



IO3 (M15-M16-M17-M18)

A Guide for Caregivers

Good practices and self-care to Personal Caregivers and Personal Assistants



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Foreword

Caring for another person is a unique and rewarding experience that comes with its own set of challenges. Personal caregivers and personal assistants have committed themselves to the noble task of providing essential support and care to those who need it. Whether it's a family member, friend, or client, they play a crucial role in helping the person they care for lead a healthy and fulfilling life.

However, caregiving is not an easy task. It requires a significant amount of time, patience, and energy to ensure that the person they care for receives the best possible care. It is also emotionally and physically demanding, and caregivers may find themselves dealing with stress, fatigue, and burnout. To be effective in their role, caregivers need to adopt good practices for caring and prioritize their own well-being.

This guide is a practical resource for personal caregivers and personal assistants, providing valuable advice on how to provide quality care while taking care of themselves. The first chapter covers good practices for caring, focusing on communication, safety, and hygiene. It provides tips on how to communicate effectively with the person they care for, create a safe environment, and maintain good hygiene practices.

The second chapter emphasizes the importance of self-care for caregivers. It offers strategies for reducing stress, building resilience, and finding support. Self-care is critical for caregivers to avoid burnout, and this chapter provides practical tips on how to prioritize their own well-being.

Throughout this guide, personal caregivers and personal assistants will find valuable tips and insights to help them become better caregivers and maintain their own well-being. Whether they are new to caregiving or have been providing care for years, this guide is a valuable resource that can help them navigate the challenges and joys of caregiving.

The **GivingCare Project** hopes that this guide proves to be informative and helpful for personal caregivers and personal assistants as they continue to provide care for those who need it. Their dedication and compassion are invaluable in making a difference in the lives of others, and I extend my heartfelt gratitude to them.

PART 1

Good Practices for Caring: A Guide for Personal Caregivers and Health Professionals

Providing care to others is a noble and fulfilling profession that requires a unique set of skills and qualities, including empathy, patience, and compassion. Personal caregivers and assistants play a crucial role in ensuring the wellbeing and quality of life of individuals who require assistance with daily activities, personal care, and medical needs. At the same time, health professionals such as doctors, nurses, and therapists provide the necessary medical expertise and support to ensure that caregivers can provide the best possible care to their care recipients.

Despite the rewards of this profession, it can be emotionally challenging and demanding for caregivers and health professionals. The job can be physically exhausting, and the pressure to deliver high-quality care can be overwhelming. Additionally, the emotional burden of providing care to vulnerable individuals can take a toll on caregivers and health professionals alike. For these reasons, it is essential to have access to information, best practices, and resources that can support and guide caregivers and health professionals in their daily routines.

This guide aims to provide a comprehensive overview of good practices for caring that can support caregivers and health professionals in providing high-quality care to their care recipients. The guide draws upon the best practices across Europe to provide caregivers and health professionals with a clear picture of the formats, practices, and delivery styles that are most effective. It is designed to be used by both formal and informal caregivers and health professionals in various care settings, including in-home care, residential care facilities, and hospitals.

Overall, this guide serves as a valuable resource for anyone who wants to enhance their skills in the field of caring. By providing practical information and best practices, this guide aims to empower caregivers and health professionals to deliver the best possible care to those who need it most.

Section 1: Understanding the Needs of Care Recipients

The first step in providing good care is understanding the needs and preferences of care recipients. This involves communicating effectively with them, learning about their medical conditions and personal histories, and respecting their autonomy and dignity. Some good practices for understanding the needs of care recipients include:

Conducting a comprehensive assessment of their health, functional, and social needs

Creating a care plan that is tailored to their individual needs and preferences

Communicating clearly and respectfully with the care recipient and their family members

Promoting independence and autonomy as much as possible

Providing emotional support and acknowledging their feelings and concerns

Respecting cultural, religious, and personal beliefs

Understanding the needs of care recipients is the foundation of good caregiving. Conducting a comprehensive assessment of their health, functional, and social needs is critical in understanding their unique situation. This assessment should include information about the care recipient's medical conditions, medications, allergies, and previous medical history. It should also include information about their functional abilities, such as mobility, communication, and cognitive functioning, as well as their social needs, including social support and engagement.

Once the assessment is complete, a care plan should be created that is tailored to the individual needs and preferences of the care recipient. The care plan should take into account their medical, functional, and social needs, as well as their personal preferences and goals. The care plan should be reviewed regularly and adjusted as needed to ensure that it remains relevant and effective.

Communication is essential in understanding the needs of care recipients. Caregivers should communicate clearly and respectfully with the care recipient and their family members to ensure that they are aware of their needs and preferences. Caregivers should also promote independence and autonomy as much as possible, encouraging the care recipient to be involved in their own care decisions and activities.

Providing emotional support is also critical in understanding the needs of care recipients. Care recipients may be dealing with a range of emotions related to their medical condition or disability, and caregivers should acknowledge their feelings and concerns. Caregivers should also respect the cultural, religious, and personal beliefs of the care recipient, as these beliefs can influence their preferences and choices.

