

# When caring comes to an end



## Introduction

Looking after someone is a huge part of your life, but it is inevitable that your caring role will change over time.

It may no longer be possible to look after the person you care for at home. There may come a time when you have to think about life after the death of the person you cared for.

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

This booklet is for carers who are experiencing significant change in their lives. It outlines the support available and the steps you can take to help you through each situation. The booklet is divided into three main sections:

- When the person you care for moves into residential or nursing care.
- When the person you care for dies.
- Life after caring.

Each section covers relevant information about benefits, as well as looking at the practical support available and where to go for more help. There is also a section at the end of this booklet with details of other useful organisations and services.

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# 1 When the person you care for moves into residential or nursing care

As a carer, residential or nursing care for the person you care for might be a difficult option to consider. It may feel like you are letting the person you care for down, or you are rejecting them, but it is important to remember that you can only do so much as a carer. Caring can be both physically and mentally exhausting and there are often limits to the level of care that can be provided in the home. If the person you care for is no longer able to look after themselves and you are unable to provide the care they need, for whatever reason, residential or nursing care is a sensible and realistic option. It is better to arrange the best care possible than struggle on until you reach crisis point.

This section outlines some of the main issues that arise for carers when the person they care for moves into residential care, including:

- Making the decision about what care is needed.
- How you can continue to be involved in their care.
- How your benefits are affected.
- What you can do if you are not happy with the care provided.

## Making the decision

If you are thinking about residential or nursing care for the person you care for, you should allow time to find out about all the options. Ask social services for a carer's assessment, and for an assessment (or re-assessment) of the person you care for. There may be more help you can get at home, for example increased support from social services, medical equipment in the home, adaptations to the house or more frequent short-term stays in residential care for the person you care for.

You also need to talk with the person you care for about what is best for both of you. You may find that they accept the situation more readily than you expect. There may be ways you can reassure them – and yourself – about the move. For example, is the home nearby, do you know anyone who already stays at the home, can the person you care for stay there on a trial basis first?

If the person you care for is unwilling to discuss the situation, or you are finding it hard to handle the move, it may help to talk it over with a friend, family member, another carer, your GP or social worker. There are organisations that can offer you support such as your local carers' centre or the Relatives and Residents Association [www.relres.org.uk](http://www.relres.org.uk)

The following organisations produce information about finding and funding care:

Counsel and Care [www.counselandcare.org.uk](http://www.counselandcare.org.uk) 0845 300 7585

MS Society [www.mssociety.org.uk](http://www.mssociety.org.uk) 020 8438 0700

Alzheimer's Society [www.alzheimers.org.uk](http://www.alzheimers.org.uk) 0845 300 0336

Elderly Accommodation Council [www.housingcare.org](http://www.housingcare.org) 0800 377 7070

Age Concern [www.ageconcern.org.uk](http://www.ageconcern.org.uk) 0800 00 99 66

## Practical matters

### Are you still a carer? Social services

When the person you care for moves into a residential care home, you may still be entitled to a carer's assessment from social services. This will be the case if the residential care is provided by social services and you are still providing 'regular and substantial' care to supplement it. Some carers find that the time they spend caring actually increases as they spend all day at the home, eg helping with personal tasks such as feeding and bathing, or offering company. Travelling to and from the care home does not count as time spent caring.

If you are no longer offering regular and substantial care, the professionals in charge of looking after the person you care for must still take into account your views and feelings when decisions are made (see below). It is a good idea to discuss with staff how you will be involved, and what you can expect from them, as early as possible.

### Are you still a carer? Employment

If you are employed and care for an adult (or a child aged under 17 or a disabled child under 18), you have the right to request flexible working from your employer. The definition of carer in the regulations allows for relatives to care for someone who does not live with them and this could include a relative who lives in a residential or nursing home.

Guidance suggests that 'care' includes emotional support, keeping the cared for person company, helping with financial matters or paperwork and escorting them to appointments.

For more information about carers' rights at work see Carers UK's booklets: *Supporting working carers: a carer's guide* and *Carers and Employment: A guide to the right to request flexible working* and Help the Hospices and Working Families guide: *Flexible working for people caring for a relative or friend at the end of life*.

## **Making decisions about treatment**

If the person you care for has the capacity to make decisions, and they continue to do so, the fact that they live in a residential home does not affect their right to make choices about their care and treatment. If the person you care for cannot make their own decisions, or may not be able to in the future, they may be able to nominate someone to make decisions for them (by giving them Lasting Power of Attorney). If the person is not capable of nominating someone, the Court of Protection can make decisions on their behalf, or appoint someone called a deputy to do so. The deputy could be a carer or a local authority, for example.

