

life after care



**A handbook to support 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' can be 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 but 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 Central Statistics Office (CSO) 2009 Q3 Quarterly National Household Survey found that 8% of respondents (aged 15 and over) provide some level of unpaid care. Generalised to the estimated population at the time, they estimate that in the region of 274,000 people aged 15 and over are providing unpaid informal care.

Estimates of the numbers of carers in 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 resource 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 your physical and mental health, your social life and your finances. The coping strategies you develop during your caring experience can influence how you cope when the person you care for dies. Former carers tend to experience a variety of emotions when their caring role ends. The feelings of grief arising from the death of your loved one are combined with the intensity of the care that you have provided over the 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 you care for dies, you may not have a social network to support you through this time. In addition to grieving for your loved one, you are also making the transition from being a full-time 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 you change your routines and activities. The third and last phase involves re-entering social life and 'coming up to the surface' again.

We hope this booklet will help you through this transition period by giving you an idea of what you can expect as well as the services that are available to support you 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



When caring 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 is 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, such as anger, sadness, helplessness, frustration, guilt.... 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 shock, anger and guilt. Sometimes it may feel like the sadness will never let up. 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're 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 feelings of shock, anger, disbelief, confusion, 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."

What we know about the experiences of former carers

While each former carers journey is unique, thanks to some recent research and some interviews with former carers, we are beginning to get a picture of what the journey seems to be like for many.

The research identified three post-caring processes: 'the loss of the caring world', 'living in loss' and 'moving on'. The researchers identified how the loss of the pre-caring world (i.e. your world prior to becoming a full-time, primary carer with all its social contacts, employment and other life opportunities) is followed post-caring with the loss of a "caring world";

Loss of Caring World

The loss of the caring world occurs at the beginning of the post-caring phase. The losses are multi-dimensional; loss of your identity as a carer, of your role as carer, of the close bond with the person you cared for, and of your social relationship with the network of healthcare professionals.

Living in Loss

This refers to the process of living in and continually experiencing the losses of post-caring. Key features are your emotional reactions such as guilt, relief, a sense of urgency and anger towards state services. The losses are exacerbated by the perceived dismissal and devaluing of the former carer by State systems becoming a barrier to 'moving on' to a new world after the caring ends.

Other barriers often include loss of carer-related financial supports and difficulties returning to the workforce. It appears that although some former carers 'move on', others continually move between the loss of the caring world and living in loss in a continual, cyclical movement. They become 'stuck' in the losses of post-caring and do not move on to the third phase enabling them to construct a new life world.

Moving on

This is the concept of former carers proactively beginning to move into a new world by caring for themselves, keeping active, becoming involved in their community and 'getting out of the house'.

For some former carers, 'moving on' involves taking up other caring activities, such as mentoring other family carers or taking care of grandchildren. Those who 'move on' from this cycle 'move out' of the 'trapped' space between worlds no longer viewing themselves as 'worldless' and construct a new world. The things that help people move on include family support and support from carers' organisations.

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**

'What our group found was that our neighbours and friends talking to us and talking us through things helped an awful lot.'

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

Bereavement support – what might help

Information

Some people find it helpful to learn more about grief and about other people's experiences. There are a range of leaflets and books available from many different sources, for example, the Irish Hospice Foundation produce a series of leaflets.

See www.hospice-foundation.ie then click on 'Bereavement' and on 'Getting Help' or phone (01) 6793188.

Information on bereavement support and advice is also available from the Citizens Information Board.

Support

You might prefer to access support from outside your family, for example from other bereaved people or trained volunteers. This may be because you have no supportive family members or you are concerned about laying too much on them.

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.

You can access support from the following organisations

AnamCara – parent bereavement support, for parents and families where a child has died.

Tel. (01) 4045378 or mobile 085 2888888

www.anamcara.ie

Bereavement Counselling Service (volunteer-based support in Dublin and Kildare – Tel. (01) 8391766)

Online support for widows is available at www.widow.ie

The Family Support Agency funds a range of support services which are listed by county at

www.fsa.ie/services/counselling-services/

Bereavement counselling or therapy

A small number of people experience significant difficulties in their bereavement. These might include: intense and unrelenting grief that lasts more than six months; prolonged agitation; depression; guilt; despair; or serious and persistent thoughts of suicide. If you are concerned, please consult your GP and consider professional help. Unlike the more usual grief reactions, these symptoms do not always decrease over time.