In conclusion, understanding the needs and preferences of care recipients is a critical aspect of good caregiving. By conducting a comprehensive assessment, creating a tailored care plan, communicating effectively, promoting independence and autonomy, providing emotional support, and respecting cultural and personal beliefs, caregivers can ensure that they are providing high-quality care that meets the unique needs of each care recipient.

Section 2: Ensuring Safe and Hygienic Care

One of the most critical aspects of caring is ensuring that the care recipient is safe and hygienic. This involves implementing good hygiene practices, preventing falls and accidents, and managing medications and medical equipment appropriately. Some good practices for ensuring safe and hygienic care include:

Regularly washing hands and using personal protective equipment when necessary

Maintaining a clean and hygienic environment, including bedding and clothing

Implementing fall prevention strategies, such as removing tripping hazards and providing mobility aids

Administering medications and using medical equipment correctly and safely

Monitoring vital signs and recognizing signs of infection or illness

Providing adequate nutrition and hydration

Ensuring safe and hygienic care is a critical responsibility for caregivers. It requires a commitment to maintaining a clean and safe environment and implementing measures to prevent accidents and illness. To achieve this, caregivers should practice good hygiene by regularly washing their hands and using personal protective equipment when necessary, such as gloves or masks.

Maintaining a clean and hygienic environment is also crucial for preventing the spread of infection. This includes regularly cleaning and disinfecting surfaces, bedding, and clothing. Caregivers should be trained on proper cleaning and disinfecting protocols to ensure they are effective in preventing the spread of germs and infection.

Implementing fall prevention strategies is another essential aspect of ensuring safe care. Caregivers should identify potential hazards, such as loose rugs or clutter, and remove them. They should also provide mobility aids, such as grab bars or walkers, to reduce the risk of falls. It is also important to ensure that the care recipient's living environment is accessible and well-lit.

Administering medications and using medical equipment correctly and safely is essential for the care recipient's well-being. Caregivers should receive proper training on medication administration and use of medical equipment. They should also keep track of the care recipient's medications, ensuring they are taken at the correct time and in the correct dosage.

Monitoring vital signs and recognizing signs of infection or illness is also critical for ensuring safe care. Caregivers should be aware of the care recipient's baseline vital signs and monitor for any changes that may indicate a problem. They should also be aware of

the signs of infection, such as fever, chills, or coughing, and take appropriate action if necessary.

Finally, providing adequate nutrition and hydration is essential for the care recipient's overall health and well-being. Caregivers should ensure that the care recipient is consuming a balanced diet and drinking enough fluids. They should also be aware of any dietary restrictions or preferences and ensure that they are respected.

In conclusion, ensuring safe and hygienic care requires a commitment to maintaining a clean and safe environment, implementing fall prevention strategies, administering medications and using medical equipment safely, monitoring vital signs and recognizing signs of illness or infection, and providing adequate nutrition and hydration. By following these good practices, caregivers can ensure that the care recipient is receiving high-quality care that promotes their overall health and well-being.

Section 3: Supporting Emotional Wellbeing

Caring for others can be emotionally demanding, and care recipients may also experience emotional distress. Supporting emotional wellbeing is essential for promoting overall health and happiness. Some good practices for supporting emotional wellbeing include:

Building a relationship of trust and respect with the care recipient

Providing emotional support and validation of feelings

Encouraging participation in activities and hobbies that bring joy

Promoting socialization and social engagement

Offering access to counseling or support groups as needed

Caring for someone can be an emotionally challenging task, and it is important to provide emotional support and promote emotional well-being for the care recipient. Caregivers should work towards building a relationship of trust and respect with the care recipient. This can be achieved by listening actively, showing empathy, and demonstrating an understanding of the care recipient's needs and feelings.

Providing emotional support and validation of feelings is essential for promoting emotional well-being. Caregivers should actively listen to the care recipient, offer emotional support, and acknowledge their feelings and concerns. It is important to remember that emotional support does not always have to involve words; small gestures such as holding a hand or providing a comforting touch can also be effective.

Encouraging participation in activities and hobbies that bring joy is also an effective way to promote emotional well-being. Caregivers should ask the care recipient about their

interests and hobbies and help them to participate in them whenever possible. This can provide a sense of purpose and boost the care recipient's mood.

Promoting socialization and social engagement is also crucial for emotional well-being. Caregivers should encourage the care recipient to engage in social activities such as group outings, family gatherings, or community events. This can provide a sense of belonging and reduce feelings of loneliness and isolation.

Finally, offering access to counseling or support groups as needed can also be effective in promoting emotional well-being. Caregivers should be aware of the care recipient's emotional needs and refer them to professional counseling or support groups if necessary.

In conclusion, supporting emotional well-being is essential for promoting overall health and happiness. Caregivers should build a relationship of trust and respect, provide emotional support and validation of feelings, encourage participation in activities and hobbies, promote socialization and social engagement, and offer access to counseling or support groups as needed. By following these good practices, caregivers can help the care recipient to maintain emotional well-being and lead a fulfilling life.

