

how to



cope as a carer

How to cope as a carer

This booklet is for you if you are supporting a friend or relative and want to know how to look after your own mental health. It offers advice on how to look after yourself and where to get further support.

Contents

| | |
|---------------------------------|----|
| What is a carer? | 4 |
| What challenges do carers face? | 5 |
| How can I look after myself? | 7 |
| How can I get help? | 16 |
| Self-help resources | 20 |
| Useful contacts | 29 |

What is a carer?

You are a carer if you are responsible for providing or arranging care for someone else who cannot care for themselves. A carer is not paid for their role, and is different from a paid professional like a care worker or home help.

You may already describe or think of yourself as a carer. However, you may not be sure if you are a carer or you may not like to use the term. This booklet is relevant to you if you are supporting:

- a family member such as your child, parent, sibling or other relative
- your partner
- a friend
- a neighbour.

You may provide a range of support, including:

- giving emotional support
- helping someone cope with a mental health problem
- cooking and cleaning
- personal care, like washing and going to the toilet
- budgeting and looking after finances
- giving medicine or providing medical care
- interpreting for someone who is deaf or who does not have English as their first language
- reading information and filling in forms for someone who has literacy or concentration difficulties.

Anyone can become a carer, no matter their age, gender or background. You may care for someone who has a long-term health condition or someone who needs support after an accident or sudden illness. The care you provide could be short- or long-term. You may or may not live with the person you are a carer for.

●● *I was completely unaware that what I was doing was a carer role and of the effect it was having on me. I didn't think about reaching out for support for myself.* ●●

What challenges do carers face?

Caring for someone else can often be demanding, and you are not alone if you feel overwhelmed at times. You might find some parts of life challenging and this may leave you feeling stressed and isolated. Over time, this can lead to mental health problems. If you already live with a mental health problem, being a carer could affect your ability to stay well.

If you are caring for someone, you may face the following challenges:

Stress and worry

You may often feel stressed and worried if you're caring for someone else. You could spend a lot of time thinking about their illness and the impact it is having on both of your lives. You may always be thinking about things you need to do as part of your role as carer, and find it hard to switch off. You may have difficulty sleeping, be eating too much or too little and find your mood is affected.

If you feel this way over a long period of time, it can have a big impact on your mental health and you can become unwell.

Social isolation

Many people find it hard to make time to socialise or carry on with hobbies or interests. You may also feel guilty if you take time for yourself.

You may feel like your life is very different from other people's, and that they don't understand how you are feeling. If you feel worried that you or the person you care for might face stigma, you may find it hard to let people know that you are a carer. This can make you feel very lonely.

Over time, social isolation can lead to mental health problems such as anxiety and depression.

👉👉 *You feel like your peers cannot relate to what you have to deal with at home. You are envious of people around you that have a 'normal' life, especially if you have no other family support.* 👉👉

Money worries

You may find that you need to pay for extra care or medical costs. You may be spending lots of money on travel costs, especially if you don't live with the person you care for. This can put a strain on your finances, and may mean you have to cut back on other things, causing practical issues and additional stress. You may also find that you are not receiving enough financial support or benefits in order to meet these costs, and experience financial worries. Many carers struggle to cover costs, and get into debt.

Physical health problems

Caring can be physically demanding. If your role as carer involves lifting or carrying, you could suffer from aches and pains, particularly in your back.

You may feel run down and tired a lot of the time. This can make you more likely to experience physical illness, which could develop into a long-term problem. You may not have enough time to be physically active or to cook healthy food.

👉👉 *Despite having physical health problems myself, I care for my sister and my elderly parents. I get so tired and have little help. I wish I could have a week off and just sleep. But you just have to keep going.* 👉👉

Depression

You may find that the challenges you face while being a carer make you feel low or depressed. If you feel very frustrated or hopeless, you may

also have thoughts of harming yourself or even of ending your life. You may also develop unhelpful coping strategies to deal with these difficult feelings, such as using drugs or alcohol, or eating more or less than you need to.

Frustration and anger



You may often feel very frustrated and angry, especially if you have had to give up parts of your own life. Or, you might feel that you have been given no choice about becoming a carer.