For more information or advice, contact the Public Guardianship Office:  
[www.guardianship.gov.uk](http://www.guardianship.gov.uk) in England and Wales 0845 330 2900  
[www.publicguardian-scotland.gov.uk](http://www.publicguardian-scotland.gov.uk) in Scotland 01324 678 300  
[www.courtsni.gov.uk](http://www.courtsni.gov.uk) in Northern Ireland 02890 328 594

If the person you care for is near the end of their life and the expectation is that their condition will deteriorate and they may lose capacity to make decisions about their care, they should be offered Advance Care Planning. This is a process used by all professionals who work with people at the end of their life, to help them understand their illness, and make decisions about and prepare for the end of life.

Through Advance Care Planning, the person you care for can make an advance statement or decision about the treatment they wish or do not wish to receive. They can instead (or also) nominate someone to have Lasting Power of Attorney over their health and welfare decisions.

For more information about Advance Care Planning, contact The Patients Association on 0845 608 4455.

Without having a Lasting Power of Attorney for the person you care for, you will not be able to make decisions about their care or treatment if they are unable to do so themselves. The professionals involved should still ask about your opinions and wishes, but you cannot make decisions on their behalf, even if you are their next of kin.

If none of the above measures are in place, decisions about the care and treatment offered to the person you care for will be made in their 'best interest' by medical and/or social care professionals.

## Charging

Unless care is provided by the NHS, local authorities or individual care homes can charge for their services. In order to do this, they must carry out a financial assessment to determine how much they can charge. Local authorities must follow statutory guidelines for charging (which includes the treatment of any property owned by the person in care). Paying for care is a complex issue and it is important to seek specialist advice.

For more information, call Counsel and Care's helpline on 0845 300 7585 or go to [www.counselandcare.org.uk](http://www.counselandcare.org.uk)

## What happens to my benefits?

If care is provided by social services, the Disability Living Allowance care component/Attendance Allowance will stop being paid to the person you care for once they have lived in the care home for 28 days. The mobility component of Disability Living Allowance can continue to be paid. If care is provided by the NHS, Disability Living Allowance (both care and mobility components)/Attendance Allowance will stop after 28 days.

Once the person you care for stops getting Disability Living Allowance/Attendance Allowance, your entitlement to Carer's Allowance will also stop (unless you are also caring for another person, and meet the criteria for Carer's Allowance as their carer). If you are receiving any means-tested benefits, eg Income Support or Pension Credit, the Carer Premium or Addition is paid for an extra eight weeks after your Carer's Allowance stops.

If the person you care for is funding their own care, all their benefits – including Disability Living Allowance/Attendance Allowance – will continue. Your entitlement to Carer's Allowance may continue if you are still caring for them for 35 hours a week or more.

If the person you care for is your partner or spouse, you will no longer be assessed as a couple for means-tested benefits. You will be assessed as a single person. You should seek advice. For more information about benefits you may be able to claim, see page 20.

## Concerns or complaints about the care home

If you are not happy with the care home, in the first instance speak to the manager of the service. All care homes must have a complaints procedure.

If a referral to the home was made by social services, you should also speak to the social worker involved in the care package. All local authorities have a complaints procedure. If you have gone through all stages of the complaints procedure and you are still not happy, you may be able to take your case to the Local Government Ombudsman.

To find out about care home standards or to make a further complaint about a service, you can contact the following organisations:

- In England, Care Quality Commission  
[www.cqc.org.uk](http://www.cqc.org.uk) 03000 616161
- In Scotland, the Scottish Commission for the Regulation of Care  
[www.carecommission.com](http://www.carecommission.com) 0845 603 0890
- In Wales, the Care Standards Inspectorate for Wales  
[www.csiw.wales.gov.uk](http://www.csiw.wales.gov.uk) 01443 848 450
- In Northern Ireland, the Department of Health, Social Services and Public Safety [www.dhsspsni.gov.uk](http://www.dhsspsni.gov.uk) 02890 520500

If the service is provided by the NHS, ask your local health authority for a copy of their complaints procedure. If, at the end of the complaints procedure, you are still not happy, you may be able to take your case to the Health Service Ombudsman.

## Hospice care

If the person you care for is nearing the end of their life, hospice care may be the most appropriate help for them.

Hospice care is for those whose illness may no longer be curable. Services include pain control, symptom relief, skilled nursing care, counselling, complementary therapies, spiritual/religious support, creative activities,

physiotherapy and bereavement support. Hospice care is provided in people's homes and through day care facilities, as well as via inpatient units when people are not able or do not wish to stay at home.

People are usually referred to a hospice by their GP, hospital doctor or district nurse. Hospices can work closely with GPs, district nurses and others to deliver the care needed.

The kind of care given in hospices is also known as palliative care and some palliative care is provided in hospitals and other settings. Hospice or palliative care is given free of charge.

