

# life after care



A handbook to support the transition to  
post-caring





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This booklet is provided as an information guide for former carers.  
The information provided is not to be seen as an endorsement of any  
particular service and/or organisation nor is it to replace appropriate  
professional advice.



# Introduction

## Being A Carer...

The term 'carer' is sometimes used to describe both a paid care worker and a family member who provides support to an older or disabled person. This can sometimes give rise to confusion and in this booklet 'carer' refers to informal or family carers.

Eurocarers define a carer as "a person that looks after family, partners, friends or neighbours in need of help because they are ill, frail or have a disability. The care they provide is unpaid."

The UK Census 2001 found that there are 6 million people providing unpaid care in the UK. 1.9 million care for more than 20 hours per week and 1.25 million care for more than 50 hours per week. 3 million people combine care with paid work. Estimates of the numbers of carers in the EU may vary due to a variety of factors, such as different definitions of carer and the methodology used to identify them. The most recent source of EU-wide data concerning carers is the second European Quality of Life Survey (EQLS), which does not estimate the actual number of carers in Europe, but describes the activities of

a significant number of the adult population. In the EU27, 3% of people state that they care for an elderly or disabled relative several times a week, 4% do it once or twice a week and 8% do so less than once a week. Altogether, a quarter of people report being involved in caring for an elderly or disabled relative, amounting to 125 million carers in Europe.

## Life after caring

Caring can have an impact on physical and mental health, social life and finances. The coping strategies developed during caring can influence how someone copes when the person they care for dies. Former carers can experience a variety of emotions when their caring role ends. The feelings of grief arising from the death of a loved one can be compounded by the intensity of care that has been provided sometimes over many years.

Many carers have health problems themselves which they may not have given attention to while they were busy caring. These can include back problems caused by regular lifting, physical tiredness and exhaustion.

Some carers can lose confidence and become isolated, as their caring responsibilities leave them with little time to maintain social contacts. This can mean that after the person they care for dies, they may not have a social network to support them. In addition to grieving for their loved one, they are also making the transition from being a carer to having no caring role.

Larkin (2008) describes this phase as 'the post-caring void'. The next phase can be called 'closing down the caring time' as routines and activities change. The third and last phase involves re-entering social life and 'coming up to the surface' again.

We hope this booklet will help former carers through this transition period by giving them an idea of what to expect as well as the services that are available to support them during this time.

This booklet has been put together by a number of organisations in four different European countries who support family carers, as part of the Life After Care Project supported by the European Commission Gruntvig Exchange Programme.

Throughout 2011 and 2012, the booklet will be distributed to former carers in Ireland, the UK, Italy and Greece in local languages. For more information on this project see page 19 or visit [www.lifeaftercare.eu](http://www.lifeaftercare.eu) [www.lifeaftercare.eu](http://www.lifeaftercare.eu)



# When caring 1 comes to an end

If you are reading this booklet you have probably been a carer in the recent past

This booklet is for former carers who are experiencing this life changing event. It gives some advice, outlines the support available and gives guidance to you on where to go for more help.

Caring for a loved one can be a huge part of your life and can be a stressful, emotional experience which often also means making sacrifices, such as giving up your work, friendships, and hobbies.

The end of your caring responsibilities can be a very difficult and distressing time. You may feel a whole range of emotions, and along with these feelings it can come as a shock to realise how much of your life you have put into your caring role.

Whatever your situation, it is important to realise that you are not alone. It will be difficult, but you can find help and support.

## Bereavement

Losing someone you love is very painful, and it can be even more painful if you have been caring for that person.

After a significant loss, you may experience all kinds of difficult and surprising emotions, such as helplessness, anger and guilt. While these feelings can be frightening and overwhelming, they are normal reactions to loss. The grieving process is hard, but it can help you to accept your loss and to carry on with your life.

Grieving is a personal and highly individual experience. How you grieve depends on many factors, including your personality and coping style, your life experience, your faith, and the nature of the loss.

However, many people experience similar symptoms when they are grieving. It may help you to know what they are, and to know that intense emotions and swift changes in mood are all normal.

