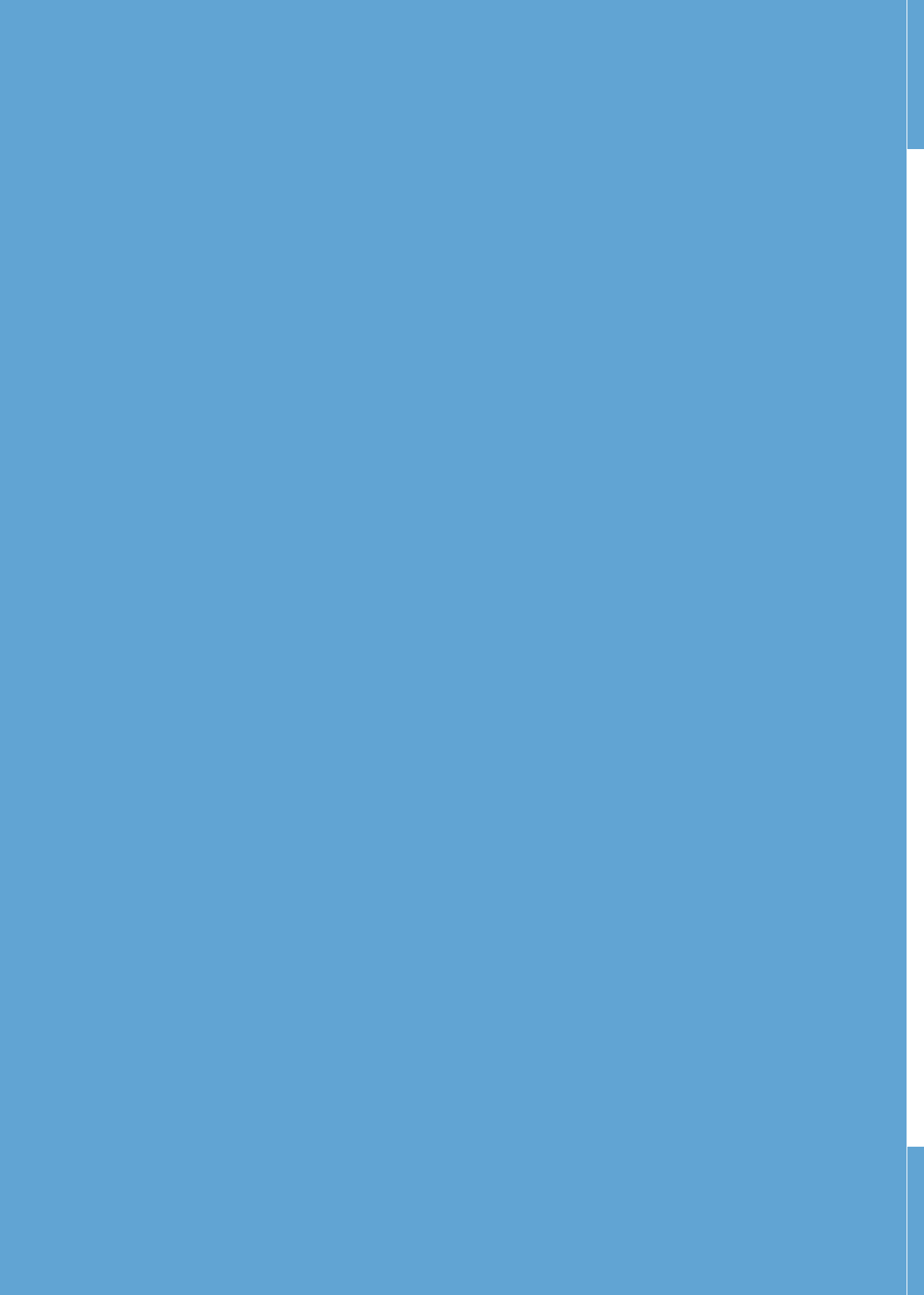


# MyCare

Caring for a parent with a  
mental health problem





## What is this booklet about?

This booklet is about young carers. Thousands of children and young people in this country live in families where one or both parents have some kind of long-term health problem. Their parent may be physically ill or disabled, or they may have a mental health problem such as depression or schizophrenia which means they struggle with everyday things that most of us take for granted (cooking, shopping, cleaning and so on). These children and young people are young carers, even if they don't actually see themselves as a 'carer'.

Many young carers in the UK do a lot around the home to help their parents. Some young carers may only live with one of their parents and there may be no other adults who can help them, which means they are main carer for their parent. They may also be caring for their younger brothers and sisters too.

