



For better
mental health

How to... cope as a carer



How to... cope as a carer

“““

“I felt my life was slowly being eaten up; she seemed to need more and more help, and there was only me. Eventually, I realised I was important too – I had to work out a way of keeping a balance.”

“I didn’t know the first thing about what he was going through, and there didn’t seem to be anything that I could do that could take away the pain he was feeling inside.”

This booklet is intended to help you give emotional and practical support to a friend or relative experiencing mental health problems. It offers advice about handling difficult situations that may arise, and suggests ways of looking after yourself.



What's the best way to give someone support?

Helping someone who's in mental distress can range from giving them emotional support (by listening to them and showing them appreciation, for example) to providing them with the practical help they need to live their lives from day-to-day.

Listening

People who are feeling bad often have a need to talk to someone about what they are experiencing. All too often, others find it hard to listen. Instead, they interrupt to talk about themselves or to tell the person what they should do or how they should feel.

If you can listen well, the person may be able to talk in a way that could help them feel better. They may express emotions in a physical way: by crying, or getting flustered and agitated, or even by laughing.

Releasing feelings in this way may help them to be more relaxed and to think more clearly. You may need to offer reassurance and encouragement ('I want to hear about it', 'It's good that you're crying'). Asking the right questions can help people to reach the most important things ('What's really bothering you?', 'Why do you think you are feeling like this?').

Listening well does not always mean keeping quiet, but it does mean thinking about how you can help the other person to open up and talk. It's not easy to listen well, but it's always worth making the effort. It can make a significant difference to someone you want to help. It could be that the person you want to help may feel too depressed, scared or untrusting to talk. You can still let them know that they are welcome to talk to you, if and when they want to.

Appreciation

We can all benefit from receiving praise. This particularly applies to someone who has lost their self-confidence. A person who has been used to leading a normal life can find it difficult to give themselves credit for small, but important achievements, such as taking a quarter less of a tranquilliser or travelling a mile on a bus. Successes such as these need to be recognised for what they are: brave and significant steps on the road back to recovery. Appreciation from you may help them to feel good and be ready to make more progress.

Touch

Being touched may help someone feel safe, secure and loved. It can also help bring buried feelings to the surface; a warming hug can turn tension into tears. Unfortunately, some people may have had such bad experiences of being touched that they find this contact difficult. This is particularly true for women who have been touched by men in ways they have not wanted.

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If you can find ways of touching that feel right for both of you, it can be relaxing and reassuring. You might hold the person's hand while they talk, or touch their arm when you say good-bye. You could learn to give a massage to the head, feet, hands or shoulders, where tension builds up. Local colleges may run suitable courses.

Laughter

We feel better after a good laugh, and this applies as much to people who are mentally distressed as to anyone else. You don't always have to be serious to show that you care. Sometimes it's best to do something that helps people forget about their problems for a while. You could go to a film you know they will enjoy, or remind your friend of amusing things you did together. Being light-hearted is different from trying to force someone to 'pull themselves together', which is never useful.

Practical help

Someone who is feeling bad can find it difficult to do day-to-day tasks like shopping, cooking, cleaning and paying bills. A period of mental distress can create extra work, such as sorting out social security payments. It can be a great relief to have some help from someone, and this can be the best way of showing them you care. But it's important not to take over, and leave the person feeling even more inadequate. So do things together.



What can community care do for me?

For more than thirty years, there has been a policy of slowly closing down the old mental hospitals and replacing them with community care. As much as possible, people experiencing mental distress stay in their own homes.

They use local services such as crisis services, counselling, drop-in or day centres, self-help groups and community mental health nurses. Some of these services are provided by social services or your local health authority, others are provided by voluntary organisations.

There are many benefits to community care but, unfortunately, not enough money has been spent on providing new services. This means that the family of someone experiencing mental distress can be left to do most of the caring that used to be done by paid workers. People do not always want to take this on. It's not always good that they do, either for themselves or the person they are caring for. On the other hand, if you do want to care for someone, it can be easier if they are still living at home or nearby, rather than in a hospital many miles away.

