

The Way Ahead



A resource to support former family carers

The Way Ahead – *A resource to support former family carers*

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The inspiration for this booklet came from a partnership of five organisations across Europe, who in 2009 came together to produce the Life After Care booklet (2011). These organisations are: Arco SAS Italy, Sofia Societal Co-operative Sociale Italy, Carers UK, Care Alliance Ireland, and the Athens Association of Alzheimer Disease.

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This is the second edition of this booklet; the first was published in March 2018.

Download: You can download this booklet for free from www.carealliance.ie

If you find any inaccuracies or omissions in this booklet, please contact Care Alliance Ireland (01) 874 7776 or info@carealliance.ie

This booklet is provided as an information guide for former carers. It does not endorse any particular service or organisation, nor does it replace appropriate professional advice. The authors have tried to ensure that the information is accurate at the time they published it.


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2020

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1. Who this booklet is for

This booklet is for former family carers.

We define former (family) carers as people who provided:

“unpaid physical or social care to a family member with an illness or disability in the home for a prolonged period. ”

Another frequently used definition of ‘carer’, taken from the census is:

“ someone who provides [provided] regular, unpaid personal help for a friend or family member with a long-term illness, health problem or disability (including problems which are due to old age). Personal help includes help with basic tasks such as feeding and dressing. ”

What's in a name?

The term 'family carer' is used to describe the work of family and friends who provide unpaid care to an individual. Research has shown that family members provide between 85% and 98% of unpaid care. That is why we refer to 'family'.

This definition does not include care associated with child rearing, although some parents whose children have long-term high care support needs may identify as family carers. The terms 'caregiver' and 'carer', as well as 'informal carer', are also used in some of the literature and internationally, but we believe it is important to differentiate paid care from unpaid care.

Carers who are lesbian, gay, bisexual or transgender

Those carers who identify as LGBT can face additional challenges post caring. For example their sexuality may have affected the extent to which their caring and bereavement is recognised by others including the family of origin of the person whom they had been caring for. Institutional barriers may also have affected such recognition and approaches to bereavement.

The Irish Hospice Foundation have a leaflet entitled

Coping with the death of your same sex partner.

<http://hospicefoundation.ie/wp-content/uploads/2012/08/00298-14-IHF-Death-of-Same-Sex-Partner-V5.pdf>

Some counselling organisations offer bereavement services specifically tailored to members of the LGBT community. See details later in this booklet.

LGBT Ireland provides a range of support services.

www.lgbt.ie Phone: 1890 929539 Email: info@lgbt.ie

Is your relative still alive and being cared for elsewhere?

This booklet is mainly for those who have completed their caring role. We know that there are many other people in the 'transition' stage of caring when, perhaps after many years of care at home, the person being cared for now needs residential care. For many families in this situation, caring continues,

albeit in a different way. If this is your situation, the following resources and organisations may be helpful:

Family Carers Ireland

Careline: 1800 240 724 www.familycarers.ie

The Alzheimer Society of Ireland

Helpline: 1800 341 341 www.alzheimer.ie

Letting go without giving up – Continuing to care for the person with dementia.
www.alzscot.org/assets/0000/0275/lettinggo.pdf (This is specifically about dementia.)

Transition to Care <https://careconversations.org/transition-care>

Life for Caregivers after Placing a Relative with Dementia in a Nursing Home
<https://bit.ly/2PMG44t>

The Alzheimer Society of Ireland – Guidelines to Choosing a Nursing Home
(July 2019) <https://bit.ly/2UlwX7C> Contact the ASI National Helpline (details above) for the most up-to-date version.

For lesbian, gay, bisexual or transgender (LGBT) carers, there may be anxiety about revealing the true nature of the relationship with the person being cared for when that person is now in residential care. This may also be the case if the children or relatives of the person being cared for are lesbian, gay, bisexual or transgender. Generally residential care settings work from assumptions of heteronormativity (assumptions that everyone in their care is heterosexual) as well as other assumptions about gender identity. Such assumptions risk rendering LGBT people invisible and can create barriers to effective communication and care.

Impact of 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 your caring role ends. Former carers experience a variety of emotions when this happens.

You may have health problems yourself which you have not paid attention to while you were busy caring. Some carers lose confidence and become isolated, as their caring responsibilities leave them with little time to maintain social contacts.

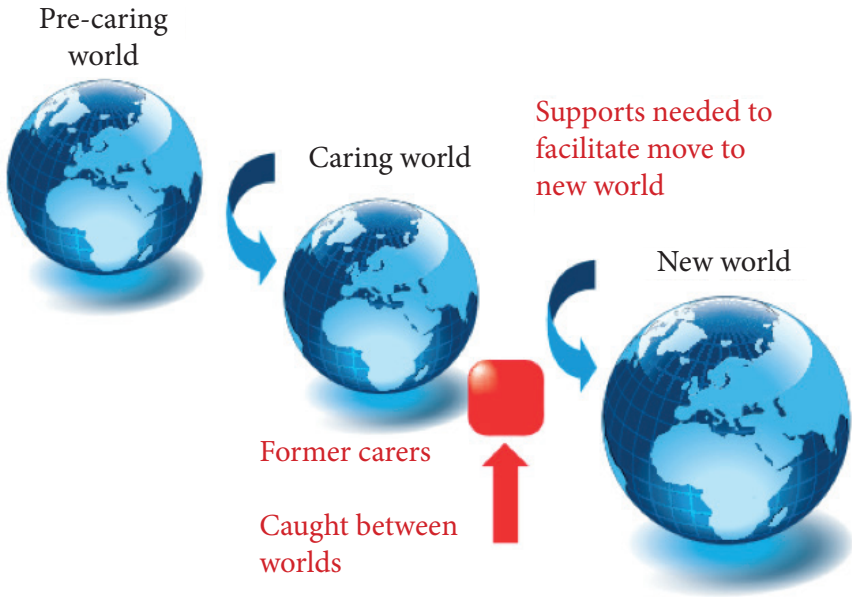
When the caring relationship has been difficult