Section 4: Communicating with Health Professionals

Personal caregivers and assistants often work alongside health professionals, including doctors, nurses, and therapists. Effective communication with health professionals is critical for ensuring the best possible care for the care recipient. Some good practices for communicating with health professionals include:

Sharing relevant information about the care recipient's health and needs

Asking questions and seeking clarification when necessary

Providing feedback on the care recipient's progress or challenges

Collaborating on care plans and strategies

Advocating for the care recipient's needs and preferences

Effective communication with health professionals is crucial to ensure that the care recipient receives the best possible care. Personal caregivers and assistants should be proactive in sharing relevant information about the care recipient's health and needs. This can include information about the care recipient's medical history, current medications, allergies, and any other pertinent information that can help the health professional to make informed decisions.

Asking questions and seeking clarification when necessary is another important practice in communicating with health professionals. Caregivers should not hesitate to ask

questions or seek clarification if they do not understand something. This can help to ensure that the care recipient's needs are being addressed appropriately.

Providing feedback on the care recipient's progress or challenges is also essential. Caregivers should communicate with health professionals about any changes in the care recipient's condition, as well as any challenges or issues that arise. This can help to ensure that the care plan is updated to reflect the care recipient's current needs.

Collaborating on care plans and strategies is also important. Caregivers should work closely with health professionals to develop a comprehensive care plan that takes into account the care recipient's needs and preferences. This can include working together to establish goals, developing strategies to manage symptoms, and identifying resources and support services that may be helpful.

Finally, advocating for the care recipient's needs and preferences is essential. Caregivers should be proactive in advocating for the care recipient's rights and preferences, such as their right to informed consent, their right to privacy, and their right to participate in decisions related to their care.

In conclusion, effective communication with health professionals is critical for ensuring the best possible care for the care recipient. Personal caregivers and assistants should be proactive in sharing relevant information, asking questions and seeking clarification, providing feedback on the care recipient's progress or challenges, collaborating on care plans and strategies, and advocating for the care recipient's needs and preferences. By following these good practices, caregivers can help to ensure that the care recipient receives the best possible care.

Conclusion

In conclusion, providing care to others is a profession that requires a unique set of skills, including knowledge, compassion, and empathy. This guide serves as a valuable resource for personal caregivers, assistants, and health professionals to ensure that they are equipped with the necessary information and best practices to deliver high-quality care to their care recipients.

By implementing the practices outlined in this guide, caregivers can better understand the needs of their care recipients, provide safe and hygienic care, support emotional wellbeing, and effectively communicate with health professionals. Additionally, this guide emphasizes the importance of continually learning and improving to ensure that caregivers are providing the best possible care for their care recipients.

Furthermore, by consistently following these good practices and continuing to educate themselves, caregivers and health professionals can develop a strong sense of satisfaction and fulfillment in their profession. They can also provide care recipients with

a sense of dignity, respect, and independence, which can significantly enhance their quality of life.

In summary, this guide emphasizes the importance of a holistic approach to caring that prioritizes the physical, emotional, and social wellbeing of the care recipient. By implementing these good practices, caregivers and health professionals can continue to make a positive impact on the lives of those they serve.

PART 2

How to take care of who cares

This section aims to empower you to care for yourself while caring for others. You will learn how to cope with the challenges and the stressing situations, how to identify depression and burn out symptoms and how to prevent them. You will also find advice on how to ease the stress related to juggling work and care, how to handle family dynamics and how to communicate effectively with doctors.

Do not assume that taking care of yourself is a selfish act. Staying healthy and whole will actually allow you to provide better care for others. It will also provide you with a strong foundation for relaunching your life when your caregiving role is over.

Section 1: Caregiving is a journey

While providing care for someone in need can bring tremendous joy, the caregiving journey does entail very specific issues for both yourself and the person for whom you are caring.

You may be filled with doubt at times or simply wonder whether you are doing the right thing or Source: doing enough. But there will also be some amazing and wonderful discoveries along the way, just like in any other journey. **Caregiving can indeed be an opportunity for personal transformation.**

You deserve to come out of your caregiving journey without being burned out or without facing health issues of your own. Remember: **As a carer, you deserve to thrive and not just survive!**

While there is only so much you can do to reduce the impact of a chronic illness or debilitating injury on the person to whom you provide care, there is a great deal that you can do to manage your personal well-being and ensure that your own needs are met. It is up to you: YOU have the ultimate choice about how your caregiving experience is going to play out.

Your caregiving journey is unique. Yet, you may find comfort in knowing that there are some common stages and that other people have experienced what you are experiencing now.

Understanding the stages of a Carer's journey may help you to anticipate what is coming next and prepare for the next stage. This will ensure that the caregiving experience is meaningful, for your care recipient, your family, yourself.