For more information about hospice care, contact the Hospice information service on 020 7520 8222 or at [www.helpthehospices.org.uk/hospiceinformation](http://www.helpthehospices.org.uk/hospiceinformation)

# 2 When the person you cared for has died

Losing someone close to you can be devastating. If you have been caring for that person, the loss can seem even greater. How you cope with the death of the person you cared for is a very personal thing. There is no right or wrong way to feel following a death.

This section includes information about:

- emotional support
- registering a death
- arranging a funeral
- dealing with the deceased person's affairs
- your benefits.

## How you feel

Everyone's reaction to losing someone is different. There is no right or wrong way to deal with your own grief. Listen to yourself. Do what feels comfortable and helpful for you. Do not do what other people say you 'should' do, unless you really want to.

There are no time limits on grief, and no set pattern of emotions and behaviours that everybody follows. Grief does not always happen straightaway. Immediately after a death there are a lot of practical things to do, like registering the death and arranging the funeral, and family and friends tend to be around a lot more. It may be that only when all the practicalities are dealt with, and the people around you get back to their everyday lives, that you really start to grieve.

*'I used to think I was going mad when I found I had bought a pack of my son's favourite biscuits without even noticing – even though it was months after his death.'*

Mary, who cared for her son who had Down's Syndrome.

*'After Dad died it was such a relief to be able to go out shopping without worrying that he would need me. I feel so guilty that I am enjoying the freedom and not having the responsibility any more.'*

Jean, who cared for her father after his stroke.

When the person you care for dies, as well as coping with the loss of the person you cared for, you also have to deal with the loss of your caring role. Like Jean, you may feel guilty about feeling relief, but you may also feel exhausted or alone. The death of the person you cared for may mean that the relationships you built up with the professionals involved in their care come to an end. Carers also talk about losing contact with friends and family because of the demands of their caring role. Picking up old social contacts or meeting new people may be the last thing you feel like doing when you have just lost someone.

## Who can help?

The best help and support often comes from the people you know best – and who know you best. You may find that some people seem awkward around you, often because they want to do and say the ‘right thing’ but are not sure what that is. If you feel able, tell the people around you what you need from them and how they can help. Close family and friends may also be able to help you do this.

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. Friends and relatives who knew the deceased and can share memories of them with you can be a great source of support.

Talking to other people who have been bereaved, and who have a better understanding of what you are going through, can also help.

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

- Cruse Bereavement Care on 0844 477 9400 or [www.cruse.org.uk](http://www.cruse.org.uk)  
Cruse also has a helpline and website for young people, 0808 808 1677 or [www.rd4u.org.uk](http://www.rd4u.org.uk)
- Help the Hospices on 020 7520 8222 or [www.helpthehospices.org.uk](http://www.helpthehospices.org.uk)
- Cruse Bereavement Care and Help the Hospices have produced a *Directory of Bereavement Services in the UK*. Order from the Resource Information Service on 020 7939 0641 or [sales@ris.org.uk](mailto:sales@ris.org.uk)

You could also ask the professionals involved in the care of the deceased if they know of any local services.

If you are finding it hard to cope with the emotions you are feeling, and it is affecting your health or daily life, you could also seek more specialist help. Your GP may be able to refer you for counselling, or contact the British Association for Counselling and Psychotherapy on 0870 443 5219 or [www.bacp.co.uk](http://www.bacp.co.uk) to find out about counsellors in your area.

You can also speak to The Samaritans, in confidence, about how you are feeling at any time on 08457 90 90 90. Your call will be charged at local rates.

## Practical matters

### Immediately after the death

*Will there be a post mortem?*

A post mortem is a medical examination of the body of the deceased. Post mortems are usually carried out when there is uncertainty about the cause of death.

Post mortems can be requested by the coroner (an independent official who inquires into unnatural death, eg sudden, unexpected or those related to procedures or operations) or by the hospital or close relatives. Permission of the close relatives of the deceased must be sought if the hospital wants a post mortem to be carried out but permission is not needed if the post mortem is requested by the coroner.

Post mortems usually take place within a couple of days of the death and the body is released on the day of the post mortem, so planning for the funeral should not be affected. Following the post mortem, reports are sent to the GP/consultant of the deceased and the coroner (if applicable). Relatives can also request a copy.

For more information about post mortems contact NHS Direct on 0845 46 47 (in Scotland, NHS24 on 08454 24 24 24). You can also find out more on the Government's website [www.direct.gov.uk/death](http://www.direct.gov.uk/death)

### *Organ donation*

It may have been the deceased's wish to donate their organs for transplant or medical research and, if you are aware that was the case, you need to inform the healthcare professionals involved in their care as soon as you can after the death.

For further advice or information go to [www.uktransplant.org.uk](http://www.uktransplant.org.uk) (0845 60 60 400) or telephone the Human Tissue Authority on 020 7211 3400.