While many family carers comment that caring for their loved ones was, overall, a positive experience, not all caring relationships are easy. In some circumstances you may have been caring for someone who was difficult to care for – or that you did not get on with. Also, many relationships can be strained by caring responsibilities, such as your friendships and relationships with other family members.

You may feel a sense of relief when your caring role ends.

Care Alliance Ireland have produced discussion papers on these and related topics – you can see these at www.carealliance.ie/discussionpapers

Life after caring



Source: McCarron, et al. (2011) *Between Worlds: The experiences and needs of former family carers*. <http://bit.ly/VBSddF>.

It may take a long time to adjust to the end of your caring role. Having more time to yourself may give you the opportunity for a much needed rest, but it can also leave you feeling that you have a lot of time to fill. If you are used to always having things to do, it can be hard to stop and think about what you would like to do now.

Some people find that once they are no longer caring, exhaustion – both physical and emotional – catches up with them and they may feel unwell for a while.



Created by Pressfoto - Freepik.com

You have to deal with practical matters fairly quickly. These might include making sure you are claiming the right benefits now that you are no longer caring, dealing with funeral arrangements and dealing with changes to your housing situation (if any).

However, you do not need to rush into making decisions about other aspects of your life.

“ Yesterday, dad died. I know life will be hectic for the next few weeks. So, today, I did something I've never done before. I have sat in my garden all day and done absolutely nothing. I didn't read or listen to music; I just sat and reflected. ”

Some statistics

- Ireland has about **391,260** family carers
- The caring role ends for at least **67,000** people in Ireland every year

“ 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 24 hours. ”



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2. How this booklet can help

We hope this booklet will help you through the difficult time after you have ended your role as a carer. It will give you an idea of what you can expect, as well as tell you about the services that may be available to support you during this time. These support services can be reached both online and through your contact with health and welfare professionals.

In this booklet you will find insights by way of quotes and links to short videos from former family carers. You will also find useful information on practical topics such as:

- registering a death,
- bereavement counselling,
- coping with finances and wills,
- returning to work or retraining, and
- filling the void left by the end of your caring role.

We also highlight the skills you may have developed during your caring role and discuss how you can look at your overall health and wellbeing.

“ 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. ”

3. Bereavement

When we lose someone or something that is important to us, we grieve. Losing someone you love is painful and it can be even more painful if you have been a carer for that person.

The grief process

Grief is both a universal experience and a unique experience and it does not follow any set course or stages. You may experience a sense of shock and disbelief when somebody dies, even if you expected it. You may appear to be coping well but often feel detached and almost as if you are in a dream. This initial reaction is a protective device that allows you to shut down in some ways as you prepare for what lies ahead. As the reality comes into focus, so too does the pain of your loss.

You may experience all kinds of difficult and surprising emotions. You may feel confused, sad, angry and lonely. You may feel guilty and regretful about things you might have done or not done. You may also feel relief that the person's pain is over or that the difficult parts of caring are over. While these feelings can be frightening, they are normal reactions to loss.

At times, you may feel your loss and grief overwhelm you. You think about what happened, cry and want to talk about the person who has died. At other times, your energy is taken up with day-to-day events. How you grieve will



depend on many things – the kind of person you are, the relationship you had with the person who died, and what support you have in your life.

Most people find that over time, and with the help of supportive family and friends, they find their way through grief. While they still may have low days or difficult days, their grief lessens and they can pick up the parts of their life they have put on hold.

Remember:

- Grief is a process and it takes time
- Everyone's grief is different
- There is no right or wrong way to grieve
- Strong emotions and thoughts are part of grief

A talk on grief

This is a 17-minute talk by Dr Susan Delaney, Irish Hospice Foundation.
See www.carers.thepalliativehub.com/bereavement.html

The experience of grief

Bereavement can be painful and confusing. There is no right or wrong way to grieve. No two people will react in the same way, but these are some of the experiences you might have:

Feelings

You may feel sad, numb, irritable, angry, relieved, guilty, lonely, depressed, frightened or helpless. There are no 'right' feelings and feelings come and go.

Physical

Grief can also affect you physically. You may find that your attention and concentration are poor or that you become absent-minded. You may feel more tired than usual, yet find it hard to sleep. Your appetite may change and energy levels may be low.

Other grief and stress reactions which are often experienced include nausea, lowered immunity, headaches and tightness in your throat or chest.

Thoughts

You might find you spend a lot of time thinking about your loss and the events leading up to it. It is normal to spend time thinking about 'if onlys' and how

things might have been different. Many people find they think a lot about why it happened.

