

CARERS UK
the voice of carers

New to caring?

Information for people who provide unpaid care by looking after an ill, frail or disabled family member, friend or partner.





So you're a carer, are you?

If you're anything like me you probably answered 'no' to that question, even though I've been caring for my wife Cathie ever since she was diagnosed with Huntington's disease many years ago. That's one of the things about being a carer – you don't really see yourself as one.

Selfish?

Looking after a family member, partner or friend is something that will happen to most people at some point in their lives yet it remains one of those things people don't talk about. A few years ago I wrote a book about caring called *The Selfish Pig's Guide to Caring*. The

title was deliberate. I wanted people to recognise that far from seeing ourselves as unsung heroes or selfless angels, for many of us caring brings a mass of confusing and conflicting emotions.

Many carers feel they are selfish because they never wanted to be a carer, they resent it, or they feel guilty about their reaction. Exhausted and isolated, carers are so worried about the person they care for, and the standard of care they are providing for them, that they forget about themselves. If that sounds like you, then don't be so hard on yourself! In the long run this isn't good for you or for the person you are looking after.

People who have been caring for a number of years tell us how important it is to maintain a life outside of caring – keeping up with friends and family, staying in work. This isn't easy to achieve and you'll need all the help you can get. Life goes on – you have to pay the bills; you have to keep healthy.

Battles

Carers UK, who have produced this booklet, are an organisation of carers battling to get carers the financial, practical and emotional help they need. And battling is something that all carers have to get used to. Endless benefit

forms, convincing professionals to take you seriously, arguing over the help you and the person you care for need. There is no doubt that caring can be a battleground. If I have one piece of advice – if I only knew then what I know now – it is to make sure you are as well informed as you can be. There is help out there, but you may have to fight to get that help.

I'm sure by now you feel like running for the hills – but it isn't all bad news and there is a positive side. Caring for someone else can be very rewarding personally. Carers now have a small but growing set of legal rights, hard won by organisations like Carers UK. With each year that goes by, caring is gaining more recognition as one of the key issues facing our society in the 21st century.

This booklet contains all the basics you'll need to know – and there is a wealth of help out there. There are thousands of carers' organisations and groups across the UK that can offer practical help and support. I hope this guide will reassure you that you are not alone and help you prepare for what might lie ahead.

Hugh Marriott

Author of *The Selfish Pig's Guide to Caring*



The emotional impact of being a carer

However much you like or love the person you care for, the emotional and physical demands of caring can be extremely stressful.

It can be especially frustrating if you feel you spend all your time and energy looking after someone else, and they do not seem to appreciate

your help. You may also feel as if you're letting down the person you care for by not doing enough to help them.

As well as dealing with a new caring role, you may also have to come to terms with a change in family relationships – suddenly having to

do everything for your parents, who have always looked after you, may mean that you have lost one of your biggest sources of support. If you're caring for a spouse or partner then the change in that relationship can be especially hard to cope with.

If you live with the person you care for you may feel you have no time to yourself to relax and unwind.

The feelings you have about your caring role may change from day to day, or even from hour to hour.

You are not alone!

Everyone reacts differently to the stresses of caring, but when carers get together they often find that they share many of the same feelings.

It can be very reassuring to talk to other carers and discover that your feelings are very similar to others in your situation.

Some of the most common feelings carers describe are:

- **Frustration**
- **Resentment**
- **Guilt**
- **Anger**
- **Fear**
- **Loneliness**
- **Depression**

Get help from:

- Your friends and family – talk to them about what's going on, ask for their help, support and advice
- Your local carers' group or centre – other carers may be the best people to understand your situation
Find out if there is a condition-specific support group for carers, e.g. through organisations like MS Society, Alzheimer's Society, MacMillan Cancer Support
- Social services can tell you about local support groups/ services or may be able to provide break services to help you get some time to yourself (see practical help section on page 10)
- Your GP may be able to refer you to a counselling service
- The Samaritans – if you need to talk to someone, the Samaritans helpline (08457 90 9090) is open 24 hours a day
- Your local college – see if they run stress management or relaxation courses.