The person you care for may have an assessment of their social and health care needs under The NHS and Community Care Act 1990. This should give them a care plan, a care co-ordinator and a regular review of their requirements and the services they are receiving. (If the person you care for has not been assessed, but would like to be, they could ask their GP to refer them to the local mental health team.

There are now two acts that acknowledge the huge amount of work carers do. The Carers Recognition and Services Act 1995 means that carers can have their own physical and mental health care needs taken into account, when services are planned for the person they care for. The Carers and Disabled Children Act 2000 gives you a right to this assessment, whether or not the person you care for is assessed. It allows services to be provided to you directly. There may be a charge for these services, depending on your financial situation. It shouldn't be assumed that you want to go on providing the person you care for with the level of help you do now.

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As a result of the assessment, you may be offered practical help, a break from caring and other services. You may also get help in contacting other carers in a similar situation. You may be entitled to Direct Payments, which free you to arrange services yourself, and Vouchers that allow you to have a regular break from caring, or a holiday for a specified period. (For more information, consult *Useful organisations*, on p. 12, and *Further reading*, on p. 14.)



How can I cope with the pressure of being a carer?

Caring for someone with mental health problems can be a difficult and painful experience. It takes up time, often the time when you should be relaxing and resting, and can be emotionally draining. It can also be very rewarding. You need to get all the support you can. No-one should be expected to do it alone.

It's important to think about your own needs (and to acknowledge how important and difficult the job is), especially if you are used to putting someone else first. Here are some suggestions:

- Involve as many people as possible. For example, if the person is in hospital, arrange a rota of visitors on different days. You could then meet up with them, regularly, to discuss how you feel and what you want to do.
- Don't be afraid to risk appearing selfish. If the person you're caring for is usually the person you go out with, don't feel you can't go out, because they are too afraid or depressed to do so. If you want a holiday, and the person can't be left alone, you may be able to arrange for them to stay in a hospital or hostel while you are away. Talk to your social worker or GP about respite care (see above).

- You will find things easier if you have someone to talk to. It can be particularly useful to talk to people who are in a similar situation to yourself. Your Community Health Council, Patient Advice and Liaison Service (PALS), local Mind or social services should know if there is a nearby carers' group, or may help if you want to set one up. There are many organisations offering support to carers of people with mental health problems.
- Consider talking to your GP, a social worker or a counsellor. Your GP may be able to refer you to a counsellor, or counselling may be offered by local voluntary organisations.

Watching someone you love suffering may be highly frustrating, as well as painful, especially if you feel they are not being offered enough help from doctors, social workers and others, who are there to provide a service. It may be particularly difficult if the person concerned feels they don't want help, but behaves in ways that cause problems for them and possibly for you, too.

How can I ensure someone gets the best treatment?

Because of the shortage of good mental health services, people are often offered the treatment that is most readily available, which is not always the best. This often means being given drugs rather than the chance to talk to someone who can help. If you think different treatments should be offered, it's worth asking any person or organisation that can give you advice or alternatives.



Advocacy

This simply means helping your friend, relative or partner to tell the professionals involved in their care what their needs and views are. It may involve helping them stand up for their rights: rights to decent treatment, to the welfare benefits they are entitled to, and so on. You need to be supportive without taking over.

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As someone who is offering support, you should expect to be informed by mental health workers about what is going on, and to tell them what you think. However, some matters will be confidential between your friend or relative and the mental health worker, unless the person you care for agrees you can be told.

If you have an assessment under the Carers' Acts, this should be an opportunity for you to talk to the workers involved about your own concerns and needs in this situation.

You may want to help the person you are caring for make a complaint about the way they have been treated. If you need advice, try your local Mind group or Citizens Advice Bureau, or Mind's Legal Unit, contactable via MindinfoLine. (See *Useful organisations*, on p. 12, for details.) Your local Community Health Council or PALS can help if your complaint is about the health service.

Sometimes, the best option may be to get help from an advocate who is not directly involved in the person's care. For further information about the different types of advocacy, see *The Mind guide to advocacy* (details under *Further reading*, on p. 14) or contact MindinfoLine.



How can I encourage someone to help themselves?

