



For better
mental health

How to... cope as a carer



How to...

cope as a carer

This booklet is intended to help you while you are supporting a friend or relative experiencing mental health problems. It offers advice about how you can look after yourself and how to handle situations that may arise.



What is a carer?

A carer is someone who is responsible for providing or arranging care for someone else who cannot care for him or herself. The term 'carer' is usually used to describe people who provide unpaid care, rather than paid professionals, such as care workers and home helps.

Being a carer includes anything from giving emotional support through to providing extensive practical support to enable someone to live their life from day to day.

People who become carers include:

- parents
- children (whether adult or not)
- siblings
- husbands, wives and partners
- other relatives
- friends
- neighbours.

What's it like caring for someone with a mental health problem?



Caring for someone with a mental health problem can be more varied than for other carers. A person with mental health problems may not need much assistance at certain times, but need a large amount of care at others. And, as the symptoms of mental health problems are sometimes unpredictable, it can be particularly worrying.

Sometimes, it can also be hard to understand why someone needs caring for if they don't have a physical illness or disorder; it may be harder to understand what they are experiencing.

Being a carer can be both challenging and rewarding: it can be emotionally draining and can place significant demands on your time and energy; it can also give you a sense of satisfaction from helping someone else. There are a number of areas where you are likely to want support:

- emotional support
- practical support e.g. with day-to-day chores
- time-off (respite) from caring
- financial support
- involvement in planning someone's care, including recognition of your role and information about their treatment.

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How do I get emotional support?

There are various forms of support you can access as a carer. Both informal help and more organised groups and agencies can be useful.

Friends

It is important, as far as possible, to maintain your own social relationships while caring for someone. This may be difficult, as being a carer can take up much of your available time, but setting aside a certain amount of time a week to catch up with friends or take part in social activities will help you to relax and maintain your own wellbeing.



"Make time for friends no matter how exhausted or stressed you are. It's that contact with people who care and understand me – who will let me rant without judgement, let me cry if I need to, then make me laugh and smile – that keeps me going."

Other Carers

Many areas have support groups where carers can meet and there are a number of websites where you can post questions or read others experiences. You may find that joining a group that offers additional social support, such as a befriending service, may be useful (see 'Useful contacts' on p. 16).

Counselling

You may find that having a professional counsellor helps you in coping as a carer. A counsellor can, for example, help you to make sense of any parts of being a carer you find particularly difficult; they can give advice on how to resolve any conflicts you may experience with the person you are caring for or other people you have to deal with, such as doctors or social workers. The counselling process varies from one counsellor to another

– the type of support you get will depend on the particular problems you are facing and the counsellor's own style.

Your GP or social services will be able to give you advice on finding a counsellor. Counsellors will also be able to say whether the style of counselling they use is likely to be useful to you. For further information on types of counselling see the Counselling Directory in 'Useful contacts' on p. 16, or Mind's booklet *Making sense of counselling*.

Alternative therapies

You may find that using an alternative therapy is useful in helping you to relax or take 'time out' from being a carer:

- Aromatherapy uses essential oils and massage to relax the body and mind.
- Massage uses touch to try to promote a sense of wellbeing in the receiver.
- Yoga includes a range of physical and mental techniques that are intended to increase relaxation.

For further information and a register of alternative therapy practitioners, contact the Complementary and Natural Healthcare Council (in 'Useful contacts' on p. 16).

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What practical and financial support is available?

There is a range of practical support available to you as a carer. This is particularly the case if you have a carer's assessment or community care assessment carried out by your local social services. These are assessments of your needs as a carer and the needs of the person you are caring for. They set out what support you should receive. If the person you are caring for has severe mental health problems and is on a Care Programme Approach (CPA) you should also receive an annual assessment of what services you should be provided with and a written care plan. If you have not received this care plan, contact the care team of the person you are caring for.

If you have not received an annual assessment, contact social services, your GP or the doctor of the person you are caring for. They will be able to arrange it. Further information is also available from NHS Choices' Carers Direct service (see 'Useful contacts' on p. 16).