See 'the stages of caregiving': <https://eurocarers.org/the-stages-of-caregiving/>

Section 2: Ways to Manage Carer Stress

Carer stress does not just affect you mentally - it can also lead to physical health problems, including chronic pain. The mind and body are connected. We therefore recommend the following strategies to help you maintain your own wellness while supporting your loved one:

1) Plan and Prepare

Learn as much as you can about your loved one's condition(s) and how it/they typically progress. Ask your loved one's doctor to be candid about the prognosis and course of the disease, read information online, ask others who have been there.

It could also help to focus on some **"if this, then this" scenarios**. This type of thinking may help you reflect on the type of assistance you need and where you may be able to find it, the kind of home adaptations - or alternative living situations - that would potentially prove helpful and how these could be put in place.

Organize medical information and legal documents, so that everything is in order and easy to find.

Have "the conversation" with your loved one before the need appears. Talking about ageing can be challenging and multifaceted, and the list of sensitive conversation topics may be intimidating. It is understandable to be anxious about having potentially awkward discussions, which can include everything from your parents' ability to continue driving to the challenges of estate planning, long-term care and even end-of-life plans. Although it is impossible to cover all of the topics that you may face when talking to your elderly loved ones, here is a selection of common topics that will give you some insight on how to tackle these conversations.

Driving

According to EU data, elderly drivers are more likely to hurt themselves than to put others at risk. The fatality rate for drivers over 75 is more than five times higher than the average, and their injury rate is twice as high. This higher vulnerability is due to the reduced physical abilities of older drivers (i.e., diminished eyesight and hearing, slower reaction time) and less day-to-day experience on the roads.

If you are concerned about your parent's safety, look for signs of unsafe driving habits, such as sudden lane changes, speeding, driving too slowly, tailgating other vehicles and getting into near misses on the road. You should also check your parent's vehicle for dents, scratches and other damage that could have been caused by a recent accident. If you do not have many opportunities to ride with your loved one, ask friends and

neighbours whether they have noticed anything concerning about your parent's driving habits. Finally, if you handle your parent's finances, watch for a sudden increase in car insurance premiums.

Long-Term Care Planning

According to EU data, the demand of long-term care services will grow substantially in the coming years as a result of Europe's demographic ageing. The number of people potentially in need of care is indeed projected to rise by more than 8 million by 2050. Despite the high likelihood to need long-term care at some point when getting older, many adults do not plan for their future needs, perhaps because they do not want to think about losing their independence or developing health problems as they get older.

You may want your parent to live with you at some point, but it is important to remember that some older adults develop medical or psychological problems that make it unsafe to live in a family home without health professionals on hand to assist. If you think your parent will need to move to assisted living or a nursing home, it is best to start planning early.

It is also important to know that many insurance companies only pay for long-term care for a set number of services, beyond which, the expense is out-of-pocket. Having a challenging conversation now can give you time to set up long-term care coverage or find a suitable facility before your parent needs long-term care.

Succession and last will

Estate planning is an important aspect of ageing, but many people may hesitate to engage in the process because they do not like to think about what will happen when they die or may believe they do not have enough assets to make estate planning worthwhile.

Yet, the period that immediately follows death is always traumatic, and when emotions are running high, it is easy for loved ones to become distressed and argue amongst each other if there is not a predetermined plan in place. Estate planning therefore ensures that a person's assets are distributed according to their wishes. Discussing your loved one's will can therefore ensure that all of their wishes are clearly laid out and agreed upon by all.

2) Make sure you have a support system

Many people choose to seek the help of a therapist to manage their Carer stress. Support groups for Carers, even highly tailored ones such as for Alzheimer's Carers, may also be available in your area. Ask at local hospitals, senior centres, places of worship, or diseases association.

Recognize that you are not hurting the caree if you talk to someone else – friends, a support group, counsellor- about the challenges you are experiencing.

3) Take care of your own health

It is just common sense, but is easy to forget: you must take care of yourself to be able to effectively support anyone else.

So, make sure to:

Get proper rest and nutrition.

Exercise regularly, even if only for 10 minutes at a time. Exercise promotes better sleep, reduces tension and depression, and increases energy and alertness. If finding time for exercise is a problem, incorporate it into your daily activity. Perhaps the care recipient can walk or do stretching exercise with you. If necessary, do frequent short exercises instead of those that require large blocks of time.

Schedule yourself in. Make your own appointments for regular exams, flu shots, dental visits, and the like at the same time you arrange a loved one's. Some practitioners allow simultaneous visits for pairs who share providers.

Listen to what your body is telling you. Chances are that ignoring a new symptom is not going to make it go away; it will only start shouting at you by getting worse.

Watch out for signs of anxiety, depression or burnout (see later) and do not delay getting professional help when you need it.

4) Ask for and accept help

Many carers are reluctant to ask for help. You may not wish to “burden” others or admit that you cannot handle everything yourself. Actually, **reaching out for help** when you need it **is a sign of personal strength**. Don't wait until you are overwhelmed and exhausted or your health fails.

Help can come from community resources, family, friends, and professionals.

When approaching potential helpers, **be specific about what is required**. When you break down the jobs into very simple tasks, it is easier for people to help.

