

Caring for yourself.

**Self-help for families and friends supporting
people with mental health problems.**



Caring for Yourself contents

Caring for Yourself is a self-help workbook for family and friends supporting people with mental health problems.

It is in eight parts. Each covers a different topic:

Booklet 1 Introduction

Booklet 2 Being a carer

Booklet 3 Information

Booklet 4 Communication skills

Booklet 5 Problem solving and goal achievement

Booklet 6 Relapse management and staying well

Booklet 7 Recovery and hope

Booklet 8 Taking care of yourself

Quick guide icons

Throughout *Caring for Yourself*, you will see these picture icons to illustrate different sections.



**Question /
To think about**



**Stories /
case studies**



Exercise



**Action /
things to do**



**Information
and resources**

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Introduction to Caring for Yourself

Rethink Mental Illness and the Meriden Family Programme have created *Caring for Yourself* to help people with mental health problems and carers, family and friends. It is for you if you support someone with any mental health condition. You may have a relative struggling with anxiety, depression or bipolar disorder, a friend with psychosis, schizophrenia or a personality disorder. Whatever the diagnosis, *Caring for Yourself* can help you to develop skills and new ways to cope.

You can use *Caring for Yourself* in two ways:

- Use it yourself independently.
- Use it as part of other training programmes for carers such as the Rethink Mental Illness 'Caring and Coping Programme' or the Meriden Family Programme's 'Caring for Carers' training.

Whichever way is best for you, you can work through it at your own pace, in your own time. Start with Booklet 1, then plan how to use the other booklets and in which order you want to use them.

Everything in *Caring for Yourself* comes from the experiences of others who have cared for people with mental illness or from professionals. There are exercises and activities to help you develop skills to help you cope with your situation, whatever that is.

You will find information about:

- Being in a caring role.
- Taking care of yourself.
- Getting your own life back.
- Finding information about what your relative or friend is going through.
- Dealing with problems.
- Talking about what is going on.
- Supporting your relative or friend.

We hope the exercises and activities will help people who cannot attend training courses or support groups. If it helps you, please get in touch. We want to know how we can help more people who are supporting a relative or friend with a mental health problem.

Gráinne Fadden
Director
Meriden Family Programme

Paul Jenkins
Chief Executive
Rethink Mental Illness

Booklet 6: Relapse management: developing a 'staying well plan'

This booklet introduces the idea that it is possible to notice when someone is becoming unwell and that by noticing the signs that this is happening early on, it is possible to minimise the likelihood of relapse and to help the person stay well. It goes on to help you identify the signs that your friend or relative is becoming unwell and to develop a plan of action so they, and you, know what helpful actions to take.

Before you start, some things to bear in mind

Before going into detail, it is worth thinking about how to use this part of *Caring for Yourself*. It includes activities that ask you to think about the last time the person you care for was unwell. It can be upsetting to remember how difficult things were at the time, particularly if things are going well at the moment. It can also be difficult to think about the fact that your friend or relative may become unwell again in the future. However we know that by recognising the signs that someone is becoming unwell, we can learn how to take action or to ask for help from others so that serious relapse can be averted or avoided. **It is possible for someone to become well and stay well.** Before looking at the rest of this section, it may be helpful to think about the following:

- **When was the last time your family member or friend was unwell?**
- **How long ago was it – very recent or some time ago?**
- **How do you feel when you think about what happened?**
- **What was the response from mental health services like?**
- **How would the person you are caring for approach this section?**
- **Can you do this together?**

As mentioned above, it may be hard to think about the last time your relative or friend was unwell. At the time you may have felt frightened, confused, worried, angry or upset about what was going on. Recalling this and the events around that time may be difficult. It may be helpful to read the following chapter with a friend, relative, carer support worker or another member of your carers' group if you belong to one. Going through this booklet with some company, especially your relative or friend, will help you both feel more in control. Together you may feel more confident that if early signs are picked up you will be able to take action to prevent things escalating.

