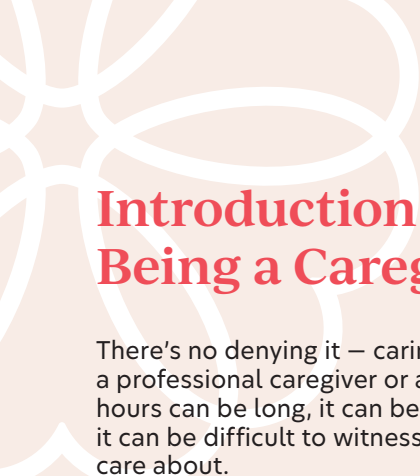


Supporting Family Caregivers

Making you a priority



DovidaTM
Your Life, Your Way



Introduction to Being a Caregiver

There's no denying it — caring for someone can be tough, whether you're a professional caregiver or a family member supporting a loved one. The hours can be long, it can be physically and emotionally exhausting, and it can be difficult to witness declining health or abilities of someone you care about.

For family caregivers, the emotional weight of this can be even greater, as there is an emotional connection with the person being cared for.

Despite the challenges, many caregivers still find their role rewarding and purposeful. Helping a loved one improve their quality of life makes a real difference in their health and wellbeing, especially in their most vulnerable years.

Sometimes though, everyone needs a break.



This guide will help caregivers recognize the signs of exhaustion and fatigue that can impact your ability to care for others. It's important to acknowledge that as a caregiver, you deserve support too.

We'll provide you with tools and resources to help you care for yourself — whether that means preventing burnout or finding ways to rest and recover when fatigue sets in.

It's never too late to look after yourself.

Supporting Family Caregivers

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Why We Care for Others

In order to prevent exhaustion and fatigue, it's important to understand the reasons why we take on the role of caring for others.

The role of a caregiver is to assist in providing the person you are caring for with the best quality of life possible, regardless of their situation. As a caregiver, it's important to remember that your role is not to fix or heal the person you're looking after. Instead, caring should focus on improving that person's quality of life.

There may be times when, despite your unwavering efforts, the person you care for continues to decline, or even nears the end of life. This can be painful, but it is not a reflection of the quality of your care. This fundamental change in attitude to your caring responsibilities may help prevent some of the mental anguish that can lead to compassion fatigue.

What is Compassion Fatigue

All caregivers need to show compassion and be empathetic as part of their job. However, it can be common for this to subside over time when caring for someone. This can lead to emotional, mental, and physical exhaustion, known as compassion fatigue.

Florida State University researcher Dr. Charles Figley defined compassion fatigue in 1995, as *“a state experienced by those helping people in distress; it is an extreme state of tension and preoccupation with the suffering of those being helped, to the degree that it is traumatizing for the helper.”* It is most common in compassionate professions such as nursing, social work, and psychology.

Empathy is commonly defined as having the ability to see another person's perspective and to sense others' emotions. For caregivers, compassion fatigue means a reduced ability to feel empathy toward clients or family members they're caring for. It can also lead to mood swings, irritability, and dissatisfaction with their role as a caregiver.

It is more common in care settings where a person's health and wellbeing is declining or not likely to improve. This means if the person is deteriorating physically or cognitively despite your best efforts to care for them, you may be much more susceptible to developing compassion fatigue. The cumulative stress of caring for someone can make this condition even more likely to occur as time goes on — which is why it's so important to recognize the signs and symptoms of compassion fatigue, so you can manage them early or help prevent them altogether.



Recognizing the Signs and Symptoms

Perhaps the first sign of compassion fatigue is when a caregiver feels a creeping sense of dissatisfaction for a growing period of time. It may go away or it can worsen, leading to more serious symptoms.

You don't need to be a professional caregiver to experience compassion fatigue. You just need to be a caring individual.

Sometimes, the first clues may be when you feel overwhelmed and start questioning your capacity to keep helping the person you are caring for. Psychologist Suzanne Osbourne says most people with compassion fatigue report an undeniable sense of not feeling like themselves. *"You get so caught up in being whoever you need to be for someone else that you end up losing yourself,"* she says.

There are two main categories of symptoms — psychological and physical.