Focus: Tips on How to Ask for help

- *Consider the person's special abilities and interests.* If you know that a friend enjoys cooking but dislikes driving, your chances of getting help improve if you ask for help with meal preparation.

- *Resist asking the same person repeatedly.* Do you keep asking the same person because she has trouble saying no?
- *Pick the best time to make a request.* Timing is important. A person who is tired and stressed might not be available to help out. Wait for a better time.
- *Prepare a list of things that need doing.* The list might include errands, gardening, or a visit with your loved one. Let the “helper” choose what she would like to do.
- *Be prepared for hesitance or refusal.* It can be upsetting for the carer when a person is unable or unwilling to help. But in the long run, it would do more harm to the relationship if the person helps only because (s)he does not want to disappoint. To the person who seems hesitant, simply say, “Why don’t you think about it.” Try not to take it personally when a request is turned down. The person is turning down the task, not you. Try not to let a refusal prevent you from asking for help again. The person who refused today may be happy to help at another time.
- *Avoid weakening your request.* “It’s only a thought, but would you consider staying with Grandma while I went to the market?” This request sounds like it is not very important to you. Use “I” statements to make specific requests: “I would like to go to the market on Sunday. Would you stay with Grandma from 9 a.m. until noon?”

Source: <https://www.Carer.org/resource/taking-care-you-self-care-family-Carers/>

5) Learn how to communicate effectively with doctors

While carers will discuss their loved one’s care with the physician, they seldom talk about their own health, which is equally important. Building a partnership with a physician that addresses the health needs of the care recipient as well as the carer is crucial. Research shows that when doctors find ways to address the unique needs of individual carers, the stress load is visibly reduced. Your loved one’s doctor may have some suggestions on how to reduce your fatigue and these can have beneficial effects on both yourself and your loved one.

The responsibility of this partnership ideally is shared between you, the carer, the physician, and other healthcare staff. However, it will often fall to you to be assertive, using good communication skills, to ensure that everyone’s needs are met—including your own.

Focus: Tips on Communicating with Your Physician

- Prepare questions ahead of time. Make a list of your most important concerns and problems. Issues you might want to discuss with the physician are changes in symptoms, medications or general health of the care recipient, your own comfort in your caregiving situation, or specific help you need to provide care. The physician only sees a moment in time with the patient. Make sure you let him/her know what your concerns are in terms of daily care/health.
- Enlist the help of the nurse. Many caregiving questions relate more to nursing than to medicine. In particular, the nurse can answer questions about various tests and

examinations, preparing for surgical procedures, providing personal care, and managing medications at home.

- Make sure your appointment meets your needs. For example, the first appointment in the morning or after lunch are the best times to reduce your waiting time or accommodate numerous questions. When you schedule your appointment, be sure you convey clearly the reasons for your visit so that enough time is allowed.
- Call ahead. Before the appointment, check to see if the doctor is on schedule. Remind the receptionist of special needs when you arrive at the office.
- Take someone with you. A companion can ask questions you feel uncomfortable asking and can help you remember what the physician and nurse said.
- Use assertive communication and “I” messages. Enlist the medical care team as partners in care. Present what you need, what your concerns are, and how the doctor and/or nurse can help. Use specific, clear “I” statements like the following: “I need to know more about the diagnosis; I will feel better prepared for the future if I know what’s in store for me.” Or “I am feeling rundown. I’d like to make an appointment for myself and my husband next week.” Or “I need a way for my mother to sleep at night as I am now exhausted being up every two hours at night with her.”

Source: <https://www.Carer.org/resource/taking-care-you-self-care-family-Carers/>

6) Bring Your Employer into the Loop

Carers are often reluctant to share their caring responsibilities in the work environment. Yet, doing so can ease the stress arising from juggling work and care (see next section for more tips).

7) Take respite breaks from caring

Caregiving is hard work, so take respite breaks often.

If you are able, schedule some “vacation time” to simply do something for yourself. A simple overnight at a friend’s house or a local B&B, a stay-cation at a nearby hotel to try a new restaurant, or even a day trip to a hiking trail or park.

Also, explore a hobby, so that you have an outlet away from caregiving. Reading novels uninterrupted, taking up knitting, joining a book club or enjoying your children and grandchildren all count, too. Anything that takes you away from caregiving for short periods of time. Bonus points if it takes you out of the house, too.

8) Allow Yourself a Social Life

You may be feeling isolated or upset that your old circle no longer seems to check up on you and how you are doing. But is it possible that you have turned them down so often

because of your caregiving duties, or that caregiving concerns dominate your life and conversation so much, that they may think you are no longer interested in them?

When you do see them, do not just talk about caregiving. If every conversation concerns one subject, it is a warning sign that the latter is governing your life.

9) Adopt a Problem-Solving Approach and find new ways to manage overwhelming care tasks

Try to break down the tasks of caregiving into specific puzzles to be solved: if bathing is stressful, try to figure out exactly why and what might be done about it. Defining concrete problems and identifying possible solutions puts you closer to getting help with them and helps you avoid feeling overwhelmed by the bigger picture.