We carried out some research with The Princess Royal Trust for Carers to try to find out more about what life is like for young carers whose parents have a mental health problem, and what they thought would help them. We talked to a lot of young carers across the country. We also talked to teachers and mental health workers and children's workers.

This booklet is for all children and young people who are caring for a parent who has a mental health problem. It is tough being a young carer and it can be particularly tough for young carers whose parent has a mental health problem.

We would like to thank the Henry Smith Charity and the Man Group plc Charitable Trust for their generous support of the MyCare Project.



# What are mental health problems?

There are a lot of different kinds of mental health problems. Later in this booklet we describe some of these. The most common mental health problems are anxiety and depression. About one in five people has depression at some time in their life. Anxiety conditions affect about one person in 20. About one person in 12 has anxiety and depression together.

Schizophrenia and bipolar disorder (which used to be called manic depression) are much less common. About one in 100 people has schizophrenia and just over one in 100 has bipolar disorder.

Mental health problems can affect your life in different ways:

- Some people feel very low, and don't feel they can face the world.
- Some people feel full of energy and may seem hyperactive.
- Some people feel very scared or worried.
- Some people get strange beliefs about other people or what is happening around them.

Mental health problems can make people think and behave in ways they wouldn't normally. They can stop people from working and studying and make it hard for them to take care of themselves. For parents, it can make it hard for them to take care of their children, home and family.

Mental health problems can last for just a short while and then go away. Sometimes they may go away for years and then come back again. A small number of people are very badly affected for much of their life.

But, mental health problems can be treated and lots of people live happy, busy, ordinary lives, even though they have quite serious mental health problems.

# Why do people get mental health problems?

If your parent has a mental health problem, it doesn't mean you are going to have mental health problems too. Very few mental health problems are definitely known to be inherited from your parents.

Most mental health problems come from a mix of:

- your genes (which you inherit from your parents);
- how you were brought up;
- the problems you have faced when growing up; and
- things that are happening in your life now.

Some people find it easier to cope with stress and pressure.

Some people can develop mental health problems if they:

- have very little money;
- have no home or live in a house which is in poor condition;
- cannot find a job;
- feel they don't have a purpose in life;
- are lonely and have no friends and family;
- are stressed because of family problems;
- are stressed or under pressure at school or college; or
- suffer physical, sexual or emotional abuse as a child or adult.

# What do young carers do?

Young carers do a lot of different things to help out at home. Mostly, they help with shopping, cooking and cleaning. Sometimes they collect prescriptions from the doctor or chemist and go with their parent to the doctor and help them take their medication. Some help their parent get up, get washed and get dressed.

# What is it like to be a young carer?

It can be tough being a young carer. Children and young people living with a parent with a mental health problem may become quite isolated. This may be because they don't go out as a family, and they don't like to ask friends round.

It can be very upsetting if you don't know how your parent is going to be when you come home from school, or if they get angry and upset and you don't understand why.

Young carers may feel guilty if they go out and leave their parent alone for too long. They may have so much to do at home that they can't go out with friends as much as they'd like. They may find it difficult to make friends because of the 'stigma' around mental health. Stigma means that other people think there is something wrong, bad or dangerous about a person with a mental health problem. This is not true. People with mental health problems are much more likely to be victims of violence from other people than to be violent themselves.

Young carers may also think they have to be especially good, so they don't upset their parent. They may even think that it is somehow their fault that their parent isn't well.



Young carers may have to live with foster carers or relatives when their parent has to go into hospital. This can be difficult and disruptive. It can also be very upsetting if their parent is very unwell and has to go into hospital, even though they don't want to.

Some young carers get worried that they will be taken into care if anyone knows about their parent's mental health problems. So, they don't tell anyone if they have problems at home.

Young carers tell us that they often get bullied at school because people think they are different.

Young carers can also get behind with schoolwork because of their responsibilities at home. They can find it hard to concentrate at school if they are worried about their parent, or if they are tired because they had to stay up late with their parent.

A lot of young carers also say that they have a very good and special relationship with their parent because they care for them, and that they grow up more quickly and are more mature. They love their parent and want to help them. They say that often professionals who work with families don't understand this (such as teachers and social workers).

The problem is that sometimes young carers find themselves having to take on too much, because there is no one else to do it. This may affect their education and their future.

# What helps young carers?

The young carers we talked to said that social workers, teachers, doctors and nurses don't always understand what it's like for them and what they do for their parent. This makes their lives much more difficult, and makes them angry and upset.

## School

Young carers may not want everyone in school to know they are caring for a parent who has a mental illness. Quite often they get bullied and they don't want to be seen as being different.