You might end up directing this anger at family or at the person you care for. This could make you feel guilty.

Low self-esteem

Being a carer can have a big impact on your self-esteem. You may feel that you are not worthy of care and attention, and that all your time should be focused on the person you care for. You may find it hard to interact socially, or feel that you are missing out on parts of having a normal life.

You may lose confidence in yourself and your abilities to do anything outside of your caring responsibilities.

 *I got no support and didn't really know there was anywhere or anyone I could turn to. It had a huge impact on my mental health. I developed obsessive compulsive disorder (OCD), anxiety and depression.* 

How can I look after myself?

When you are a carer you spend a lot of your time focusing on someone else. It can feel unnatural to think about yourself and your needs. But it's important that you look after your own wellbeing too. Taking positive

steps to look after yourself can help you avoid physical and mental health problems. If you are able to stay well, you are more likely to be able to provide good support for longer, without getting too overwhelmed. So looking after your wellbeing is good for you and the person you care for. Here are some ideas about how to do this:

Try to stay healthy

If you are really busy, you might not always feel you have time to focus on looking after yourself. But it's important that you make time to look after your physical health, and there are lots of things you can do to improve it.

For example:

- **Eat healthily** – try to eat regular meals, with plenty of fresh fruit and vegetables. It may help to plan your meals and make extra portions that you can keep for when time is short. If you find you forget to eat, try sticking a reminder on your fridge, or an alarm on your phone. (See Mind's leaflet *Food and Mood* for more information.)
- **Get enough rest** – lack of sleep can make it more difficult to cope with day-to-day challenges, and make stress and depression worse. There are lots of positive steps you can take to improve your sleep. You may find that you need to change your sleep pattern, for example sleeping for four hours twice a day, rather than trying to get eight hours, sleep every night. This could help you feel less worried about not getting enough sleep. (See Mind's booklet *How to cope with sleep problems* for more information.)
- **Do regular physical activity** – even a short walk can be good exercise and can help you clear your head. If you struggle to get going on your own, you could join a class. If you find it hard to make time for exercise, try to build it into your daily routine, for example by walking or cycling to work. (See Mind's booklet *Mind tips for better mental health: physical activity* for more information.)

- **Look after your general health and wellbeing** – take time to notice when you are becoming unwell and try to take a break. For example, if you tend to develop cold-like symptoms when you are getting ill, take a break next time you notice that you feel this way. (See Mind’s booklet *How to improve and maintain your mental wellbeing* for more information.)

Share your feelings with someone you trust

It can be really important to have someone to talk to, especially if you’re struggling to cope. Think about the people in your life you can turn to for support. You may have a family member who helps you relax, or a friend who is good at taking your mind off things.

You may find it hard to ask for help or tell people how you’re feeling. Time to Change has some ideas about how you can start the conversation (see ‘Useful contacts’ on p.30). If you don’t have time to meet up with people, you could try to stay in touch by email or text, or use online video chat.

Learn a relaxation technique

Using relaxation techniques can help you feel more rested. They can also help you make time for yourself. Most of the techniques here can be practised for a few minutes a day, so they don’t have to take lots of time if you’re struggling to make space for activities.

Yoga, meditation and mindfulness are all techniques you can use to relax and to help switch off from your caring role. Search online for a yoga or guided meditation class in your area. If you can’t go to a class, you can find videos and websites with instructions online.

Mindfulness is a therapeutic technique that involves paying attention in a deliberate way. You can take a course or learn mindfulness online. (See ‘Useful contacts’ on p.29 for more information about mindfulness and details of groups in your area.)

Take a break

Try to take a break when you need it, especially if you are worried about your own mental health. Having some time away from caring can help you feel refreshed, and enable you to manage your own mental health.

It can be hard to make a decision about when to take a break, especially if you feel guilty or worried about what will happen to the person you care for while you're not there. You may feel more able to take a break if you ensure that the person you care for knows what to expect and has any other support they need. This may mean asking the person you care for to find ways to cope without you for a while, or arranging for family and friends to help cover your caring responsibilities. If you need some help to organise a break, you could find out more about respite care (see p.18) or ask your local social services for support.

