

Dementia Caregiver Survival Guide

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We as caregivers have accepted an important responsibility, in most instances not really understanding the importance of the task, the length of it, the behavior changes of our loved one (LO) as the illness progresses, and the strain it will levy on our health, psyche, and finances. It will be a long process, sometimes more than what we bargained for, with implications for your health, social interactions, finances, and survival.

This article represents the joint efforts of a number of experienced caregivers. The writing style of the article is varied because each of the contributors wrote their section based on their own experience, emotions, and their journey. We decided to keep it as written for authenticity and individuality.

Each of the caregivers who has written here has been involved in caring for their spouse. The perspective and some of the comments apply to these specific relationships. However, the basic issues are the same whether your relationship is a spousal one, or that of a child, a sibling or friend, or a parent.



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I - Survival Research

The most important advice that anyone can give you as a caregiver is that you should stay healthy and strong in order to be able to care for your LO. If you are incapacitated for whatever reason, your LO's care will encounter major, sometimes irreparable setbacks. There are additional reasons to make sure you take care of yourself during the dementia journey. Previously expectable support from your LO may not be possible if something happens to you. If you have assumed responsibility for most practical matters, these too could suffer if you fall ill yourself.

Here are a few research briefs to emphasize the fact that you have to first take care of yourself in order to survive to be able to care for your LO.

- **Psychological morbidity**

Dialogues Clin Neurosci. 2009 Jun; 11(2): 217–228. PMID: [19585957](#)

Strain can manifest as psychological morbidity, including depression and anxiety. A robust relationship between dementia caregiving and negative effects on psychological health has been demonstrated in numerous studies.^{31,34,35} Rates of depression vary between 23% and 85% in developed countries,^{33,36} and of anxiety between 16% and 45%.^{34,37-39} In the developing countries psychiatric morbidity range from 40% to 75%.¹⁰

- **Depression and distress predict time to cardiovascular disease in dementia caregivers.**

By Mausbach, Brent T.... Health Psychology, Vol 26(5), Sep 2007, 539-544

Conclusion: This study suggests that increased depressive symptoms and reaction to patient problem behaviors (i.e., distress) may increase caregivers' risk for experiencing negative health outcomes, specifically CVD. (PsycINFO Database Record (c) 2016 APA, all rights reserved)

- **Caregiving as a Risk Factor for Mortality. The Caregiver Health Effects Study**

Richard Schulz, PhD; Scott R. Beach, PhD, *JAMA*. 1999

After adjusting for sociodemographic factors, prevalent disease, and subclinical cardiovascular disease, participants who were providing care and experiencing

caregiver strain had mortality risks that were 63% higher than non-caregiving controls. More research on the complex interaction of attachment style, personal history, premorbid mental health and other factors will undoubtedly sharpen our understanding of who is at highest risk among strained caregivers.

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II – Planning

How to get help from others

- Caregiving for someone with dementia is not a one-person job
- Sleep deprivation, behavior changes, patient's hygiene, housework, and doctor's visits all can in turn cause major health problems for the caregiver
- You might be able to manage the load at the beginning but as the disease progresses, the caregiving process will become more time-consuming and specialized, and no one can do it alone 24/7
- Involve family, friends, neighbors, and other community possibilities. Recruit help early so that they have opportunity to learn, before the learning gap becomes too large
- Have a list of things that others can do and test acquaintances to see if they are serious in extending a helping hand
- Remember that even though it can be challenging to do, asking for help does not make you a bad person
- Educate yourself about the illness and know what problems might lie ahead
- Join support groups

Get the family involved

- The burden of caregiving falls on the shoulders of whoever is most available, often a single primary person
- This could be an unmarried daughter who becomes caregiver by default
- At the end of the caregiving process, without planning she may become a middle aged woman, potentially worn out physically and mentally, with an interrupted work history, more limited career options, less education, and perhaps alone
- Other family members, if they exist, should be encouraged to share the load. There are many creative ways to get others involved, and all should be explored
- Seek ways to get the family to share the burden both financially and physically

- In the end some may refuse or drift away from this responsibility, and you will need to make plans to involve others instead

Join support groups and forums which are appropriate for you

- Not all forums are made equal
- Look for those which are not trying to sell you their stuff
- Do not waste your time with those who advise you to leave your doctor and start new untested methods of cure
- A good forum is managed well, respects privacy issues, and does not sell anything to you
- Joining a forum will help you alleviate feeling of being alone, will help you gain from others experience, will teach you what might lie ahead, will help reduce feelings of stress and depression, provide advise with the legal and health insurance issues, and lead you to other sources of community support.