People experiencing mental distress may feel as if they have no power over their own lives. It may seem as though they are at the mercy of feelings they can't control. They might not know what they can do about this. But, if other people then tell them what they should do, and make decisions on their behalf, it only makes things worse.

Empowerment

Empowerment simply means helping people to regain a sense of being in charge of their lives. One way of doing that is to try and help them to think about what they want, rather than tell them what to do. You can do this by asking questions, or you can make suggestions, or say what you think and ask for their response. You can involve your friend, relative or partner in your own decisions about caring, by asking them how they want you to care for them.

Self-help groups

Another way people who are mentally distressed can feel powerful is by helping each other, rather than just relying on professional workers. You could find out about local self-help groups for people who have similar problems, and see if your friend or relative is interested in joining. People who have had experience themselves are very often the most willing and understanding carers. (Using the list of *Useful organisations*, on p. 12, you may be able to find out about groups in your area. Alternatively, you could call *MindinfoLine*).

Resolving relationships

If you have a close relationship with someone in mental distress, perhaps as their parent, wife or husband, then it's important to recognise that there may be problems between you that need to be sorted out. If you are willing to do this, it may help the person to feel that it's possible to change things for the better. This could make them feel more powerful. If you would like help with this, you could contact an organisation, such as *Relate*. (See *Useful organisations*, on p. 12, for more information.)

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You could also try family therapy, which helps families to sort out their relationships with each other. If you and your relative are interested in this, you should talk to your GP or social worker who may be able to arrange it for you.

Advance directives

If appropriate, it can be very useful to talk to the person, in advance, about what they would like to happen if they experience a period of mental distress. You could talk to them about writing an advance directive, which means setting out what treatment they would and wouldn't want, if an emergency situation arose.



What should I do if there is an emergency?

There are a number of difficult situations that you might face as a carer. Even if they never happen, if you're worried that they might, it's a good idea to work out what you would do, beforehand. Then, if they do happen, you will be prepared to handle them.

Threatened suicide

It's often thought that people who talk about killing themselves don't actually do it. This is not true. If someone is threatening suicide, take it seriously. Often, people who are suicidal are angry, but can't express their anger, so they turn it in on themselves. Try and find out if your friend or relative is feeling angry. If they are, encourage them to talk about it. If the person has to be left alone, make sure they have some numbers, such as the Samaritans, they can contact for help. (See *Useful organisations*, on p. 12, for more information.)

If you feel it's an emergency, but the GP says they can't help and your best efforts can't persuade the person to seek help themselves, you might think about compulsory admission to hospital (see p. 12). Caring for someone who feels suicidal is extremely stressful, and you may want to talk to the Samaritans yourself, as they also give advice and support to carers. (See also Mind's booklet *How to help someone who is suicidal*, details on p. 14.)

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. If you think there is the possibility of violence, it's worth working out what you would do, in advance. Generally, it's best to remove yourself from a potentially violent situation. Have a practical escape plan worked out, just in case (arrange to run to a neighbour's house or flat, if necessary).

It may become necessary to use the law to protect yourself. One possibility is compulsory admission to hospital. If you want to stop someone who has been violent from entering your home, you could try taking out an injunction, which denies them access. Mind's Legal Unit, a Citizens Advice Bureau or a law centre can give advice. (See your telephone directory for phone numbers.)

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. Usually, it's worth letting the police know, as they are often the first to come across someone who is in a distressed state. You could also contact the casualty department.

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What is compulsory admission to hospital?

Under the Mental Health Act 1983, someone can be compulsorily detained in hospital for their own health or safety, or the protection of others. Powers granted under the Mental Health Act should only be used as a last resort. Unfortunately, it's sometimes necessary.

Applications for compulsory admission are usually made by social workers approved under the Act. The 'nearest relative', as defined under the Act, has the legal right to ask for a social worker to visit and assess whether admission is necessary. The nearest relative can also apply to the hospital managers for compulsory admission. The application must be supported by two medical recommendations (or one, if it's an emergency).

As a carer, you might also be in the position of wanting to stop someone from being compulsorily detained. Some sections of the Act require the social worker to seek the agreement of the nearest relative, before admission, so this may provide an opportunity. For more information about this, see *Getting the best from your Approved Social Worker*, and *Mind rights guide 1*. (For details, see *Further reading*, on p. 14.)