The length of your break will depend on how you are feeling. You may only need an hour or two to clear your head, or a day to help you feel more rested. You could go out, take a bath or turn your phone off for an agreed period of time.

It may be helpful to build a regular break into your routine. This can help you make plans in advance, give you something to look forward to and ensure that the person you care for knows what to expect.

You may find that you need a longer break, especially if you are worried you might be becoming unwell. At this stage, you may want to think about respite care (see p.18).

Make time for yourself

Spending quality time with your partner, family or friends can give you a break from your caring responsibilities, help you stay positive and boost your confidence. Try to make time for the things that you enjoy, for example going for a coffee or a short walk.

Take time to pursue hobbies and activities that interest you or make you feel fulfilled. Try to do something regularly, like a yoga class or going to the cinema with a friend.

👉👉 *I get up half an hour early to do my own thing and start the day as I like to.* 👉👉

Try to be organised

Finding a way to feel in control of your responsibilities can help you manage feelings of stress and anxiety. You could:

- **Make a schedule or planner** – keeping a schedule of the key parts of your day-to-day routine, such as bathing, cooking or taking children to school, can be very helpful. You could also plan in more detail, for example, by keeping shopping lists and a schedule of meals if cooking is part of your role as a carer.
- **Keep important information in one place** – for example, emergency contact details and information about medication (see 'Self-help resources, on p.28). You could make sure someone else (such as a social worker, friend or family member) also knows where this information is kept in case it is needed when you are unwell or not at home.

Be realistic about what you can do

It's important to be realistic about what you can do. If you take on too much, you may feel like you never get to finish or achieve anything. You may want to make the person you care for better or take away the impact of their illness, and feel very upset that you can't. This can lead to stress, anxiety, guilt or low self-esteem. Having a clear idea about what you can do, and accepting parts that you can't change or do alone, helps to reduce this stress and can make you feel more able to cope.

You might find it helpful to:

- Make a list of the kind of support the person you care for needs – this helps to identify what needs doing and can give you a clearer idea of how much support the person you care for needs.
- Identify what you can do, and what you need help with. Work out a plan with the person you care for about who will provide the care you can't. For example, you may need medical support or some professional care.
- Think about how you will be able to tell when things are getting too much and you need a break. For example, you may struggle to sleep when you're feeling low and this could be something you notice as a sign that you need a break. You could write these signs down as a reminder to yourself (see 'Self-help resources' on p.26). You may also want to share them with someone you trust and ask them to let you know if they recognise that you are becoming too stressed and need a break.

Make sure you have all the information you need

Making sure you have access to reliable, clear information can help you feel more in control. This could be medical information about any diagnoses the person you care for has, or advice about your rights. If you're not sure where to find this, looking online or asking your GP are both good starting points.

Plan for appointments and take notes of things you want to talk about. This will help you remember what you want to say and to get the information you feel you need.

Medical language can be really complicated, so don't be afraid to ask for further explanations if you don't understand. You can look at the National Institute for Health and Care Excellence (NICE) guidelines which give official recommendations about treatment (See 'Useful contacts' on p.29).

If the person you care for has a mental health problem, you could have a look at Mind's information booklets, either online or in print. You could also look at the Mental Health Foundation and Rethink websites. The Carers Trust and Carers UK have lots of information specifically for carers, and forums where you can exchange ideas with other carers. (See 'Useful contacts' on pp.29-30.)

Information about medical treatment

The person I am caring for wants me to know about their treatment

Make sure that the person you care for has told any medical professionals, social workers and support staff that they are happy for you to have access to your medical information. You could ask for a note to be put on any records confirming that you have permission to see them.

The person I am caring for is too unwell to make decisions, or may be too unwell to make them in the future

If you are concerned someone may not have the mental capacity to make a decision about their treatment, read Mind's legal briefing on the Mental Capacity Act 2005 to find out what they can do in advance to make their wishes known and what your rights are to make decisions on their behalf.

The person I am caring for does not want me to know about their treatment

If the person you are caring for does not consent to you receiving information about their treatment, you may still be able to receive general information. For example, a doctor may give you information about a health problem, but not specific details of the treatment that is being offered.