Avoid forums which are not appropriate for you

- Are there membership fees? If so, to what use would they be put?
- Are the objectives of the forum well defined and adhered to?
- Is the forum managed well, to its objectives, with the help of experienced people?
- Do the meetings and other timing issues fit your schedule?
- Does the forum suggest to stop your current medical routine and adapt something new?
- Always avoid providing your personal information, real name and address, phone number, etc. when interacting with people in an open, or even moderated, online forum. This is for your privacy and that of your LO.

Watch your health

- Don't miss your annual check ups
- Listen to your body and do not ignore its warnings
- Get enough rest
- Remain social
- Exercise
- Eat a healthy diet
- Find ways to let off steam, take a break, go to the movies, join a friend for coffee

- Watch for stress signs and learn ways to reduce them. Commence dreams of “life after dementia” long before there is any opportunity to start planning.
- Watch for depression signs and learn ways to bring them under control. See a doctor if needed
- Counselling can be very helpful in recognizing and dealing with mental health problems if these arise

Your role changes as the disease progresses

- Initially, the patient is active and you can enjoy various activities together when their mood allows
- You are a companion and friend during part of the first phase of the illness although this may not be what most of the caregivers experience, especially in the case of frontotemporal dementia
- Towards the end of first stage and during the second stage, you will be confronted with major behavior changes like agitation, aggression, depression, apathy, confabulation, etc. While the specific expression of second stage symptoms varies by individual, they are generally more intense than first stage symptoms, and more resistant to shifting. The caregiver challenge is to manage these behavioral changes and intensifications as best as possible. Pharmacological intervention, in the form of calming medications, is available if care-based approaches are insufficient
- In the third stage of the illness, physical problems develop such as trouble swallowing, frequent UTIs, aspiration pneumonia, balance problems and falls,
- As the disease progresses caregiving duties become more difficult, require special skills, and professional help
- If you find the care of your LO at home overwhelming, consider placement in a nursing home.
- You are not inadequate or a bad person if you decide upon placement. Ultimately, both your LO and yourself benefit from the additional structure, care, and support that a placement can provide. There comes a time that the caregiving workload is greater than one or two people can provide on the worst of days. When it takes a village, you need a village. If you cannot muster a village at home, you need a residence. Your involvement remains but shifts to more of an oversight role, and you can enjoy quality time with your LO

Get help, do not try to do it alone

This is especially true if you already have a diagnosis. Getting a diagnosis is not easy and may take years, mainly due to the fact that there are no specific tests or imaging that can

firmly diagnose dementia, let alone its type. That is why thinking about getting help usually happens after diagnosis when the gravity and the weight of the illness sinks in.

- The best help is provided by friends and the family and especially during the first and middle stage of the disease progression. Professional help is needed mostly during the third phase of the illness.
- The most independent, but an often difficult route to finding caregiving help is to place ads in the local newspapers, interview applicants, and select someone who fits the job at hand. If you find a reliable person, it is worth some effort to keep him/her happy so that he/she stays.
- The next alternative is to go through agencies. They can guarantee the credentials of the applicant, they will replace the worker if you are not happy with the service. The downside to not initially vetting the person yourself is that you may end up training a series of new workers over time if they don't work out
- The best time to look for hired help is earlier than you actually need the help, i.e., as soon as you can anticipate that it will become necessary in the foreseeable future
- Most LO's find it easier to adapt to caregiver helpers during the early phases of the illness
- Also valuable are Adult Day Care agencies, especially while your LO is mobile and can enjoy the company
- And think long term. If you cannot care for you LO at home through the end, which most people cannot, it is useful to start looking at nursing homes possibilities during middle stages of decline. Choosing a facility that is a good fit for you and your LO requires research and evaluation of the options open to you, both of which will take time. There might also be wait times to find a vacancy at your chosen facility.
- Another possibility for external placement is establishments with senior living facilities backed up by full-fledged nursing homes.
- And do not forget to call for Hospice care when the time comes

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III - The four stages of caregiver role

Overview

What is different about caring for a person with dementia is that we lose the person and our relationship progressively with fading cognition, therefore our grieving starts during the caregiving journey.