However, if you find it very distressing or it feels too raw, then it may be helpful to wait until you are feeling stronger. Furthermore, if you don't feel confident in getting support from mental health services in a crisis, it may be helpful to focus on establishing a support network first. You could do this through carers' online networks and talking with others who are in a similar position, or through carer groups such as those run by Rethink Mental Illness. Having done this, you can then look at early warning signs and relapse planning with the support of both family/friends and mental health services. Booklet 3 of *Caring for Yourself* helps you collect information on your local mental health resources. Other sources of support might be:

- Friends or other family members.
- Your GP.
- Local carers services.
- Rethink Mental Illness and Mind.

6.1 What are early warning signs?

The term Early Warning Signs means just that – early signs that someone who has previously experienced a mental illness is becoming unwell again (relapsing). People who experience mental health problems don't become unwell out of the blue. It may well have felt like that the first time your friend or relative experienced an episode of psychosis or depression. It may still feel like that if your family member or friend has experienced a number of episodes where they have been unwell.

However, there are *always* signs that the difficulties are returning and these signs are similar in many mental health issues. They can occur at least a week, or sometimes several weeks, before a relapse. Some signs are common and others are very individual. Your friend or family member is likely to have signs that are the unique to them. In this way they are a bit like a fingerprint or a signature. These signs show that the person is under stress and at risk of relapse. You may have spent some time reading Booklet 3 which shows how stress is related to mental health problems.

The chances of relapse can be reduced if the early signs of the person becoming unwell are recognised and acted upon. That is why this is also referred to as 'staying well' planning. It is possible to prevent a relapse if the early warning signs are recognised and appropriate support is found in time. So, knowing the signs that your friend or relative is becoming unwell, noticing them and having a plan of action is important for your friend or relative and you in supporting them to manage their mental health issue.

Common early warning signs are:

- Sleeping much more or much less than usual.
- Eating much more or less than usual.
- Feeling anxious.
- Pain in muscles due to tension.
- Being irritable or snappy.
- Avoiding family, friends and other social or work activities.

Signs that can happen, sometimes a bit later can include:

- An increase in symptoms (for example hallucinations).
- Being suspicious.
- Getting the wrong impression or being frightened of being talked about.

Another set of signs are very particular to the individual (idiosyncratic). These signs are those that are unique to your relative or friend. Family and friends and others who know the person well are likely to notice these more than professionals, as they are in more contact with the person. You might notice changes in your friend or relative's behaviour, appearance or activities. For example he or she might start eating in a particular way, reading a particular book or talking about some topics. It could be something as simple as a particular expression on their face that you recognise. Your friend or relative will also be aware of things themselves that they notice happening, so it is good if you are able to talk together about the things that you both notice. In that way, you have a better chance of noticing things really early on.





The following is an example of how a young woman, her partner and a friend identified her early warning signs.

Linda

Linda had experienced an episode of severe depression after being made redundant. After seeing a psychiatrist, as well as a clinical psychologist, taking medication and having weekly visits from her community nurse, Linda began to feel well enough to do some voluntary work in a charity shop. However, around Christmas time, worries about money and an argument with a friend led to her becoming unwell again.

After her recovery the following year Linda, her partner, Cheryl and a close friend Maureen spent some time thinking about the weeks before Linda became unwell. It was difficult, particularly for Linda and Cheryl, to think about what had been a very painful episode in their life together. However, they thought it might be helpful to have an idea about what to do if Linda were to experience depression again. Together Cheryl, Linda and Maureen remembered that just before her relapse Linda had become very withdrawn.

She would spend more time in her bedroom and avoid going out with both Cheryl and Maureen. Maureen thought that Linda was snappier than usual, but the other two did not agree with this. They all agreed that Linda became less concerned about her appearance and would sometimes avoid having a bath or shower. Cheryl also remembered that Linda would seem slowed down and sleep more. In the end they all agreed the following signs might show that Linda was becoming depressed again:

1. Spending more time in the bedroom.
2. Avoiding having a bath or shower.
3. Sleeping more.

Before going on to activities to help you identify early warning signs, it might be useful to recap on the advantages, as well as any worries you might have about doing this work.

6.2 How might this be helpful for me?



Advantages

What advantages can you think of for identifying signs that your friend or relative is becoming unwell?