Useful organisations

Mind

Mind is the leading mental health organisation in England and Wales, providing a unique range of services through its local associations, to enable people with experience of mental distress to have a better quality of life. For more information about any mental health issues, including details of your nearest local Mind association, contact the Mind website: www.mind.org.uk or Mind*in*foline on 0845 766 0163.

Carers UK

20–25 Glasshouse Yard, London EC1A 4JT
carers line: 0808 808 7777, web: www.carersonline.org.uk
Information and advice on all aspects of caring

Careline

326–328 High Road, Ilford, Essex IG1 1QP
counselling line: 020 8514 1177, web: www.carelineuk.org
Crisis telephone counselling service for children, young people and adults on any issue, including depression

Relate

Herbert Gray College, Little Church Street, Rugby CV21 3AP
tel. 0845 456 1310 or 01788 573 241, web: www.relate.org.uk
Offers counselling for adults with relationship difficulties

Samaritans

The Upper Mill, Kingston Road, Ewell, Surrey KT17 2AF
helpline: 08457 90 90 90, fax: 020 8394 8301
textphone: 08457 90 91 92, email: jo@samaritans.org
web: www.samaritans.org
24-hour telephone helpline

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Further reading

- The burden of sympathy: how families cope with mental illness*
D. A. Karp (OUP 2001) £10.99
- Children caring for parents with mental illness: perspectives of young carers, parents and professionals* J. Aldridge, S. Becker
(Policy Press 2003) £19.99
- Getting the best from your approved social worker* (Mind 2001) £1
- How to assert yourself* (Mind 2003) £1
- How to cope with loneliness* (Mind 2002) £1
- How to help someone who is suicidal* (Mind 2002) £1
- How to increase your self-esteem* (Mind 2003) £1
- How to look after yourself* (Mind 2002) £1
- How to recognise the early signs of mental distress* (Mind 2002) £1
- How to restrain your violent impulses* (Mind 2002) £1
- How to stop worrying* (Mind 2003) £1
- Keyfacts: dangerousness* (Mind 2000) £5.50
- Living with mental illness: a book for relatives and friends*
E. Kuipers, P. Bebbington (Souvenir Press 1997) £9.99
- Making sense of herbal remedies* (Mind 2000) £3.50
- Making sense of homeopathy* (Mind 2001) £3.50
- Making sense of traditional Chinese medicine* (Mind 2001) £3.50
- Mental Health Act 1983: an outline guide* (Mind 2002) £1
- Mental illness; a handbook for carers* eds. R. Ramsay, C. Gerada, S. Mars, G. Szmukler (JKP 2001) £15.95
- The Mind guide to advocacy* (Mind 2000) £1
- The Mind guide to managing stress* (Mind 2003) £1
- The Mind guide to relaxation* (Mind 2001) £1
- Mind rights guide 1: civil admission to hospital* (Mind 2003) £1
- Understanding anxiety* (Mind 2002) £1
- Understanding dementia* (Mind 2002) £1
- Understanding depression* (Mind 2003) £1
- Understanding mental illness* (Mind 2003) £1
- Understanding talking treatments* (Mind 2002) £1

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Mind works for a better life for everyone with experience of mental distress

Mind does this by:

- advancing the views, needs and ambitions of people with experience of mental distress
- promoting inclusion through challenging discrimination
- influencing policy through campaigning and education
- inspiring the development of quality services which reflect expressed need and diversity
- achieving equal civil and legal rights through campaigning and education.

The values and principles which underpin Mind's work are:
autonomy, equality, knowledge, participation and respect.

For details of your nearest Mind association and of local services contact Mind's helpline, *MindinfoLine*: **0845 766 0163** Monday to Friday 9.15am to 5.15pm. Speech-impaired or Deaf enquirers can contact us on the same number (if you are using BT Textdirect, add the prefix 18001). For interpretation, *MindinfoLine* has access to 100 languages via Language Line.

Scottish Association for Mental Health tel. 0141 568 7000

Northern Ireland Association for Mental Health tel. 028 9032 8474

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