Although you know the person has died, you may 'forget' briefly, particularly when you wake up. These thoughts may overwhelm or frighten you, but they are a normal reaction to grief.

Social changes

You may find you need time alone or you may feel a need to tell the story of your loss many times over. You may find you seek out people who can understand your need to talk and distance yourself from people who are uncomfortable with this. You may be surprised at who can support you and who cannot. You may miss the people who helped care for the person who died and miss the routine in your life, your home help coming in, going to a day centre or visiting a nursing home.

How long does grieving take?

There is no set time for grieving. Grieving can be a lifetime process, with some feelings coming back many times. You may find that you feel a 'dip' around important dates such as anniversaries and birthdays.

You will find that your grief is less intense and eases over time. That does not mean that you are over your grief but that you are finding a way to re-engage in life without the person who died.




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Know that people may not understand your grief

People may have different ideas or expectations about bereavement. If you were caring for the person or the person you cared for was ill for a long time some people may think you have had time to come to terms with the loss. Your grief is your grief; not everyone may understand the complexity of your role as a carer and the toll it took.

Remember that grief comes and goes

Even though you may be coping quite well most of the time, there may be times when you feel particularly sad or upset. You may be reminded of the person who has died by something you see or hear, or on certain significant days like anniversaries or birthdays. This can bring on a surge of grief.



This does not mean that you are not making progress; this is simply the normal process of grieving. Your life has been changed forever by the person's death, but you may find strength within yourself you didn't know you had.

Remember

Death ends a life, not a relationship. The person who died can still be important in your life. Try to find meaningful ways to keep a connection to them, such as telling stories about them, looking at photos of them and including their name in your conversations.

When to look for extra help

Grief and loss are normal life experiences and 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 might find it helpful to meet other former carers who have been bereaved, and attend a bereavement support group or avail of one-to-one support in your locality. It may help you to talk to people outside of family and friends or to get extra information.

An experienced therapist can help you work through intense emotions and overcome obstacles to your grieving.

The pyramid of bereavement support outlines the different levels of support people may need after the death of someone close. See section 14 (Page 48) of this booklet for the different types of services available.



The pyramid of bereavement supports and resources

(Irish Hospice Foundation. <https://hospicefoundation.ie/bereavement-2-2/understanding-bereavement/levels-of-bereavement-support/>)



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4. Caring for Yourself

While each former carer's journey is unique, we are beginning to get a picture of what the journey is like for many. As a former carer you may experience many losses after the death.

Some losses and experiences include:

- the loss of your identity as a carer and your caring role,
- the loss of the close bond you may have had with the person you cared for,
- the loss of the relationships with the network of healthcare professionals,
- the loss of carer-related financial supports, and
- difficulties returning to the workforce.

Health and wellbeing

It may be some time before you feel ready to move on after the loss of your caring role. But there will come a time when you feel like making changes in your life and deciding what to do next – what you would like to do for yourself.

Looking after yourself means taking care of your physical, emotional and mental wellbeing. When we begin to look after one aspect of ourselves, like starting to exercise more, or joining a new group, it can benefit us in lots of unexpected ways. Below are some tips and guidance on steps you might like to take to begin to care for yourself.

Accept your feelings

Know that it is common to feel conflicting emotions. Relief is often mentioned as a feeling experienced by carers. Allow yourself to notice and accept any feelings of relief. Acknowledging feelings of relief is not disloyal – the person who has died was still loved and valued by you.

Be kind to yourself

Try to rest, eat well and keep some structure to your day. Try to express your feelings with a good friend or write them down.

“ It is afterwards that it is difficult – because you have lost your role, but that has been your entire role really, and you are happy to be in it, and then overnight it is gone. It is very odd. It is a strange feeling. ”

Be informed

Consider reading about, or talking to, other people who were carers. You may connect with other carers through a carer support group, or by joining activities or events offered specifically to former carers, such as those available through Family Carers Ireland (www.familycarers.ie).

While no two experiences are the same, you may share something in common. Seek out accurate information about grief and loss, and the other supports available to you as a former carer.

Asking for and accepting help

Ask for and accept support, both emotional and practical, from friends and family.

Combat feelings of isolation and loneliness

If you felt isolated in your former caring role or lost contact with friends, it can take some time to feel able and confident to meet people or join in social

activities. If you feel you would like new challenges, you could contact your local community centre or local gym or join evening classes to participate in hobbies that you have previously enjoyed. Arrange to meet friends to do something you enjoy.

Talk to someone you trust about your feelings

This can be a good friend, another carer, an understanding professional, or supportive members of your family. The important thing is that you feel safe and accepted.

Health and wellbeing – a recovery guide

- Recovering your sense of being includes allowing yourself to STOP what you have been doing and make a deliberate decision to take time out.
- Recovering a sense of your own health. It is easy to skip meals, but good healthy food helps not only your body but also your mind.
- Recovering your sense of peace. Forgiveness is the first step in self-healing. You did the very best you could at your time of caring. Be gentle, be easy on yourself.

Source: Three of Audrey Jenkinson's '12 Steps, A Recovery Guide', in her 2004 book *Past Caring*, Polperro Heritage Press, available on Amazon.