## Registering the death

### How quickly does this need to be done?

In England, Wales and Northern Ireland a death must be registered within five days. This can be extended in certain circumstances. In Scotland the death must be registered within eight days.

### Where do I register the death?

Deaths are registered at the local registry office. You do not have to register the death yourself. Another relative may be able to register the death as long as they take all the necessary documents – including the medical certificate you were given by the hospital, hospice or GP. Many registry offices now only see people by appointment so it is a good idea to phone the office first.

You can find details of your local registry office in the telephone directory or use the search facility at:

- [www.gro.gov.uk](http://www.gro.gov.uk) for England and Wales
- [www.gro-scotland.gov.uk](http://www.gro-scotland.gov.uk) for Scotland
- [www.groni.gov.uk](http://www.groni.gov.uk) for Northern Ireland

### What documents do I need to take with me?

When you register the death, the registrar will need:

- The medical certificate showing cause of death.
- The deceased's NHS medical card (if possible).

You will also need to tell the registrar:

- The date and place the deceased was born and the date and place they died.
- Their full name (including any maiden name).
- Their occupation and the name and occupation of their spouse or civil partner.
- Their usual address.
- Whether or not the deceased received a pension or any state benefits.

## What do I need to get from the registrar?

The registrar will give you:

- The certificate for burial or cremation (you will normally need to give this to the funeral director).
- A death certificate. A small fee will be charged. It is advisable to have a few extra copies for dealing with the Will and other tasks.
- A certificate for social security benefits (Form BD8).
- A booklet called *What to do after a death* with advice on probate and other administrative issues.

## The funeral

The funeral can be very important in helping you and friends and family of the deceased to mourn. It is an event where the person's life can be thought of, valued, and celebrated. It is a time to think of the person who lived, and not just the difficulties of the last few weeks, months or years spent caring for them.

### Arranging the funeral

When the funeral takes place may depend on factors such as religious or cultural requirements. Aside from that, the funeral or cremation does not have to happen immediately, unless that is what you want. In any case, you will not be able to finalise the date until the death has been registered.

When planning the funeral, you should find out whether the deceased left any instructions about their funeral in a Will or other written document. Other than that you can choose between burial, cremation or alternative burials of various sorts and, if you choose to use one, a professional funeral director will help you make the arrangements. There is further information about these options at [www.direct.gov.uk](http://www.direct.gov.uk) or [www.ifishoulddie.co.uk](http://www.ifishoulddie.co.uk)

### Paying for the funeral

Funeral costs can be quite high so it is worth obtaining quotes from more than one funeral director. Make sure that everything has been included (church or other venue for the service, burial or cremation fees, cars for the mourners, flowers etc). You can ask for written quotations.

If you arrange the funeral, you will be the person responsible for ensuring the fees are paid, so it is sensible to check in advance if the deceased had money available to cover the funeral costs.

You could check their paperwork to find out:

- Whether they took out a prepayment funeral plan.
- Whether they had a pension scheme or insurance plan which included a lump sum for funeral costs.
- Whether they belonged to a union or professional association which pays benefits when a member dies.
- Whether a lump sum could be released from a national savings account (bank or building society accounts may be frozen until probate is granted but some banks or building societies may agree to release funds).

Alternatively, you or the executor (the person responsible for sorting out the deceased's estate) may be able to pay the costs of the funeral yourself and then recover those costs from the estate.

### **Help with funeral costs for people with a low income**

If there are no other means of paying for a funeral, you may be able to claim a Social Fund Funeral Payment from the Department for Work and Pensions (DWP). Eligibility is based on your circumstances (rather than those of the deceased) and you may be eligible if you, or your partner, are in receipt of at least one of the following benefits:

- Income Support
- Income-based Jobseeker's Allowance
- Income-related Employment and Support Allowance
- Pension Credit
- Housing Benefit
- Council Tax Benefit
- Child Tax Credit (which includes an amount higher than the family element)
- Working Tax Credit (where a disability or severe disability element is included).

You can claim the Funeral Payment any time between the date of the death and up to three months after the date of the funeral. The DWP must accept that it is reasonable for you to be responsible for the funeral expenses. There are specific rules about this and you should seek advice. The payment you receive will cover the cost of specified necessary items and services (eg burial fees) and up to £700 for other funeral expenses. Be aware, though, that the payment will not necessarily cover all the costs of the funeral, so there may be an outstanding amount that you have to pay.

For further information and to download the claim form, go to [www.direct.gov.uk](http://www.direct.gov.uk) or apply at your local Jobcentre Plus office.

## After the funeral

After the death of someone close to you, there are many practical tasks that need to be carried out. The property and possessions of the deceased will need to be dealt with and your own situation may change, eg the benefits you can claim, where you live, etc. Here are some of the commonly asked questions.