By the time you get to suspect "dementia", you have been living with your LO's symptoms for years, probably a decade, and have suffered misunderstandings, relationship damage and you have reacted and maybe responded. But suddenly with diagnosis (dx) comes a new opportunity to see the bigger picture, to recognize that your past has dealt with neurological disease and to see where degeneration will take you. Caregivers need more validation at this time and they don't get it from doctors. Doctors deal with patients, not caregivers. Doctors typically think dementia starts with diagnosis.

Caring for a person with dementia is stressful. The same may well be true of other fatal diseases, but it is very significant when your LO does not know who you are. And it is that stress which raises the caregiver mortality by 63% compared to non-caregivers. This says risks are real and severe and require conscious management and a superior strategy.

In summary:

- Practice self-care
- Exercise regularly
- Eat well
- Sleep well
- Get company and understanding
- Get out and about
- Seek solace in prayer, music or library
- Check out any new health concerns
- Consider counseling
- Get legal and financial planning done
- Beware making big changes (house, job) while grieving

Which of those make a significant difference in survival? How do we know which are the right strategies for us? NIA and NIH have no information. I can tell you which of these made most difference for me, but I know from my discussions with many other caregivers that the answers are different for each individual. You have your own unique combination of issues, not only from that NIA list. Your LO has other medical conditions. You may have your own unique disabilities. There may be guns or drugs in the house. The way to survive is to use this as a checklist to identify what is troubling you, and use your friends and mentors to make improvements. You need your own unique custom survival strategy and it needs to be effective for you.

The solutions promoted by the Alzheimer's Assoc. are respite or placement, but respite is often declined by the person with dementia or unacceptable on grounds of behaviors. Even permanent residential placement is not an end of the caring and advocacy roles.

Way back in 2012, the assessor asked me "How do you cope"? I misunderstood the question and started to describe the things I did... "But... HOW do you cope?" I said "We lower our standards" and I think she immediately regretted asking. But it was true. Cleaning happened less often. Some objectives were abandoned. We choose our battles. We lower our standards. We abandon some retirement plans. And we forgive ourselves some of our failings and limitations. These are necessary adjustments for caregiver survival and the tolerance of the loads that otherwise result in caregiver burnout.

A big tip for caregiver survival is to have dreams of a future ...it is healthy to dream about "life after dementia". And later, to plan that. A good friend of mine, another caregiver to his wife resident in a nursing home, was very despondent about the impending death of his wife. I made him a scrapbook with pockets, inserted pics of him and his wife, his kids, his grandkids, his sibs and a few of his hobbies. I called it "My Life After Dementia" and encouraged him to fill in the blanks and show his family. He told me that these activities literally saved his life. And he drove eleven hours each way to visit me and tell me again.

I used to find a relief by starting to nourish ideas of "life after dementia". When I put my head down, I would give a minute to think of hobbies, trips, or friendships to be renewed. I found it my kind of sanity therapy. You can choose a primal scream instead, whatever works for you as an escape valve.

Your Survival Strategy does not end with the death of your LO. It has to extend at least as far into the grieving period as the turning point at which renewal starts. Grieving presents risks of depression and isolation and giving up. Some of your dreams of Life After Dementia have to develop into plans and progress before you can feel you have survived.

Divorce

Following years of changed behaviors, lost empathy and eroding relationships, many couples are driven to consider divorce. This question frequently arises before diagnosis is reached, but also after dx. And the initiative can come from either the partner with dementia or from the caregiver.

The caregiver who observes the degenerating cognition and the changing behaviors (Ref: Managing The Rage Stage) will most commonly remark “This is not the person I married.” In many cases, that is almost literally true, when obsessions and rages have changed the personality of the patient and simultaneously eroded the couple’s relationship.