Psychological symptoms include:

- Lack of empathy
- Irritability, anger, and limited tolerance for stress
- Apathy and sadness, no longer finding joy
- Questioning meaning and purpose of life
- Depression and mood swings
- Anxiety, unrelenting thoughts, and concerns
- Difficulty concentrating and functioning
- Feelings of isolation from colleagues or friends
- Nightmares or flashbacks to traumatic events
- Poor self-esteem

Physical symptoms include:

- Exhaustion, including constant feelings of tiredness
- Insomnia and sleep disturbances
- Digestive issues including nausea or stomach pain
- Muscle tension or body aches
- Headaches or migraines
- Racing heart or elevated blood pressure
- Difficulty coping with increased likelihood of self-medicating or substance use
- Feeling run down or increased susceptibility to illness
- Reduced motivation to maintain own hygiene and appearance



How to Prevent Compassion Fatigue

Looking after yourself, remaining positive, and staying healthy is the key. Exhaustion leads to a myriad of health problems, especially compassion fatigue.

When caregivers get tired and rundown, they simply must take time to rest and recharge. It's impossible for caregivers or health workers of any kind to help others if they're not well themselves. If you're a family caregiver, it can affect your relationship with the loved one you're caring for – and may well jeopardize the quality of care they need to receive from you. If you're a professional caregiver, it can also affect your career – a lack of empathy may mean you are not meeting your duty of care because compassion fatigue can negatively affect your ability to provide the level of care required.

The best solution is to try and prevent compassion fatigue from occurring in the first place. So, how do we best look after ourselves?

Make time for you

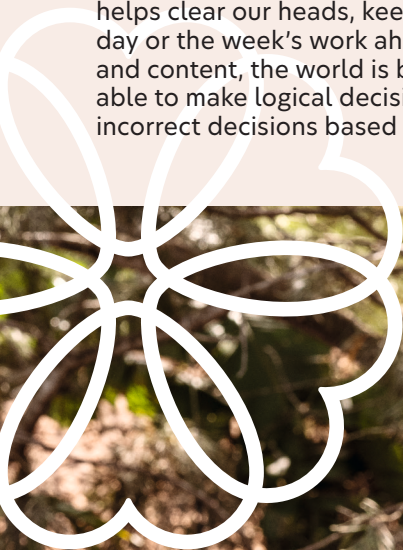
First of all, stop putting it off! Make yourself a priority, no matter what, without feeling guilty for doing it. You can't help others if you are not coping yourself. Allocate time to yourself every day, or whenever you know you need it. Do whatever it takes to have a whole day to yourself, if you know that's what you need.

Don't avoid asking others for help. Some people find it hard to accept help, but if you know you need it, you also know that you will feel so much better after having some time to yourself. Caregivers know the value of helping others, but you must also be able to ask for help to look after yourself effectively.

Do something you enjoy

So you've taken time off from your caring role, even if it's just a little while – now, make it count. Don't do chores or tasks. You must do something you really enjoy! Think about what you'd really like to do if you had the time. Write it down, schedule it in, make a firm plan, and stick to it.

Doing things we enjoy makes us happier and more content. Being happier helps clear our heads, keeping us fresh and capable to tackle the rest of the day or the week's work ahead – whatever it involves. When you're happy and content, the world is brighter and full of possibilities. You are also more able to make logical decisions and be more objective, rather than make incorrect decisions based on emotional reactions.



Look after your body

We all know how to best look after our bodies, but when it comes to the crunch, our bodies often bear the brunt of our lack of time for ourselves. We might not eat properly, we get less sleep, we don't exercise as often as we should – the list goes on.

It's up to you to take a stand, and put what you know into practice. Make a promise to yourself to look after you – first and foremost. Eat well, get the sleep you need, and make daily exercise a priority. It can mean the difference between developing compassion fatigue and keeping it at bay – or the difference between feeling good and feeling poorly.

Checking in

It's always a good idea to stop and take stock for a few moments – each day if you can. Psychologist Suzanne Osbourne recommends rating how you feel on a scale of 1 to 10, where 1 is when you feel very much like yourself and 10 is when you feel you're being untrue to yourself.

“Regularly gauging where you sit on the scale in this manner allows you to monitor change and engage in appropriate support as required. Education and self-awareness are key to supporting yourself to recognize the signs of compassion fatigue – that means knowing how it presents in you, so you can regularly check in and review where you are at,” she says.