Do not try to solve the problem by yourself. Brainstorm possible solutions with other family members, a social worker or geriatric care manager, doctors, and friends who may have experienced similar issues.

Ensure that a thorough physical exam takes place to see if a problem, such as incontinence, can be fixed. Adult diapers and toileting schedules, or a change in medications, may make incontinence more manageable, for example. Frequent falls and problems getting up are other physiological problems that may be treatable. For behavioural issues such as wandering, get informed about the basic solutions to address the problem (for example: floor alarms, locks, reducing anxiety) and see if they make a difference.

Be open to new technologies that can ease your care “burden”.

10) Give yourself credit for doing the best you can in one of the toughest jobs in the world!

Forgive yourself for any bad days; give yourself a fresh start the next day. And consider: in five years, when you look back at this time, what actions and decisions will make you proud?

Section 3: How to handle your emotions

The experience of being a Carer can bring out all kinds of emotions.

You may feel more love for the person than ever before and greater inner strength and resolve to do your very best for your loved one.

But it is equally normal to feel sad, angry, afraid, anxious, guilty and emotionally exhausted.

You may feel one way on one day and another on the following day. Or you may feel sad and angry, for example, all at the same time. You may *fear* the loss of your loved one, *anger* at why this person is so sick or dying, *frustrated* by your inability to “do enough” and *anxious* due to how much responsibility you now have. Take comfort in knowing that all of these feelings are perfectly normal!

Feelings are neither good nor bad; nor right or wrong. They just are. Be gentle with yourself about how you are feeling BUT take action to relieve the pressure. Just like a pot boiling on the stove, you need to let off some “steam” if you are to continue to be a strong and capable carer.

Coping strategies

- Pound a pillow
- Sit in the car and scream
- Go for an energetic walk or run
- Get the resentment off your chest by talking to a friend, family member or your doctor
- Access the visiting or wellness programs at your local nursing home
- Take a yoga class
- Practice meditation
- Join a support group of other carers
- Talk to your spiritual or religious leader
- Avoid people that make you angry
- Walk away, step outside, take a break if your frustration is getting the better of you
- Cry if that helps (It is one of the coping mechanisms of the human body)
- Laugh and do not feel guilty (laughter breaks tension and is a wonderful stress relief.)
- Write/ sketch in a journal about how you are feeling
- Practice deep breathing and relaxation techniques
- Make arrangements for someone to stay with your loved one so you can have just a couple of hours to yourself even if you only go walk around the mall or sit in the park
- Get a good night sleep

Source: <http://Carersupport.hpco.ca/ocp/topic-3-care-for-the-Carer-and-handling-your-emotions/>

Depression and anxiety: symptoms and how to manage them

Symptoms of depression include feelings of sadness and despair that interfere with daily activities. Other warning signs include:

- Loss of appetite or overeating
- Problems sleeping, such as not being able to sleep or sleeping too much
- Lack of energy

- Loss of interest in enjoyable activities
- Trouble with focus, memory, and making decisions
- Feeling irritable and restless
- Excessive crying
- Headaches or constant, unexplained, physical symptoms that do not improve with treatment
- Drinking too much alcohol or increasing the use of mood-changing drugs

Anxiety is a common and normal response to a stressful situation, such as caring. However, too much anxiety can lead to health problems and interfere with daily activities.

Symptoms of anxiety include:

- Trouble solving problems, making decisions, or focusing
- Feeling excitable or restless
- Increased muscle tension or feeling tense
- Headaches
- Unexplained and constant anger or irritability
- Not being able to sleep
- Too much worrying

You can manage depression and anxiety with the following steps:

- Avoid drinking too much alcohol
- Plan enjoyable activities with family and friends
- Join a support group for Carers
- Arrange activities that bring you happiness and comfort
- Exercise, even as little as 10 to 15 minutes at a time
- Practice relaxation techniques, such as meditation and yoga

When these strategies do not bring the desired result, it is important for you to seek professional help.

Source: <https://www.cancer.net/coping-with-cancer/caring-loved-one/Carers-taking-care-themselves>

Carer burnout

Carer burnout, also called Carer fatigue, is mental, emotional and physical exhaustion that may develop through the responsibilities of supporting and caring for another individual.

Burnout may be easily misunderstood as simply feeling overly tired, or even occasionally exhausted. Unfortunately, while being tired can often be resolved by taking a break,

getting a little more sleep, or actively trying to relax, burnout is more often less easily relieved. Individuals who experience carer burnout, tend to face an all-encompassing fatigue that impacts multiple areas of their lives.

Carer burnout can happen to anyone who is providing care for another person, whether it is hands-on care, occasional care, from a distance, or even at the “managerial” level.

The Carer Burnout Symptoms

1. A Short Fuse

Losing your temper easily or feeling angry toward friends, family members or even the person for whom you are caring is one obvious sign of carer stress. Frustration may particularly increase when obstacles or challenges come up, whether major or minor.

