

RUNNING ON EMPTY

WHO CARES FOR THE CAREGIVERS?



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"In this life we cannot do great things. We can only do small things with great love."

Mother Teresa

Who is a Caregiver?

A caregiver is anyone who provides assistance to another person so that person can maintain an independent lifestyle. Family caregivers, friends and neighbours are the backbone of Ireland's long-term care system.

For many people, caregiving isn't a job or a duty. It is doing what is right for a loved one. Caregiving can be an unspoken promise that so many of us make in our relationships, to be there for our loved ones when they need us.

Caregiving can evolve slowly, over a period of time or suddenly, in the case of an accident or illness. Depending on the specific need caregiving can include a great deal of activities including:

- Providing round the clock care or supervision
- Listening, talking and providing emotional support
- Supervising others who give direct care
- Shopping for someone else
- Travelling to and from the cared for person's home
- Maintaining two homes
- Managing financial and legal affairs
- Providing social activity
- Supervising medication
- Arranging healthcare

It is estimated that there are over 161,000 caregivers in Ireland alone. Another group who are often unrecognised are the large numbers of children under 18 years who are caring for a parent or sibling. The average age of caregivers is 45 to 64 years of age.

Caregiver Stress

Caregiver stress research, from Home Instead Senior Care, shows that 41% of caregivers say that stress/nervous tension is the most specific problem they have. Other problems include: back problems (26%), anxiety (23%), depression (18%).

Caregiver stress is the emotional strain of caregiving for a loved one, or attending to the needs of a child or dependent adult. Caregiving can have a major impact on the caregiver's own health.

Caregiving can also become stressful if the caregiver has other important and pressing responsibilities, including a job, children to care for, a busy social life, some distance to travel to care for an elderly relative and so on. Caregiving can be particularly hard for a spouse, especially when the care recipient requires around-the-clock assistance.

It can become dangerous if the spousal caregiver has his/her own health issues to deal with, since these health problems are often exacerbated by the stress and lack of attention to their own needs. A caregiver who takes care of herself or himself - body and mind - will ultimately be a better caregiver.

Signs of Caregiver Stress

The first step in dealing with caregiver stress is to recognise the signs of stress. You can then find ways to deal with it and enlist support or medical help when needed. Common signs that stress may be affecting your physical health include:

- Disturbed sleep, insomnia
- Back, shoulder or neck pain, muscle tension
- Headaches
- Stomach/digestive problems (upset or acid stomach, cramps, heartburn, gas, irritable bowel syndrome, constipation, diarrhoea)
- Weight fluctuation (gain or loss)
- Loss of hair
- Fatigue
- High blood pressure, irregular heart beat, palpitations
- Chest pain
- Perspiration
- Skin disorders i.e. non specific rashes, hives, eczema, psoriasis, tics, itching
- Slow wound healing
- Periodontal disease, jaw pain
- Reproductive problems
- Weakened immune system

Common signs that stress may be affecting your emotional health include:

- | | |
|---|-----------------------|
| • Anxiety | • Phobias |
| • Grief | • Argumentative |
| • Depression | • Feeling isolated |
| • Moodiness/mood swings | • Job dissatisfaction |
| • Butterflies | • Bereavement issues |
| • Memory problems and lack of concentration | • Resentment |
| • Feeling out of control | • Anger |
| • Increased substance abuse | • Helplessness |

If you are experiencing the signs listed above, consider talking with a healthcare professional who can help you to evaluate your situation.

The following testimonial shows how one family caregiver was showing signs of stress:

“ *I have been looking after my mother for the last four years. In the beginning, I would come over every morning and get her out of bed, wash her and prepare her breakfast. I would also do some light house keeping and prepare her lunch. In the afternoon, I would pop to the shops to buy groceries if needed and then pop back to her around six and prepare dinner and then put her to bed at around 9.30pm. I really enjoyed caring for my mother but after a while, I was getting headaches, not sleeping and feeling isolated. I realised that it was all becoming physically and emotionally too much for me.* ”

Nancy, Blackrock, Dublin



You Are Not Alone

It is important that a family caregiver realises that she or he is not alone. Getting support will help reduce caregiver stress, and the associated physical and emotional risks of ongoing stress.

Most family caregivers struggle to balance care for an ageing parent or relative with other major responsibilities, including jobs and caring for children. This often means that there is little time to care for themselves, which can result in poor health and high levels of stress. In fact, according to a Home Instead Senior Care survey, 55% of the family caregivers who utilise their professional caregiving services appear to have significant lower levels of stress.