Mindfulness and the practice of being mindful can also help – being present in each moment and enjoying the small things in your day. Enjoy the calming effects of taking the time to understand what is happening around you. There are some resources around mindfulness offered in the Resources section of this guide.

Develop your own self-care plan

Take all of the above points that work for you and write them down. Allocate time for each activity in your schedule every week and stick to it. That's the essence of a self-care plan!

As a general rule of thumb, make sure the activities in your self-care plan bring you a sense of rest, relaxation, or revitalization, so your time for you can have a significant positive impact on your wellbeing and resilience.

You can find a template for your own self-care plan in the Resources section of this guide.

How To Recover From Compassion Fatigue

Prevention is a wonderful idea in theory, but sometimes compassion fatigue overwhelms us before we even know it exists. Perhaps it's been there in the background for years.

So how can we recover from compassion fatigue after it's set in?

The good news is the solutions are very similar to the prevention methods outlined in the previous chapter. It's all about taking time for yourself, finding the positives, and looking after yourself every single day.

Perhaps the most important step in recovering from compassion fatigue is changing your mindset. The way you think can allow compassion fatigue to creep in. You may have thought to yourself: "I can keep going, I'm fine, I can do this without a break. I don't need help, I'm coping okay." That's the mindset that sets you up for exhaustion. It's okay to acknowledge that you were wrong, and you were overdoing it.

It can be very helpful to focus on the sense of satisfaction you can gain from helping those you are caring for. This focus on your own satisfaction can in turn help you to detach from their suffering, especially in cases where the person you are caring for is very ill or dying. You can still be a great caregiver, but simply allow yourself some time each day to focus on your own needs and feelings.

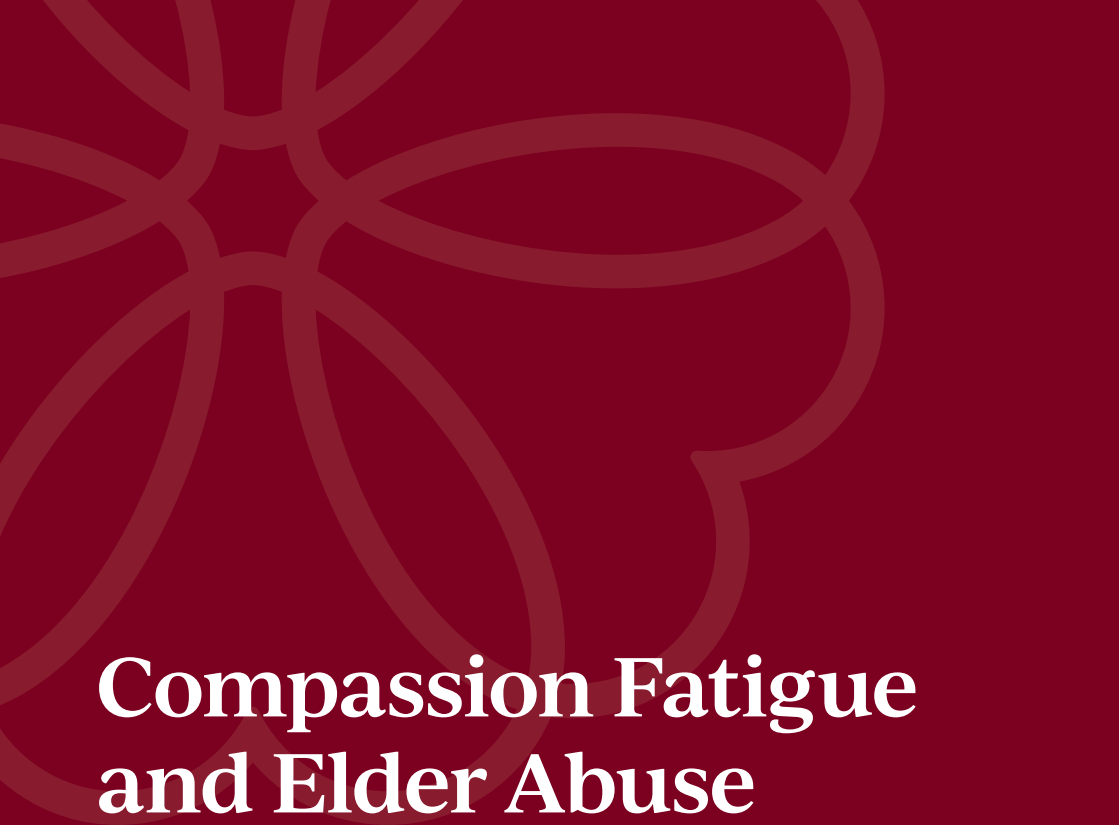
Remember, once compassion fatigue is present, you need to be disciplined in your approach to combatting it:

