resources available to guide you through this detour.



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Not All Planning is Created Equal

If there is a dementia diagnosis in your family, it is important that you don't travel this journey alone.

When you are making a plan to pay for the care of your loved one, you must remember that not all estate planning documents, such as durable powers of attorney, are created equal and it is so important that you prepare for what is to come. This means being sure the language used in your legal documents includes provisions for cognitive issues should you have to make decisions on your loved one's behalf when they are not able to do so.

Call us today to discuss your next steps. We will help you pave the road to your peace of mind, and be with you every step of the way.



At Van Dyck Law Group, we can:

- Help you plan ahead for long-term care expenses
- Estimate the cost of care and provide asset protection from the cost of nursing home or in-home care
- Prepare your legal documents so that you and your loved ones are protected
- Assist you in learning about the available resources in your community and guide you through the process of senior living placement
- Provide education on:
 - Stages of the disease
 - Communication needs
 - Expression interventions
 - Avoiding and managing caregiver stress
 - Grief and loss
 - Discussions with loved ones
 - Empowering your loved one to stay as independent as possible for as long as possible
- Provide resources for you if you are choosing to care for your loved one at home
- Connect you with our Director of Life Care Resources to learn how to manage expressions in the home and communicate with your loved one who has dementia
- Provide you with ongoing support through your journey

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