### **How do I sort out the property and possessions of the deceased?**

When someone dies, everything they own (their money, property and possessions) is called their estate. If the person who has died has left a Will, this will indicate how they wanted their estate to be divided after their death. It will also usually name executors (the people they want to deal with the Will).

The estate cannot be used to pay bills or debts, or be divided up for gifts and inheritance until either:

- the Will has been granted probate – this is a formality which confirms that a Will is legally in order; or
- a grant of administration has been given – this is a formality which allows the personal representative to deal with the estate when there is no Will. In Scotland, a grant of administration is called a confirmation.

This means that any bank accounts in the deceased person's name will be frozen until the formalities have been completed. Bank accounts in joint names can be used by the other account holder.

### **I had Power of Attorney for the deceased – does this carry on?**

If you had Power of Attorney for the person you cared for, because they were no longer able to deal with their own money and affairs, the Power of Attorney stops being in force as soon as the person dies. You will not be able to continue to use their bank account, or carry out any business on their behalf.

## Will I have to pay Inheritance Tax?

If the person you cared for has an estate worth more than £325,000, Inheritance Tax will have to be paid on any amount above that. However, Inheritance Tax does not have to be paid if the estate goes to the deceased's spouse or civil partner (no matter how much they inherit).

For more information about how Inheritance Tax is calculated and paid, contact the Probate and Inheritance Tax helpline on 0845 3020 900.

## What else do I need to do?

The following would be useful to get done as soon as you can manage it:

- Send the certificate for social security benefits (Form BD8) to the Department for Work and Pensions so that they can deal with the pension and/or benefits of the deceased.
- Contact the local tax office to inform them of the death.
- Contact the local authority in connection with Council Tax, any Housing or Council Tax benefit, any support from social services, parking permits, etc.
- Contact any relevant insurance companies, pension providers, banks and building societies.
- Contact the executors of the Will if there is one or, if there is no Will, decide who will apply for letters of administration.
- If the person you cared for had any NHS equipment on loan, eg crutches, wheelchair or medical equipment, you will need to arrange for this to be returned. The person's GP or local health trust will be able to tell you how to do this.

## What about my own finances?

The death of the person you cared for may have an effect on your own financial situation and you may need to find out which benefits you can claim.

### Carer's Allowance and carer premium/carers addition

If you were receiving Carer's Allowance when the person you cared for died, this will usually continue for eight weeks from the Sunday following their death. If you were receiving a carer premium as part of your Income Support or Pension Credit this will also continue for eight weeks.

If you were 65 or over and entitled to Invalid Care Allowance (as Carer's Allowance was then called) on 27 October 2002, you will be entitled to Carer's Allowance indefinitely after the person you cared for has died.

## Bereavement benefits

Bereavement benefits are not means tested, but they will be taken into account as income if you claim any means tested benefits.

A **bereavement payment** is a one off lump sum, tax free payment of £2,000 paid on the death of your spouse or civil partner. It is only payable if you are under State Pension age when your spouse died, unless they were not entitled to a Category A pension. There are also National Insurance Contribution conditions based on your spouse or civil partner's contribution record, unless they died as a result of an industrial injury or disease. You should claim within 12 months of your spouse or civil partner's death.

**Bereavement Allowance** is a regular taxable payment made if you were aged 45 or over when your spouse or civil partner died. It is payable for 52 weeks. The amount you are paid relates to your age when your spouse or civil partner died but it is only payable up to State Pension age and will be reduced if your spouse or civil partner's National Insurance Contribution record was incomplete.

**Widowed Parent's Allowance (WPA)** is a regular, taxable payment for men or women under pension age who have been bereaved and have dependent children (or for women if they are pregnant). If your spouse or civil partner met the National Insurance Contributions conditions the full rate is payable. If not, you receive a proportionately reduced amount of the allowance, unless they died of an industrial injury or disease.

**Note:** You cannot be paid Widowed Parent's Allowance and Bereavement Allowance at the same time. A Bereavement Payment can be paid in addition to Widowed Parent's Allowance or Bereavement Allowance.

To claim a bereavement benefit, ask for the appropriate claim form from any Department for Work and Pensions or Jobcentre Plus office or Social Security Office in Northern Ireland.

You can also call 0800 055 6688 for information if you live in England, Scotland and Wales or find more information and download claim forms at [www.direct.gov.uk](http://www.direct.gov.uk) (search for bereavement benefits) or [www.nidirect.gov.uk](http://www.nidirect.gov.uk) if you are in Northern Ireland.