Often, the same behaviors go unnoticed by other family members who see the patient infrequently, for short periods, when on their best behavior (“show-timing”). Similarly, the patient’s doctor, with short consultations, has no opportunity to assess the trends (Ref: Diagnosing Dementia). The caregiver, as a result, becomes increasingly isolated in this perspective, often concluding the patient has become a complete jerk.

The patient most commonly has no insight into their own degraded behaviors (this is anosognosia, wholly involuntary and not to be confused with denial) but can observe the results of the failing relationship, the harsh words, the time sought apart. So the patient too is likely to initiate divorce.

Divorce is not necessarily a bad outcome and is not necessarily avoidable. When divorce is initiated by an undiagnosed patient, the caregiver may not be motivated to contest the matter and may be constrained by privacy considerations from providing complete evidence. After diagnosis, medical records become subject to further privacy constraints.

In some western jurisdictions, divorce can provide a separation of the partners’ assets so as to protect the caregiver from becoming liable for the future care costs of the patient. The advice of an elder care attorney should be sought immediately if divorce is contemplated. Financial liability may be able to be simplified and reduced. A divorced spouse will not subsequently be next of kin to the person with dementia and will not be able to make decisions for the patient’s medical care.

Overwhelmed

You are overwhelmed. You have extra work. You have duties outside your normal role. And you are grieving the progressive loss of your relationship. This load is heavy and the emotional load that comes with it has some unfamiliar elements.

You are on a journey you did not seek. It may have come wholly as a surprise to you when you first learned that the person you care for has dementia. The emotions of grief, sadness and loss may exceed any such emotions you have previously experienced. That burden will so overwhelm you that you will become an emotional casualty of your journey with dementia unless you can find a survival strategy.

There are opportunities that differ in every individual journey. But there are some that are common. The first is to recognize that, for you, there may be a life after dementia. As soon as that sinks in, you will ask yourself its shape and a dream is born. There is little opportunity during your caregiving journey for that dream to evolve into anything like a plan, but in that dream there is hope and hope is nourishing.

The second may surprise you as it did me. A diagnosis of dementia contains an element of relief. There was nothing you could have done to avert the onset of the disease and there is nothing you can do to stop the inevitable degeneration. Your burden carries no element of blame or shame. Recognition brings a balm.

The third is your journey offers you opportunities for happiness and pride. You might discover you have an unsuspected Mother Teresa gene. You will certainly have memories of happy times as you sit with the person for whom you are caring. There are moments of intimacy in acts as simple as helping them to eat or drink. These emotions may not have come your way had you not taken this dementia journey together.

Fourth is that you are not alone in adversity. You will meet other caregivers and, in some, you will find a kind of comradeship that comes from facing the same challenge. You will encounter some dedicated people and you will see them under strain, when they reveal much character. If you make the time to acknowledge them, you can make lasting friends.

One Day at a Time

You will encounter much advice urging you to not get too far ahead of yourself. When caring duties are onerous, survival becomes a daily issue and looking ahead can be overwhelmingly depressing.

Along similar lines is the advice “apply your own oxygen mask first.” The 'oxygen mask' anecdote is a reminder that the caregiver is the one in charge now (and it was not always like that). The LO can no longer make quick, correct decisions, and the caregiver must do that every time and be ready to do it again tomorrow if necessary.

But the caring journey is unlike an airplane emergency. Caring is a marathon. I am not enamored of analogies like 'oxygen mask' or 'parachute'. But they serve a purpose when a caregiver may otherwise panic and not find a solution.

There is help available. There are strategies that make the caring journey survivable.

To be around for your LO in the future, you must survive every crisis. To do that, you have to take care of yourself, all the time. You are now the only responsible, capable adult in this relationship. It is not selfish to look after yourself. If you are run into the ground, you cannot effectively care for your LO.

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Pre-diagnosis

Medicine and drug management: The patient insists on managing her own meds. This can cause missing a dose or an overdose both of which can cause serious problems.

Legal and financial decision: The patient thinks that she is in charge of her faculties and may donate some of her wealth or make wrong financial decision causing the loss of all the savings made during a lifetime.