A normal grief reaction may include a few or many of the following:

## Physical Symptoms:

We often think of grief as a strictly emotional process, but grief often involves physical problems, including fatigue and lack of energy, nausea, lowered immunity, weight loss or weight gain, sleep or appetite disturbances, headaches, tightness in throat or chest and insomnia.

## Social and Behavioural symptoms:

During the grieving period you may experience behavioural changes, such as restlessness, inability to sit still, withdrawal from friends, social situations and activities, excessive activity to keep from thinking, auditory or visual hallucinations, having a sense of the deceased's presence, dreaming of the person who has died.

## Psychological Symptoms:

Any of these symptoms may accompany the emotions that are experienced after a loss, such as shock, anger, helplessness, depression and loneliness.

The difficult periods should become less intense and shorter as time goes by, but it takes time to work through a loss. Even years afterwards, especially at special events such as a family wedding or the birth of a child, you may still experience a strong sense of grief.

Take your time and don't be rushed into things either by yourself or by other people's expectations of you. You deserve time to grieve and to rest. There is life after caring, but it may take some time before you want or are able to move on or make decisions.

“...Then, when she died, I missed her even at home. It's strange because she hasn't stayed at home for four years (she lived in the nursing home), but after her death I missed her at home. I haven't missed her at home for four years. Now I really do miss her at home: I miss her presence during the dinners and the lunches, I miss her room...maybe because we expected to see her at home again...”

The voice of  
former carers

“Your world, even though you were a carer, at the time and all the rest of it, that world is gone and you're in no world because your life as a carer, that's gone and that was twenty four hours”

“Yes, you imagine them calling you or talking to you or sometimes you look around quick to see if they're back in their chair. You're in the kitchen doing something and you look around quick.”

## Who can help?

As this can be such a very painful time it is often a good idea to talk to someone about your feelings.

The best help and support often comes from people who care about you, like friends and relatives. Talking about what has happened, and about the person who died, can help you to come to terms with their death, and to cope with the feelings you have.

You may wish to draw loved ones close, rather than avoiding them, and accept the assistance they offer. You may find that some people seem uncomfortable around you, often because they want to do and say the 'right



thing' but are not sure what that is. Often, people want to help but don't know how, so try to tell them what you need – whether it's a shoulder to cry on or help with funeral arrangements.

On the other hand, sometimes even people who love you can be a little insensitive. For example, they may expect you to feel glad about the fact that you no longer have such caring responsibilities. They may not understand the impact caring had on you or meant to you. Sometimes people may expect you to be able to quickly pick up where your life left off when you started caring. For this reason, sometimes sharing your sorrow with others who have experienced similar losses can help: look for a bereavement support group in your area or online.

Finally, if your grief feels like too much to bear, contact a trained professional with experience in grief counselling. An experienced therapist can help you work through intense emotions and overcome obstacles to your grieving.

“During my father's funeral I said “Please don't leave me alone because I'm afraid I won't be able to go on”. After this event for 100 days I was always visited by someone: my cousin, a colleague, a neighbour... I've really appreciated this solidarity”

The voice of  
former carers

“Maybe what might help, I suppose for me (...) sharing and to realise that we all kind of go through the same”

“What our group found was that our neighbours and friends talking to us and talking us through things helped”

## Bereavement support – what might help

Some people find it helpful to learn more about grief and about other people's experiences. You might otherwise prefer to access support from outside your family, for example from other bereaved people or trained volunteers.

This type of talking and peer support is different from counselling. Well run bereavement support agencies ensure that their volunteers are carefully selected, receive on-going training and are supervised by professionals. They are trained to provide a listening ear, to facilitate people in talking about their experience and to support them in finding their way through their grief. Internationally, bereavement support services delivered by volunteers have been found to work extremely well. There is no charge attached to this bereavement support.

To find out about local bereavement support groups or services contact:

Carers UK: [www.carersuk.org](http://www.carersuk.org), telephone the Adviceline on UK: 0808 808 7777, open between 10pm-12pm and 2pm -4pm on Wednesdays and Thursdays.