## **I am over State Pension age; can I still get bereavement benefits?**

Widowed Parent's Allowance and Bereavement Allowance cannot be paid beyond State Pension age. When you reach State Pension age, and if you have not remarried or formed a civil partnership, you will be entitled to a Category B pension, if your late spouse/civil partner satisfied the National Insurance Contributions or died as a result of an industrial injury or disease. You could qualify for a Category A pension based on both your own National Insurance Contributions record and your spouse/civil partner's record, if that would give you a higher State Pension. For further details contact The Pension Service on 0845 60 60 265 or go to [www.thepensionservice.gov.uk](http://www.thepensionservice.gov.uk)

## **The person I was caring for was a council tenant and I had been living in the property with him. Does this mean I will be evicted now he has died?**

If you are the husband, wife or civil partner of the person you cared for, the tenancy will usually pass to you, giving you the right to stay in the property. Partners or other family members of the tenant who have lived in the property for at least 12 months will usually have the right to take over the tenancy and remain in the property. However, if the person you were looking after already took over the tenancy from a family member or partner in this way they may not pass the tenancy on to you. In addition, if the council considers the accommodation unsuitable for you to live in, (eg it is too big for your needs or has been adapted for a disabled person), they may ask you to move to another property.

If you and the person you cared for were joint tenants, you will have the right to take over the tenancy yourself. Be aware that if you take over the tenancy completely, you could also inherit and have to pay back any rent arrears that have built up for the property.

If you are not the spouse, partner, civil partner or a family member of the deceased, and have not signed a joint tenancy or lived in the property long enough, you may still be able to take over the tenancy.

Housing law is not the same throughout the UK. Different rules apply in England and Wales, Scotland and Northern Ireland so it is important to seek local advice about your housing situation.

If you need advice about your housing situation call Shelter on 0808 808 4444.

# 3 Life after caring

The end of your caring role may take some time to adjust to. Having more time to yourself may give you the opportunity for a much needed rest, but it can also leave you with 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, and to be able to make choices for yourself. Some carers find that once they are no longer caring, exhaustion – both physical and emotional – catches up with them and they feel unwell for a while. Having spent time caring for someone else and putting their needs first, it is really important to look after yourself and let other people look after you.

When caring ends, some practical matters will have to be dealt with fairly quickly, for example, benefits and housing, but you do not need to rush into making decisions about what you do next straight away. The following information outlines some of the issues you may need or want to think about.

## Benefits

If you are under pension age and your ability to work is limited due to illness or disability, you may be able to claim **Employment and Support Allowance (ESA)**. ESA was introduced in October 2008, and replaced Incapacity Benefit and Income Support paid on incapacity grounds for new claimants. It is initially for new claimants only however, those who receive incapacity benefit or income support will be transferred over to ESA eventually.

**Contributory ESA** can be claimed if you have paid enough National Insurance Contributions. Contributions usually have to be paid in one of the three most recent tax years. However, if you were getting Carer's Allowance for at least one week in the most recent tax year, the rules are relaxed to allow any year's contributions to count. The most recent tax year is the one that ended in the April before the calendar year in which you want to claim ESA.

**Income-related ESA** can also be paid in addition to or instead of contributory ESA. Whether it will be paid or not will depend on your income and savings.

Once ESA has been claimed you will have to take part in some assessments of your ability to engage in work-related activity. Claimants will then be placed in one of two groups, depending on the outcome of the assessment:

- **The work-related activity group** – Those claimants who are identified as having 'limited capability for work' but who can undertake some form of work-related activity will be required to attend work-focused interviews.
- **The support group** – Those identified as not able to take part in any work-related activity (the most severely disabled group) will not be expected to take part in work-focused activities unless they want to do so.

You may also be entitled to **Disability Living Allowance** (if under 65) or **Attendance Allowance** (if 65 or over) if you need help to look after yourself or with getting around. Disability Living Allowance and Attendance Allowance are not means tested and you do not need to have paid National Insurance Contributions to qualify. They can be paid in addition to other benefits/income, and can sometimes increase the amount of help you get from other benefits.

## Other benefits

If your income is relatively low, you may be able to claim one or more of the following means tested benefits. For most means tested benefits the savings limit is £16,000 but can be higher for Pension Credit:

- **Income Support** – for people aged under 60 who do not have to look for work, eg single parents of young children and carers. If you have an illness of disability and your ability to work is limited due to this, see the section on ESA.
- **Jobseeker's Allowance (JSA)** – for people aged under 60 who are available for and actively seeking work. It is important to sign on if you want to continue to get National Insurance Contribution Credits and you can sign on even if you will not be paid any JSA.
- **Pension Credit** – for people aged 60 or over.
- **Housing Benefit** – help to pay the rent.
- **Council Tax Benefit** – help to pay your Council Tax.

NB. If you were getting a Council Tax discount because of your caring responsibilities, remember to let your local council know that your caring responsibilities have ended. If you are living alone, you may still be entitled to a single occupant's discount (25%) on your bill.

For more information about any of these benefits and how to claim them, contact CarersLine on 0808 808 7777.