What advantages might there be for having a plan that can help them stay well?

There are a number of things that are positive about identifying early warning signs and drawing up a 'staying well' plan, and they are:

- A relapse may be prevented if early warning signs are noticed and acted upon appropriately (relapse stopped).
- Noticing and acting on early warning signs can reduce the chances of a serious relapse (a shorter or less severe relapse).
- You are taking some control in circumstances where you and your friend/relative may feel you have very little.
- If you have a plan you have agreed with your friend or relative beforehand, this may avoid disagreements about what has to happen when/if they show these signs.
- It also means that you don't have to think too hard about what needs to happen at a time that may be very stressful.
- It may make it easier to communicate your concerns clearly to professionals involved in the care of your relative or friend.
- It's a bit like having car insurance – you might never need it but if you do, you'll be glad you have it.



Concerns

What are the difficult things about identifying signs that your friend or relative is becoming unwell?

What are your concerns or worries about having a plan for when/if they relapse?

You may have concerns about getting it wrong. Or, if you're doing this with your friend or relative or other family members, you may worry that you will disagree over what an early warning sign is. The person with the mental health problems may feel that they are being observed or monitored all the time. Also, a relapse plan often involves contacting your GP or local mental health services and you may have concerns about this – it can feel uncomfortable, like you're telling on someone. If children are involved, there may be additional worries such as being taken into care if a parent has to go back into hospital.

Some things to bear in mind are:

- There are no right or wrong signs. However, you may notice that some signs happened more often and for longer and these are ones to look out for in the future.

6.3 Identifying early warning signs



- If your friend or relative still has a relapse (even though you have done some work on early warning signs), it doesn't mean you have failed. It means that it can take some time to become familiar with the mental health issues your friend or relative experiences. Perhaps the relapse was inevitable but your work helped lessen its impact?
- You may all remember different things about the past, and so you may disagree. This can happen, as people often remember things in their own way. However, the chances are you will all be able to find two or three signs that you can agree on.
- Making a plan whilst your friend or relative is well, and agrees to your contacting services if they don't feel able to, may give you permission to do this. This may make it less likely that you feel guilty and they feel less resentful or angry about you contacting services.
- Getting help and support early is important, as it may help you and your friend or relative avoid the things you are most concerned about. That could be admission to hospital, involving lots of other people or needing to contact a social worker for support with the children.
- For some people having a clear plan of action means they feel less reliant on mental health services. For others, the involvement of services is crucial and having a clear understanding of 'What? Who? Where? When?' helps everyone understand their role. In this respect, sharing this exercise with your friend or relative's care team has many advantages. You, your relative or friend, and the health professionals all agreeing on what the early warning signs are and who will do what if these are recognised will produce the best outcome for everyone.



If you decide that identifying early warning signs is going to be helpful, the next step is to think about what you can remember from when your relative or friend was unwell.

Think about the last time your friend or relative was unwell. Try to remember the weeks or month leading up to this. It might help to think about:

- The time of year.
- Where you were.
- Who else was around.
- What was happening at the time.

It might also help to look at an old diary or calendar or to talk things through with a friend or other family members.

- What did you notice in general?

More specifically, what did you notice about:

- What your friend/relative was doing (their behaviour).
- What they said about how they were feeling physically?
- How things were with their thinking. For example, could they concentrate to read or watch TV or did they seem more distracted than usual?
- How was their mood?

Make a note of the things you can remember. If you are doing this with other people, make a note of the things that you can all agree on.

Early warning signs: Behaviour, thought, feeling or physical sensation

1.

2.

3.

4.

6.4 'Off days' or the start of a relapse?

When thinking about early warning signs, the person themselves, friends and family members may end up thinking they have to keep a very close eye on things. This is natural, particularly if a previous episode was very difficult and appeared to come out of the blue. However, over-monitoring (or being hyper vigilant) is not helpful. It creates an added pressure for you as a carer and your friend or relative may feel as if they are being watched all the time. So, it's sensible to try and get a balance between being alert and noticing the signs and switching off and missing the obvious ones.