Coping with Caring

There are five basic strategies can help control the destructive effects of stress.

1. Set realistic expectations and goals
2. Establish your limits
3. Ask for and accept help
4. Take care of yourself
5. Involve other people

Goals and Expectations

The basic goals of caregiving are to ensure the person receiving care has physical comfort, quality of life and is safe. These goals can be accomplished in many ways – you may be the direct care provider or the person who arranges, coordinates and monitors the care required. You may be dealing with a mix of all of the above. When setting goals it is important to consider how caregiving will affect other areas of your life.

- How is your current health?
- Will caregiving adversely affect your health and wellbeing?
- What is your relationship like with your partner and children?
- What other demands and obligations do you have?
- Are you employed?

Preventing caregiver burnout means accepting the limitations of what you can accomplish. As well as understanding yourself, you also need to know:

- How the illness or disability affects your family members
- What is likely to occur medically

It is important to set goals that are short term and focused, these are easier to attain. Long term goals are more difficult to achieve and may create a heavier burden if not reached.

Developing Realistic Expectations

Caregivers often struggle to balance their self-expectations with what they can actually achieve. Sometimes we expect too much of ourselves and get into a state of constant worry or anxiety because of not doing what we feel we should. When unable to do all you “feel” you should do, you may become guilty or depressed. Sometimes old promises drive caregivers to attempt to do more than is realistic. Promises can get in the way of looking objectively at the current situation. Objectivity is reduced, as is the ability to make the best decisions for all concerned.

Establish Your Limits

You have a right to set limits for yourself. It is all right to say “no”. Doing this may be very difficult, especially if painful choices are needed. However, when additional choices are not available in caring then you may not be able to say no. If, however, you are caregiving at the expense of your own mental and physical health or your relationships with others, then there is no benefit to anyone.

Asking for and Accepting Help

According to a survey conducted by Home Instead Senior Care, 72% of adults who are currently providing care for an ageing loved one, do so without any outside help.

A very common cause of stress and depression in caregivers is resistance to accepting help. Some caregivers view asking for help as a sign of helplessness, inadequacy or failure.

Friends, family and neighbours are often willing to help but may be afraid of the illness, feel uncomfortable around the person who is ill, don't want to upset you, don't want to interfere or don't know what they can do to help.

People can help best if you:

- Give them specific tasks and tell them exactly how you are feeling and what you need
- Be specific and positive
- Let them know you appreciate their help and that it is making your burden slightly less
- Sometimes these tasks may be unrelated to direct caring and can be easier for some people. Examples of these are shopping, gardening, house maintenance, cleaning and cooking
- Let people know how much their efforts have helped – they will continue to assist you if they feel appreciated

Taking Care of Yourself

It is very important that you have someone with whom you can talk openly about your situation and your emotions. Someone who will not judge you or express surprise or shock when you need to offload your feelings.

Being a caregiver and seeing a loved one decline is very difficult. Every caregiver experiences a range of emotions at some stage during their caring. Some of these emotions may be conflicting, confusing and ambivalent. You may feel love; sadness; frustration; dislike; repugnancy; guilt; grief; fear; resentment; hopelessness; or despair. You may feel angry at the increased dependency of your loved one and the multiple demands on your energy, time and money. You may also be grieving for the loss of your loved one as the illness progresses.

All these feelings are normal and none are “good” or “bad” nor do they reflect the level of your caregiving. Feeling anger and loss does not mean you love your relative less. What is very important is learning to express your feelings and learning to deal with your emotions.

Coping with these feelings in a constructive way is vital to your emotional and physical wellness. Stress is reduced when people can admit their feelings and learn to accept them. Repressing or denying feelings can lead to irritability, depression or physical problems.

Recognition and appreciation are important to us all. If you are feeling unappreciated then let people know. Look for positive feedback about how you are doing, for example, if you and the person you are caregiving for can share a conversation about how you are both feeling and how you are both coping. This may help to clear the air and you may learn in the process how it feels to be on the receiving end of your care.

Maintaining Your Health



To provide constant effective care you must look after your own health. Neglecting yourself can have far reaching consequences for you but also for the person you care for. It's important to ensure you have:

- Good nutrition
- Enough sleep
- Exercise

Without rest and food you may become exhausted, depressed or feel overburdened. If interrupted sleep is an issue find someone who will provide occasional or regular cover at night. It may be possible for you to sleep elsewhere on some of these occasions and truly benefit from the break.

