



information for
carers
from change mental health

**Information for carers and their
families and friends**

www.changemh.org

about change mental health

We are building a future where no one needs to face mental illness alone

We are Change Mental Health: We provide transformational services for people ensuring that everyone has access to the support they need, when they need it and in a way which works best for them.

We seek to change society by changing attitudes, fighting stigma and influencing government to ensure a better quality of life for those affected by mental illness.

our values

Courage and Commitment

We face challenges head on and speak out when we see injustice.

Dignity and Compassion

We care for our staff and the people we support. We recognise human beings as complex and unique. We reach out to others and show kindness.

Leadership

We innovate. We are the first to our own rescue and that of others. We do the difficult things. We work in and build partnerships with others.

Lived Experience

We are driven by the lived experiences of the people we support and work with. We are committed to person centred approaches and meaningful participation.

Integrity

We do the right thing. We are transparent, open and honest.

We run a Carer Support service

We improve the health and wellbeing of carers through a range of emotional, individual and peer group support in Highland, Tayside, Fife, Edinburgh, and Dumfries and Galloway.

We launched the service decades ago in response to the unique challenges of being a carer to a relative, friend or partner of someone living with a mental illness.

Our team provide a safe space where carers can talk about their needs without judgement. We identify and develop coping skills and strategies to support you.



About this information book

This information book aims to meet some of the basic information for carers, family members and friends of people who have been diagnosed of having a mental illness or serious mental health issues.

This book will list where you can receive more comprehensive information and support, and will signpost to relevant organisations where necessary. Much of

the information might be useful to carers of people with other mental health issues.

If you have any questions about the content of this book, please contact our Advice and Support Service:

w: www.changemh.org/advice-and-support

e: advice@changemh.org

t: 0808 8010 515

information for carers


Caring for and about someone with mental illness can be very demanding on you in many ways – emotionally, physically and perhaps financially. Learning how to support someone with a mental illness will help not only the person who is ill, but also you, other family members and friends.

A carer is anyone who has had to change their lifestyle to care for and take responsibility for another person who is experiencing mental health issues. They don't necessarily have to live with the person who is ill.

You might be someone who looks after or supports a family member, partner, friend or neighbour in need of help because of mental illness, being frail or having a disability.

In some cases, a carer may also be a cared for person. Carers are not paid for providing care and support, although there may be financial assistance and other support available.

Caring can be physical or emotional support: this can include helping someone seek help for their mental health issue or supporting with day-to-day tasks, such as cooking and cleaning or personal care.



"For me, it's about walking beside someone and taking baby steps to introduce them to other support available, going through it with them so they know what's right for them to show that they're not alone."

Heather
Carer Support Worker
Change Mental Health

your rights

One of the difficulties for the carers, friends and relatives of someone who is affected by mental illness is knowing what legislation is relevant to them and the person they care for.

The **Carers (Scotland) Act 2016** was passed to ensure that Scotland's carers are better and consistently supported so that they can continue to care in good health and have a life alongside caring.

Adult carers have a right to an 'adult carer support plan'

The responsible local authority must offer an adult carer support plan to anyone they identify as an adult carer. They must prepare an adult carer support plan for anyone who accepts this offer or requests one. **It must contain:**

- the nature and extent of the care provided and the impact on your wellbeing and day-to-day life
- the extent to which you are able and willing to provide care
- emergency and future care planning, including any arrangements that are in place
- what 'personal outcomes' matter to you in order to help you carry out your caring responsibilities, to have a life alongside caring, and to improve your own health and wellbeing

- support available to you if you live in a different local authority from the person you care for
- whether support should be provided as a break from caring
- general support available to you locally
- any support which the responsible local authority intends to provide to you
- the circumstances in which your adult carer support plan is to be reviewed.

Some serious mental health conditions can affect a person's judgement and capacity to make decisions for themselves and the decisions might have to be made by other people. The **Adults with Incapacity (Scotland) Act 2000** provides a framework for safeguarding the welfare and managing the finances of adults who might have an inability to communicate due to mental illness. Main provisions include Power of Attorney, Access to Funds, and Guardianship and Intervention Orders.

mental illness

Mental illness can affect people from all walks of life. It cuts across age, class, religion, gender and profession. The first symptoms can often develop in early adulthood but may remain undiagnosed for a long time.

Mental illness can fluctuate between periods of being well and able to manage and periods of being less well. Its onset can vary from person to person: it can start suddenly with an acute episode or it might be more gradual, with signs of withdrawal or uncharacteristic behaviour.