Cruse Bereavement Care: [www.crusebereavementcare.org.uk](http://www.crusebereavementcare.org.uk) and their website for young people: [www.rd4u.org.uk](http://www.rd4u.org.uk). Helpline: 0844 477 9400 and helpline for young people: 0808 808 1677

Help the Hospices, [www.helpthehospices.org.uk](http://www.helpthehospices.org.uk) or 020 7520 8222



# Finances

When caring ends, some practical matters will have to be dealt with rather quickly.

For example, finances can be a problem, especially if you had to stop working to care and relied on a carer payment or on the pension or benefits of the person you cared for.



“You might get the carer’s allowance for six weeks but after that then you get nothing, you are thrown to one side. It’s like: see you, good luck, we don’t care what you do.”

## When state benefits stop

In the UK, certain payments stop when the person you care for dies. For example, if you are caring for someone who receives a disability benefit, this will stop. You have a responsibility to inform the Department for Work and Pensions when the person you care for dies so that any benefits paid to them can be stopped.

If you are or were receiving Carer’s Allowance, the main benefit for carers, this will usually continue for 8 weeks after the person you care for has died. If you get an extra amount as part of your Income Support, this will also continue for 8 weeks.

Other things that you may rely on, such as the family car may also have to be returned if they are linked to disability benefits under the Motability scheme.

## Bereavement payments

There are also a series of bereavement benefits that you may be able to claim:

- a bereavement payment – a one off lump sum, tax free payment of £2,000 for people of working age.
- Bereavement Allowance – a regular taxable payment if you were aged 45 or over if your spouse or civil partner dies for people of working age.
- Widowed Parent’s Allowance (WPA), a regular taxable payment for parents

## Financial support

If you do not have any other source of income, there are several benefits that you may be able to claim. It is important to claim benefits as these give you National Insurance Credits towards your pension and other benefits. The benefits you can claim include:

- Jobseeker's Allowance – for people aged under 60 who are available for and actively seeking work.
- Employment and Support Allowance for people whose ability to work is limited due to illness or disability. There are two levels of payments of ESA depending on how many National Insurance Credits you have. There is an assessment to look at your ability to engage in work-related activity. If ESA is awarded, claimants will either be in a work-related activity group or a support group where they do not have to undertake work-focussed activities unless they want to.

To find out more about financial support for former carers, contact:

- Carers UK, [www.carersuk.org](http://www.carersuk.org) or Adviceline on: 0808 808 7777 between 10am – 12pm and 2pm - 4pm.
- Directgov: [www.direct.gov.uk/disabledpeople](http://www.direct.gov.uk/disabledpeople) and benefits sections

## Wills

In the UK, it is important for the person you are caring for to think about making a will if they have not already made one. It is important because:-

- If you die without a will, there are certain rules which dictate how the money, property or possessions should be allocated. This may not be the way that you would have wished your money and possessions to be distributed
- Unmarried partners and partners who have not registered a civil partnership cannot inherit from each other unless there is a will, so the death of one partner may create serious financial problems for the remaining partner
- If you have children, you will need to make a will so that arrangements for the children can be made if either one or both parents die
- It may be possible to reduce the amount of tax payable on the inheritance if advice is taken in advance and a will is made
- If your circumstances have changed, it is important that you make a will to ensure that your money and possessions are distributed according to your wishes. For example, if you have separated and your ex-partner now lives with someone else, you may want to change your will. If you are married or enter into a registered civil partnership, this will make any previous will you

have made invalid.

To find out about making a will contact:

- Carers UK has basic information on its website: [www.carersuk.org](http://www.carersuk.org)
- Citizen's Advice Bureau: [www.adviceguide.org.uk](http://www.adviceguide.org.uk)

## Working carers and former carers

The majority of carers are of working age, and many combine their caring role with paid work. As the population ages and the pool of people available to provide informal care shrinks, it will be increasingly important to help carers combine their caring role with paid work. Forward looking employers already recognise the benefits of supporting their employees with caring responsibilities - for their business, for their people and for the wider society in which they work. There are many ways in which employers can support carers while they are caring, and ways too in which they can support carers as caring comes to an end and beyond.

In the UK Employers for Carers, a membership forum for employers who want to support their employees with caring responsibilities, offers practical help and advice and promotes the business case for workplace support.