Money

For most people, becoming a carer brings big changes to their financial situation. Your income may take a dramatic drop through giving up work or reducing your working hours; you may face extra costs, such as heating and laundry, because you are looking after someone.

Sorting out your financial situation can seem daunting. You may have to think about claiming benefits for the first time in your life, and may be unsure

where to start looking for help. But there is help out there so you don't have to face it alone.

Benefits

The benefits system can seem like a maze; you have to decide which of the many available benefits you should apply for, which office to go to, and which forms you need to fill in. The benefits you can claim will depend on a number of factors including your income, savings, how old you are and whether you have worked and paid

National Insurance contributions. The best way to start is to get advice. Call CarersLine or go to your local advice/carers' centre – they will be able to tell you which benefits you can claim and how to do it, and can usually carry out a benefits check for you to make sure you get all the help you can. Your local advice centre may also be able to help you complete forms.

Other help

Benefits are not the only way of getting financial help. You may be able to apply for:

- a reduction in your Council Tax bill
- help with health costs, e.g. to pay for dental treatment
- a grant to help adapt your home to meet the needs of the person you care for
- help to manage your heating costs, e.g. to install central heating, changing to a better tariff to reduce fuel bills
- charity grants

CarersLine or your local advice/carers' centre will be able to tell you about the range of help available, so make sure you get in touch with them as soon as you can.

Carers UK also produce a range of factsheets about benefits and other financial help – for more information

go to www.carersuk.org

You can also find more information and make online claims for some benefits at www.direct.gov.uk

It is also worth checking your insurance policy/mortgage agreement to see if they can offer any help, e.g. can you cover any costs through your insurance? Does your mortgage allow breaks in repayments?

Debt

If you have built up debts or are worried that you will, it is important to seek advice as soon as you can. National DebtLine (0808 808 4000) or your local advice agency will be able to help you.

Pension

Sorting out your current finances is one thing, but you should also think about the impact that caring is having on your future income. Are you keeping up your National Insurance record for your State Pension? Can you pay into a personal or occupational pension? For more advice about this, call CarersLine.

Looking after your health

There is no doubt that without the right support caring can damage your health. You'll need to find the balance between caring and looking after your own health needs. It's not an easy balance to find, but remember – the better your physical and emotional wellbeing, the better you will be able to cope with the demands of caring.

We could fill a book with advice about your health but here are three things to remember...

1. Tell your GP

As soon as you begin caring tell your GP that you are a carer. If they know you are likely to be under pressure at times, they will find it easier to diagnose and treat you and offer the advice and support you need. As a carer, you will probably carry on regardless through coughs, flu, stomach upsets and worse; but don't put off seeing your doctor if you feel ill.

2. Watch your stress levels

Stress is a fact of life for most carers. One carer put it like this: "When a dog goes to sleep, it's got one ear up. That's what it's like to care for someone." Not being able to relax

"When a dog goes to sleep, it's got one ear up. That's what it's like to care for someone."

has long-term detrimental effects on your health. It's easier said than done but it is vital that you learn to recognise the signs of stress and take action.

3. Look after your back

You may find that lifting the person you care for, helping them dress or move around places a strain on your back. It may be impossible to avoid lifting and handling the person you care for but you can get advice and guidelines that may reduce the risk of injury from Backcare –

www.backcare.org.uk

Social services may also be able to tell you more about training available in your area, and many local carer centres offer training on how to lift without harming your back. You can also get equipment and aids that will minimise the strain. For more information, see pages 10 and 11.

Laura's tips



"I believe that keeping well and strong is so important for carers. So, how do we stay sane and manage the stress of caring? When there just aren't enough hours in the day how is it possible to get all our caring tasks completed, and still have time to ourselves? The answer is - to think smarter, not work harder. Here are my tips which have worked for me."