2. Emotional Outbursts

If you find yourself crying or feeling despair unexpectedly or more often, that could be another warning sign. Of course, if you are caring for a loved one with a declining condition, it is natural to grieve, and caregiving can stir up a range of complicated emotions. But if you are increasingly emotional or feeling emotionally fragile, there may be something more going on.

3. Sleep Problems

If you are having trouble falling asleep, staying asleep, or waking up tired, that could be another warning sign. Caregiving — especially full-time caregiving — requires tremendous physical effort, but the emotions involved can lead to sleepless nights. Sometimes the issues your care recipient may be suffering from, like wandering or waking up in the middle of the night in pain, can cost you opportunities to rest on top of the tiring work you do all day. It can be a vicious cycle too, as trouble getting to sleep or staying asleep can also be caused by stress, anxiety, and depression.

4. Significant Weight Change

Suddenly gaining or losing weight can be another warning sign. For some people, stress can result in weight loss when they cannot seem to find time to eat adequately or nutritiously. Anxiety often lowers the appetite as well. For others, feeling stressed leads to weight gain from emotionally triggered eating, frequent snacking, or quick but unhealthy food choices.

5. Physical Ailments

If you find yourself getting headaches more often or feeling like you just catch one cold after another, that could be another warning sign. Or if you are getting chronic back or neck aches or developed high blood pressure. Mental and emotional stress can cause physical disorders. For example, stress can lead to headaches that are more frequent, more persistent, or stronger than you are used to. You will also lack the time or inclination to properly take care of yourself, setting the stage for more stress. Stress lowers immunity,

6. Social Isolation

If you find yourself going entire days without seeing anyone but your care recipient or are dropping out of your usual activities to care for someone, that can lead to burnout as well.

If you notice yourself experiencing these symptoms regularly, it may be time for you to seek professional help. Call your family doctor now and schedule an appointment!

Source: <https://www.caring.com/caregivers/burnout/>

Section 4: Balancing care and work

Reconciling professional and caregiving responsibilities is not an easy task. Delivering on professional tasks in due time while being a devoted carer indeed may generate a lot of stress. Holding down a paid job and caring for a friend or relative may ultimately feel as if you were juggling two jobs. Yet, there are things you can do to cope with the pressures of work and care.

✓ **Know your rights and benefits as a carer**

The good news is that carers have some legal rights and more and more employers are realising the benefits of supporting carers.

Most working carers should have guaranteed access to the following rights:

- the right to request flexible working
- the right to time off in case of emergencies and care leave
- the right not to be discriminated against or harassed because of your caring responsibilities. This is because you are counted as being 'associated' with someone who is protected by the law because of their age or disability.

Seek information about the regional and national legislation that may be relevant to you. In addition to your legal rights, your employer may offer more support. For example, you may be able to use leave arrangements, paid or unpaid, at the discretion of your employer to cover intensive periods of care. Other benefits may include advice and information on services and support, lunch-time seminars, subsidized back-up care, flexible working time and counselling services. In some companies, employees who have accrued vacation time can donate it to others – you may therefore benefit from your colleagues' generosity.

Check with your Human Resources department to see whether your employer offers any benefits.

✓ **Talk with your employer**

A key factor to reconcile work and care is to raise awareness among your colleagues and employers. Sometimes people do not realise what you are going through, they need more information!

You may fear that you will be stigmatised at work if you communicate your caregiving challenges to supervisors and colleagues. Yet, work environments can be very supportive. Remember that employers value skilled, experienced and committed members of staff and are keen to keep them. Your employer may be able to help in ways you have not considered.

Ask your employer for a confidential meeting so you can briefly explain your situation. Reassure that you remain willing and able to do your job but that you may also need some help and understanding while attending to caregiving demands.

Emphasize the positive. Mention specific ways you can accommodate work, such as your dad's dialysis site is now equipped with Wi-Fi so you can keep up with work email while there, or your mom will be starting at an adult care centre three days a week.

Explain the caregiving situation, how you plan to manage it, and ask for feedback. You may start a discussion this way: "My father is not doing well and is now living with me. I have hired help and organised my family to assist to ensure that my father is okay while I am here at work. It is nevertheless possible that I may encounter a crisis because my father's health is unstable. What would be the best way for me to handle any crisis with you?" You may also want to ask your boss for suggestions on how to communicate this situation with your colleagues.

✓ **Ask for help with caring**

Investigate alternative care arrangements (professional care or help from family and friends), so that you can focus on your work without distractions.

Set limits with family members and care recipients about your availability during working hours. Perhaps you can be available for field calls during lunch time or for a few minutes in the afternoon? (Of course, during crises – and you may want to define these as others' definitions of a crisis may differ from yours – you are always available).

✓ **Thinking of leaving your job?**

Making alternative care arrangements to allow you to work can may generate conflicts and/or cause feelings of guilt. What you decide must be right for you – **you have the right to choose, and that includes choosing to give up work as well as to stay.**

If you are thinking of leaving your job, it is important to consider the full implications and to ensure that all options have been explored before you resign. Indeed, work can be important for your wellbeing, income and for maintaining social contacts.