Support can include:

- Flexible working practices, including special working arrangements for end of life care
- Flexible leave arrangements, including special leave arrangements for end of life care
- Signposting to information on external services and support, including help when caring comes to an end
- Workplace support such as in-house networks for peer support and counselling, including bereavement counselling
- Practical support such as access to a private space to make telephone calls

Employers have identified a particular need for additional counselling support as caring ends, as former carers can experience feelings of guilt and a loss of purpose in addition to grief at the loss of a loved one.

Former carers have a wealth of information and experience that can benefit current carers in the workplace, and employers can help them find a new role and a new purpose by involving them for example in peer support networks.



# Filling the gap

# 2

## What to do next?

It can take time – sometimes a long time – to feel ready to move on after the loss of your caring role. But there will come a time when you feel like thinking about what to do next and what you would like to do for yourself.

As you start to move on you may feel it is time to develop new interests. This can be important, as an experience you did not share with your loved one is more about the new 'you' than the bereaved you. Talk to friends or work colleagues to see what they do in their spare time, it could be that they have a hobby you never knew about and they can take you along.

If you have been involved with charities or voluntary organisations while caring you may want to give something back through fundraising or indeed become part of a carer support group, if this is appropriate. Maybe you still feel like taking care of someone in need through volunteering. Or you may like to consider becoming a paid care worker, or returning to education or joining an adult education class.

The voice of  
former carers

“The retirement club gets you out and about, gets you playing bowls, gets you into exercise, gets you into core groups because when you're caring the weight piles on from getting no exercise because you can't get out.”

“I take care of my grandson, I do the gardening. I wasn't able to do that when I was caring for my sister.”



# Volunteering

A lot of carers think about volunteering after their caring comes to an end.

There are two main reasons why you might find it a good way to spend the time you have now that you no longer have caring duties: the first one is that you might feel like you owe a debt of gratitude to the organisations that helped you. Therefore, you may decide to offer some of your time to carry on fundraising activities or to help manage services.

The second reason is that you may have enjoyed the feeling of being helpful to someone else you experienced while caring and you would like to experience it again.

Whatever reason you might find for yourself, as someone who has cared for someone you have a set of invaluable skills that may be of use to support others. This can be incredibly rewarding and also help you come to terms with your own loss. Moreover, volunteering can be a very social activity, and can be a good way to meet new people.

## Who can help?

If you have been supported by a charity or a carers association while caring, you could contact them and inform them that you may be available to lend a hand. They are likely to be happy to involve you in their activities, making use of your experience as a former carer. While your experience will be valuable they will probably ask you to do some training or briefing before you directly support people, just to make sure that you are well prepared and equipped.

It is also possible that you are interested in volunteering but for whatever reason you don't want to get involved with an association you already know. In this case, you could first spend some time thinking which kind of volunteering activities would interest you. In fact, volunteering opportunities can range from befriending older or disabled people, offering your skills (e.g. administration, fundraising, legal advice, etc) to a local charity, to helping out on a community development project... Try to get some information about the volunteering opportunities available in your area and see if there is one matching both your interest and the skills you have to offer (don't forget that some activities, even if unpaid, might require specific skills).

To find out about volunteering opportunities in your area contact:  
Your local volunteer bureau – details are in your telephone directory or in  
England, on: [www.volunteering.org.uk](http://www.volunteering.org.uk)

Do-it: [www.do-it.org.uk](http://www.do-it.org.uk)

Community Service Volunteers: [www.csv.org.uk](http://www.csv.org.uk) or 020 7278 6601



“In my opinion volunteering is great because, besides providing help to others, it is useful for yourself. You might have the need to do it”.

“When it is all over [the caring activity] you feel lost and you don't know what to do because everything falls down. Suddenly you have no more interests, then – step by step – volunteering becomes a resource, a luck. I believe that volunteering doesn't help others as much as it helps yourself”.

## Learn something new

Learning something new might be an excellent opportunity to invigorate yourself after many years dedicated to caring. Acquiring new skills will also help to build your confidence and to progress any plans to enter further education or to return to work (see below).

There are countless opportunities to learn something new: they can range from a short evening course to a degree; from a DIY class to vocational accredited/certified training.

