



# Caregiving for a Parent with Dementia at Home

A guide for family caregivers that covers documents you should have in place after diagnosis, self-care tips, and long-term care considerations

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## I. Important Documents

There are several documents you'll want to have in place shortly after your family member's diagnosis. It's essential to draw up these documents while your loved one is still able to make decisions about their future. This [Legal & Financial Document Locator](#) is intended to be a helpful tool for use at home to organize your loved one's legal and financial records.

Your loved one will gain peace of mind and a sense of control of their own future and your life will be a lot less stressful knowing you have a road map to their wishes.

### Legal Documents

#### 1. Financial Power of Attorney

A [power of attorney \(POA\)](#)<sup>2</sup> is appointed by your loved one. They will manage your loved one's affairs once they are unable to do so.

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1 <https://info.highgateseniorliving.com/legal-and-financial-document-locator-checklist>

2 <https://blog.highgateseniorliving.com/two-must-have-powers-of-attorney-for-seniors>

## 2. Health Care Power of Attorney

Also called an advanced directive or health care proxy, a health care POA is appointed by your loved one. They will speak for and manage your loved one's health care once they are unable to do so.

## 3. Living Will

A living will specifies your loved one's end-of-life health care wishes (e.g., whether they want to be kept on life support or would like a feeding tube in the event they cannot eat). It also helps you from having to make difficult end-of-life decisions for them.

## 4. Updated Will

If your loved one doesn't have a will, now's the time to get one. It will ensure that their assets, heirlooms, and anything else is distributed how they wish. It can avoid a lot of family dissent and/or hurt feelings later on.

If your loved one has a will, it's time to make sure it reflects their current wishes.

*TIP: Keeping all of your loved one's paperwork organized and in one place is a time saver and stress reliever. A binder – physical or electronic – can be your best friend.*

## Critical Information Document

In addition to legal records, it's helpful to document other useful information about your loved one's care that you would want another caregiver to know if you can't be reached or in case of emergency. Examples of things to include:

- Doctors names and contact numbers
- Medications, doses, and times
- Dietary needs or restrictions
- Triggers and antidotes (i.e., things that either distress or calm your loved one), such as the type of music that soothes your loved one if they seem anxious.

## Where to Find More Information

The following resources provide more detail about legal documents that ensure that your loved one's wishes are known.

- [www.alz.org/care/alzheimers-dementia-planning-ahead.asp](http://www.alz.org/care/alzheimers-dementia-planning-ahead.asp)
- [www.alz.org/care/alzheimers-dementia-legal-documents.asp](http://www.alz.org/care/alzheimers-dementia-legal-documents.asp)
- [www.aarp.org/caregiving/financial-legal](http://www.aarp.org/caregiving/financial-legal)



## II. Resources to Create a Network of Support

Once you receive the diagnosis, you may feel alone and overwhelmed. Having a good support network you can turn to for advice and encouragement when you feel alone, overwhelmed, or even frustrated can ensure that, even on the toughest of days, you have the support you need to support your loved one.

Here are some ways to expand your network of support:

### Online Support

Facebook groups, for example, provide support at any time. If you can't sleep at 3 a.m. or have a question at 9 p.m., there's likely someone online who will respond to your question, empathize with your situation, or acknowledge your pain.

Because most of those online are people just like you, be sure to supplement with a group moderated by an individual professionally trained in Alzheimer's and dementia care.

## Support Groups

If time and geography allow, nothing beats a face-to-face group. They provide support and information from fellow caregivers and often from professionals in dementia care. Some organizations may offer online support groups via Skype or similar technologies.

Start attending or participating in support groups as soon as you're able. The more you learn and connect with others, the better you'll be prepared for the journey ahead. You'll also help others on their journeys!

## Form Your Own Support Network

There are many people and resources out there. Only you know what you need and want. Talk with others about what's been helpful for them, but ultimately, what you need is personal to you.