What causes mental illness?

It is not clear but it can be triggered by factors such as stressful life events, childhood trauma, Post-Traumatic Stress Disorder (PTSD), bereavement, employment, and more.

It cannot be diagnosed by a physical test and reaching a diagnosis is not always a simple process. People might be referred to a service and not have a definitive diagnosis initially but can still receive support to help their mental health. Symptoms can change over time and present different mental illnesses, making it difficult to tell conditions apart.

Over time, the diagnosis might become clear if someone's thought patterns, perceptions, emotions and behaviour significantly alter through a recognisable pattern.

People can feel embarrassed, guilty or afraid that they will be judged and this stops people asking for the help they need, making crisis more likely. There is clear evidence that early intervention

may lead to a better long-term outcome. People experience mental illness in very different ways and should always seek help early to make sure they receive the most appropriate advice and support.

Many people can and do recover from mental illness, especially those who have support from family and friends.



conditions

Psychosis

when someone might hear voices, experience sensory disturbances, or hallucinations or delusions

Schizophrenia

affects how you think and cope with daily life, experiencing hallucinations and delusions with disorganised thinking

Bipolar

extreme high and lows and patterns of mood swings differing widely between people

Personality Disorders

affects how a person feels, thinks and behaves with extreme outbursts of emotion and volatile behaviour

Anxiety

feeling irritable or worried and having trouble concentrating or sleeping because of issues or situations

Depression

physical and mental state characterised by low mood and low emotion that can be mild, moderate or severe

The above is not exhaustive and another conditions can include obsessive-compulsive disorder (OCD), phobias, and more. Our website has detailed information on mental health conditions and resources about how to deal with certain situations, causes, symptoms and more: www.changemh.org/about-mental-health



coping strategies

After the initial shock of realising that someone close to you has a mental illness, you may experience all sorts of emotions ranging from confusion, an overwhelming sadness, grief or anger to guilt and loss. These emotions are perfectly normal.

Many carers don't realise they are experiencing grief. Unlike the grieving process related to death, you may find yourself flitting in and out of this depending on the nature and pattern of the illness that the person you're caring for is experiencing.

You are likely to have many unanswered questions and conflicting emotions. You may be worried about what to tell family and friends. This is okay.

Looking after yourself is paramount

It may not sound achievable just now, but you can help yourself and the person you care for by looking after yourself in everyday life and keeping yourself safe. You must look after your own health and not isolate yourself from other people.

Finding things that help you relax is important. Taking time out for yourself is essential to protect your own mental health.

Your physical health is important

It's important for everyone to look after their physical health. Carers often experience poorer physical and mental health as a result of their caring role and often ignore their own physical health, which can lead to further health issues.

Stress can cause increased physical health problems due to exhaustion, anxiety and having less time to

concentrate on your needs. Many carers say that they only attend health appointments to speak about their relative and not about themselves, or that they don't have time to attend routine appointments.

The nature of mental illness can mean that people are less motivated to look after themselves physically, particularly with certain treatments that can bring unwanted physical side effects such as weight gain, more snacking and low energy levels.

It is important to eat well, exercise and sleep well, which can be encouraged with support and therapies that can kickstart a more healthy lifestyle. Find out about activities that might be available to you in your area – this is not a luxury when you are feeling stressed and juggling your own life with your caring role.

wellbeing

Take some 'me' time

Focus your energy on a hobby or activity that brings you joy. That could be reading a book, watching your favourite film, listening to music or socialising.

Connect with others

Take time out of your day to chat with friends or family and be as open with them as possible.

Nourish your body

Allow your body to feel good by eating a good meal, wearing comfortable clothes or exercising, which can make the brain feel good.

Write down your feelings

Putting pen to paper can be a stress reliever and help you rationalise and accept your experiences.

Communicating with or about someone with mental illness can be very difficult for a number of reasons. However, an essential part of supporting the person is by maintaining good communication with your cared for person, complementing the treatment and help the person is receiving.

Communication with the person can be difficult because of the direct result of their illness. They might experience unusual thoughts or behaviours, making effective communication nearly impossible. Sometimes communication can be difficult when people are unsure what to say or because the relationship has broken down. A person might not believe they are unwell or have irrational beliefs that you cannot change or challenge, making it hugely distressing for carers.

Communication with those who may need to know

Think about who needs to know, what they need to know and what the cared for person wants people to know. Your cared for person always has a right to confidentiality and so do you.