- **Take time for yourself every day.** Stick to a routine of self-care, and be compassionate with yourself to fight compassion fatigue.
- **Eat a healthy diet.** Plenty of vegetables, protein and fiber; avoid sugary foods, especially to combat tiredness at the end of a long day.
- **Exercise every day, no matter what.** Whether it's walking with the person you're caring for (if possible) or pushing them in a wheelchair at the store; you may also consider relaxing exercises such as yoga, stretching, and even massage.
- **Pay special attention to your sleep.** Make sure you get a good night's sleep every night, especially during times of extra work or high stress; new bedding can be a self-care treat that's also comforting.
- **Do one relaxing self-care activity every day.** Whether it be a warm bath, a body scrub in the shower, cleaning and painting your toenails, or even just moisturizing your face and hands; you'll be surprised how good it makes you feel to just do that one thing for yourself each day.

- **Breathe.** Focusing on your breathing can make an extraordinary difference, especially if you are feeling frustrated, angry or overwhelmed; take deep, slow breaths and you can often feel your heart rate return to normal.
- **Spend some time in nature.** A strong connection to the natural environment enhances emotional wellbeing and reduces feelings of isolation. Spending even 10 minutes in nature has been shown to significantly increase our happiness levels.
- **Catch up with friends and people who care about you.** If you can't or don't want to go out at night, exercise with a friend during the day or talk on speakerphone while you do chores; maintaining your social connections is vital and it's especially wonderful to hear familiar voices in challenging times.
- **Talk about your experiences of compassion fatigue with colleagues who understand.** Find out what works for others and try it; sharing your concerns can be a great comfort.
- **Laugh.** This might mean watching a funny movie or some comedy videos online; laughter really is the best medicine and this can be a great activity to do with the person you are caring for, to give you both a lift.
- **Practice gratitude.** This can mean making a list of who and what we appreciate, because being grateful can help us positively influence our thoughts.
- **Be mindful.** Being actively present in the here and now offers space for you to reflect and consider the actions that you can take to improve a situation.
- **Set emotional boundaries.** This is clearly more of a challenge for family caregivers who are often related to the person they are caring for, but professional caregivers are advised to think about setting clear emotional boundaries to maintain compassion and empathy for others while maintaining emotional safety.
- **Review your journal before bed each night to make time for you.** Be proactive rather than reactive by scheduling things you want to achieve, and avoid spending time on things that worry or especially challenge you; only take on what you feel you can handle.
- **You are not a failure.** Caregivers sometimes feel their contribution is not making a difference when the health of the person they are caring for declines; this is not a failure, rather it is a caregiver's role to help enable the best quality of life right to the very end.
- **If nothing is working to make you feel better, seek some professional help.** This could mean finding a therapist through your primary care doctor or contacting your health insurance company; Dovidia employees are encouraged to contact our employee assistance program if they need any help.

As you can see, recovering from and preventing compassion fatigue are really entwined. The focus is on you: investing in you and improving your quality of life.

Remember, you are not alone and support is always available.



Compassion Fatigue and Elder Abuse

The Centers for Disease Control (CDC) defines elder abuse as “an intentional act or failure to act that causes or creates a risk of harm to an older adult.”

There is documented evidence that compassion fatigue has been linked to the occurrence of elder abuse. Research published through the National Institutes of Health identifies caregiver burnout as a risk factor for elder abuse and neglect, alongside high stress, isolation, and lack of social support. When caregivers are overwhelmed and without adequate help, the risk of mistreatment — even unintentional — increases.

This is further proof that self-care and looking after yourself can help prevent a myriad of problems for both you and the person you care for.