To choose the right course for you, you should first of all be asking yourself why you want to attend a class. Is it just about time for you or are you planning to use your new skills to return to work? It is also important to estimate how much time you think you will be able to



dedicate to learning. Are you ready to be involved full-time or will you be able to give it just a couple of hours a week? Maybe you would prefer e-learning?

Answering these questions may be the starting point to find your way through the world of learning.

To find out about learning opportunities in your area, contact:

Learn Direct: [www.learndirect.co.uk](http://www.learndirect.co.uk) or 0800 101 901 for impartial information and advice on courses, including funding, and careers.

Directgov: [www.direct.gov.uk/adultlearning](http://www.direct.gov.uk/adultlearning) to find a course and for information about financial support, training and workplace learning.

“

“My return to the education process re-awakened my intellectual and creative abilities, which had been dormant during my caring role. A real boost to my self esteem and enthusiasm for life again.”

”

The voice of a  
former carer

# Returning to work

When the person you're looking after dies, you not only lose a loved one but may also lose a sense of purpose as your caring role ends. You may need to return to work in order to gain financial security. Returning to work may also help you regain a sense of purpose and provide a new structure to your life.

As a former carer, you may face the challenges of having been out of the workplace for a while, not being up to date with technology, a lack of confidence, or feel you no longer have the skills you once had. However, you may have acquired new skills as a carer that may be attractive to potential employers. Indeed, some organisations actively seek to recruit carers and former carers returning to work.

A good way to start is to recognise the skills you have. Think about what you have learned from:

- any paid work that you have done in the past
- activities that you do, for example voluntary work, committees, etc.
- tasks and responsibilities involved in your role as a carer.

Research has shown, in fact, that carers develop several skills that might be useful in a wide range of jobs. For instance, showing initiative, flexibility, problem solving, empathy... can be mentioned when applying for a job.

The voice of  
former carers

“I tried to work in a nursing home before, but the impact with 10 people had been too strong for me and I turned out depressed. Now, instead, I feel brave enough to help: I see the suffering but it becomes an inspiration to work. I see the work with elderly as a job in which I could have a lot to give” ”

“When John's mum passed on in 1999 I returned to nursing, to work, so I chose to do that because I had to get some sort of balance on your life” ”

The next step is to identify your interests, what you enjoy doing, how you would like to use your new skills. Then it is time to prepare your new CV. While writing it, try to highlight the skills you have gained through caring, especially those that could be transferred to the job you are looking for.

## Who can help?

If you are not sure where to start and think you need some help, don't hesitate to turn to your local job centre. They will guide you through your job search.

For help finding jobs in your area, contact:

[www.direct.gov.uk/en/Employment/Jobseekers/ContactJobcentrePlus](http://www.direct.gov.uk/en/Employment/Jobseekers/ContactJobcentrePlus)

## Advice from former carers like you

Get out of the house, and keep  
your mind active



Be good to yourself



Take satisfaction in your  
years of caring



Try to get your life  
back



Let go of your guilt

Join organisations  
who may be able to  
help



Don't expect life to return to  
normal





# The Life After Care Project

3



Life After Care is a project funded by the European Commission under the European Programme Life Long Learning – Grundtvig.

The Life After Care partnership brings together organisations involved in training, support and advocacy of family carers. Former family carers often experience significant difficulties in re-engaging in wider society after many years dedicated to full-time caring.

The partnership focuses on strategies for the empowerment of former carers through acknowledgment and enhancement of interpersonal (stress management, negotiation capacities, empathy, organisational skills...) and technical (lifting and transferring, medication management...) skills acquired in unpaid caring in order to help their transition from caring to post-caring.

Through networking and fieldwork in the four countries involved, the partners are developing innovative strategies for the acknowledgment and enhancement of these skills and their use in three areas:

- (Re)integration into the formal labour market
- Volunteering in community services
- Involvement in carers' organisation



# Partner organisations



Sofia Società Cooperativa Sociale – Italy (project coordinator)



Arco S.A.S. – Italy



Care Alliance – Ireland



Carers UK – United Kingdom



Associazione Malati di Alzheimer di Atene - Greece

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European Commission**



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the voice of carers



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