Exercise is very valuable as it reduces tension, promotes better quality of sleep, it lifts the spirits and increases energy. If you feel that it would be just one extra demand try to incorporate it into your day. If getting out for a walk proves impossible try and do some stretching exercises while watching TV.

Relaxation techniques are also recommended to reduce stress. Try and find something that suits you and aim to do it for 20 - 30 minutes, three times a week if possible.

Visit your GP often and make sure that your doctor is aware of the stress or problem you are encountering.

Take Time for Yourself

Try to ensure if you do get a break that it involves something you want to do for yourself and is not taken as an opportunity to catch up with household chores. Do you save time for yourself on a daily basis or is your day fully taken up with caregiving? All too often caregivers place their own needs last. Remember to:

- Take regular breaks - Without breaks you will become exhausted, depressed and physically break down.
- Trust others - Objective evaluation usually shows that others can provide adequate care, at least for a short time. If you are concerned about leaving your loved one, give some thought to what is the “worst thing that could happen”, then make a contingency plan for handling the “worst thing”.
- Take breaks early in your caregiving role - if you leave it until you are experiencing burn out then short breaks may not be enough for your recovery.

Finding appropriate substitutes for you in your caregiving role can take time and planning. You will feel better about taking breaks if you have spent some time with your replacement and take this time to build a good solid, trusting relationship with the person or people.

Whatever type of care you choose, it's worth asking the following questions:

- What type of help do I need - regular or occasional?
- What times would be the best?
- How much advance notice would I need to give?
- What information will I need to give to the new care provider?
- How would the provider deal with an emergency?
- How can I prepare my loved one for my absence?

If you have always been available then you may need to spend more time preparing your loved one and a trial period may be useful.

Involve Other People

Hold a family meeting if possible. Often caregiving within the family falls to one or two people but all family members should be involved in planning and continuing support. The following approaches may be helpful:

- Try and hold the meeting as soon as caregiving issues arise
- The meeting can be used to give everyone the chance to air their concerns and to identify problems and solutions
- Family members should not be excluded because of distance, personality, family history with the person receiving care or limited resources
- Keep everyone informed and this will help them feel part of the decision making process

Acknowledge there may be conflict. It is a stressful and difficult time but the best interests of the person who is being cared for should be the focus of all discussions. It is important to agree some basic parameters for the care of your loved one.

The following testimonial shows how one caregiver involved other people to help deal with her situation:

“Two years ago, my father suffered a stroke and it left him immobile and in need of constant care. My mother didn't have the strength or capacity to manage on her own and as an only child, we really needed to pull together to establish the best way of caring for him. Being in a full time job and with my own family to look after, it was tough.

Initially we were struggling to manage, so we eventually put a schedule together for everyone to help out. I even got my husband and children involved and they helped out with some of the lighter duties around the house.

To cover our holidays or in times that we needed more help, we organised for a caregiver to come in and care for him. It's a very stressful and emotional situation but with help from others and with good time management, we are able to provide the best care for my father and he is much happier for it.”

Jeanie, Galway

Spousal Caregivers

While this is a natural reaction in a loving situation, it is important to note that spousal caregiving often leads to significant changes in your marital relationship and it can sometimes leave the caregiver feeling overwhelmed and stressed. This can be compounded if the caregiver is also taking over responsibilities that were once handled solely by their ailing spouse, from cooking and doing laundry, to balancing the cheque book and heading up the financial decisions.

In fact, if you are a spousal caregiver between the ages of 66 and 96, and are experiencing ongoing mental or emotional strain as a result of your caregiving duties, there's a 63% increased risk of serious health issues over those people in the same age group who are not caring for a spouse. The combination of loss, prolonged stress, the physical demands of caregiving and the health vulnerabilities that simply come with age place an older spousal caregiver in a danger zone.

Caregiving for a Parent

For some people caregiving for a parent is an opportunity to repay the care they received as a child. For others, finding themselves in the role of caregiving for a parent can be very upsetting. You may miss having someone you can turn to for support or feel uncomfortable about providing intimate personal care such as bathing and toileting.