Respite Options for Family Caregivers

Often, compassion fatigue in family caregivers can be the result of sheer overwork. In some situations, alternative care options may be limited. Perhaps the family caregiver feels it is their role, and no one else's, to care for their loved one 24 hours a day.

Then, when a loved one's condition deteriorates, the workload for the caregiver becomes even greater.

It's important to know that help is available to relieve family caregivers of some of their workload and enable them to have a break. Remember, if you can't take time to care for yourself, how can you care for others?

Dovida provides the highest quality of care that recognizes the uniqueness of each individual we support. We can provide in-home respite care at short notice for a few hours, a few days, or even longer.

We create a Circle of Care that centers around the individual we are supporting, enabling family caregivers to rest and recharge with peace of mind that their loved one is cared for.



Focusing on Your Mental Health

Caring for others can be a huge strain on our mental health, regardless of the individual circumstances.

Whether you have experienced compassion fatigue or not, looking after your mental health is crucial to being a good caregiver. Here are a few tips and activities you can do to make sure your mental health is as robust as possible.

Talk to someone

Talk to a friend about how you're feeling. Tell a trusted colleague or a family member. Talking about our woes or worries can help them seem smaller and easier to deal with. Talking about any problem or challenge helps you process and sound out possible solutions, and that makes us all feel better.

Be a listener, too. It can be very enlightening to hear how others have dealt with similar problems to yours.

Keep a journal

Writing it all down works wonders. This is especially the case during times when it might not be possible to talk to a friend.

Keeping a journal helps us express our own self-reflections. It clarifies our thoughts and helps us to think things through calmly. The Writers' Digest states "...journal writing helps to clear the mind by transcribing emotional clutter onto the written page. The writer becomes a witness to past behaviors, paving the way for fresh thought and perspective." Why not give it a try?

Enjoy sunlight

Getting out and about in the sun really does make us feel better, which leads to improved mental health. Sometimes all it takes is sitting in the garden or on a sunny verandah for a few minutes each day. Sunlight naturally increases our melatonin levels. Melatonin is a hormone associated with regulating our moods and reducing anxiety. It also helps us sleep.

Sleep quality

Don't feel guilty about heading to bed early – if you're exhausted, get some extra rest. Learn to recognize how you feel when you wake up; this is where journalling also helps. It takes more than one night of good sleep to improve your mental outlook, so aim for consistency.



If you're having trouble falling or staying asleep, pay special attention to your pre-sleep routine — make adjustments to your night-time eating habits, try a warm bath, new or clean bedding, and perhaps read a relaxing novel. Try different things to see what works best for you.

Avoid alcohol or other drugs

Be very careful of substance use and abuse as a coping mechanism. It's widely documented in medical literature that alcohol can make the symptoms of mental illness worse, so it's best to avoid alcohol if you are struggling to maintain your mental health.

It's wise to avoid alcohol during times of extreme personal or professional stress. If you notice you are under pressure, you'll be better able to perform at your best without the added recovery time from alcohol or other drugs. Ask yourself: Is there a better and healthier way to deal with your current stress levels?

Build resilience

We know it can help to plan and schedule self-care time in advance, especially when you know you've got a busy period ahead. Write your own self-care plan, either with pen and paper or electronically — there are some suggestions in the Resources section of this booklet to help you stick to your new self-care routine.

Sticking to a routine or a schedule can help you build strength, resilience, and willpower in challenging times. If you start by scheduling self-care times and activities, you're more likely to stick with them. You'll thank yourself at the end of each busy week if you set aside some time for yourself.

It might also help to identify in your plan the barriers that may stop you from taking self-care time, and try and plan to overcome those barriers before they may happen. For example, if you think picking your children up from school would prevent you from enjoying some self-care time, you could arrange for a friend to pick your children up one day a week, and perhaps you can return the favor.

Top Self-Care Tips: A Checklist

- ✓ Make Time for Yourself Every Day: Do Things You Enjoy
- ✓ Look After Your Body: Eat Well, Exercise, and Sleep
- ✓ Design a Self-Care Plan: Make it Routine
- ✓ Be With Friends: Laugh Together
- ✓ Meditation Techniques: Breathing, Mindfulness, and Gratitude
- ✓ Plan Your Day: Keep A Journal
- ✓ Check In: Rate How You Feel
- ✓ Seek Help: Talk About It

Change your mindset. Self-care is a necessity, not a luxury.