Respite

As a carer you may be entitled to support to have breaks. This can be a regular arrangement – such as your local authority arranging for someone to take over your caring responsibilities for one day per week – or a more occasional approach, such as paying for the person you are caring for to be looked after for a period of time so you can take a holiday. If you have a carer's assessment, it should include information on how often respite should be provided and what form it should take.

Some voluntary organisations also provide respite services; your local Mind or social services will be able to give further information. Further information is also available from NHS Choice's Carers Direct service (see 'Useful contacts' on p. 16) (Also see Mind's online booklet *The Mind guide to holidays.*)

Home support

You may find that a lot of your time as a carer is spent on dealing with routine tasks such as cleaning or helping with cooking meals. You may be able to get paid care workers (often known as 'home helps') to support you with this, enabling you to take a break. Further information on home support is available from NHS Choices' Carers Direct service (see 'Useful contacts' on p. 16).

Legal rights

As well as the **right to an assessment of your needs** as a carer (see opposite) you have some specific legal rights:

- **The right to receive direct payments.** These are payments given by your local authority to buy services or support to help you in your caring role. This can include support that is intended to maintain your health and wellbeing – such as private counselling, or a holiday so that you have time to yourself. Your local authority will be able to advise you on what payments you are entitled to. Further information is also available in the *Mind guide to Personal Budgets*.
- **Equal opportunities.** Under the Carers (Equal Opportunities) Act you have the right to not be disadvantaged because you are caring for another person. In particular, this means that it is your local authority's responsibility to tell you about your rights, take into account your work, education and leisure needs, and co-operate with other agencies (such as housing, education or the NHS) to provide assistance.
- **Employment.** In some circumstances you may have the right to request flexible working arrangements (for example, changes to hours or part-time working) to enable you to more easily carry out your caring responsibilities. Your employer does not have to grant your request, but must

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consider it sensibly and give clear reasons why they are unable or choose not to do so. Your local Citizen's Advice Bureau, or your trade union (if you are a member), will be able to provide advice on how best to make requests. Further information is also available from Acas (see 'Useful contacts' on p. 16).

Benefits

As well as direct payments (see 'legal rights' p. 7) you may be entitled to receive carer's allowance. This is a regular payment intended to help with your living expenses. You may be able to get carer's allowance if you spend at least 35 hours a week caring for someone and are on a low income. Your local JobCentre Plus will be able to advise you on how to apply.

Depending on your personal circumstances, you may also be eligible for other benefits:

- Income Support/Pension Credit
- National Insurances Credits/Home Responsibilities Protection
- Working Tax Credit
- Child Tax Credit
- Health benefits such as free prescriptions
- Council Tax Benefit
- Housing Benefit

Many carers find financial worries particularly stressful. It is important to ensure that you claim benefits you are entitled to, and that the person you are caring for also does so. Your local Citizens Advice Bureau will be able to give more advice on what you are entitled to claim. Further information on benefits is also available from www.direct.gov.uk

How do I ensure I am involved in the care plan?

Information sharing and confidentiality can be a complicated area. It is likely that you will want to know as much as possible about the treatment and care the person you are caring for is receiving from professionals within the NHS or other agencies such as social workers. How this happens depends on whether the person you are caring for wants you to be informed.



The person I'm caring for wants me to know how they are being treated

If this is the case, then it is important to ensure that the professionals, such as psychiatrists, other doctors or social workers involved in their care know this, so that you should be given all relevant information. The person you caring for, must tell them this.

The person I'm caring for may lose the 'capacity' to decide whether I should be given information

If you are caring for someone now and it is possible or likely that they will not be able to make decisions in the future, you may wish to suggest to them that they make an Advance Statement. An Advance Statement is used if a time comes when someone is judged to lack the capacity to make decisions for themselves. It will indicate how they want things to be done. Capacity is determined by the medical staff treating the person.

The Advance Statement can be a simple, signed statement explaining that they wish to nominate you as someone who can be informed about their treatment and, if necessary, make decisions for them. It can also be used to describe particular treatments the person does or does not want. It can be used should professionals require evidence that you are entitled to information. It can be helpful, and avoid worry for both of you,

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if an independent person such as an advocacy worker (see UKAN in 'Useful contacts') or solicitor witnesses this statement. They will be able to advise you on the exact wording.