How might you get this balance?

Everyone can have an 'off day'. You know the sort? Where nothing seems to go right, and you can just feel miserable, low or grumpy. Or sometimes you might feel very happy or excited and full of beans. This can happen for everyone, but if a person has had mental health problems in the past it can be difficult for them, and the people around them, to know whether or not this is a sign that they are becoming unwell again. It might just be that they are having a really bad day, not a sign that they are becoming depressed. Or it might be that someone is having a really good day, not experiencing early signs of becoming manic.

Early warning signs can be seen as:

- A cluster of changes.
- Happening together.
- Lasting over a period of time.
- Gradually getting worse.
- Following the same pattern as before.

So what you are looking for is something that persists over time or becomes a pattern rather than one off events. One way of being clearer about the difference between an off day and the start of a relapse is to be very specific about what the early warning signs are. Some questions that help are:

How often do these things happen (frequency)?

How long do they go on for (duration)?

How bad is it (severity)?

Remember in the earlier example, Maureen thought that Linda being snappier might be a sign that she was becoming unwell? The following shows how they managed this.

Cheryl

Cheryl pointed out that Maureen's comment about Linda being snappier might just mean that Linda was having a bad day. Linda agreed and said that she was worried that every time she showed one of the signs they identified, Cheryl and Maureen would be nagging her to contact her key worker. So, they spent some time thinking about the difference between an 'off day' and signs of a relapse.

They came up with the following:

1	2	3
Behaviour, thought, feeling or physical sensation.	Having an 'off day'.	Early warning sign including frequency, severity and duration.
Spending more time in the bedroom.	Yes, but only for the day.	Yes, for four or more hours, three days in a row.
Avoiding having a bath or shower.	No.	Yes, for more than five days in a row.
Sleeping more.	No.	Yes, at least 10 hours every night for a week, nearly all day on weekends, getting worse over the week.
Snappy.	Yes, but only for the first hour or so in the morning. I cheer up after breakfast.	No.
Being slowed down.	No.	Yes, all the time for more than three days. Gets worse over the three days.

Go back to the list you made in the previous section and write the signs in column 1. Next, think about whether each item tends to happen when your relative or friend has an 'off day'. It may be helpful here to talk about how they usually are on an 'off day' and note these in column 2. Finally, describe, as specifically as you can, how long, how often and how severe each sign was before your friend or relative became unwell. Note these in the final column.



6.5 Planning to stay well



Now you have some idea about the early warning signs that show your friend or relative is becoming unwell, the next and final step, is to develop a plan of action to follow if you and your friend or relative notice they are experiencing these signs.

1	2	3
Behaviour, thought, feeling or physical sensation.	Having an 'off day'.	Early warning sign including frequency, severity and duration.



Identifying early warning signs is a great step towards managing mental health difficulties. Knowing what to do once you and your relative or friend notice signs is vital in reducing the chances of a relapse. When developing a plan it can be helpful to divide up the plan into things that your friend or relative can do, things you can do, things you can ask mental health services to do.

What could your friend or relative do?

What could you do?

What would you like your local mental health team to do?

Your friend or relative might:

- Try and find some relaxing or pleasurable activities to do.
- Reduce stress or the reason for stress.
- Take medication as prescribed by psychiatrist/GP.
- Contact their GP.
- Telephone their key worker.
- Arrange an emergency family meeting or problem-solving discussion with friends (see Booklet 5).

You could:

- Support your friend or relative in doing the above.
- If they are unable to, contact their GP and mental health professionals with their agreement.
- Spend time with them.
- Identify trigger(s) to increased level of stress.
- Do what you can to remove or reduce that stress.

Your relative or friend and you could ask the mental health service to agree to:

- Arrange a visit by the key worker on the same day.
- Arrange a visit by the community nurse within a week.
- Arrange an appointment with the psychiatrist.

Going back to the example, you can see a plan agreed by Linda, Cheryl and Maureen.

6.6 Putting it all together



Linda, Cheryl and Maureen

Linda, Cheryl and Maureen agreed a plan as to what to do if Linda showed her early warning signs for more than five days in a row. They also talked to Linda's key worker who discussed the plan with her team. The team agreed to their part in the plan.