Caregiving for a Child

Caregiving for a child with an illness or special needs can be both rewarding and challenging. Parents expect that their children will grow up to become adults and start their own lives. Parents may grieve for the hopes they had for their child for the future. Caregivers may feel frustrated they can't stop what is happening to their child or solve the problem. They may feel guilty about having less time and energy to spend with other members of the family. They may worry there are not enough services to support their child.

Signs that caregiving may becoming too risky for you or your loved one:

- Missing or delaying your/their own doctor appointments
- Ignoring your/their own health problems or symptoms
- Not eating a healthy diet for lack of time
- Overusing tobacco or alcohol when you/they feel stressed
- Giving up exercise habits
- Losing sleep
- Losing connections with friends due to a lack of time to socialise
- Bottling up feelings of anger and frustration and then being surprised by angry, even violent, outbursts directed at your spouse, other family members, co-workers or even strangers
- Feeling sad, down, depressed or hopeless
- Loss of energy

- Lacking interest in things that used to give you (and your spouse) pleasure
- Feeling resentful towards your spouse
- Blaming your spouse for the situation
- Feeling that people ask more of you than they should
- Feeling like caregiving has affected family relationships in a negative way
- Feeling annoyed by other family members who don't help out or who criticise your care

The hardest part for many is knowing when to ask, since some believe asking for help is a sign they aren't handling the situation well. All caregivers who experience elevated levels of stress are at an increased risk for physical and emotional issues, so it's important to get support.

Dementia

Many family caregivers currently care for a parent or spouse who has some form of dementia. Caregiving for someone with dementia often requires a great deal of time and patience, and it can cause great stress to the caregiver, particularly as memory loss progresses.

While we will all have memory lapses as we age, the term dementia describes a group of symptoms that are caused by changes in brain function, leading to serious changes in memory, personality and behaviour. Those with dementia tend to repeat questions, become disoriented in familiar places, neglect personal hygiene or nutrition, or get confused about people or time.

Alzheimer's disease is progressive. This can be physically demanding for a family caregiver, a grown child taking care of her/his parent, or a spouse caring for his/her lifelong partner, etc. It is also highly emotional as your relative may eventually look at you like you are a total stranger, despite all of the time and effort you are devoting to their care and well-being. Often, a person with this disease can become abusive, verbally and physically, which further compounds stress.

In order to better understand and care for a relative with severe dementia or Alzheimer's disease, the following tips are recommended:

- **Understand the disease.** Read about the disease, its affects, etc., so you are prepared as it progresses. With this understanding also comes additional patience, as you realise that the person is not doing this on purpose or to make you angry. It is a medical condition.
- **Enter their world.** Instead of trying to correct a person with Alzheimer's disease, ask them simple questions about their statements, even if they seem strange or are about a person who is no longer living. This will make you and your relative less frustrated.
- **Strike a balance.** Encourage as much independence as possible. Help the person by prompting them to do things for themselves, when possible, but realise you'll need to step in if the person's safety or well-being will be compromised in any way.

- **Get support.** Enlist the help of family and friends to spend some time with the person, if possible, to give you respite. Join a local support group for people who care for those with dementia/Alzheimer's Disease to hear their stories and know you aren't alone.
- **Tap into resources.** Find professionals in your area to assist with practical, yet emotional tasks, such as making care decisions, legal issues/Power of Attorney, asset management or creating a will.
- **Decide on assistance.** Family caregivers often find they are spending quantity time vs. quality time.
- **Environmental distractions,** such as street noise, a loud television or radio, can lead to agitation or anxiety. It is important to create a positive and comfortable environment.
- **Use effective communication** when speaking to someone with dementia. Be aware of your rate of speech, your pitch and tone.
- **Use positive body language.** Greet the individual with relaxed facial expressions and shoulders. If you are tense the person with dementia may pick up on it.

The following example shows how a family caregiver sought help and how it has made a huge difference to his life;



“Unfortunately my Mum was diagnosed with dementia. My whole life changed and I packed in my job so I could move back home to be with her as her full time caregiver. I stopped socialising with my friends and doing the things that I really enjoyed and this began to have a major impact on my life. I loved caring for my Mum but it was causing me great emotional stress and depression. Looking back, it was clear I needed help but it took me so long to realise and I had great fear in asking for it. Eventually I sought help and it made a huge difference in my life. I got the help

of a caregiver to assist me and to allow me to take some well deserved breaks. The neighbours also helped out hugely and some friends.”