You can help yourself by:

- joining a walking or health club,
- taking up a new hobby,
- eating more healthily,
- socialising, catching up with old friends or workmates,
- searching websites where you can find information about a topic you will enjoy,
- pampering yourself or trying a complementary therapy,
- learning something new,
- thinking about what paid role you would like to try, and
- looking up volunteer websites or going to your local voluntary agencies to enquire about a volunteer role.

When to talk to your GP

Being a carer for any length of time may have affected your own health and emotional wellbeing. Some physical and emotional symptoms do not present themselves until you have time to think about your own health, or you may have ignored health issues. You should consider making an appointment with your GP to speak about how you are feeling or to discuss any health issues you might have. This might identify difficulties that can be treated before they become a problem.

It's a good idea to talk to your doctor if:

- You feel that your anxiety or low mood is impacting upon your day-to-day life
- You are avoiding your family or friends
- You are relying upon alcohol or other substances to help you cope and are finding it difficult to give up
- You have serious and persistent thoughts or plans to harm yourself or end your own life or feel prolonged agitation, depression, guilt or despair.

Talking about your worries may help you to better understand how you are feeling. Making an appointment with your GP is an important first step. Your GP can support you or can refer you to more specialised health services including mental health services if you require additional supports.

Emotional wellbeing

The burden of caring can also take its toll on your emotional wellbeing. Many people withdraw from their social circles or give up paid employment during their caring role, which can lead to a sense of loneliness or feeling of lack of purpose when your role ends. This may affect your emotional wellbeing. You may have dealt with feelings of anxiety or depression in the past, which may have worsened during your caring role.

Anxiety

Anxiety is a normal response to stressful situations and is something that everyone will experience at some point. The triggers for anxiety are different for everyone.

Anxiety can present as:

- feelings of irritability
- the avoidance of social situations
- persistent worry that something bad is going to happen or needing constant reassurance.

The physical effects of anxiety can include a dry mouth, nightmares, poor concentration and a flare up of other health issues. Anxiety can become a difficulty if anxious feelings persist for more than a few weeks.

Depression

Most people go through periods of feeling down or sad; however if you feel sad for a period of weeks or months you may have depression. You may try to cope with the feelings and not realise that you are unwell. It is not a sign of weakness or something that you can simply pull yourself out of. Depression affects people's physical and emotional wellbeing in different ways. Symptoms include:

- Feeling sad, hopeless or not enjoying things that you used to enjoy
- Feeling anxious or worried
- Feeling worthless
- Feeling irritable

yourmentalhealth.ie

Provides information on mental health supports and services available to you.

Information line: [1800 111 888](tel:1800111888)

5. Family Carers Ireland

Family Carers Ireland are a national charity dedicated to supporting all family carers. There are a number of resources and supports you can access as you transition from your caring role, and a number of opportunities that you can engage with when you feel ready. You can find out more about what we offer on our website www.familycarers.ie or by contacting your local Carer Support Manager. You can find your local Carer Support Manager on our website, or by contacting the Careline on 1800 240724. Some of the resources which may be of interest to you are listed below.

Workshops for former carers

Family Carers Ireland offer workshops for former carers that give you the opportunity to reflect on your caring role and to think about what you might like to do next. You will be supported to identify the skills you developed whilst you were caring. With the support of a life coach, you will have the opportunity to think about what direction you would like to take next. You might like to continue in a caring role, either paid or through volunteering, or you may be interested in taking a new direction. The workshop will support you to develop your own vision for the future.

Carer support groups

There are carer support groups around the country, which you would be welcome to join. These groups can help you connect with other carers in a

similar situation to yourself, and can help combat the social isolation some carers feel when their caring role ends.

Activities and social events

We run activities, social events and information sessions around the country. You can find events near you on our website. Joining these events and activities can be an ideal way to meet new people, and perhaps find a new hobby.

Individual advice and support

Family Carers Ireland Carer Support Managers are located around the country and are available to give one-to-one advice and support as you transition from your caring role. To find the Carer Support Manager closest to you visit our website or call 1800 240724.

Volunteering

There are volunteer opportunities with Family Carers Ireland. You may be interested in becoming a carer mentor, supporting someone who is currently caring for a loved one, or you may wish to become involved in the organisation another way. To explore volunteering opportunities in your area please contact your local Carer Support Manager.

www.familycarers.ie Phone: 1800 24 07 24 Email: info@familycarers.ie
<https://www.facebook.com/familycarers>

6. Books and videos from former carers

You might find comfort in reading other people's stories and hearing about their experience post-caring.

Two books on the topic that you may find helpful are:



Past Caring

by Audrey Jenkinson

“This is an inspirational book that explores family caring and supports people who are feeling overcome and are unsure how to move forward from their caring role.”

“It encourages the reader to celebrate the life and love of our loved ones, and to move forward gently with our lives.”

H is for Hawk by Helen MacDonald

“This is an account of how Helen MacDonald explores her grief at the loss of her father by taming a hawk; and how doing so allows the author to explore the possibilities of resolving her own feelings about death.”

“ You are moving on to something else, and I suppose you have to think of the chrysalis, the moth and the butterfly and everything, and who knows, sometimes after what seems to be a pretty dire situation you can get wonderful wings after it you know. ”

In 2017, a number of current and former family carers were interviewed about their caring experiences. The videos, detailed below, tell their story.