Think about the things you would be giving up, and whether you really want to lose them:

- Will you manage with less money?
- Do you want to give up the independence and social network you can access through your work?
- Will you lose valuable skills if you leave?
- How would leaving work affect your future pension entitlement?

Then think about ways around the problem, could you:

- Make a request for flexible working arrangements?
- Take paid or unpaid leave to think about your long-term options?
- Take a career break?
- Ask for extra help from social services?
- Buy in private care?

Easing the stress of family dynamics

Family dynamics can be a challenging aspect of caregiving, given the tremendous financial, physical and emotional demands involved. Here is a quick guide on how to avoid conflicts with family members (and how to work through them when they occur).

✓ Hold regular family meetings

As soon as the person starts experiencing health problems, organise regular family meetings with your siblings and other family members who will be involved in his/her care. The goal is to share information and make decisions as a group; the meetings can also be a source of support and provide a forum to resolve disagreements. Reserve a little time at the end of the meeting or conference call to chat and catch up.

✓ Divide the labour

Rather than insist that all of the caregiving tasks be equally divided, consider a division of labour that takes into account each family member's interests and skills as well as their availability. For instance, your sister may find it difficult to get away during the day to take your dependent family member to doctor's appointments, but she may be willing to handle his/her finances or take the lead in finding an appropriate long-term care situation.

A fair division of labour can mitigate resentment and make caregiving more efficient. The family meeting is an excellent venue for setting up a caregiving schedule and dividing up tasks.

✓ Remember why communication is important

Most families have taboo subjects that everyone tries to avoid. The topic may be a sensitive one, like a drinking habit or a family tragedy but in many cases, family members

just avoid speaking up because they are afraid of hurting feelings — or simply because openness has never been part of the family culture.

✓ **Talk about it**

If you feel that you are carrying too much of the burden, consider discussing it with siblings and other family members. They may not realise that you are feeling overwhelmed — or even know how much you are doing. Choose a quiet moment — perhaps at the next family meeting — to explain how you feel in a matter-of-fact, non-confrontational way. Try to be concrete and specific when you ask for help. For example, ask your sister if she can take over the grocery shopping, or find out if your niece can regularly drive your dependent family member to doctor's appointments.

It is also important to communicate with other family members if you are burned out and need a break. Likewise, if another sibling or family member is doing most of the caregiving, offer support and encourage her to express her frustrations and talk about what would make it easier for her/him.

✓ **Offer help even if you live far away**

If you live far from your family member and other relatives are responsible for most of the care, be sure to offer support. Check in often to see how things are going and to offer whatever assistance you can. Ask about how the Carer is doing and be a sounding board for frustrations and concerns. Be patient if the Carer needs to vent.

See more here: <https://www.caring.com/Carers/family-Carers/#how-to-deal-with-caregiving-related-family-conflicts>

Focus: Tips for honest and open communication.

- Use “I” language. When you use “I” language (“I feel”, “I want”, “I worry”), you take responsibility for what you feel, what you want and what you need. “I” language minimises the blame game (“You make me feel so bad!”) and when blame is out of the equation, you communicate effectively.
- Bring the other person into the solution so that s/he becomes involved in making the situation better. When you are both working toward improvements, you have created a team.
- Be assertive, state what you want and what you would like to see happen. Other persons, no matter how well he or she knows you, cannot read your mind.
- Use active listening skills, such as reflective listening. Reflective listening involves repeating back what you heard to ensure that what you heard is what your spouse meant to say. Clarifying (“I heard this...”) before responding helps to minimise misunderstandings.

- Avoid reacting defensively. Tell yourself: “I will be calm”. If you feel yourself becoming defensive, ask the other person to rephrase or re-word statements. If you really feel the heat of the moment taking control, then take a time out and agree to revisit the discussion when you are both calmer.
- Think of communication as a process. Discuss a situation, allow time for brainstorming, consider a potential solution, try the solution, then re-visit how successful the solution is. Participating in the process—and expecting that the right solution will come with trial and error—removes the pressure.
- Put yourself in the other person’s shoes. Understanding how (s)he feels will help you communicate effectively and work toward solutions that work for both of you.
- Look for solutions that work for everyone, including, but not exclusively, yourself (or your care recipient). Everyone can make compromises; no one person should make all the sacrifices.

Source: Eurocarers

Sources:

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[https://www.cancer.net/coping-with-cancer/caring-loved-one/Carers-taking-care-](https://www.cancer.net/coping-with-cancer/caring-loved-one/Carers-taking-care-themselves)
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Further resources:

<https://www.Carer.org/Carer-resources/all-resources/>

<https://www.Carer.org/resource/depression-and-caregiving/>

<https://www.Carer.org/resource/dementia-caregiving-and-controlling-frustration/>

<https://www.helpguide.org/articles/stress/Carer-stress-and-burnout.htm>

[http://Carersupport.hpcoc.ca/ocp/topic-11-how-to-communicate-effectively-with-](http://Carersupport.hpcoc.ca/ocp/topic-11-how-to-communicate-effectively-with-family-doctors-volunteers-and-helpers/)
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