If the person you are caring for does not have capacity to say that you should be informed and has not completed an Advance Statement naming you, it is a decision for the medical staff treating the person, as to what information you should have access to. The medical staff have a legal responsibility to take decisions that are 'necessary' in the best interests of the patient. It may help if you ask the medical team to explain to the person you are caring for, why they are doing this.

The person I'm caring for doesn't want me to be informed

If the person you are caring for does not consent to you receiving information about his or her care or treatment, you will only be given general information. For example, you might be given information about the type of mental health problem the person you are caring for has been diagnosed with, but not details of the treatment.

It is 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 the psychiatrist or other medical staff involved. They will then decide whether you should be given information without the agreement of the person you are caring for. While this may be distressing, you should not be expected to provide care without essential information.

What do I do when someone doesn't want to be helped?



If the person with mental health problems you are caring for does not accept that they need help, or is unwilling to take help that is offered, there could be a number of explanations for this.

- They could be worried about talking to professionals such as doctors, in case they might be treated against their will.
- They may be embarrassed or ashamed to seek help for a mental health problem due to the stigma often attached to it.
- They may have cultural reasons discouraging them from seeking support.
- They may not realise or understand that they are experiencing a mental health problem.

In all cases, it is important to think about why the person might not want help. You may then be able to help them get a kind of support that is suitable for them. There are a wide range of potential treatments for mental health problems that someone may be willing to accept if you are able to discuss it with them. See if they can explain what they think is happening, and what they think would help them.

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How do I maintain a positive relationship with the person I am caring for?

While, usually, the person you are caring for will accept that they need help and support, it is important, and sometimes difficult, to maintain a positive relationship between you.

Where possible, it is useful to explain to the person that you are helping them because you care about them – not because you want to be 'bossy' or controlling.

Also, when they are well enough, you could consider discussing your needs and feelings. Try to talk honestly with the person about how you feel, particularly if there are times when you feel especially tired or stressed. This can also help the person with a mental health problem understand that you care and are trying your best.

People with mental health problems often find dealing with change or the unexpected difficult. If you know that there are going to be changes to their routine – such as a new home help or a change in an everyday activity, such as food shopping – it is useful to explain what will be happening in advance. It is also a good idea to discuss what will happen if you are unexpectedly unavailable one day; for example, through being ill yourself.

Remember that it is natural to wish that the person did not have a mental health problem and, particularly if you knew them before symptoms developed, want them to return to 'normal'. This does not mean that you resent them.

What do I do in an emergency?

There are a number of difficult situations that you might face as a carer. While it is unlikely that you will have to face many of them, it is normal to feel worried about what might happen. If you are worried, it can be useful to think about what you might do if something happens. Then, if it does, you will be prepared.



"I find having an agreed plan of what I should do if my partner has a manic episode makes me less fearful and reassures him when he is well."



Threatened suicide

It is often said that people who talk about killing themselves don't actually do it. However, any threat of suicide should be taken seriously. Try to encourage your friend or relative to talk about their feelings. If the person has to be left alone, try and make sure they have some telephone numbers, such as the Samaritans or Maytree (see 'Useful contacts' on p. 16) they can use for support.

If you feel a situation is an emergency, and you are unable to get help from a GP or persuade the person to seek help themselves, you might want to consider compulsory admission to hospital. If you are the person's nearest relative, you have the legal right to ask your local social services authority to ask for an Approved Mental Health Practitioner (AMHP) to consider whether the person should be detained under the Mental Health Act. If you are not the nearest relative, you can still contact social services who should arrange for an AMHP to visit. (See *Mind rights guide 1: civil admission to hospital* for more information.)

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Violent behaviour

People's fears about mental distress often lead them to believe that those who are labelled 'mentally ill' are likely to be violent. This is very seldom the case, but violence can occur. Nobody should have to live with violence or the threat of it.