Driving: The patient may insist to continue to drive while his impaired judgment may create dangers to himself and others.

Disorientation: She may be confused, wander around, not remember how to get back home and get lost.

Poor hygiene: Due to apathy or forgetfulness, the patient may not be able to do her usual hygiene routines. She may smell, wear dirty clothes, and develop various infections.

Stubbornness: Patient may appear to be stubborn. She is not. This is the disease which makes her act like that. She cannot change. The caregiver has to change.

Appliances safe use: The patient may forget how to use electrical and gas appliances and as a result cause dangerous situations for herself and the family.

Cleaning agents: She may mistakenly drink liquid detergents or bleach and end up in the ER. Precautions should be taken to avoid such wrong use of materials and dangerous kitchen tools like knives.

Hoarding: The patient may buy and store household items over and above the needs of the household.

Shoplifting: She may take items from the racks of supermarket, consume them, and not pay for them.

Accusing others: The patient may accuse family members of theft of her belongings and infidelity.

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Phase one of the illness

Legal and financial: Put all the family and business financial and legal matters in order like preparing POAs, and living wills. Consult an elder care attorney.

Education: Knowledge is power. Chances are you know nothing about dementia. The more you know, the more prepared you will be for the long journey.

Behavior changes: Get ready for patient's behavior changes like depression, aggression, restlessness, repetition, and improper sexual behavior.

Daily log: Start recoding daily events in a tabular form. Not only it helps you with ensuring adherence to daily routines like meals times, meds, and activities, but it also helps analyze changes and find their root cause by looking at the history of events.

Medical: Do not delay pending medical issues like fitting eye glasses, hearing aids, dental work and the like. Perform them as soon as possible while the patient is able to follow instructions and cooperate.

Dementia friendly home: Make your home dementia friendly as soon as possible. Install hand rails and grab bars, prevent falls, remove clutter, and provide proper lighting.

Forums: Find appropriate forums and join them. Also investigate support organizations in your area.

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Phase two of the illness

Behavior changes: Get ready for more behavior changes like hallucination, suspicion, wandering, sleep disruption, incontinences, apathy, and lack of empathy.

Daily and weekly schedule: Prepare a daily and weekly schedule of activities based on patient's capabilities and interest. Be prepared to make changes to this schedule as the disease progress.

Nutrition, exercise, and activities: Insure a proper diet for yourself and your loved one. Include exercise and refreshing activities in your daily and weekly schedule.

Equipment: Get ready with the necessary caregiving equipment like wheelchair, walker, hospital bed, and hoists. It is better to stay ahead of the curve and be ready before the need arises.

Your health: Listen to your body. Ensure you get respite help, do fun activities, and do not miss your medical appointment. Do not miss your annual checkups. Release the pressure on a regular basis.

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Phase three of the illness

Caring at home: Evaluate the situation carefully. Can you provide care for your LO at home to the end? If necessary, evaluate and plan placement.

Swallowing: Get ready and educate yourself on swallowing issues. As the autonomous swallowing activity gets impaired, serious coughing episodes for the patient and distress for both the patient and the caregiver ensue. You need careful planning and education to mitigate these issues.

Infections: Anticipate recurring infections requiring medical intervention. Lack of activity, improper hygiene, and being bedridden for most of the time can cause recurring urinary tract infections. Swallowing problems can develop into aspiration pneumonia.

Bed sores: At this stage, the patient will be in her wheelchair or in her bed for long hours on a daily basis. This increases the risks of developing pressure sores which are painful and difficult to treat. Remember that it is much easier to prevent bed sores than treat them.

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IV – Caregiver emotions

You are caring for a person with dementia. You love, or used to love, or feel an obligation towards that person. You probably already find yourself on an emotional rollercoaster. You have no time at all to read this, but you should anyway, because it contains tips that will help you hang on for dear life.

All our journeys as caregivers are individual, and all have points in common. My story is one of caring for my husband diagnosed with behavioral variant fronto-temporal dementia. He has been in a Skilled Nursing Facility for three years at the time of writing. I write from my own experience, but will attempt to address the common. If you don't see your emotion listed here, don't worry. Everything you feel is real, even if you think you feel nothing.