It's important that you are given the information you need to provide care safely and effectively. If you are concerned that you or the person you care for will be put at risk because you do not have essential information, you should raise this concern with any medical staff involved. They will then decide whether you should be given information without the agreement of the person you are caring for.

Find positives in your relationship

Being a carer can have a big impact on the relationship you have with the person you support. Sometimes you may feel very close and connected, while at other times you may feel distant or irritated with each other. It can help to talk openly and honestly to find ways of coping with these challenges together.

For example, you could try to:

- think of yourself not only as their carer but also as their friend, partner or family member
- talk to each other about how you will strengthen and maintain positive parts of your relationship
- see each other as whole people, with interests, characteristics and hobbies
- try to do nice things together, as well as carrying out day-to-day responsibilities – this will help maintain your relationship outside of being a carer, and help you connect on a different level
- think about what you get out of caring, and write down a list of positive things that you can look at when you are feeling frustrated or low
- recognise practical and specialist skills and knowledge you have gained, or people you have met that you wouldn't otherwise get to know.

Focusing on these positives can help you feel that you have a deeper relationship and understanding of the person you care for, and appreciate that they may feel this way about you too.

👏👏 *I would urge anyone who is a carer to try to see the positives in your situation and to realise you are there out of love and respect for the person you are caring for.* 🗣️🗣️

Support the independence of the person you care for

Work with the person you care for to see how they can help themselves. Together you may be able to enable the person you care for to make some decisions about their care on their own, and identify times they can cope on their own. It is important to try to respect the opinion of the person you care for and help them have some control over their care. This could mean making sure their wishes are expressed to doctors, or letting them try activities on their own. You may find that this means taking a step back, or supporting decisions that are not what you would do. But this could help the person you are caring for feel respected and in control.

You may also find it helpful to talk about what support they would like from you. This may change over time, so it's worth revisiting this conversation.

Make a crisis plan

If you are concerned about what would happen if you become unwell, having a crisis plan in place can help to reduce stress (see 'Self-help resources' on p.28).

Thinking about the following things when you are well can help you feel prepared for a crisis:

- Discuss what will happen in an emergency with the person you care for, and agree a plan with friends, family or paid care workers.
- Write a list of who should be contacted in the event of an emergency and keep it somewhere easily accessible.

- Leave details about your caring responsibilities, such as medication you normally give and ongoing treatment the person you care for is having, and make sure someone else knows where this information is. This could be a friend, family member or health or social care professional.

How can I get help?

You may feel that you need additional help to cope with being a carer. There is a range of options available for getting help and support.

Peer support

It can help to talk to other people who have faced similar situations. Even if their experience isn't exactly the same as yours, finding common ground with other carers can make you feel less alone and isolated.

There are different ways that you can get in touch with others:

- Find a local carers group. You can find out what is available in your area by searching online, contacting NHS Choices' Carers Direct, your local Mind, or Mind Infoline for details of groups in your area. (See 'Useful contacts' on p.29.)
- Use an online forum or discussion group for carers, for example the Carers UK forum. (See 'Useful contacts' on p.29 and Mind's online booklet *How to stay safe online* for more information.)
- Get in touch with a carers' organisation or charity like Carers UK or Carers Trust. Organisations that deal with specific conditions may also provide support for carers. For example, some local Minds provide support services to people who care for someone with a mental health problem (see 'Useful contacts' on p.29).

●● Social media like Facebook has been really helpful to get emotional support from friends. I wish I'd have had Twitter when I was younger, it would have been a great way to vent frustration and talk to others in a similar place. ●●

Your GP

If you think you might need medical help or that you might be experiencing a mental health problem, the first step is usually to talk to your GP. They will be able to talk about treatment options, which could include talking treatments or medication.

Your GP should also be able to help you identify ways of getting support, including local carers' services and social care support.

Talking treatments

Talking treatments provide a regular time for you to talk about your worries and explore difficult feelings with a trained professional. You might find it particularly helpful to be given the space and time to talk about how being a carer affects you, without having to feel guilty for expressing parts that are difficult or frustrating. This can help you to deal with specific problems, cope with a crisis, improve your relationships or develop better ways of living. (See Mind's booklet *Making sense of talking treatments* for more information.)

