

How to cope with becoming an end of life caregiver

Many people choose to spend the end of their lives at home, rather than in another setting such as a hospital, hospice or a residential care home.

There can be many reasons for this decision, but often it is because of the familiarity and good memories that come with a familiar



environment. However, living at home in those final days almost always requires the support of others, often with the responsibility for care being passed to loved ones, friends or family members to help them through their end of life journey. However, care is a two-way street and the same amount of consideration, must also be given to the caregiver who can often find themselves dealing with a huge amount of stress.

Who are caregivers?

Quite often, caregivers do not even consider themselves as such. If you are a caregiver, then in your eyes you may simply be doing the things you have always done to look after someone close to you. However, if you do regular unpaid tasks like make meals, help with chores such as cleaning, shopping, make calls to check-in on them, provide help cleaning, bathing and going to the toilet, help someone make medical decisions, or assist them with their personal finances then you could be classed as a caregiver – and may be able to benefit from additional help and support that can sometimes be available.

A home death requires an incredible amount of planning and practical care. Caring for loved one, as well as coordinating with a number of professionals, specialists and agencies visiting the home, can be a great undertaking and prove to be very stressful on the caregiver. According to figures from [The National Council For Palliative Care](#), caregivers provide on average 20 hours of their time every week to look after someone close to them. Therefore, it is critical that if

you are a caregiver you are able to find suitable support and understand what to do when you are feeling overwhelmed.

Caregivers needs

Caregivers must remember that to serve their loved one's needs, they must also serve their own needs. It is not unusual for caregivers to experience an array of difficult feelings, such as resentment and hostility during this time. If you feel this way, then you should know that it is completely normal, and you shouldn't feel ashamed. Anyone that is having to meet the demands of caregiving is likely to feel a toll on their physical, mental and emotional needs.



As a caregiver your usual routine and lifestyle can be deeply changed as you find yourself adjusting to taking care of a loved one. You may find yourself spending time doing things that you don't really want to do, and with little time for the things that you do enjoy such as enjoying your hobbies or relationships. You may find yourself in scenarios where you are finding yourself feeling resentment and hostility towards your loved one, and when this happens it is best to be upfront and honest about your feelings. Simply saying "I'm finding this tough right now and I am struggling with my temper" can avoid your resentment building up to an unmanageable point and coming out in other ways which could lead to an argument or falling out.

Caregivers can often feel isolated and alone in their duties and feel as if there is lots of pressure on them to be caring and loving every moment of the day. This is unrealistic and often these high expectations and stress can snowball into anger. As a caregiver you have every right to feel angry if you are left alone in your

duties with no support at all, so you should ask for help from others and explore the resources that might be available to you as a caregiver.

However, if you do not address your anger then it can erupt in unhelpful ways, and you can find yourself directing that anger at people who do not deserve it when something trivial happens. In order to deal with anger, you should take a moment before you enter a room, have a deep breath, relax your body and try to center yourself. Often, humour can also help, and even a smile can be a good way to sidestep negative thoughts. There are times though when the best way to combat feelings of resentment or anger can be to deal with the root causes themselves.

Root causes of stress for caregivers

There can be many underlying causes of stress for caregivers and it may be helpful for you to know that many people will experience the same feelings as you. Here are some of the common causes of stress for caregivers:



- Needing a break from caring
- Tiredness
- Sadness, fear, or other reactions to a personality change in the person you care for
- Financial difficulties
- Having to undertake tasks that you find difficult, embarrassing or unpleasant
- Guilt
- Family conflicts
- Changes in family dynamics
- A lack of freedom
- A loss of social activities
- A loss of recreational time
- A loss of romantic relations

- Feelings of isolation
- Not having the knowledge, training or skills to undertake certain tasks
- Your own health problems
- Not wanting to be a caregiver
- Not knowing how long you will be a caregiver for

How to deal with stress of being a caregiver

One of the biggest issues that caregivers can come face to face with is a sudden change in the dynamic in their relationship. Whether you are best friends, partners, or siblings, it can be easy starting to feel as if caring has taken over your lives and left little time to act how you used to act. When this happens, it can be a good idea to switch things up, whether through sharing a relaxed conversation together, watching a film, or even just taking some time for yourself to walk your dog, visit friends, go shopping or do something else that is purely for your own enjoyment and can help you feel more 'normal' in what is often a very difficult time.



Counselling can also be a huge help to caregivers. Counselling is completely confidential, and you will not be judged for anything that you say. Counselling is used to help people navigate tough life experiences and situations and being a caregiver can quite often fall into that category. If you are looking for a counsellor, then you should contact the [British Association for Counselling](#) or ask your GP for advice on finding one.

Many people who find themselves becoming a caregiver have no practical experience doing so, they simply try their best and try to learn from their mistakes along the way. However, there is plenty of support for caregivers available from charities and organisations. Here are just a few for you to reach out to if you are struggling to cope, or would just like more information to navigate the world of caregiving:



AGE UK has a scheme called Homeshare where a person at the end of their life is matched up with someone seeking low-cost accommodation, in return for up to ten hours of household tasks or companionship per week. For example, tasks like driving, dog walking, and cooking. Click here to find out more:

<https://www.ageuk.org.uk/our-impact/programmes/homeshare/>

Carers Trust offer advice on money and benefits, carers assessments, caring breaks, health and wellbeing and much more. Click here to find out how they can help you: <https://carers.org>

Carers UK are a British based charity who provide expert advice, information and support to carers in need. Click here to find out more:

<https://www.carersuk.org>

Marie Curie volunteers can provide support to people at the end of their lives and also their carers from within their own homes. Click here to find out more:

<https://www.mariecurie.org.uk/professionals/refer-patients>

Additionally, many hospices offer dedicated support and social activities for caregivers such as tea mornings, discussion groups and social events. Speak to your local hospices to find out about such events.

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