The following is a starting list of caregiver resources:

- [National Alliance for Caregiving](http://www.caregiving.org)<sup>3</sup>
- Local senior center, hospital, assisted living, or [memory care facilities](https://info.highgateseniorliving.com/guide-to-memory-care-and-dementia-communities-lp).<sup>4</sup> These facilities will be acquainted with resources in the community.
- [Alzheimer's Association](http://www.alz.org)<sup>5</sup>
- [Alzheimer's Association resources](http://www.alz.org/resources)<sup>6</sup> in your community, including support groups and programs
- [Veterans Administration](http://www.caregiver.va.gov)<sup>7</sup>
- [Family Caregiver Alliance](http://www.caregiver.org)<sup>8</sup>

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<sup>3</sup> [www.caregiving.org](http://www.caregiving.org)

<sup>4</sup> <https://info.highgateseniorliving.com/guide-to-memory-care-and-dementia-communities-lp>

<sup>5</sup> [www.alz.org](http://www.alz.org)

<sup>6</sup> [www.alz.org/apps/findus.asp](http://www.alz.org/apps/findus.asp)

<sup>7</sup> [www.caregiver.va.gov](http://www.caregiver.va.gov)

<sup>8</sup> [www.caregiver.org](http://www.caregiver.org)



### III. Considerations When Considering Family Caregiving

Caring for a loved one with dementia can pose many [challenges for families and caregivers.](#)<sup>9</sup>

As dementia progresses, it becomes more difficult to remember things, think clearly, communicate with others, and take care of yourself. Dementia can also cause mood swings and even change a person's personality and behavior.

Caring for a loved one with [Alzheimer's or other forms of dementia](#)<sup>10</sup> is a big commitment and there are many things to consider. If you haven't decided, here are a few things to think about.

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<sup>9</sup> <https://blog.highgateseniorliving.com/why-dementia-caregivers-experience-higher-levels-of-stress-and-burnout>

<sup>10</sup> <https://blog.highgateseniorliving.com/dementia-alzheimers-parkinsons-mild-cognitive-impairment-whats-the-difference>

- Do you have the time and energy for anything additional on your plate? Caring for a loved one with dementia impacts every aspect of your life. And it's long term.
- How flexible is your schedule? Will you be able to bring your loved one to and from doctor appointments? Handle a wealth of phone calls to doctors, insurance companies, and more? (If you are your family's sole provider, this is an especially important consideration.)
- Can you care for a loved one who may experience dramatic mood changes, including anger and acting out, as they try to make sense of their world? Do you have other family members with whom you can share caregiving responsibilities?

It's completely natural if you're feeling conflicted. Take the time to decide what's best for them and for you.





## IV. Taking Care of Yourself as a Caregiver

Whether you're the primary caregiver or you share caregiving responsibilities with others, taking care of yourself is likely the last thing you think about.

Let's put things into perspective a bit.

We're all familiar with it — the part of the preflight instructions where they say, "Put your own oxygen mask on before assisting others." Why? Because it's impossible to give 100 percent to taking care of another if your emotional or physical health is suffering.

This sounds dire, but most of us put self-care last no matter our circumstances. When you're caring for your loved one with dementia — a disease that lasts years — not caring for yourself can lead to [caregiver stress and burnout](#).<sup>11</sup>

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<sup>11</sup> <https://blog.highgateseniorliving.com/8-warning-signs-of-caregiver-stress-or-burnout>

## Signs You Need to Take Better Care of Yourself

Keep an eye out for these symptoms. They're early warning signs that you need to apply self-care first aid now, before you burn out.

Do you:

- Fly off the handle and stay angry?
- Have trouble concentrating?
- Find it's difficult to fall or stay asleep?
- Feel tired all of the time?
- Feel worried most of the time?
- Feel you're alone, that friends and family don't care or can't relate?

If any of the following happen to you, it's time to ask for help:

- You forget to pay bills
- You're visibly gaining or losing weight
- You no longer participate in social activities that you love
- You no longer do things you enjoy (hobbies, for example)
- Your once-clean house is always a mess

## Self-care Ideas

### Weekly

It's not easy to carve out an hour each week for "me time." It may seem self-indulgent. Considering how [stress can negatively impact your physical and emotional wellbeing](#),<sup>12</sup> this time is really preventative care. You'll reconnect with yourself and recharge for caregiving — and all the other aspects of your life.

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12 <https://www.nimh.nih.gov/health/publications/stress/index.shtml>

## **1. Flex your creative muscles.**

Take a dance class or go dancing, play an instrument, color, do woodworking, knit, paint, draw. The possibilities are endless. It doesn't matter if the end product is "good." The point is the doing. Creative activities help you express yourself as you, outside any of your other responsibilities or roles.

## **2. Connect with friends.**

It's easy to disconnect from friends and social activities when you're caring for a loved one. Make a date with a friend once a month. Meet for coffee, see a movie, take a walk. You'll connect to other parts of yourself, beyond being a caregiver.

## **3. Enjoy a little quiet.**

Have you noticed how rare quiet is? People talking, TV, appliances running, traffic outside. Even when it isn't "noisy," over time, noise can overwhelm. Quiet gives you time to recharge and the space to reconnect with your whole self. Meditation and prayer are two examples. There are many free or low-cost instructional apps and videos to guide you.