Invest In You



Real Advice from Caregivers

Marg has 35 years' experience working in senior care:

"My message would be to love yourself first before you love others. Write things down – the exercise of reflecting is very valuable. Think of how much you've achieved, identify some of the challenging times, and some of the opportunities that have come from those challenges. Having challenges builds resilience – you learn from what's happened to you. I love journaling. Having that check-in allows you that luxury of down tools time. – 'Am I on track?' It's okay to get help, it's okay to link with a colleague or a therapist. Connect with things that are important to you and see what fits for you."

Camille who works in palliative care and says a self-care plan is the best way to get started:

"Self-care is really now a priority in my life and I don't see it as an indulgence, I see it as a necessity. It's a vital part of my day-to-day practice and I see it as part of my responsibility to my clients and my colleagues. I personally find that being strategic and proactive about it really works for me. I think we're all so busy that if we don't make time to practice self-care, days and weeks and months tend to fly by and often we're very run down or reaching an edge state, pre-burnout – and that's when we realize. Putting aside time every day, even if it's only 10 minutes or half an hour; it makes a lot of sense."

Kristy is a caregiver who experienced compassion fatigue after working for months on limited sleep:

"Self-care is not an option, it's always a must. We cannot pour from an empty cup, so we need to practice self-care. It's an opportunity for you as well, to reflect, and to be self-aware – what do you like best? Self-care is something you really need to do for yourself because you have a responsibility to provide care to others. In senior care, you really need to look into yourself first, because you've got vulnerable people who require much of your care. I didn't realize how important self-care was until I started to burn out. I became emotionally drained and it made me realize the importance of self-care. It's not selfish, it's a must."

David mostly works with dementia clients who have changed behaviors:

"You can't look after others unless you look after yourself. I've got hobbies, I try to switch off as much as I can. I love my garden; I have a vegetable plot. I like cooking. My partner and I go for walks, we socialize – self-care can be just thinking of yourself. You've got to recharge your batteries. When you're gardening, you've got to fertilize, mulch, and water plants. You've basically got to do that for yourself, too. Eat, drink, rest, and chill out."

Rachel is a palliative care nurse who recommends self-care plans:

"I ask people to tell me about their self-care plans and they say, 'What?!' When you are writing a care plan for a patient, you are thinking about their physical, emotional, spiritual needs, etc. What do you do for yourself? I think putting pen to paper has a commitment behind it. It's about not forgetting – that's what self-care is about. It's about prioritizing yourself in the picture. It's not just about giving and doing – it's about you as well."

Resources for You

The following resources provide further information on self-care:

- **CaringInfo.org** offers free resources for family caregivers navigating serious illness and end-of-life care, including guidance on caregiver self-care and support.
- **Mindful** provides information on how to get started with mindfulness: mindful.org/meditation/mindfulness-getting-started
- The **Family Caregiver Alliance** has a video series of relaxation exercises on practicing mindful breathing and meditation: caregiver.org/resource/caregiver-relaxation-exercises-series-english/
- **Self-Compassion.org** provides information about self-compassion and offers practice sessions to support with this.

Here are some additional support organizations for yourself and your aging loved one:

Eldercare Locator	eldercare.acl.gov	1-800-677-1116
Family Caregiver Alliance	caregiver.org	1-800-445-8106
Alzheimer's Association 24/7 Helpline	alz.org	1-800-272-3900



“

A wonderful, professional, empathetic organization. The care and attention given to my mother is beyond appreciated. All of the staff are attentive and thoughtful and I am beyond blessed with my mom's well-being. Cannot recommend more highly.

– **Kathryn, daughter of a Dovidia client**



Together, We Create Care That Centers Around You

Dovida recognizes that your uniqueness is key to providing the highest quality of care. With you at the center of everything we do, we help you live the life you want in the comfort of your own home, for as long as possible.

Together with you, your family, and multidisciplinary team, we create a Circle of Care that centers around you. Because we don't just want to improve your day – we want to empower you to live your life, your way.

We provide a range of services including companionship, domestic assistance, personal care, meal preparation, medication reminders, and transport to appointments, shopping, and social outings. Care is available from two hours to 24 hours a day and includes dementia care and palliative care.



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