Caring Lives – Looking Back; Moving Forward

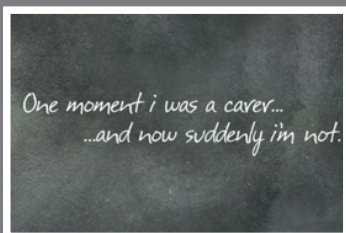


www.vimeo.com/239427924
(1-minute video)

“We did as good a job as we could possibly do.”

www.vimeo.com/239443227
(9-minute video)

“Sometimes I have to thank him for giving me this experience... at a great cost to himself.”



<https://youtu.be/z8YljEeYrtc>
(Australian 2-minute animated video)

“It feels like there’s this void – and I have no idea what filled that void before I was a carer.”



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7. Finances

The 12-week rule

Carer's Allowance continues to be paid for 12 weeks after the person who you cared for dies or goes into long-term care.

You may have had to stop working to become a carer and may have relied on a carer payment or on the pension or benefits of the person you cared for. When caring ends, you will have to deal with some practical matters. For example, you may have to register the death and pay for the funeral.

You may need to get access to the deceased person's money to help pay funeral or other expenses. It is not easy to get access to money in a bank or building society unless you shared a joint account with the deceased. If the money is in their name only, then you usually cannot access it until after probate – the proving of the will.

If your income is low, you may be able to claim an Exceptional Needs Payment to help you pay for the funeral. An official from the Department of Employment Affairs and Social Protection will decide if you qualify.

Contact your local Intreo office for information.

<http://www.welfare.ie/en/Pages/Intreo-Centres-and-Local-and-Branch-Offices.aspx>

You may have questions about pension rights, insurance policies, income and inheritance tax. You might find a resource from the Citizens Information Board useful:

http://www.citizensinformation.ie/en/social_welfare/social_welfare_payments/death_related_benefits/benefits_and_entitlements_following_a_death.html

Phone: 0761 07 4000

The Revenue Commissioners have some useful information on tax following bereavement at

www.revenue.ie/en/life-events-and-personal-circumstances/death-and-bereavement/information-on-tax-after-a-bereavement/index.aspx

If you have financial difficulties following a bereavement, supports such as the Money Advice and Budgeting Service (MABS) can help. MABS is a free, confidential service staffed by trained money advisors who can provide advice and assistance during this difficult time.

Phone: 0761 07 2000 Monday–Friday 9am–8pm

www.mabs.ie



8. Wills and legal advice

The person you have been caring for may or may not have made a will. If you, as a carer, were living with the person you were caring for, you may have questions about your right to remain in your accommodation after caring has ended. You should seek independent legal advice.

FLAC (Free Legal Advice Centre) runs a phone information and referral line offering basic legal information to the public.

Lo-Call: **1890 350 250** or **(01) 874 5690**.

The information line team provides basic legal information only, and cannot give legal advice over the phone. If your query is complex, you may be directed to your local free legal advice clinic, where you can talk face-to-face with a volunteer solicitor or barrister. In some cases, you may be referred to another voluntary body or state service.

Registering a death

A death can be registered in the office of any Registrar of Births, Marriages, Civil Partnerships and Deaths no matter where it happens. If the death happened in a hospital, the staff can advise you. You can also get information from your local health centre about where to go to register a death.

Deaths must be registered as soon as possible after they happen and no more than three months later. They are usually registered by the deceased's next of kin but can also be registered by a person who was present at the death or final illness of the deceased, or who knew them.

www.welfare.ie/en/Pages/Registering_Death.aspx

9. 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, or reconnect with friends and hobbies you have enjoyed in the past. Talk to friends or work colleagues to see what they do in their spare time; maybe they have a hobby you never knew about and can take you along.

If you have been involved with charities or voluntary organisations while caring you may want to give something back through mentoring or fundraising or indeed become part of supporting the organisation in other ways.

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.

“ I suppose I am beginning to think now it is time I changed and that, when I stopped minding Mum, I felt at a loss as to what do I do now. Whereas now, I know that I have to begin looking after me more, and it has taken me a while to realise that. If you are a carer, it stays with you for a long time, and you see yourself as that is your role for a long time after. ”



10. Returning to work

When your caring role ends you may need to think about returning to work 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 challenges such as:

- having been out of the workplace for a while,
- not being up to date with technology,
- lack of confidence,
- feeling that you no longer have the skills you once had,
- feeling apprehensive about seeing work colleagues again, and
- being disconnected from colleagues and developments in your workplace such as a change in management.

If you are considering re-entering the workforce, remember, you will have acquired new skills as a carer (see boxes in the next few pages) 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, working on committees; and
- tasks and responsibilities involved in your role as a carer.

Research shows that carers develop several skills that may be useful in a wide range of jobs. For instance, they must show initiative, be flexible, solve a variety of problems, be empathetic – all valid skills to bring up when applying for a job.

If you are returning to work after having taken Carer's Leave, then you should notify your employer of your intent to return to work (at least 4 weeks before you are due to return to work). You are entitled to return to the same position and contract and the terms and conditions of employment you had before you took the leave. If you are in receipt of Carer's Benefit, then this payment will continue to be paid for 12 weeks after the person you cared for dies.