### **Daily**

There are many things you can do quickly each day to lighten your mood and relieve stress.

#### **1. Laugh.**

Watch a funny cat video, look at a favorite cartoon, tell a joke, or read something that makes you laugh. Laughing releases endorphins, which make us feel happy and help lower stress

#### **2. Breathe deep.**

Sit or stand upright. Breathe in through your nose to the count of four. Breathe out through your nose to the count of four. Repeat several times.

Focusing on your breathing is a great way to calm your body and mind. There are many free and low-cost tools to help, such as phone apps and YouTube videos.

### 3. Work on a puzzle.

When you concentrate on a crossword or sudoku puzzle, it's hard to focus on other things. Your mind can go on a little vacation from your cares and worries.

Lastly, remember:

- You're not perfect. No one is. You're doing the best you can.
- You have a right to feel what you're feeling.
- You're human. [Set realistic expectations.<sup>13</sup>](#)
- Eating right, getting enough sleep (seven to eight hours) and exercising (even a little) will serve you well.

There's a wealth of resources about self-care. These two will get you started:

- [AARP articles<sup>14</sup>](#), tools, and tips for caregivers
- Google “self-care” or “self-care for caregivers” and you will find thousands of ideas!

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13 <https://blog.highgateseniorliving.com/5-tips-for-setting-realistic-boundaries-and-expectations-as-a-family-caregiver>

14 [www.aarp.org/caregiving/life-balance](http://www.aarp.org/caregiving/life-balance)



## V. Long-term Planning

There's a lot to do and digest right now. In the not too distant future, however, you'll want to begin talking with your loved one about long-term plans.

At some point, your loved one's needs may outgrow the care you're able to provide. What might that look like in your case? At what point should you think about memory care?

### What is Memory Care?

Memory care<sup>15</sup> is specially designed for those with dementia. Memory care communities can vary dramatically. The best facilities provide:

- Staff who are specially trained to work with those with memory loss
- Secure facilities so that your loved one is able to be in or outside yet can't wander off

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<sup>15</sup> <https://blog.highgateseniorliving.com/what-is-memory-care-part-i-an-overview>

- 24/7 care
- Help with feeding, laundry, and other activities of daily living<sup>16</sup> (like grooming and dressing)
- Assistance with medications and medical conditions. For example, if your loved one has a complicated diabetes management regimen or colostomy bag, be sure that the memory care facility you choose can accommodate appropriately.
- Socialization and activities appropriate to your loved one's abilities

If you choose to tour a community, be sure to make scheduled and unscheduled visits. Unscheduled visits will show you whether the day-to-day matches what you saw on your tour.

## Is it Time to Look at Memory Care?

“Is it time?” It’s a difficult and emotional question. It’s important to be honest with yourself. Sometimes your loved one’s care becomes more than you can handle. Every situation and caregiver is different.

If your loved one is experiencing any of these, it’s time to consider memory care:

### **Wandering**

Does your loved one leave the house? This can be quite dangerous because your loved one might not remember where they live or how to get there, even in familiar surroundings.

### **Mobility**

Does your loved one need help moving, for example, in and out of the bathtub? Are you able to do this without hurting yourself?

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<sup>16</sup> <https://blog.highgateseniorliving.com/slideshow-what-are-activities-of-daily-living-anyway>

## Sundowners

Does your loved one's mood change near sunset? Do they become fearful, agitated, sad? Do they lash out?

If you have or plan to become the primary caregiver, at some point the stress of caring for your loved one, or their daily needs, might become too much for you. There's no shame in saying, "I can't do this anymore."

Being prepared for the day where your loved one might need more help and support that you can offer alone allows you to have a plan in place that makes a possible transition easier on both you and the person you are caring for.

Also, take into consideration how much input you'd like to have from your loved one. Beginning your research early means you're able to discuss with your loved one what the day might look like when you need additional support. It also allows them to determine how involved they'd like to be in long-term care planning.

The journey of caring for a loved one with dementia begins at diagnosis. Whether you are the primary caregiver or share the responsibility with others, caring for them will have its ups and downs.

It may be tiring and even emotionally exhausting at times, but ensuring you have a solid support system, the proper resources, and a long-term plan allows you to give your loved one the care and support they need.



*This guide is brought to you by Highgate Senior Living, an industry-leading assisted living and memory care provider offering a holistic approach to care. Pioneering change in the senior living industry, Highgate is committed to creating a unique and desirable living option where each resident can live a life of purpose.*

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