But, they do want teachers to be sympathetic, to listen to them, and to try to understand the pressures they have at home. Young carers may:

- need to keep their mobile phone on in class if they are worried about their parent;
- be very tired because of all the caring work they do;
- be late in the morning because they've been helping their parent get up and get dressed, or have had to go with them to the doctor;
- need extra time for homework because they can't work at home, or they haven't had time to do assignments;
- need to leave the class if they get upset, without always having to ask permission or explain why; and
- need somewhere quiet and safe where they can go when they feel upset.

Young carers want teachers to ask them what would help, and listen to what they say. They don't want to be given detention when they are late or don't give in their homework on time. That only makes their lives even harder.

In some schools the teachers arrange special groups for pupils who care for their parent so they can get together and talk without having to explain about their problems at home.

## Social workers and mental health workers

Young carers say that social workers and mental health workers should ask them about how their parent is and what kind of support would be helpful, as often as they know more about this than anyone else.

They also say that mental health workers and social workers don't always tell them what is going on, and ignore them. They say they would rather know what's happening as not knowing is much more frightening.

In some parts of the country children's charities work with social workers and mental health professionals to make sure the whole family gets help, and they run special groups for young carers so they get support too. For more information, please see page 8.

## Young carers' groups

What young carers say they find really helpful are special groups and projects for young people like them who are caring for a parent with a mental health problem. At these groups they can meet other young carers and have fun and find someone to talk to.

The workers in these projects know what life can be like for young carers, and will listen to them. It's good for young carers get to know other young carers who will understand what they are going through.

# Mental Health Problems

This section of the booklet gives you more information about the most common mental health problems.

## Depression

Lots of people sometimes feel a bit miserable. Depression is when you feel really down, not just unhappy. Sometimes you can't sleep (this is called insomnia). Sometimes you just want to stay under the duvet and sleep all the time. You don't want to eat, or you eat too much to try to comfort yourself. You may feel really tired all the time, or you may be really restless and not able to sit down or relax. You may also get very anxious and upset.

There are lots of treatments for depression. A doctor may prescribe antidepressant pills, or may refer you for 'talking treatments' like counselling, psychotherapy and cognitive behavioural therapy (CBT), which is therapy that helps you think more positively about yourself and your life.

Some people find 'alternative' and 'complementary' therapies helpful. These include relaxation techniques, yoga and massage. Exercise and gentle and creative activities like gardening and art can help people with depression. Getting involved in activities and social groups can also help.

## Anxiety

Anxiety is when you feel really worried all the time. You may find it hard to concentrate and lose your temper easily. You may have panic attacks and feel so stressed that your heart races. You may even get physical pains in your chest. Some people have phobias – they may become terrified of going outside, of being in small spaces, or of meeting new people or going to new places.

You can treat anxiety and phobias using medication and talking treatments. A lot of people find self-help groups useful. CBT is also helpful and some people learn relaxation techniques to help them cope with difficult situations.

## Bipolar disorder

Bipolar disorder is when you get very big mood swings. Your mood goes from feeling very depressed to feeling on top of the world and that you can do anything. Bipolar disorder is also sometimes called 'manic depression'.

People on a high tend to talk quickly and are very energetic and seem to need hardly any sleep. They can also take risks and get angry and impatient if other people try to stop them.

Bipolar disorder tends to happen in cycles of weeks or months or years. Bipolar disorder can also be 'triggered' by stress or bad events.

Bipolar disorder is mostly treated with medication. You can also learn how to manage your bipolar illness by looking out for signs that you are starting on an 'up' or 'down' cycle. If you know it is happening, you can take medication to stop it and try to avoid stressful situations that make your mood swings worse.

## Schizophrenia

Schizophrenia isn't really one illness. It's a name for a lot of different symptoms. They include hallucinations (hearing voices and seeing, feeling or even smelling things that no one else can), and delusions (believing things that aren't based on what is really happening). Sometimes people believe they are being controlled by outside forces, like the TV or radio, or by other people.

People with schizophrenia can feel very confused and find it difficult to concentrate. They can also have low energy and feel down so they don't feel like doing anything.

Schizophrenia is mostly treated with what is known as 'antipsychotic medication'. The medication helps reduce the effects of the hallucinations and delusions so the person feels calmer and less frightened. Antipsychotic medication doesn't cure schizophrenia, it just helps the person cope with the symptoms. There are some special talking treatments that can help the person manage their symptoms too, and help families cope better when the person is unwell.

## Other mental health problems

There are a lot of other mental health problems.