If you are returning to work after a career break or after having agreed flexible working arrangements while you were caring, you may wish to discuss these arrangements with your employer. You can see if you can return to your original working arrangements.

Qualities and skills family carers may have to offer an employer

Personal	Management	Practical
Perseverance Loyalty Dependability Patience Tolerance Self-motivation and initiative	Financial management Negotiating Advocacy Staff management and co-ordination Information gathering Dealing with difficult behaviour	Physical handling skills Personal caring skills Domestic management First Aid knowledge

‘Vacancy – family carer’

Education:	No specific requirement	
Abilities:	Effective verbal, written and communication skills	<i>Essential</i>
	Good listening and negotiating skills	<i>Essential</i>
	Able to manage pressure and organise own work	<i>Essential</i>
	Ability to organise and record information accurately	<i>Essential</i>
	Ability to deal with difficult or challenging behaviour	<i>Essential</i>
	Ability to manage on a tight budget	<i>Essential</i>
	Ability to act as an advocate	<i>Essential</i>
	Confident to make own needs known to those who can provide help and support	<i>Essential</i>
	Computer literate	<i>Desirable</i>
Personal skills & experience:	Self-motivated and able to use own initiative	<i>Essential</i>
	Able to work under pressure	<i>Essential</i>
	Able to work on own and as part of a team	<i>Essential</i>
	Aware of confidentiality issues	<i>Essential</i>
	Willing and able to undertake training	<i>Essential</i>
	Able to take a flexible and creative approach to problem solving	<i>Essential</i>
	Household management including budgeting, shopping, cleaning, cooking, washing and ironing	<i>Essential</i>
	Co-ordinating a wide range of professional support	<i>Essential</i>
	Knowledge of the benefits system, services and support available in the local area and how to access these	<i>Essential</i>
	Aware of Health and Safety issues	<i>Desirable</i>
Other:	Car driver and ability to travel	<i>Desirable</i>
	Willingness to be available 24 hours a day, 7 days a week, with no guaranteed days off or holidays	<i>Essential</i>

Skills – “NONE – I’ve only been a carer”

Tasks	Working with data	Working with people	Working with things	Working with ideas
Personal care		Sensitivity	Using specialist equipment	Time management
Organising respite care	Budgeting and research skills	Liaison skills	Telephone skills	Assessment and problem solving skills
Arranging daily activities		Ability to work as part of a team		Organisational skills
Meetings and reviews		Negotiation skills		Planning skills
Benefit applications	Detailed presentation of information	Assertiveness	Administration skills and form filling	Ability to present ideas in writing
Benefit check	Problem solving		Keeping accurate records	
Finding out about the disability or illness	Research skills	Communication skills		
Transport	Knowledge of the local area		Driving a vehicle	
Managing behaviour		Communication skills	Ability to use safe restraint techniques	Adaptability and flexibility
Visits to doctor/hospital	Presentation and understanding of information	Communication skills		Ability to ask relevant questions



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Who can help?

Intreo is a service from the Department of Employment Affairs and Social Protection. It is a single point of contact for all employment and income supports. Designed to provide a more streamlined approach, Intreo offers practical, tailored employment services and supports for jobseekers and employers.

A list of local Intreo Centres is available at

www.welfare.ie/en/Pages/Intreo-Centres-and-Local-and-Branch-Offices.aspx



11. Retraining and study

Learning something new may be an excellent opportunity to reinvigorate yourself after many years dedicated to caring. Acquiring new skills will also help to build your confidence and progress your plans to enter further education or to return to work. 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.

Springboard – open to current and former family carers

The Springboard+ upskilling initiative in higher education offers free courses at certificate, degree and master's level leading to qualifications in areas where there are job opportunities.

See www.springboardcourses.ie

Many people, including early school leavers, unemployed people and those who want to retrain for a new job, may be interested in returning to full-time or part-time education. If you are interested in returning to education, there are a number of organisations and resources where you can get information about the courses available to you.

Education and Training Boards (ETBs) are the main providers of adult education, through local schools and colleges. (VEC and FÁS training were integrated into ETBs in recent years.) Community education groups offer a variety of courses, catering for learners at all levels. Third-level colleges provide a wide range of courses too.

www.etbi.ie/etbs/directory-of-etbs

AONTAS (National Adult Learning Organisation) promotes adult education and lifelong learning. AONTAS operates an information and referral service which aims to make the adult learner's first encounter with education as easy as possible.

www.aontas.com

Phone: (01) 406 8220

“ 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. ”

NALA The National Adult Literacy Agency is a charity which aims to ensure that adults with literacy difficulties have access to high-quality learning opportunities. NALA can help you to improve your reading, writing or maths. It offers a distance-learning service so you can learn over the phone or online. NALA can also refer you to your local ETB (Education and Training Board) centre for adult literacy classes. To find out more, Freephone 1800 20 20 65 and talk to one of NALA's friendly tutors. Or, you might prefer to visit NALA's website – www.nala.ie

Qualifax is the Irish national database of all third-level and further education courses. It provides the information you need to make informed choices about your education, training and career path. It also provides a list of Adult Guidance Services. See www.qualifax.ie for information about training courses. Your local Intreo office or Local Employment Services Network (LESN) office can also provide information about courses. See www.localemploymentservices.ie/

Massive Open Online Courses (MOOCs)

MOOCs are online courses aimed at unlimited participation and open access through the web. In addition to traditional course materials such as filmed lectures, readings, and problem sets, many MOOCs provide interactive user forums to support community interactions among students, professors, and teaching assistants. MOOCs are a recent and widely researched development in distance education and have become a popular way to learn.