When you tell close family or friends initially, take baby steps and work from there.

It's important to provide them and yourself with accurate, up-to-date information about the illness, reassurance about the effectiveness of the support being received, and guidance in ways of being supportive as a collective.

Make sure you all have the opportunity to talk about your concerns. This is particularly important to siblings and children of those experiencing mental illness. They might be worried about

their own mental health and the risk of developing the same. Young adults and children are also able to access support for carers specifically tailored to young people.

You will need to consider the wishes and sensitivities of the person who is experiencing the illness. All discussions around the illness should be gentle but honest. The support you're provided with will guide you on how to have these conversations.

A communication skill is showing interest by practicing good eye contact. You will listen to understand rather than respond, paraphrase and reflect on what has been said, withhold judgement and advice, and ask open-ended questions to engage. This will keep the conversation positive and make the person feel heard and valued.

When communicating with the cared for person, you might experience:

- **Problems with their thinking and speech:** This could indicate paranoia and delusions and you should accept the fact that the person sees things in a particular way by acknowledging that what they are feeling is real to them. Don't argue or collude; be simple and straightforward but don't always expect rational discussion.
- **Difficulty in concentrating:** It is hard to stay patient but this will help both of you. Be calm, direct and brief, and keep things simple and straightforward.
- **Social withdrawal or loss of motivation:** This can be a way of someone staying safe. Take each situation one step at a time and avoid situations that will raise high emotions and put the individual under pressure.
- **Over dependency:** Consider how well the person you care for is coping with day-to-day life. Sometimes it's easier to do things for someone who lacks the motivation to do things for themselves. But it is important that they are encouraged to take responsibility for themselves if they can.
- **Aggression:** It's important to deal with anger in a healthy way that doesn't harm you or anyone else. Sometimes people don't recognise that their anger is a problem for themselves and for other people. They may see other people or things as the problem instead.
- **Self-harming:** Some people who are experiencing a mental health issue might self-harm as a way of coping with emotional distress. The people around a person who self-harms can often be affected by it too.
- **Suicidal thoughts:** It is very frightening to hear when anyone is expressing suicidal thoughts. Let them know you are taking their feelings seriously and encourage them to talk to a professional or a dedicated helpline: **Samaritans on 116 123** or **Breathing Space on 0800 83 85 87**.
- **Refusal to take your advice or any support:** This can be frustrating but remember that the person you care for is an adult who has their need for independence, and their own rights and wishes. Once appropriate, it might be useful to have a conversation about what helps to best manage with their symptoms.



getting support

You may feel that it is more important for the person in your care to receive support and treatment, and that you do not need support for yourself. However, research has shown that people who care for their relatives and friends may feel isolated or have poor mental and physical health themselves. It is important that you seek support for yourself.

Most people in Scotland get help and support for mental health problems in the same way as anyone who has a physical illness, and can and do make decisions about the help they need. By being informed and receiving adequate support, you are in a better position to support your relative in a more effective way.

Types of support

- **Person-centred care:** focusing on the needs of the individual to ensure that their preferences, needs and values are met and that the care is respectful and responsive to them. It encourages us all to actively listen to the people being supported to best understand what they want to improve their lives.

The seven core values of person-centred care are: individuality, independence, privacy, partnership, choice, dignity, respect and rights.

So often for people who have long-term conditions, outcomes may be imposed on them by the services supporting them. Ensuring that we support people to develop person-centred outcomes means that they are much more likely to achieve success.
- **Talking therapies:** this safe space with a trained professional to talk about your worries and how you're feeling can enable you to explore how looking after someone affects you.
- **Peer support groups:** There is good evidence that discussion with those who have had similar experiences can help people to develop effective coping strategies.

There are also self-help and support groups for carers across the country and speaking to other carers can help carers understand that they are not alone, and that there is help available. Peer support can also help to create a sense of hope that life can get better.

Support can be emotional, practical, financial or even environmental. Support for people experiencing mental illness, their families and their carers is available through a range of services and organisations. The ways you will come into contact and refer to these professionals will be different.