The most well-known of these are:

- eating disorders, such as anorexia and bulimia; and
- obsessive compulsive disorders, where people need to do things repeatedly, such as washing their hands or doing things a set number of times, even though it takes over their life.

## Personality disorders

Our personality is the way we think and feel and behave. Some people think and feel and behave in ways that make it very difficult for them to get on with other people and cope with ordinary life. They may have trouble keeping control of their feelings and behaviour and may get very angry and upset and even hurt themselves or other people. These kinds of behaviour are called personality disorders.

You cannot cure personality disorders with medication, but antidepressants and antipsychotics can help with some of the symptoms. Personality disorders are mainly treated with talking treatments, such as CBT and group therapy, to help the person change the way they see the world and how they behave towards other people.

## Who can help?

If you are worried about your parent, the first person to go for help is their GP. They can then refer your parent to a hospital to see a psychiatrist or a psychologist.

A psychiatrist is a medically trained doctor who specialises in mental health problems. They can prescribe medication to treat the mental health problem and may put a person in hospital for a while, especially if they think the person may harm themselves or get into a situation where other people get hurt.

A psychologist has special training in how the mind works and in techniques such as CBT. Psychologists are not medical doctors. They can help the person look at how they see the world and themselves and teach them techniques for managing obsessive thoughts or behaviour.

Mental health nurses are nurses who have done special training in treating mental health problems. They work on hospital wards or in the community, in community mental health teams. Community mental health teams provide care in the community. They have lots of different workers in them, including a psychiatrist, sometimes a psychologist, nurses, mental health care assistants and support workers, and also social workers with special mental health training. Often people with mental health problems have a care co-ordinator, who is a community mental health worker responsible for making sure that they get all the care and support they need.

There are other mental health workers who provide help and support in hospitals and in the community. Occupational therapists organise activities for people with mental health problems, and help them find training and jobs. Support workers have lots of experience of working with people with mental health problems and can help with practical problems people face day-to-day.

Some GP surgeries have counsellors who offer short courses of talking treatments. There are also special mental health services for children and young people, called Child and Adolescent Mental Health Services (CAMHS). The psychiatrists, nurses and social workers in these services have special training in working with children and young people who are experiencing mental health problems.

## The Mental Health Act (2007)

Sometimes if someone is really unwell, they may have to go into hospital against their will under the Mental Health Act (2007).

Under the Mental Health Act (2007), mental health services can take someone into hospital and give them medication against their will, because otherwise they may come to harm or harm someone else. The person won't be allowed to leave hospital until the doctors have decided they are well enough. Sometimes the police may be involved if the person is very upset.

People can also be given treatment under a community treatment order. If this happens, the person does not have to stay in hospital, but a community treatment order will say where they have to live, and that they must follow the treatment recommended by their doctor, otherwise they may have to go back into hospital.



## Help and Information

If you are worried about your parent, you should get help from your GP. They will be able to refer you to other services that can help you.

If your parent is already getting treatment from your local mental health service, make sure you have an emergency contact phone number for the service.

If you are a young carer and need to talk to someone urgently, phone ChildLine on 0800 11 11 11.

You can also visit the young carers' website run by The Princess Royal Trust for Carers at [www.youngcarers.net](http://www.youngcarers.net). The website has advice and information for all young carers, and access to the YCNet Interactive young carers' online community, where you can talk to other young carers.

The Children's Society's Include Project also has a lot of information for young carers, and has details of different services for young carers all over the UK. You can find them at [www.youngcarer.com](http://www.youngcarer.com).

You can also phone NHS CarersDirect on 0808 802 0202, or email [CarersDirect@nhschoices.nhs.uk](mailto:CarersDirect@nhschoices.nhs.uk).

Many organisations, such as Barnardo's, The Princess Royal Trust for Carers and the Children's Society run young carers' projects in many locations in the UK. Ask if there is one in your area – and if there isn't, ask them why not.

## More information for young carers

### Rethink

Website: [www.rethink.org/siblings](http://www.rethink.org/siblings)

You can read the leaflet 'A sibling's introduction to mental illness'

### Young Minds

Website: [www.youngminds.org.uk](http://www.youngminds.org.uk)

You can read the leaflet 'Mental illness in your family?' which you can get online at [www.youngminds.org.uk/publications/all-publications/mental-illness-in-your-family/file](http://www.youngminds.org.uk/publications/all-publications/mental-illness-in-your-family/file)

### Gloucestershire Young Carers

Website: [www.glosyoungcarers.org.uk](http://www.glosyoungcarers.org.uk)