This is the first lesson: to recognize that all emotions are valid, including numbness. It is very helpful to name them, if only to yourself. Once you have named them, you have given them shape, and it becomes easier to live with them.

On my own journey, I have found the following phrases invaluable, and recite them like a mantra:

- “This too shall pass”, because you know, it shall, one way or another
- “We cannot control outcomes”
- “Don't go borrowing trouble from tomorrow”, or in the biblical version “Sufficient unto the day is the evil thereof” (Matthew 6:34)
- “Put aside all anxious thoughts and imaginations” That's St Francis de Sales, but if you're not Christian, it does not matter a jot. You get the point.

Below you will find the most common emotions with subsections to each one and suggestions on where they come from and how best to deal with them. They are arranged in pairs - positive and negative, and it would be a good idea to read the positive as well as the negative.

The emotions covered are Love (affection, loyalty, fidelity, happiness); Grief (sadness, loss, recollection); Joy (relief, personal happiness, other people); Anger (guilt, frustration & resentment, disgust & contempt); Wonder (pride, satisfaction, accomplishment); Fear (anguish, dread, anxiety, physical fear)

Love

What does that even mean? You're in the middle of finding out. All we know is that it doesn't mean whatever it's supposed to mean. If you are caring for somebody with dementia, you are loving them, whatever the circumstances. Acknowledge that, and let it sink in.

Affection: this is what carries the caregiver through the daily grind. However much you resent, despise, are irritated by the person you care for, you can find a moment to touch them, to chuckle with them and the absurdity of the situation, to smile and remember a good time spent with them. They may not know you, but you know them.

Loyalty: that's why you're here. Give yourself a pat on the back and admit all the times when you were so tempted to run away and didn't. Remember why you are loyal to that person, and count the ways in which you have remained so.

Fidelity: you are a loyal spouse, or child, or parent, or relative, or friend. And you stay faithful to that bond. Only you can define what fidelity means to you, but I believe that it doesn't mean you can't find love elsewhere, or that you shouldn't. There are no shoulds or shouldn'ts on this journey, and provided you continue to do your best by the person you care for, you are remaining faithful. This may not be what your spiritual leader of choice says, but they probably have not walked in your shoes.

Happiness: yup, you can find happiness, even though the terrible times. You see a glance, a glimmer of the person that they used to be, and you remember. You see them enjoy a moment, and even if you don't understand their joy, you can share it. You find a way to calm them for a moment, or to get them to eat or drink, and you can feel happiness. Moments of happiness is all we can hope for, and they are enough.

Grief

Such a short word to cover so much feeling. You are already in the midst of grieving, whether you name it as such or not. You are grieving the parts of the person you care for that have disappeared from sight, the dreams you may have had of a shared future or even a reconciliation, the questions that will go forever unanswered.

Sadness: it is normal to feel overwhelmingly sad at the disintegration of a person you used to love. It is hard to hide this, and a good place to accept and express your sadness is in a place where that person can't see you. You can cry in the bathroom, hide your face from them as you make a cup of coffee, wail in the woods. Try not to show them your distress; they will neither understand nor sympathize, and it will only upset them. Your sadness is a measure of your love, and it must come out. Best name it and acknowledge it.

Loss: yes, you have lost a person you love, and any thoughts you may have nourished as to the life you would lead with them. Every day is a reminder of all you have lost. But you are still here, and showing proof of love, and every day you are gaining that which you could not

even imagine before being hit sideways by a terrible disease. Count what you have learnt every day, and set that aside as treasure.

Recollection: memories assail us at the least expected or wanted moments, and catch our breath. It is lonely, sometimes desperately, to be the sole guardian of a shared past. In our rare moments of solitude, we find ourselves looking at photos or re-reading letters, handling objects, talking to others about the past. This is a way of loving and preserving memory, or of exorcising demons, and it's necessary. We have to bear in mind all the time that the person we care for cannot share in this, or at least not in the way we would like, because they are ill.