## Finding new challenges

It can take time to come to terms with the loss of your caring role, but there will come a time when you are ready to think about what to do next. Keeping in touch with friends, family and your local community can be difficult when you do not have much time for yourself. You may feel isolated after many years of caring and you may feel that this has knocked your confidence. You could start by finding out what help or services your local carers' centre or group offers to former carers. Listed below are some other suggestions to help you get started.

### Volunteering

If you have time to spare, you could consider volunteering. As well as offering much needed help to local people or organisations, volunteering can be a very social activity, and can be a good way to meet new people. Volunteering opportunities can range from befriending older or disabled people, offering your skills (eg administration, fundraising, legal advice, etc) to a local charity, to helping out on a local conservation project.

There are many ways to find out about volunteering:

**Contact your local volunteer bureau** – details will be in your phone directory, or in England, search for it on [www.volunteering.org.uk](http://www.volunteering.org.uk)

**'Do-it'** [www.do-it.org.uk](http://www.do-it.org.uk) or 020 7250 5700

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

### Learn something new

You may feel that you would like to refresh skills that you have not used for a while, or learn something completely new. You might have gained new skills or interests from your caring role that you also want to pursue. Taking a course can also be a great way to meet new people.

Contact your local library or adult education centres to find out about courses in your area. You may also find the following websites helpful:

**Learndirect** [www.learndirect-advice.co.uk](http://www.learndirect-advice.co.uk) or 0800 101 901

For impartial information and advice on courses (including funding) and careers.

**Direct Gov** [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.

**nextstep** [www.nextstep.org.uk](http://www.nextstep.org.uk)

Funded by the Learning and Skills Council, nextstep offers face-to-face information and advice services to adults over 20 years of age wanting to learn new skills, retrain or gain new qualifications and improve their career prospects.

## Returning to work

If you have given up work (or not worked at all) because of your caring responsibilities, you may want to work or return to work once your caring role ends. If you are not sure what you would like to do, start by recognising the skills and interests you have. Think about what you have learned from:

- any paid work that you have done
- tasks and responsibilities involved in your role as a carer or parent, or in running a home
- other activities that you do, for example voluntary work, committees, etc.

Then identify your interests. Think about:

- what you enjoy doing
- how you would like to use your skills
- things you miss doing that you once did, eg previous work.

You may want to contact Careers Advice on *0800 100 900* to discuss possible careers with an adviser.

Think about how you can gain confidence to use your skills in new ways.

You may want to find a personal development training course, for example confidence building, assertiveness training or managing stress.

City & Guilds, the leading provider of vocational qualifications, has developed a learning programme specifically for carers and former carers. For more information go to [www.learning-for-living.co.uk](http://www.learning-for-living.co.uk) or telephone *01455 201 020*.

Think about what employers want:

- Make the time you have spent caring and your caring role a positive feature of your CV and job application.
- Identify the transferable skills you have gained through caring that fit with employers' needs.

Think about short and long-term goals and make a plan of what you would like to do. Make sure the plan is achievable – include small steps as well as your long-term goals. Once you know what you want to do, you can look for the right kind of support to help you.

### **Support to get back into training and work**

Jobcentre Plus (or Jobs and Benefits Office in Northern Ireland) can tell you about the range of help they offer, both to find work and to help you out when you start work. This could be:

- training programmes to learn new skills or refresh existing skills
- support in writing job applications or your CV, and in preparing for interviews
- financial help when you move into work, eg Tax Credits, Housing Benefit/Council Tax Benefit (including a four-week run on when you start work) or Job Grant.

When you make a claim for Jobseeker's Allowance, you will have a jobseeker's interview that looks at your skills and qualifications, the type of work you want and the steps you will take to find work. When you are asked about your job skills and experience, make sure that you include the skills you have gained and used as a carer as well as those you may have from previous employment.

Learndirect can also offer careers advice, including signposting to training opportunities. Call them on *0800 100 900*.

## **Helping to improve support for carers**

Many former carers go on to become great campaigners. They have the experience of knowing what it is like to be at the sharp end of caring and they often have more time than those who are still caring.

To find out about how you could get involved:

- Contact your local carers centre or branch to find out if you can help out.
- Contact your local council to find out about opportunities to get involved in the planning and development of services for carers in your area.