If the person you cared for died in a hospice, it is likely that, a bereavement support service will be in place. In Ireland there is no professional qualification in bereavement counselling. Professionally trained therapists such as those will be registered with a governing body such as those listed below. These organisations can give you the names of qualified therapists who specialise in issues of loss and grief.

The Irish Association of Counselling and Psychotherapy (IACP)
Tel. (01) 2723427

The Irish Association of Humanistic and Integrative Psychotherapy Ltd.
Tel. (01) 2841665 (up to 2.30pm Monday to Friday)

The Psychological Society of Ireland (PSI) Tel. (01) 4749160

If you are looking for help around a child's bereavement, Barnardos
Tel. (01) 4530355 can provide counselling and advice.

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.

The voice of former carer

"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."

Who can help?

To find out about financial supports for former carers, contact:

- The Citizens Information Offices around the country offer free information and advice. Tel. 1890 777 121 or see www.citizensinformation.ie
- There is also a free Money Advice and Budgeting Service (MABS). Tel. 1890 283 438 or see www.mabs.ie
- If you are in immediate financial need you should contact the Community Welfare Officer in your local health centre who may be able to offer you short-term financial support while you get to grips with your finances.

Wills

The person you have been caring for may or may not have made a will. It is generally recommended that everyone makes a will, even if you feel you do not have many assets. It does not cost much.

Your local Citizens Information Centre (Lo Call 1890 777 121) will be able to advise you on the process. Alternatively you can visit www.citizensinformation.ie and type 'will' in the search engine.

For people with diminished mental capacity (such as dementia, learning disability), the process can be more complex. This is to protect their best interests. Independent legal advice should be sought at all times and ideally they should also have an independent advocate.

If you, as a carer, are living with the person you are caring for, you may have questions about your rights to remain in your accommodation after your caring has ended. Again, you should seek independent legal advice.

FLAC (Free legal Advice centres) have a booklet on wills. You can get it by calling 1890 350 250 or by downloading it from their website. **www.flac.ie**

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Filling the gap

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

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

"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."

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:

Volunteering Ireland – Tel. (01) 6369446

See **www.volunteeringireland.ie** or e-mail
info@volunteeringireland.ie

**The voice of
former carers**

“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”

“I now have the privilege of working on the Careline (Carers Association of Ireland)”

“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”.

■ 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.

**The voice of
former carer**

“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.”

Who can help?

It can be hard thinking about what is right for you when you might not have thought about yourself or your needs for a long time.

Your local VEC offers an Adult Learner Guidance Service free of charge where you can discuss options available to you on a one-to-one basis.

If money is an issue, do not forget to ask for information about grants, scholarships or to access to free courses.

To find out about learning opportunities in your area, contact your local VEC or Fás office for a list of current courses running or contact AONTAS:

AONTAS – Adult Education
Tel. (01) 4068220/1
or e-mail mail@aontas.com
or visit www.aontas.com

Fás www.fas.ie

VEC www.ivea.ie

■ 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.

"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"

**The voice of
former carers**

"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's time to prepare your 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?

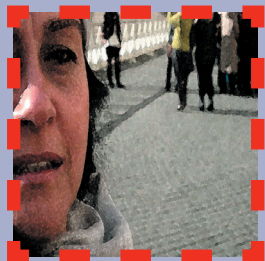
If you are not sure where to start and think you need some help, don't hesitate to turn to your local job centre. They will guide you through your job search.

For help finding jobs in your area, contact:

FÁS – Employment Service
Tel. (01) 6070500 or visit www.fas.ie

Advice from former carers like you...

Get out of the house, and keep your mind active



Let go of the guilt



Be good to yourself

Take satisfaction in your years of caring



Try to get your life back



Join some organisation



Don't expect life to return to normal



The Life After Care Project

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 will focus 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 so as to help their transition from caring to post-caring.

Through networking and fieldwork in the four countries involved, the partners aim to develop 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

List of partner organisations:



Sofia
SOCIETÀ COOPERATIVA SOCIALE

Sofia Società Cooperativa Sociale – Italy
(project coordinator)



Arco S.A.S. – Italy



Care Alliance – Ireland

CARERS ^{UK}
the voice of carers

Carers UK – United Kingdom



Athens Association of Alzheimer Disease - Greece

If you need further information please contact:

Care Alliance Ireland (01) 8747776 or info@carealliance.ie

You can download these booklets from www.lifeaftercare.eu

Hard copies may be available from each partner organisation in the local language (English, Italian, Greek)

With the support of the Grundtvig Programme of the European Commission.



CARERS UK
the voice of carers