Linda will:

- Contact her GP.
- Telephone her keyworker.
- Arrange to spend the day/evening with Cheryl and/or Maureen.

Cheryl and Maureen will:

- Support Linda to do the above.
- Spend some time with Linda.
- Contact her key worker if this is what Linda would like.

Mental health services will:

- Arrange a visit by the key worker within 24 hours.
- Arrange an appointment with the psychiatrist within a week.

You may find it difficult to discuss this last point with mental health services. It may be that you have not had a great experience with them in the past, so it might feel difficult to trust them. Or perhaps you don't feel confident knowing your way around the system. Services vary. Some are extremely responsive and people have good relationships with key workers, others can appear less helpful.

It may be helpful to consider the following:

- Is there someone you feel comfortable discussing this with? A worker at your local carers' centre? A voluntary worker? Your GP?
- Your GP can make a referral to your local mental health service.
- Some areas have a Crisis team, which may accept self-referrals, as well as referrals from GPs.
- Rethink Mental Illness (www.rethink.org) has experience of supporting people to get help.
- Other local mental health charities such as Mind or local support groups may be able to access support more easily.
- It may feel difficult at times, but be persistent.

A note of caution: There may be circumstances where this is difficult to do. For example, if your relative or friend has a severe mental illness such as psychosis or severe depression, they may not notice or be aware of these signs. There may be confidentiality issues, e.g. where an adult may not want their parents involved or contacting mental health services on their behalf. In these circumstances, it is really important to establish a good relationship with the service over time, so you can discuss these issues, and draw up a plan that is agreeable to everyone and that ensures your relative gets the support they need.



So, you have a clear idea of the signs, and a plan outlining the roles people will take in responding to those signs. It may be helpful to pull it all together on one sheet, and keep this somewhere that is visible to those who are involved in the plan. In the example below, Linda and Cheryl kept a copy on the inside of a kitchen cupboard door, Maureen kept one in her diary and the key worker put a copy on the front of Linda's clinical file.

Where might you keep yours?

Who else might need a copy?

Early warning signs

Name: Linda Cunningham

My early warning signs are:

1. Spending more than four hours in my bedroom for more than three days in a row.
2. Avoiding having a bath or shower for more than five days in a row.
3. Sleeping for at least 10 hours every night for a week, nearly all day on weekends, getting worse over the week.
4. Being slowed down all the time, getting worse over three days.

Whenever I experience any of these signs I will respond by:

- a) Talking to Cheryl and Maureen about this and arrange to spend some more time with them.
- b) Informing my key worker (David Campbell) by phone immediately.
- c) Informing my doctor by phone immediately.

The mental health service has agreed to respond by:

- a) Arranging a visit by my key worker within 24 hours.
- b) Arranging an appointment with my psychiatrist within a week.

My GP/doctor is: Dr Crosby **Telephone:** 496305

My key worker is: David Campbell **Telephone:** 938476

My family worker is: Janie Lewis **Telephone:** 496308

6.7 Summary



Now you have seen the example, try to complete one with your relative and preferably involve someone from the mental health service as well.

Early warning signs

Name:

My early warning signs are:

- 1.
- 2.
- 3.
- 4.

Whenever I experience any of these signs I will respond by:

- a)
- b)
- c)

The mental health service has agreed to respond by:

- a)
- b)
- c)

My GP/doctor is:

Telephone:

My key worker is:

Telephone:

My family worker is:

Telephone:

This booklet has introduced the idea that you and your friend or relative can identify signs that they are becoming unwell. You have developed a plan which will give you some clear ideas about what to look out for and what to do if you notice these signs happening. If you notice these signs early on, you may reduce the chances of relapse and increase the chances of your friend or relative staying well.

Doing this may also give you a sense of control at a time when you may feel like you have very little. It may take some time to get used to noticing these signs or acting on the plan, so it may be helpful to think of this as work in progress. This is something you may add to over time, reviewing and amending as you go along. Over time, you and your friend or relative will become more familiar and confident at spotting the signs and knowing what to do when they appear.