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12. Volunteering

Many people think about volunteering after their caring comes to an end. You may decide to offer some of your time to become a mentor to carry out fundraising activities or to help deliver services. You may have enjoyed the feeling of being helpful to someone else that you experienced while caring and would like to experience that again.

“ 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. ”

As someone who has cared for someone else you have a set of invaluable skills that may be of use to support others. Volunteering can be incredibly rewarding and may also help you come to terms with your loss. Moreover, volunteering can be a very social activity, and can be a good way to meet new people.

Former family carers as advocates and champions of carers' issues

Many former carers go on to become great campaigners, championing the role of carers in society and standing up for carers' rights. They bring their valuable experiences with them, knowing without question the many challenges that carers face.

How to volunteer

If you have been supported by a charity or not-for-profit organisation while caring, you could tell them that you may be available to lend a hand. While your experience will be valuable they will probably ask you to do some training or attend briefings before you directly support people, to make sure that you are well prepared and equipped.

You may be interested in volunteering but, for whatever reason, don't want to get involved with an organisation you had contact with in the past. In this case, you could first spend some time thinking about the kind of volunteering activities that would interest you. In fact, volunteering opportunities can range from

befriending people to offering your specific skills to a local charity. For example, you might help with administration, IT, fundraising or with legal issues. You might like to become a board member of a not-for-profit organisation.

Your local volunteer centre will tell you about volunteering opportunities in your area. All of the contact details for local Volunteer Centres are also available on:

Volunteer Ireland:

www.volunteer.ie

Phone: (01) 636 9446 Email: info@volunteer.ie

There are currently over 100,000 people in Ireland who volunteer at board or committee level with registered charities or not-for-profit organisations. Diversifying the skills, expertise, and background of charity trustees and board directors is an important aspect of good governance, and a vital part in helping to develop and strengthen boards.

BoardMatch run a free board recruitment website for those interested in offering their skills and time to a cause they are passionate about. Simply register your profile, search the current board vacancies, and find your perfect board match. If you are interested in volunteering on a charity or not-for-profit board or committee, contact

BoardMatch Ireland:

www.boardmatch.ie

Phone: (01) 671 5005 Email: hello@boardmatch.ie



13. What the research tells us

Research can be a valuable tool to help us understand how best to support former family carers. In recent years a growing number of people in Ireland and beyond have undertaken research in this area. Increasingly this research is being used to help inform health and social care professionals on how best they can understand the lived experience of former family carers. It can also be a tool which can be used to advocate for recognition and awareness, as well as for supports and services.

If you want to read more about the research on former family carers, go to
<https://www.carealliance.ie/Former-Carers>

14. Resources

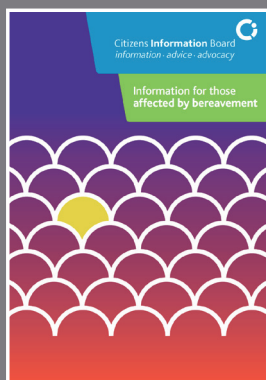
General support and information

Citizens Information

Citizens Information provides useful information on dealing with practical matters before and after a death, and with financial issues, bereavement counselling and support and sudden or unexplained deaths. They have also published two booklets entitled 'When Someone Dies' and 'When Someone Dies Unexpectedly'.

www.citizensinformation.ie/en/death/

Bereavement resources



Bereavement Guide

https://www.citizensinformationboard.ie/downloads/guides/Bereavement_Guide_2018.pdf

You can order a free copy of this by calling 0761 074 000

www.bereaved.ie

This dedicated bereavement site provides information for the public and professionals. This information includes understanding bereavement, coping with loss, helping with supporting a bereaved person and managing grief in the workplace. Resources include leaflets and videos on a variety of aspects of bereavement and loss.

Irish Childhood Bereavement Network (ICBN)

The ICBN is a network of professionals working directly with bereaved children, with those who occasionally support them, and with people interested in the area of children's and young people's loss. Their website provides information and resources for parents, guardians and professionals who care for grieving children and young people. www.childhoodbereavement.ie

Irish Hospice Foundation

The Irish Hospice Foundation maintains a list of therapists with additional training to support those experiencing a more difficult bereavement.

www.hospicefoundation.ie Phone: (01) 679 3188

Lesbian Gay Bi-sexual Transgender (LGBT) Ireland

LGBT Ireland offer a specific support service for lesbian, gay, bisexual and transgender individuals, including specific supports for older LGBT people.

www.lgbt.ie Phone: 1890 929539 email: info@lgbt.ie

www.widow.ie is a useful site with a lot of relevant information.

Online support

Many people get support online these days. This can include online counselling; peer support from online forums, Facebook, or Twitter; or just watching short videos on YouTube.

International sites

There are a number of sites for former family carers operating outside of Ireland. While much of the general information may be relevant, more specific information may not be. This is due to a different use of language, different cultures, different health and social care practices and different rules about public entitlements and supports.