Generally, it is best to remove yourself from a potentially violent situation. If you think violence is possible, it's worth considering what you would do if it happens. Have a practical escape plan worked out, such as leaving quickly for a neighbour's house.

It may be necessary to use the law to protect yourself. Compulsory admission to hospital or an injunction denying someone access to your home are possibilities. The Mind Legal Advice Service, a Citizens Advice Bureau or a law centre can give advice (see 'Useful contacts' on p. 16).

Going missing

If the person you are caring for goes missing, and you think they are at risk, don't be afraid to make a fuss. Contact everyone who might be able to help. Let the Police know and emphasise to them that you think the person is at risk of harm.

How else can I help myself?

It is important to look after yourself as well as using other services to help you as a carer.



Some things to consider are:

- **Plan your time** carefully to ensure you have breaks, whether they are formal respite time or not (see 'Friends' on p. 4)
- **Develop your understanding of the condition(s)** that the person you are caring for has. It is often less stressful or worrying to be a carer for someone with a mental health problem when you have an understanding of what they are facing. If they have a diagnosis, you might want to read about the condition, e.g. in Mind booklets. Remember to be careful you get information from a reliable source – some websites may not be accurate.
- **Maintain your own interests.** As well as any 'organised' activities like work commitments, education or social groups, try to make time for things you are interested in e.g. reading the newspapers, or arts and crafts. While this can be difficult if most of your time is taken up caring, the chance to relax, even briefly, can be helpful.
- **Looking after your own physical health** – it is important to try to get exercise, get outdoors when you can, and eat a healthy varied diet.

"If you don't look after yourself, then you will not be able to look after anyone else."



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Useful contacts

Mind

Mind infoline: 0300 123 3393 (Monday to Friday 9am to 6pm)

email: info@mind.org.uk

web: www.mind.org.uk

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

Acas

web: www.acas.org.uk

Information on rights at work, including flexible working

Carers UK

tel. 0808 8808 7777

web: www.carersuk.org

Independent Information and support for carers.

Citizens Advice

web: www.citizensadvice.org.uk

Provides advice on legal, money and other problems

The Counselling Directory

tel. 0844 8030 240

web: www.counselling-directory.org.uk

Information on counselling and a list of registered counsellors

Complementary and Natural Health Council

tel. 020 3178 2199

web: www.cnhc.org.uk

A register of complementary and alternative health practitioners

Law Centres

tel. 0845 345 4 345

web: www.lawcentres.org.uk

Free legal advice and representation for disadvantaged people

Maytree

tel. 020 7263 7070

web: www.maytree.org.uk

A respite centre for anyone feeling suicidal

MDF the Bipolar Organisation

tel. 020 7931 6480

web: www.mdf.org.uk

Support for people with bipolar, their families and carers

National Institute for Health and Clinical Excellence

web: www.nice.org.uk

Evidence-based guidance on treatments

NHS Choices: Carers Direct

tel. 0808 802 0202

web: www.nhs.uk/carersdirect

Information from the NHS on support available to carers

The Princess Royal Trust for Carers

tel. 0844 800 4361

web: www.carers.org

Information, advice and a network of carers' centres

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Rethink

tel. 0845 456 0455

web: www.rethink.org

Have a carer's assessment pack which is designed to help carers, advisors and professionals identify carers' needs

Samaritans

tel. 08457 90 90 90

textphone: 08457 909 192

email: jo@samaritans.org.uk

web: www.samaritans.org.uk

24-hour emotional support

United Kingdom Advocacy Network (UKAN)

tel. 0114 272 8171

web: www.u-kan.co.uk

Further information

Mind offers a range of mental health information, covering:

- diagnoses
- treatments
- wellbeing

Mind's information is ideal for anyone looking for further information on any of these topics.

For more details, contact us on:

tel. 0844 448 4448

email: publications@mind.org.uk

web: www.mind.org.uk/shop

fax: 020 8534 6399

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 would like to support our work with a donation, please contact us on:

tel. 020 8215 2243

email: dons@mind.org.uk

web: www.mind.org.uk/donate

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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.
- Whether you're stressed, depressed or in crisis.
- We'll listen, give support and fight your corner.



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