Joy

This seems unlikely, doesn't it? And the best you can hope for is brief, fleeting moments of intense happiness that blindside you and make you wish they would last. You have to learn to recognize and accept those moments, because they are vital. They keep us going.

Relief: you can feel relief at finally getting a diagnosis, relief at getting away from the person you love for a too-brief spell, relief at somebody else doing the dirty work, relief that someone has cooked a meal for you. Relief is legitimate when your burden is relieved in any way, even temporarily, and you should allow yourself to bask in it and welcome it. Do not feel guilty at how you use moments of reprieve; they strengthen you for the next bout of caregiving.

Personal happiness: during the course of caring for somebody with one of these diseases, you need to learn to recognize when you are happy, and tell yourself gently that it is okay to be happy. A caregiver who has happiness in their life can transmit that to the person they care for. You are not taking anything away from that person by being happy, and you need whatever happiness you can find to mitigate the strain.

Other people: close or distant family members, friends, medical and care personnel, random strangers, all can provide a laugh, a shoulder to cry on, a sounding board, a place to go where dementia is not. Make it a rule to speak to at least one person a day who does not have dementia, even if it's just somebody serving you a coffee or checking you in at the doctor's office. People like to help as much as you like to help people.

Anger

We all feel anger at the fate which has befallen us. That's normal. It's important to try not to show anger towards others (unless they really deserve it) and to remember that however angry you feel towards the person you are caring for, it's likely to end very badly if you express it. Scream in the woods, hit a cushion, shut yourself in the bathroom and breathe deeply 10 times, but try not to get angry with them. If you do, or you feel yourself in danger of becoming so, physically remove yourself from them and do whatever you can to acknowledge, then control, your emotion.

Guilt: remember AT ALL TIMES that there is nothing to feel guilty about when it comes to caring for somebody else. If you treat them badly, recognize it, apologize as you would to anybody else, and work out what straw broke your particular camel's back and know that next time you have to avoid that straw. Knock the guilt monkey off your shoulder, because all he does is prevent you from doing your best as a caregiver.

Frustration and resentment: you will feel these. Often. So you have to find tactics that work for you to avoid expressing them inappropriately. Say to yourself that showing your frustration or resentment towards the person you care for will change absolutely nothing for the better, and since you haven't got time to do anything that isn't necessary, don't bother doing that. If you are frustrated or resentful towards others because you need help and they are not stepping up, try asking them for help that they are capable of giving, or accepting that they just can't help. Then don't waste your time on them; you can always pick up the relationship later.

Disgust and contempt: you may have to clean up appalling messes. You may have to apologize for your loved one's inappropriate behavior. You may have to turn your head and hold your breath to avoid gagging, or find yourself agreeing with a statement so preposterous as to be laughable. Do these things and say to yourself that the person you love is ill, that they cannot help what they are doing, and you will soon be moving on to another set of challenging circumstances. It's normal to find certain aspects of this disease repugnant, but you can wash your hands, paste a smile on your face and save the anecdote for an understanding friend.

Wonder

You are probably wondering what there is to wonder at, apart from how this particular ton of bricks fell on you. You can turn that puzzlement on its head though, and see the experience as a chance to learn more about the human brain than you ever wanted to know, as an adventure in love and loss, as an opportunity to discover how strong you really are and how extraordinary this world and this life are.

Pride: take pride in all that you are learning. You have a way to get your loved one to take their pills without a fight? You found out that counting to three under your breath and smiling really does make a difference? Feel proud of yourself, for these are examples of things that you probably thought you couldn't do. Just managing to get yourself dressed in the morning on some days is something to be proud of. List all you have done at the end of the day and pat yourself on the back, because the list will be long.

Satisfaction: notice when you have managed to look after yourself a little. Did you wash your hair in spite of the bathroom door being bashed by a demented person on the other side? Did you go for a ten-minute walk and hear a bird sing? Did you hold your loved one's hand while they slept? Did you lie in the dark and remember with a smile why you care for this person? Every day you can say to yourself that you are present and real and making a difference, and that although all is imperfect you are doing what you can.