Laura Collins is a carer. Here she shares her tips for coping with caring:

1. Time spent worrying is time wasted. Instead make your decisions by first making a list of the positives and negatives, and once you have made the decision do not spend time worrying about the consequences.
 2. Don't put things off. Make a list of all the tasks you need to do. Schedule the worst tasks first, and plan free time for yourself.
 3. Give yourself a treat, no matter how small. This brings a sense of control over your life and reduces feelings of stress.
 4. Get help from friends and family. It can be difficult to ask, but remember you can't do everything yourself. A burnt-out carer is of no use to the person you care for.
 5. Tidy house, tidy mind. Reducing the clutter in my life makes me feel able to cope so much better.
 6. You must learn to ask for help and be prepared to accept it.
- My reward might be an afternoon spent gardening or just spending some time with my cats!



Getting some practical help

You may be many things, but you're not superhuman. Caring can be physically and mentally exhausting and every carer needs help and support. Getting practical help could be:

- someone to come in and help with the practical tasks you have to do, e.g. personal care, bathing
- adaptations or equipment for your home to make it easier for you to help the person you care for, or to enable them to do more for themselves

- a few hours break to give you some time for yourself
- a more substantial break of a week or more where the person you care for goes into residential care

Help from social services

The best place to start looking for help like this is your local social services department.

Carers can ask for a carer's assessment from social services. A social worker will meet you to look

at your needs as a carer and identify the support services that help you manage your caring role. You may be able to get Direct Payments instead of services – this allows you to choose the help that works best for you.

It's all too easy to focus on the needs of the person you care for and forget about yourself. If possible make sure you and the person you care for have separate assessments – ideally both assessments should be carried out at the same time so that they can look at your needs together and offer the help that best suits you both.

Contact details for your local social services department should be in your telephone directory, or phone CarersLine for more information. Your GP or other professionals you have contact with may also be able to refer you to social services.

For more information about carers' assessments, order a copy of the Carers UK leaflet '**How do I get help? Carers' assessments made clear**'.

Equipment and adaptations to your home

- Ask your GP to refer you for an occupational therapy assessment – this will usually be done by your community

health team who can advise on, or in some cases provide, equipment and adaptations.

- The Red Cross offers a range of services including equipment loan, support for people when they have been discharged from hospital and transport services. More information at www.redcross.org.uk
- The Disabled Living Foundation can advise on aids and adaptations – contact them on 0845 130 9177
- You may be able to get a housing grant if you need to make alterations to your home – contact your local council for more information.

Getting a break :

Charities/voluntary organisations

- Crossroads offer a sitting service for the person you care for so that you can have some time to yourself. To find out more call 0845 450 0350 or find your local scheme at www.crossroads.org.uk
- Leonard Cheshire offer respite and short breaks to enable carers to have a break – more information at www.leonard-cheshire.org



Employment

Working and caring can feel like holding down two jobs. After a hard day's work and a long journey home, the last thing you may feel like doing is looking after someone else. On a bad day giving up work may seem like the easiest solution. But before you do this, take some time to think about what you might

lose by giving up work and consider your options.

As well as an income, work can also give you an opportunity to socialise, a different set of skills to the ones you need as a carer and an escape from your caring role for a few hours a day or week. Around 3 million carers

combine work and care – this means that 1 in 8 employees are carers, so the chances are that you are not the only carer at your workplace.

Support at work

It's a good idea to check your company's policies for supporting carers in the first instance. You do not have to tell your employer about your caring responsibilities, but you might find that if you inform your manager or personnel officer about your situation they can help you manage your two roles.

Having an understanding employer or manager can make juggling work and care easier, but as an employed carer, you do have some rights that all employers must adhere to that could make it easier for you to manage your work and caring responsibilities.

Your employer should be able to tell you about:

- your right to take time off in an emergency, e.g. to arrange alternative care if the care package you have in place breaks down
- your right to ask for flexible working, e.g. to work part-time, flexi-time, to do some or all of job from home
- their own policies for carers in the workplace, e.g. career breaks, early retirement.

You could also ask your employer for more practical help that they could give you such as access to a phone – perhaps in a private space – so that you can contact the person you care for if you need to, or for more information about support services they can refer you to.