Your GP or social services will be able to give you more information and tell you how to find a therapist. Therapists will also be able to tell you about the kind of support they offer and whether it will be useful to you. Talking treatments are free on the NHS, but their availability varies from area to area and waiting times can be long. Because of this, you may choose to see a therapist privately. The British Association for Counselling and Psychotherapy (BACP) lists registered private therapists on their website (see 'Useful contacts' on p.29).

Social care support

Social services can provide support to you and the person you are caring for. They may be able to provide practical support or put you in touch with a support group.

The kind of support you are offered will depend on your needs and the needs of the person you care for, but could include:

- equipment
- technology such as adapted telephones or monitoring devices which help people stay as independent as possible
- respite care (see below)
- professional care workers, sometimes known as 'home help'.

Carer's assessments

All carers have a legal right to a carer's assessment. This is how social services make decisions about the support you should have to help you provide care.

How to get a carer's assessment:

- You can ask social services, your GP or the doctor of the person you care for to organise an assessment.
- If the person you care for has a community care assessment, you should also be offered a carer's assessment automatically.

If your care responsibilities don't meet the criteria for this level of help, social services should still ask for your input when they carry out an assessment of the person you care for.

Respite care



You may be entitled to support to help you have a break from caring. This is known as respite care. It could happen regularly or as and when you need it. Respite might include:

- your local authority arranging for someone to take over your caring responsibilities for an agreed period of time
- support for you, from a local authority or charity, to take a holiday
- paying a professional carer to look after the person you support so you can have a break, for a long or short period of time.

If you have a carer's assessment, it should include information about respite care.

Some voluntary organisations also provide respite services. Your local Mind or social services will be able to give you more details. Further information is also available from NHS Choices' Carers Direct service (see 'Useful contacts' on p.29). You can find details of organisations offering breaks in Mind's online directory *Holidays and respite care*.

Respite care may also come from friends and family.

 *We coped with help from family as respite for a couple of hours. Accepting offers of help gave us an easier time.* 

Financial support

Financial benefits that are available for carers include:

- **a carer's allowance** – for carers of people with disabilities, who care for more than 35 hours a week and are not in full-time education
- **housing and council tax benefits** – some carers are eligible to receive money to cover some or all of the cost of their home, reductions in council tax and help with fuel costs.

The person that you care for may also be entitled to some benefits. They could choose to spend some of that money on care, so you may want to discuss this with them. These include:

- **personal independence payments (PIPs)** – available to people with a disability to help with day-to-day living and mobility costs

- **a personal budget** – this is a way of receiving money allocated by the council to help cover day-to-day living costs. It allows for some independence about how this money is spent. (For more information, see Mind’s online booklet *The Mind guide to personal budgets for social care*.)

Working out what benefits or financial support you’re entitled to can be complicated, and many carers don’t claim everything they’re entitled to. To find out what you might be eligible for, speak to a benefits adviser or use an online tool to check what’s available. (See Benefits Adviser and Citizens Advice in ‘Useful contacts’ on p.29.)

Support at work

If you are finding it hard to balance paid employment and your caring responsibilities, you can ask your employer if you are entitled to flexible working arrangements. This could include going part time, changing your working pattern or job-sharing.

The Equality Act 2010 protects you from being discriminated against or harassed at work because you are a carer. If you think you are being treated unfairly at work, you should seek specialist advice. You can contact Citizens Advice or Mind’s Legal Line for more information (see ‘Useful contacts’ on p.29).

Self-help resources

These sections are for you to print or download and fill out. Put them in a prominent place, like on the fridge, and look at them when you’re feeling stressed.

You may also want to share this information with other people who offer you support, so that they know what you’re doing as a carer and can recognise the signs if you are struggling.