In Ireland there is no moderated online space specifically for former family carers. Carers UK have an online forum which you may find helpful. As a guest you can see posts, but you cannot post unless you live in the UK. See www.carersuk.org/forum/support-and-advice/former-carers

Caregiving.com (US-based) has a dedicated section for former family carers: www.caregiving.com/articles/blogged/after-caregiving-ends/
They also have moderated online chatrooms twice a month for those adjusting to life after caring, in their 'After Caregiving Ends' chatroom: www.caregiving.com/groups/after-caregiving-ends/

Extra support

You might prefer to access additional help from outside your family to support you through your bereavement. For example, you might make contact with other bereaved people or trained volunteers who can provide you with an opportunity to reflect in a focused way on your experience of loss. This support is generally provided by volunteers who have themselves been bereaved and have had specialised training in bereavement support.

This kind of support can be provided on a one-to-one basis or in groups. Voluntary bereavement support services, self-help groups, faith groups and community groups all offer this kind of service, as do some hospitals and hospices. Well-run bereavement support agencies ensure that their volunteers are carefully selected, given ongoing training, and supervised by professionals. They are trained to provide a listening ear so people can talk about their experience, and to support them as they find their way through their grief.

Bereavement counselling and psychotherapy

A small number of people find bereavement so difficult that they find it hard to function in their daily lives. These difficulties might include:

- intense and unrelenting grief that lasts more than six months;
- prolonged agitation, guilt or despair; and
- depression; or
- serious and persistent thoughts of suicide.



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If your grief feels too much to bear, consult your GP and consider getting professional help. Unlike the more usual grief reactions, severe symptoms do not always decrease over time.

Some sources of extra support include:

Hospice and hospital support

If you have been bereaved through a hospice death, it is more than likely that there is a bereavement support and counselling service available in the hospice. Contact the hospice where the death occurred. If you have been bereaved through a death in an acute hospital, the hospital may provide bereavement support. Contact the hospital social work department or chaplaincy service.

Bethany Bereavement Support

Bethany Bereavement Support is a community-based service provided by volunteers. It offers phone support, group meetings, personal support, and home visits to people recently bereaved.

www.bethany.ie

Helpline: 087 990 5299

Anam Cara

Anam Cara supports parents and families after the death of a child, regardless of the age of the child or the circumstances of the death. Their website provides links to information and resources including the Anam Cara Information Pack. Anam Cara also provides support through their monthly open 'drop in' groups throughout Ireland. All services are provided free of charge.

www.anamcara.ie

Phone: 01 4045378

The Samaritans

The Samaritans provide immediate support through a

Free 24-hour Call Line: (116 123)

<https://www.samaritans.org/ireland/samaritans-ireland/>

Email: jo@samaritans.org

Counselling in Primary Care (CIPC)

Counselling in Primary Care (CIPC) is a short-term counselling service for people with a medical card that provides up to eight counselling sessions with a professionally qualified and accredited counsellor or therapist. The service is suitable for people experiencing depression, anxiety, panic reactions, relationship problems, loss issues and stress.

www.hse.ie/eng/services/list/4/Mental_Health_Services/counsellingpc/

If you do not have a medical card, you may be able to get low-cost professional bereavement counselling or psychotherapy. Some professionals offer counselling at a modest fee. Your local health centre should have information on low-cost services in your area.

Online counselling

Turn2me was set up to provide immediate online access to mental health support in Ireland. It provides a number of free one-to-one counselling sessions and numerous support groups each week, in partnership with the HSE.

Turn2me has a team of professional psychotherapists and psychologists available to provide support for people who cannot or do not wish to access local services or who would prefer to remain anonymous.

To take part in one-to-one counselling and support groups, simply log on to www.turn2me.org and sign up. (Free to people who live in Ireland.)

The Irish Association of Counselling and Psychotherapy (IACP)

The IACP links people in need of counselling / psychotherapy with accredited professionals. IACP has a telephone referral system and free online directory. For more information or to find a therapist in your area, visit www.iacp.ie.

Phone: (01) 230 3536

Association for Agency-based Counselling in Ireland (AACPI)

The AACPI is an association of agencies who provide a wide range of counselling services including marriage, bereavement and child counselling.

A list of the services in the association can be found here

www.aacpi.ie/current-members

Insightmatters

Based in Dublin city centre, they offer a range of counselling and psychotherapy services; including a low-cost service (subject to availability).

They also highlight that their services are specifically tailored to members of the LGBT community.

www.insightmatters.ie

Phone: (01) 891 0703 Email: info@insightmatters.ie



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Turning Point

Turning Point offers individual counselling and psychotherapy to address a host of different life challenges, including bereavement.

Phone: (01) 280 1603

<http://www.turningpoint.ie/counselling-psychotherapy-2/>

MyMind

MyMind has created a unique movement for community-based mental health services that work towards giving every person in Ireland equal access to mental health support early, affordably, directly, without stigma or delay.

www.mymind.org

Phone: 076 680 1060

Email: hq@mymind.org

CHY No: 14644

Charity Registration No: 20048303

Company No: 461315

Registered office:

Coleraine House, Coleraine Street,
Dublin, D07 E8XF, Ireland

Telephone: +353 (01) 874 7776

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A resource to support former family carers



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