Elizabeth, Charleville, Co. Cork

For additional support on Alzheimer's or dementia care visit www.HomeInstead.ie/Alzheimers-Dementia-Care.ie.

Financial Issues

Financial issues may also cause caregivers great stress. Many caregivers do not look or apply for some financial assistance because they are unsure whom to contact or are put off by the procedures. Don't feel ashamed or embarrassed about asking for assistance. A good starting point for assistance and information on such matters is your local Citizens Information Centres or MABS (Money Advice and Budgeting Service). Phone numbers of your local office is available in the phone book or online.

Loss and Bereavement

Everyone experiences loss during life. However, for caregivers many of the changes and losses experienced come quickly and often. These losses can lead to feelings of grief. Grief is a natural reaction to a loss. It is not an illness. It is as much a part of your emotions as joy and sadness etc. Grief can occur not only through death (bereavement) but also from major changes and losses in our lives, such as separation or divorce; changing or losing your job; moving or migrating; and children leaving home.

Losses such as the death of a family member may be very obvious to other people. Personal or private losses may be less obvious and not always recognised by other people yet still very painful. Some of the losses that carers talk about include:

- Losing your sense of being and individuality
- Independence, privacy and time for yourself
- Missing out on employment and career opportunities and your financial security being affected
- Not seeing friends or family due to caring commitment
- Missing the relationship you used to have or might have had with the person you care for
- The person you care for going into residential care so you feel you are no longer valued or needed

These kinds of losses may affect your self-esteem and confidence and your hopes and dreams about the future. You may also experience grief before an actual loss occurs. This may happen when someone you care for has a terminal illness and you know you will have to face a loss. Everyone responds to grief differently. If you are grieving you may sometimes feel physically unwell as well as emotionally upset.

Physical symptoms can include:

- Shortness of breath
- Dryness of mouth
- Loss of appetite
- Crying
- Tiredness
- Sleep problems

Grief can also cause deep feelings of loneliness, anger, fear, guilt, rage, resentment, confusion, ongoing sadness, not wanting to go out or do the things you used to do. These symptoms can be frightening but are normal reactions to grief. Recognising your grief and talking about how you're feeling can help. Making some time for you each day and having some plans in place for those bad times may make it easier to cope. Some of the signs described above may also be symptoms of other problems so it's a good idea to talk about them with your doctor.

Whatever your situation there are support groups you can join to meet other caregivers with similar experiences. Support groups can be a safe place to talk about your worries and to hear how other caregivers have coped with difficult situations. Caregiver support groups offer different types of support and if you find that one particular group doesn't suit you then ask about others in your area. Your local Carers Association can help put you in touch with carer support groups in your area.

No matter who you are caregiving for and no matter what the illness is there are ways you can be helped and ways you can reduce your stress levels. Many of the issues discussed in this booklet can be of assistance and if you can recognise how stress affects you then you can take steps to deal with it. Communicating with others is often the first step. This may be with a close friend, family members or a sympathetic GP. Remember you are not alone but you must reach out to others to minimise your stress.

Home Instead Senior Care Resources

HomeInstead.ie/Alzheimers-Dementia-Care



The Home Instead Senior Care website provides a variety of resources to assist families in coping with an Alzheimer's disease or other dementias diagnosis. Find tips, get expert answers to common questions and locate in-depth learning tools. In addition, you'll have easy access to locate professional Alzheimer's care service providers in your locality. Learn about free workshops led by trained professionals, tips and other advice for families dealing with dementia.

Dementia Care at Home



This booklet shares the Home Instead Senior Care approach to Alzheimer's and Dementia Care. The approach focuses on personalising the care experience and looks at practical ways of dealing with some of the most common issues associated with dementia such as keeping your loved one engaged in life, and understanding and reducing behaviour that is a sign of unhappiness in your loved one. There is also a section about you, the caregiver, which provides realistic ideas about how you can take good care of yourself.

Confidence to Care



For caregivers looking for a more in-depth resource, the book Confidence to Care is filled with helpful tips and strategies, care approaches and conversation starters for families dealing with the most common actions and behavioural symptoms of dementia, along with a section on help for the family caregiver and other resources.

Useful Contact:

Caring for Carers Ireland
 National Office, Carmody Street, Business Park, Ennis, Co Clare.
 Tel : 065 6866515 www.caringforcarers.org



Running on Empty: Who Cares for the Caregivers?

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