Daily planning

Write down what you do each day, week or month. This could include things you do as a carer, and things you do for yourself.

| Example | As a carer | For myself |
|-----------|--|--|
| Every day | Cooking Giving medication Helping with getting dressed | 5 minutes of mindfulness Reading a book |
| Weekly | Driving to therapy Helping with coursework | Yoga class Carer's group |
| Monthly | Accompanying to doctor's appointment | Night out with friends |
| Other | Carer's assessment | Holiday |

How to cope as a carer

| | As a carer | For myself |
|-----------|------------|------------|
| Every day | | |
| Weekly | | |
| Monthly | | |
| Other | | |

Useful contacts

Mind

Mind Infoline: 0300 123 3393
(Monday to Friday 9am to 6pm)
email: info@mind.org.uk
web: mind.org.uk

Details of local Minds, other local services, and Mind's Legal Advice Line. Language Line is available for talking in a language other than English.

Be Mindful

web: bemindful.co.uk
Website explaining mindfulness. Gives details of local and online courses.

Benefits Adviser

web: gov.uk/benefits-adviser
Online calculator to help you work out what benefits you can claim.

British Association for Counselling and Psychotherapy (BACP)

tel: 01455 883 300
web: bacp.co.uk
Information about counselling and therapy. See sister website, itsgoodtotalk.org.uk for details of local practitioners.

Carers Trust

web: carers.org
Information and support for carers, including an online chatroom.

Carers UK

tel: 0808 808 7777
web: carersuk.org
email: advice@carersuk.org
Independent information and support for carers.

Citizens Advice

web: citizensadvice.org.uk
Advice on legal issues, money and other problems.

Mental Health Foundation

web: mentalhealthorg.uk
Information about mental health problems, including advice for carers.

National Institute for Health and Care Excellence (NICE)

tel: 0845 003 7780
web: www.nice.org.uk
A clinical standards body which provides evidence-based guidance on conditions and treatments for healthcare professionals and also for the public.

NHS Choices: Carers Direct

tel: 0300 123 0153

web: [nhs.uk/carersdirect](https://www.nhs.uk/carersdirect)

Information from the NHS on support available to carers.

Young Carers

tel: 0844 800 4361

web: [youngcarers.net](https://www.youngcarers.net)

Support and information for young carers.

Rethink Mental Illness

advice line: 0300 5000 927

web: www.rethink.org

Information for carers including a carer's assessment pack, message board and sibling support network.

Samaritans

Freepost RSRB-KKBY-CYJK

Chris PO Box 90 90

Stirling FK8 2SA

24-hour helpline: 08457 90 90 90

email: jo@samaritans.org

web: [samaritans.org](https://www.samaritans.org)

24-hour emotional support for anyone struggling to cope.

Time to Change

web: [time-to-change.org.uk](https://www.time-to-change.org.uk)

Mind and Rethink's anti-stigma campaign.

Further information

Mind offers a range of mental health information on:

- diagnoses
- treatments
- practical help for wellbeing
- mental health legislation
- where to get help

To read or print Mind's information booklets for free, visit mind.org.uk or contact Mind Infoline on 0300 123 3393 or at info@mind.org.uk

To buy copies of Mind's information booklets, visit mind.org.uk/shop or phone 0844 448 4448 or email publications@mind.org.uk

This booklet was written by Rachel Boyd

This booklet was funded by:

The Alchemy Foundation
The Astor Foundation
The February Foundation
The Kirby Laing Foundation

Published by Mind 2014 © 2014
To be revised 2017

ISBN 978-1-906759-91-9

No reproduction without permission
References available on request
Mind is a registered charity No. 219830

Support Mind

Providing information costs money. We really value donations, which enable us to get our information to more people who need it.

Just £5 could help another 15 people in need receive essential practical information booklets.

If you found the information in this booklet helpful and would like to support our work with a donation, please contact us on:
tel: 020 8215 2243
email: dons@mind.org.uk
web: mind.org.uk/donate

Mind
(National Association for Mental Health)
15-19 Broadway
London E15 4BQ
tel: 020 8519 2122
fax: 020 8522 1725
web: mind.org.uk

Mind

We're Mind, the mental health charity for England and Wales. We believe no one should have to face a mental health problem alone. We're here for you. Today. Now. We're on your doorstep, on the end of a phone or online. Whether you're stressed, depressed or in crisis. We'll listen, give you advice, support and fight your corner. And we'll push for a better deal and respect for everyone experiencing a mental health problem.

Mind Infoline: 0300 123 3393
info@mind.org.uk
mind.org.uk