You can get 'Minds, myths and me – a fact pack for young people who live with someone with a mental illness' online at [www.glosyoungcarers.org.uk/Website%20copy.pdf](http://www.glosyoungcarers.org.uk/Website%20copy.pdf)

## The Royal College of Psychiatrists

Website: [www.rcpsych.ac.uk](http://www.rcpsych.ac.uk)

If your parent has a mental illness, there is a film which might help online at [www.rcpsych.ac.uk/mentalhealthinfo/youngpeople/caringforparent.aspx](http://www.rcpsych.ac.uk/mentalhealthinfo/youngpeople/caringforparent.aspx)

There is information about mental health for children and young people at [www.rcpsych.ac.uk/mentalhealthinformation/childrenandyoungpeople.asp](http://www.rcpsych.ac.uk/mentalhealthinformation/childrenandyoungpeople.asp)

There is also information for young carers at [www.rcpsych.ac.uk/campaigns/partnersincare/caringaroundtheclock.aspx](http://www.rcpsych.ac.uk/campaigns/partnersincare/caringaroundtheclock.aspx)

## The Wise Mouse by Virginia Ironside

This is a book for children aged 5-11. It aims to help them understand what is happening to a family member who may be experiencing a mental illness.

## The Illustrated Mum by Jacqueline Wilson

This is a book that tells the story of two young girls looking after their mother who has bipolar disorder.

# More information for professionals working with young carers

## Barnardo's

Website: [www.barnardos.org.uk](http://www.barnardos.org.uk)

The Barnardo's 'Keeping the Family in Mind' pack is aimed at anyone who works with parents with mental health problems, their children and their families. It is a multimedia package of training resources designed to raise awareness of the issues that families face. All the resources have been written and produced by Barnardo's with the participation of young carers. 'Telling it like it is' is the heart of the pack; a 15 minute film which conveys key issues, promotes understanding and insight all from a young person's point of view.

## The Children's Society

Website: [www.childrensociety.org.uk](http://www.childrensociety.org.uk)

The Children's Society's Include Project includes a Young Carers Initiative, which gives you information and training on working with young carers. This is available online at [www.youngcarer.com](http://www.youngcarer.com)

The Children's Society's STARS national initiative website gives you information, support and advice on parents with drug or alcohol problems, and the effect this has on children and families. Website: [www.parentsusingdrugs.org.uk](http://www.parentsusingdrugs.org.uk)

## The Parental Mental Health and Child Welfare Network

Website: [www.pmhcwn.org.uk](http://www.pmhcwn.org.uk)

The Parental Mental Health and Child Welfare Network have a range of useful information, as well as providing regular training and holding conferences

## The Princess Royal Trust for Carers

Website: [www.carers.org/professionals](http://www.carers.org/professionals)

This is a website for professionals and has a range of materials covering issues young carers face, how to spot a young carer that needs help, and what you can do to help.

## Rethink and Turning Point

Website: [www.rethink.org](http://www.rethink.org)

Rethink and Turning Point's 'Dual Diagnosis' report is an excellent introduction to conditions, treatment and policies relating to adults with mental health problems and substance-abuse problems in the UK.

## The Royal College of Psychiatrists

Website: [www.rcpsych.ac.uk](http://www.rcpsych.ac.uk)

On this website there is a guide for psychiatrists who work with children of parents with mental health problems. Go to [www.rcpsych.ac.uk/PDF/Checklist\\_professionals.pdf](http://www.rcpsych.ac.uk/PDF/Checklist_professionals.pdf)

# Mental Health Foundation

Founded in 1949, the Mental Health Foundation is the leading UK charity working in mental health and learning disabilities.

We are unique in the way we work. We bring together teams that undertake research, develop services, design training, influence policy and raise public awareness within one organisation. We are keen to tackle difficult issues and try different approaches, many of them led by service users themselves. We use our findings to promote survival, recovery and prevention. We do this by working with statutory and voluntary organisations, from GP practices to primary schools. We enable them to provide better help for people with mental health problems or learning disabilities, and promote mental well-being.

We also work to influence policy, including Government at the highest levels. We use our knowledge to raise awareness and to help tackle stigma attached to mental illness and learning disabilities. We reach millions of people every year through our media work, information booklets and online services. We can only continue our work with the support of many individuals, charitable trusts and companies. If you would like to make a donation, please call us on 020 7803 1121.

Visit [www.mentalhealth.org.uk](http://www.mentalhealth.org.uk) for free information on a range of mental health issues for policy, professional and public audiences, and free materials to raise awareness about how people can look after their mental health.

## The Mental Health Foundation

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[www.mentalhealth.org.uk](http://www.mentalhealth.org.uk)