6.8 Key learning points

It is possible for someone to become well and stay well. When someone experiences mental health difficulties, they do not become unwell out of the blue. It is possible to become aware of and to learn to recognise the early signs of someone becoming unwell. It is really useful to draw up a list of these signs so that everyone is aware if there is a risk of relapse. Having a plan of action that lists who will do what in the event of early warning signs appearing means that something can be done early on to prevent things escalating.

While it is important to be aware of early signs of relapse, it is equally important not to become over-vigilant. Nobody likes being under observation all the time and we all have our 'off days'.

Thank you to . . .

Producing a resource such as this relies on the support and contribution of a wide range of people. We consulted widely at the various stages of the development of the material in terms of content, layout and presentation, and would like to thank all of those who gave so generously of their time and ideas.

In terms of initial discussions on content, Thurstine Bassett, Alison Faulkner, Michele Gladden, Becky Heelis, Peter Woodhams and Aiesha Wright were particularly helpful. Martin Atchison and Chris Mansell kindly provided materials for some of the case examples and exercises. Thanks also to Claudia Benzies and the 'COOL' group of carers for allowing us to share some of their material on recovery.

One of the biggest tasks was reading through the earlier versions of the different sections which was a really time-consuming activity. We wanted to ensure that the material is meaningful, helpful and presented in a way that is easily accessible to carers and family members, so we enlisted the help of family members recruited through Rethink Mental Illness and the Meriden Family Programme. We are so grateful to those helped with this task – June Cooley, George Gladden, Michele Gladden, Edward Haslam, Christine Lewis, Philippa Lewis, Philippa Lowe, Maggie Morgans, Jeanette Partridge and Peter Woodhams. A number of other carers who equally spent hours reading through drafts and providing feedback did not wish to be named in person, so our heartfelt thanks to those 'anonymous' family members for all their time, commitment and valuable comments.

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About the authors

Gráinne Fadden is a Consultant Clinical Psychologist based in Birmingham and Solihull Mental Health NHS Trust, Honorary Senior Research Fellow at the University of Birmingham and Director of the Meriden Family Programme. The cascade method of training and system of organisational change for improving services to families developed through the Meriden Programme have been adopted by several organisations within the UK and abroad. The Programme has been the recipient of numerous awards for 'Modernising Mental Health Services' and for 'Mental Health Innovation'. She was awarded the prestigious Marsh Lifetime Achievement Award by Rethink Mental Illness in 2009 for her outstanding contribution to mental health. Gráinne has been involved in family work and research throughout her career, and has written extensively on the effects of mental health problems on families, on how family members can be supported, and the training of mental health professionals. She links with a range of national bodies on issues relating to families and carers and has delivered training around the world.

Carolyn James qualified as a Clinical Psychologist in 2003. Currently she works in clinical health psychology and training, and prior to this she was part of a child and adolescent mental health team in East Birmingham. Before training Carolyn worked as a Research Assistant on a number of projects, including the Meriden Programme. Carolyn is proud to have been part of the Programme since the very beginning. She has maintained her links with the team since that time and returned to talking with families and therapists as part of her doctoral research. Carolyn was interested to find out what helped engagement in family therapy and, as a result of her work, developed a theory about some of the factors that therapists may need to consider when talking with families about Behavioural Family Therapy (BFT).

Vanessa Pinfold is a health services researcher. She joined Rethink Mental Illness in 2003 to establish a research team within the charity. Previously she worked at the Institute of Psychiatry, Kings College London. She is currently working as a part time research fellow at Rethink Mental Illness and is chair of The McPin Foundation – a small family charity that supports mental health research and promotes mental well being through innovative projects.

Vanessa has always had an interest in mental health carers and through research programmes has sought to develop practical tools to assist families and relatives of people with mental illness. She has been involved in the Time to Change campaign to end mental health discrimination and the re-development of Rethink Mental Illness 'Caring and Coping' training programme. Vanessa has also led the development of an online package to assist practitioners to work with families through timely and appropriate information sharing in mental health.



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