- **Change Mental Health:** We offer Carer Support in Highland, Tayside, Fife, Edinburgh and Dumfries and Galloway. Our Carer Support Workers have expertise and detailed understanding of the issues that affect carers and people with mental illness through emotional support and one-to-one or peer group support. Call our Advice and Support Service on **0808 8010 515** to find out more about our services or how we find relevant support to fit your needs.
- **Your GP:** This can be a first point of contact for someone beginning to experience mental health issues or even if you're yet to experience them. They may refer you to a psychiatrist, psychologist, occupational therapist, Community Psychiatric Nurse (CPN), Community Mental Health Team (CMHT) or a social worker.
- **Carers centres:** They offer additional information, support and practical help. To find out about your nearest centre, go to: www.carers.org/scotland
- **Short Breaks for carers:** As an unpaid carer, you may need a break from caring and there are local funds available to fund short respite and other activities that might relieve stress. Find out more at: www.sharedcarescotland.org.uk
- **Financial and welfare assistance:** As a carer, you might be entitled to welfare financial assistance for yourself. Ran by Change Mental Health's sister charity, Mental Health UK, Mental Health and Money Advice can help carers and people needing support with finances and their mental health. Read more at: www.mentalhealthandmoneyadvice.org
- **Citizens Advice Scotland** are a local bureau that can offer you a range of services and advice on finances, money matters, employment and other things. Find your local bureau at: www.cas.org.uk
- **Carer Support Payment** is financial assistance for unpaid carers, normally paid every 4 weeks.

other help and information for carers

triangle of care

The Triangle of Care encourages better recognition of carers as key partners in the planning and provision of mental health care.

The Triangle of Care, through its self-assessment tool, guidance notes and best practice examples, provides mental health services with the opportunity to assess their own practice around engaging with carers and helps them to look at ways of improving/increasing this way of working and to do so in partnership with carers, people who use mental health services and other support organisations.

Triangle of Care principles translate across many different specialisms and fields in mental health. They are based upon the core principle that carers, people who use services and professionals should work in equal partnership to promote safety, support recovery and sustain wellbeing.

The Menu of Questions for Carers is a guide produced in partnership by Carers Trust Scotland and Change Mental Health. It lists common questions you can ask including about the illness, diagnosis, assessment and the Care Programme Approach, advance statements and medications and treatments.

- The Triangle of Care is an alliance between the service user, staff member and carer.
- Better recognition that carers are key partners in mental health through using Triangle of Care is an investment in safety, quality and continuity of care at relatively little financial cost.
- The Triangle of Care approach encourages partnership working with carers at all levels of care from the individual to overall service planning in line with carers' rights under the Carers (Scotland) Act.

"Carers play a vital role. This menu of topics provides an easily accessible aid to help form conversations about how recovery can be achieved and sustained."

quotes

Through support, carers live meaningful and fulfilling lives while dealing with their caring responsibilities. It can and will get better. Below are some quotes from carers who have been through hardship and can see light at the end of the tunnel.

"Your support and the respite holiday has been invaluable. I hope many others will be able to access support in their time of need."

"Thank you for all your support. It is because of you that I have some confidence back. I have never been able to talk to someone like you."

"The Carers Group was a revelation to find that there were so many other older carers caring for their adult children as I thought it would only be me. It makes you feel that you are not alone."

"I felt heard for the first time. It gave me a boost in speaking up at parent consultation at school and joining support group. I received plenty of valuable advice on other organisations that will help me."

contact



t: 0808 8010 515

e: advice@changemh.org
Monday to Friday,
10am to 4pm



t: 0800 83 85 87

Monday to Thursday,
6pm to 2am
Friday 6pm to
Monday 6am



**t: 111
24/7**



t: 116 123

e: jo@samaritans.org
24/7

Carers Trust Scotland

Information about local carer and
young carer services

t: 0300 772 7701

w: carers.org/scotland

Relationships Scotland

Counselling and support services for
couples, families and young people

t: 0345 119 2020

w: relationships-scotland.org.uk

Scottish Independent Advocacy Alliance

An individual and collective
independent advocacy to people
and groups across Scotland

t: 0131 510 9410

w: siaa.org.uk

Carers Scotland

Find a supportive listening ear by
signing up to a series of calls from
trained volunteers

w: carersuk.org/scotland/

Mental Health Tribunal for Scotland (MHTS)

Considers and determines
applications for compulsory
treatment orders

t: 0800 345 70 60

w: mhtscotland.gov.uk

Mental Welfare Commission for Scotland (MWC)

Provide advice on rights to do with
mental health and incapacity law,
and care and treatment

t: 0800 389 6809

w: mwcscot.org.uk



Change Mental Health

is a charity registered in Scotland
SC013649.

www.changemh.org