As well as your employer, trade unions can also tell you about your rights and, if you are a member, can support you through disputes. To find out about joining a union call the TUC's 'know your rights' line on **0870 600 4882**.

For more information about your rights to time off in emergencies, parental leave and flexible working, call CarersLine or order Carers UK's booklet '**An employee's guide to work and caring**'.

Social services should also take into account your work (or wish to work) when they carry out your carer's assessment (see 'Getting some practical help', page 10).

Remember that you have the right to choose – and that means choosing to give up work as well as staying.



“Going fishing is time for me – time when I’m recharging my batteries so that I can continue looking after my daughter.”

“I love being in my garden, so was really pleased when I found a course on growing and arranging flowers. It’s not just the course. It’s about being with people who share my interests and who I can talk to. It’s about being me...”

Having a life of your own

Caring is an incredibly valuable role, but it can all too easily become isolating. Your time can be spent thinking about the wellbeing of someone else rather than your own. It can be hard to keep up with friends.

Because you are worth it...

Having some time to yourself, away from caring, even for just a few hours can make all the difference to your own quality of life. Many carers say that having a life outside of caring helps them to feel more able to cope with the ups and downs of caring.

Food for thought...

Time for you might be catching up with friends, doing a spot of

gardening, pursuing a new interest or learning a new skill or hobby. You might want to do a course at an adult education centre or college or a course through the internet. Some carers’ organisations have activities for carers – outings, pamper days and opportunities to make friends who share similar experiences and understand your situation.

Making it happen...

You may need to get help with caring in order to get some time for yourself. If you have a carer’s assessment make sure that it covers how you will get time for you. In England and Wales the law says carer assessments must cover work, learning and leisure.

Facing the future

Nobody knows for sure what their future holds but for some carers there are some certainties that you have to be prepared for. With caring nothing ever stays the same and it is almost certain that the disability or illness of person you look after will change over time. Don't assume that professionals like your GP or social worker will know about these changes. You may need more help. Let them know and ask for a re-assessment of your situation. Likewise there may also be changes to benefits that you or the person you care for can receive.

You may also find that your need for emotional support changes once you have been caring for a while. Contact with other carers who know what you're going through may become more important, or you may find it harder to get out to meet up with other people or to go to events. Contact your local carers centre to find out if they can help you.

Residential care

If the person you care for moves into residential care, your situation will change dramatically. You may be living on your own for the first time, you have to get to know the staff at the care home and establish your role in this new set up, and your benefits are likely to be

affected. Whilst you may no longer be a 'carer' in the eyes of the benefits system or social services, you may still be caring for your loved one. Some carers find they spend more time caring when the person they care for leaves home because as well as visiting (and often still helping with practical tasks like washing and dressing), they also have to spend extra time travelling to and from the care home.

When caring ends

There will come a time when caring will end and it is important that you are prepared. In a few cases this may be because the person's health has improved and they have regained their independence. However for most carers this will be in sadder circumstances – caring usually ends because the person being cared for has died. When your own life has been focused on someone else, as is the case with many carers, it can be extremely hard to adjust to a life after caring.

For advice about how to manage the changes in your situation, call CarersLine. You could also check to see if your local carers' centre or group offers any support to former carers, as many do.

For information and useful organisations to help you cope with bereavement, go to:

www.carersuk.org/Information/Caringandbereavement

Further information

This guide gives only a brief overview of help for carers. To get the best help you need to know what's out there. As a first step find out your local carers' organisation by visiting Carers UK's website. Details of the main organisations providing help to carers are given below.

And a final word. If you can't find help, call Carers UK's helpline.

The following are UK organisations. Some of them may have specially tailored advice if you live in Wales, Scotland or Northern Ireland.

Carers UK

CarersLine 0808 808 7777

www.carersuk.org

Information and advice on benefits, community care and employment issues affecting carers. Our website also has details of local carers' centres across the UK

Crossroads

0845 450 0350

www.crossroads.org.uk

Offers a care attendant scheme to enable carers to take a break

The Princess Royal Trust for Carers (PRTC)

020 7480 7788

www.carers.org

Provides information, advice and support services across the UK through a network of local carers' centres.