# Further information/support

## General

**Carers UK** *CarersLine* 0808 808 7777 [www.carersuk.org](http://www.carersuk.org) 10am-2pm and 2pm-4pm Wednesdays and Thursdays

**Samaritans** 08457 90 90 90 [www.samaritans.org.uk](http://www.samaritans.org.uk)

**Citizens' Advice** [www.adviceguide.org.uk](http://www.adviceguide.org.uk)

**Princess Royal Trust for Carers** 0844 800 4361 [www.carers.org](http://www.carers.org)

**Directgov** [www.direct.gov.uk](http://www.direct.gov.uk)

## Residential and nursing care

**Counsel and Care Helpline** 0845 300 7585 [www.counselandcare.org.uk](http://www.counselandcare.org.uk)

**Relatives and Residents Association** 020 7359 8136 [www.relres.org.uk](http://www.relres.org.uk)

**Elderly Accommodation Council** 0800 377 7070 [www.housingcare.org](http://www.housingcare.org)

## Hospice care

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

## Bereavement

**Cruse Bereavement Care Helpline** 0844 477 9400 [www.cruse.org.uk](http://www.cruse.org.uk)

*Helpline for young people* 0808 808 1677

*Website for young people* [www.rd4u.org.uk](http://www.rd4u.org.uk)

### Directory of Bereavement Services

*Order from Resource Information Service* 020 7939 0641 [sales@ris.org.uk](mailto:sales@ris.org.uk)

**Childhood Bereavement Network** 020 7843 6309

[www.childhoodbereavementnetwork.org.uk](http://www.childhoodbereavementnetwork.org.uk)

**Child Bereavement Trust Helpline** 0845 357 1000

[www.childbereavement.org.uk](http://www.childbereavement.org.uk)

**Winston's Wish Helpline** 0845 2030405

[www.winstonswish.org.uk](http://www.winstonswish.org.uk)

Email response service: [info@winstonswish.org.uk](mailto:info@winstonswish.org.uk)

**Compassionate Friends Helpline** 0845 123 2304 [www.tcf.org.uk](http://www.tcf.org.uk)

## Help the Hospices

Help the Hospices supports over 240 local hospices across the UK. This includes training and grants for hospice staff and volunteers, national programmes of advice, information and support, special award programmes to fund new services and the coordination of national fundraising initiatives.

Hospice or palliative care is for those whose illness may no longer be curable. It allows them to achieve the best possible quality of life.

Hospices also support families and carers. Hospice care is based on the simple idea that a person has unique physical, emotional and spiritual needs and the belief that every patient should be treated as a whole person.

Help the Hospices Care for the Carers of the Terminally Ill project, funded by the Tubney Charitable Trust, aims to support people who provide unpaid care for a relative or friend, through the development of information and support services. Visit [www.helpthehospices.org.uk/carers](http://www.helpthehospices.org.uk/carers) for further information.

Address: Hospice House, 34-44 Britannia St, London WC1X 9JG

General enquiries: 020 7520 8200

Email: [info@helpthehospices.org.uk](mailto:info@helpthehospices.org.uk)

Website: [www.helpthehospices.org.uk](http://www.helpthehospices.org.uk)



## Carers UK

Carers UK is the voice of carers.

Carers provide unpaid care by looking after an ill, frail or disabled family member, friend or partner. Carers give so much to society yet they experience ill health, poverty and discrimination because they provide care. Carers UK campaigns to end this injustice.

Carers UK improves carers' lives by:

- campaigning for the changes that make a real difference for carers
- providing information and advice to carers about their rights and how to get support
- mobilising carers and supporters to influence decision-makers
- gathering hard evidence about what needs to change
- transforming the understanding of caring so that carers are valued and not discriminated against.

Join Carers UK and help achieve a world where carers are fully valued for their contribution to society and get the help they and their loved ones need.

Visit [www.carersuk.org](http://www.carersuk.org), call 020 7378 4931 or email [membership@carersuk.org](mailto:membership@carersuk.org)

**CARERS** UK  
the voice of carers

## **Carers UK**

20 Great Dover Street,  
London SE1 4LX  
Tel 020 7378 4999  
Fax 020 7378 97814999  
info@carersuk.org  
www.carersuk.org

## **Carers Scotland**

The Cottage, 21 Pearce Street,  
Glasgow G51 3UT  
Tel 0141 221 9141  
info@carerscotland.org  
www.carerscotland.org

## **Carers Wales**

River House, Ynys Bridge Court,  
Gwaelod y Garth, Cardiff CF15 9SS  
Tel 029 2081 1370  
info@carerswales.org  
www.carerswales.org

## **Carers Northern Ireland**

58 Howard Street,  
Belfast BT1 6JP  
Tel 028 9043 9843  
info@carersni.org  
www.carersni.org

Carers UK is a charity registered in England and Wales (246329) and in Scotland (SC039307) and a company limited by guarantee registered in England and Wales (864097). Registered office 20 Great Dover Street, London SE1 4LX

CarersLine: 0808 808 7777 (open Wednesday and Thursday 10am-12pm and 2pm-4pm)

Publication number UK9021

Disclaimer: The information in this leaflet is for guidance only and is not an authoritative statement of the law. The information is correct as of July 2009.

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The Big Lottery Fund funds the Advice and Information Team at Carers UK who wrote the material for this booklet.