Accomplishment: sometimes it's really hard to think that you have accomplished anything at all, because you almost certainly did not get through your to-do list. Perhaps you managed to buy toilet paper before the house ran out. Perhaps you managed to put an edible meal together in difficult circumstances. Perhaps you spent three hours on the phone and sorted out the internet connection while the person you care for was talking to you and criticizing you non-stop. If we stop striving to do what we think we should be able to do, and instead count what we have done, including prioritizing, we can allow ourselves a little self-congratulation.

Fear

Fear is tricky, because it takes so many shapes. And it is literally impossible not to be afraid of what will happen when life has become so very unpredictable. So you have to find ways to live with fear, but not to nurture it. It helps to say to yourself "I am afraid. My heart pounds, I cannot sleep, and I dread what the future holds." Then say to yourself "What am I actually afraid of right now? Because I do not know what the future holds" Often what we are afraid of right now is what we think might happen tomorrow, or next month, or next year, but you know what, you will deal with it just as you have dealt with everything else so far on this crazy journey. With more or less grace, more or less success - that's all we can hope for.

Anguish: you are terrified of what will happen to the person we love. But whatever that is, they will remain the person you love, and you will continue to love them, in different ways than up until now. The pain of losing a person little by little is difficult to share except with those who have experienced something similar, and whether it's online or in-person, a support group consisting of caregivers is immensely helpful. The others may not understand your precise pain, but they have felt or are feeling something comparable.

Dread: I associate dread with specific events. You have to get to this doctor's appointment, you have to make this journey, you have to go to this family event, you have to explain the diagnosis to others. And underlying is a feeling of loss - loss of hopes and dreams, loss of a shared life, loss of the particular relationship we once had. Sometimes you dread what will happen to you without that person by our side. You can only tame this dread by admitting how little you control outcomes. All we can control is our actions and reactions.

Anxiety: we dither. We cannot make decisions. We don't know what's right. There's no blueprint. And we lie sleepless at night, worrying about what will happen. Anxiety is so normal during the caregivers journey that we just have to recognize it and find strategies to minimize it. It could be taking a few gulps of fresh air, laughing at a joke or a silly video, sitting in silence in a darkened room for a few minutes. This is a time to make lists and not worry too much about getting to the end of them, for setting reminders on phones and remembering that anything that we can do to make our day-to-day lives a little easier is worth doing.

Physical fear: this does not apply to all caregivers but it did to me, and it's too large an issue to ignore. If you have reason to be physically afraid of the person you care for, take

precautions and do not be ashamed to do so. Tell a trusted friend or family member that you are afraid and why. Keep your cell phone on your person and fully charged, hide a set of house and car keys outside, have a go-bag with a night's worth of essentials either hidden outside or at a friend's house nearby. Let your local police know about the situation. Literally anything can be used as a weapon, but if possible remove the most obvious ones. Wear shoes that you can move fast in, and be prepared to run. Be prepared to dial the emergency services, or to shout loudly enough for help that someone else will. In my case, it was a great help that I had logged my husband's diagnosis with the local police department. He assaulted me in a public place, the police were called and were immediately able to see on their computer that he needed medical help rather than to be arrested. I had already reached the point mentally where I knew that this was the most likely outcome to an increasingly dangerous and unlivable situation, and I felt no guilt. In order to care for him adequately, I had to be safe.

This is an extraordinarily distressing journey, and emotions run high. If you have a chance to express them with a friend, a therapist, a spiritual leader, please do so. It is best, I think, that this person be somewhat removed emotionally themselves from the person you care for, because otherwise you may not feel free to explore your own emotions for fear of theirs. You can use email, or texts, but your creative juices are likely to run dry during the most extreme moments. Don't reproach yourself for this. Be ruthless about your own need to survive, because not only does the person you care for depend on you, but your life and the life of those others you love is as valuable as theirs.

References:

What can we do to improve our odds?

This is what NIH and NIA say about surviving grief:

<https://mailchi.mp/nih.gov/taking-care-of-yourself-while-grieving?e=1087ccce67>

https://www.nia.nih.gov/health/mourning-death-spouse?utm_source=NIA+Main&utm_campaign=17f6681b17-20200130_caregivingmourning&utm_medium=email&utm_term=0_ffe42fdac3-17f6681b17-18468599



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