Direct Gov

www.direct.gov.uk/carers

Government website offering advice and help for carers

Citizens Advice

www.adviceguide.org.uk

Network of local offices offering advice and representation e.g. on benefits, debt, housing issues

Age Concern

0800 00 9966

www.ace.org.uk

Provides national and local services offering information and support for older people (60+)

Contact-a-Family

0808 808 3555

www.cafamily.org.uk

Provides information and support to parents and families who care for children with a disability or special need

Rethink

020 8794 6814

www.rethink.org

Offers information, advice and community services for people affected by severe mental illness and their carers

Mencap

0808 808 1111

www.mencap.org.uk

Provides information, advice and services for people with a learning disability and their carers

Disabled Living Foundation

0845 130 9177

www.dlf.org.uk

Provides advice and information on equipment for independent living

Lynda Wisbach



“ My son was seriously ill in hospital 200 miles away. I desperately wanted to be with him, but couldn’t leave my disabled husband because I couldn’t find any emergency replacement care. I told Carers UK about it and they took my story, along with 1000 similar experiences of carers and turned it into the Back Me Up campaign. As a result of that campaign the Government has pledged £25 million to help set up Carers Emergency Schemes. I’m now a

trustee of Carers UK and would urge all carers to join us and become a member. Together we can make a difference for all carers.”

CARERS UK

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.

We were set up by carers to improve carers’ lives. To this day carers run the organisation and decide what needs to be done. Carers UK will not stop until people recognise the true value of carers’ contribution to society and carers get the practical, financial and emotional support they need.

Carers UK improves carers’ lives through campaigning, providing information to carers and professionals and carrying out research into the impact of caring on people’s lives.

Join for free

At Carers UK we want carers to be recognised for the contribution they make to society. We are an organisation of carers fighting to end the financial hardship, ill health and discrimination faced by carers as a direct consequence of caring. We need you to add your voice by joining Carers UK to help us win better support for carers.

We welcome any individual who supports our aims. You will benefit by receiving the latest information written by our team of experts.

We're offering free membership. Yes, free membership because we know that carers have many calls on their finances. Of course, if you can afford to make a donation it will help us provide free information to carers, strengthen our campaigns and keep the organisation running.

Join today and you'll receive

- Our quarterly members' magazine, *Caring*, with the latest information on caring, carers' stories and how Carers UK is making a difference.
- Helpful free telephone advice on all aspects of caring from our CarersLine experts.
- Free information booklets written by experts covering a wide range of topics from carer benefits to practical help.
- An invitation to our Members' Conference and Annual General Meeting
- You'll also have a say in how Carers UK is run with a vote on electing our Trustees, the majority of whom are carers themselves and who ensure Carers UK is carer- led.

Join today at www.carersuk.org or simply return the form below and we'll send you more information.

Name
Address

- Please send me information about Carers UK
- Please subscribe me to your free email newsletter

Postcode
Email
Phone

Return this form to : Carers UK, 20/25
Glasshouse Yard, London, EC1A 4JT

My useful contacts

This page is for you to use to keep details of your local services.

We have suggested some services that we think you will find useful, but have also left space for you to add other resources.

Organisation	Address	Phone number	Opening hours
Social services / Social work department		Office number: Out of hours:	
GP/Community Health Team		Office number: Out of hours:	
Carers' centre			
Advice centre e.g. CAB			

Carers UK

20-25 Glasshouse Yard,
London EC1A 4JT
Tel. 020 7490 8818
info@carersuk.org
www.carersuk.org

Carers Scotland

91 Mitchell Street,
Glasgow G1 3LN
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

CarersLine 0808 808 7777

(free advice from 10am – 12pm
and 2pm – 4pm Wednesday
and Thursday)

For more
information
about caring,
visit our website
www.carersuk.org

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