

# Family, friends, carers



This factsheet aims to give an overview of the situation that family, friends and carers of those with a mental health diagnosis may encounter, and to provide some helpful information.

## **Impact of mental illness**

Mental illness may have an impact on everyone close to the individual concerned. This can include family, friends and work colleagues. The degree of impact can depend on the relationship and the type of mental illness.

There is also a point where 'being concerned about', or 'affected by' someone with a mental health diagnosis, may become a situation where an individual or individuals take on a significant caring role for the person affected. The point at which this happens may not always be clear to either party, but as there is specific help and support available to anyone in a caring role, it may be helpful to be aware of the options available.

## **How might you become a carer?**

The experience of family, friends and carers is likely to change over time. The early stages of mental illness may have some common qualities, regardless of the diagnosis. Thereafter, there are likely to be aspects that are specific to particular diagnoses.

It may be helpful to have a brief overview of the early stages of mental illness, and what family and friends can do, as well as some detail about specific diagnoses, and how family, friends and carers can help support the individual concerned, as well as taking care of their own needs.

### *Early stages of mental illness / concerned about someone's mental health*

For many people, the first thing that alerts them to the possibility that mental illness is affecting a friend or family member is a change in behaviour of the person concerned.

*Depression and anxiety* – these can manifest in many different ways, and the two are often linked. People may become withdrawn and quiet, or they may become irritable and easily upset. They may appear to be constantly tired; their appetite may change.

The way they relate to people may also undergo changes. For instance, they may be less patient; they may get easily irritated with children, pets or other family members. You may notice they are less careful about, or interested in, personal hygiene and dress.

People may have difficulties at work, or in relating to work colleagues; they may find it hard to find the motivation to go to work. People may lose interest in activities and hobbies that they have previously enjoyed. They may also find difficulty in socialising with people outside the family, or be reluctant to go out. For many people, making decisions becomes very difficult, even over relatively simple matters.

*Mood disorders* – as the name suggests, people with mood disorders are likely to display changes in mood that are different from the 'normal' mood swings that everyone experiences.

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The affected individual may be aware of their mood swings, but perhaps not in the same way as friends and family experience them.

People may change from being euphoric and 'on top of the world', where anything seems possible, and where energy is super-abundant, to a very low, dark place, where there is little energy available even for the most routine of day-to-day activities.

The mood disorder spectrum is a broad one, and switches between moods can vary between individuals. The length of time a particular mood lasts can also be different with different individuals. However, the mood swings are likely to be disruptive or distressing to the individual themselves, and, possibly more so to family and friends who are likely to be even more aware of the disruption and distress caused.

The situation can be even more distressing for family and friends if the individual is not particularly aware of the effect of their mood swings, either on themselves or on other people. Very 'high' or manic episodes may be even more destructive and disruptive than 'low' or depressive episodes, yet are likely to be experienced as life-enhancing and positive by the affected individual. These differences in perception and insight can lead to difficulties in getting appropriate help and support.

*Paranoia* – the saying, 'X is paranoid about...' is a common one, and its regular usage may tend to undermine the seriousness of, and distress caused by, paranoia. This is not an illness in itself, but can manifest as a symptom in a number of conditions, such as severe depression or anxiety, bi-polar disorder, schizophrenia and some kinds of personality disorder. Paranoia can also be a feature of conditions like dementia and Alzheimer's.

Paranoia may manifest as distrust, suspicion, fear, jealousy or apprehension of a situation or person. For example, people may believe they are being followed, or listened in to; they may believe someone is 'out to get them', or do them harm in some way.

Some individuals may have insight and be aware of the irrationality of their thoughts, while also being distressed by the reality of the feelings resulting from such thoughts and beliefs. Others may have no awareness of their condition, and be fully convinced of the truth of their own experience. This can be particularly difficult for family, friends or colleagues to deal with; even when people have some insight into their condition, it can be hard for family or friends, particularly if they are the focus of the paranoia.

Paranoia may result in people feeling very isolated, their own fears and suspicions causing them to reject or be fearful of family, friends and colleagues, while those close to them may become very frustrated at trying to reason with their paranoid thoughts and not knowing how to help.

In extreme cases, where people cannot tell reality from fantasy or their paranoid thoughts, they may be considered delusional or psychotic.

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*Psychotic illnesses or episodes* – schizophrenia is considered a psychotic illness, where people experience thoughts, beliefs and sensory hallucinations (most commonly auditory), which are not experienced by others.

Conditions like bi-polar disorder and very severe depression or anxiety may also include psychotic episodes. These can be particularly distressing for family and friends as the affected individual may have lost touch with reality, but may have no awareness that they have done so.

## **If you are worried about someone**

Generally, the first point of contact for anyone concerned about a mental health issue is their GP. Sometimes the person you are concerned about may not be aware that they are causing concern, or they may be anxious about, or unwilling to, see their GP. However, encouraging them to go, perhaps offering to go with them may be helpful, and this may be sufficient to encourage them to attend for an appointment.

If the person is unwilling to attend the doctor themselves, you may wish make an appointment with their GP yourself. The doctor will not be able to discuss anything relating to the individual about whom you are concerned, but you may find it helpful to share your concerns, the doctor will have been made aware of your concerns, and they may be able to offer advice or support.

## **Mental Health Assessment**

If you are seriously concerned about an individual you can request a mental health assessment. Under section 13 (4) of the Mental Health Act 2007 the 'nearest relative' has the power to request a mental health assessment. This can be done via the GP, or through the local Community Mental Health Team (CMHT).

'Nearest relative' is a legal term. The relevant person is identified by law in the following order:

- Husband/wife (this also includes civil partners and people who have been living as man and wife for at least six months)
- Son/daughter (if aged over 18)
- Father/mother
- Brother/sister
- Grandparent
- Grandchild
- Uncle/aunt
- Nephew/niece

If there is no one in the first category, move to the second category and so on. If there is more than one person in a category, the older one takes priority. (Only those living in England and Wales can be counted.) However, a relative who is actually caring for someone takes priority over all the others. A person who is not a relative, but has been living with the person concerned for at least five years, can also be considered as the 'nearest relative'.

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## **What constitutes a carer?**

A carer is a person who provides help and support to someone with a mental health problem. The term “carer” is usually used to describe friends or family who provide voluntary support rather than paid professionals or care workers who are employed to provide a service, though the term is sometimes, confusingly, used to describe these workers too.

In the context of this factsheet, an unpaid carer may be a relative of the person they care for, or they may be a friend or neighbour. They may live with the person, or live apart.

The one unifying factor is that they provide some degree of emotional support or practical help for the person they are caring for and that the person they are caring for cannot manage without their help. For the purposes of receiving financial or practical support from the local authority an unpaid carer is usually defined as someone who provides ‘regular and substantial’ help or assistance to the cared for person.

## **Emotional impact of being a carer**

The role of a carer can be very demanding and challenging, physically, psychologically and emotionally. There may be practical and financial support available for carers, but it is crucial that carers, family and friends are conscious of the full range of demands pertaining to the caring role and try to attend to the emotional and psychological needs of carers.

The general and mental health of carers can be affected by the demands of the role; this needs to be recognised, acknowledged and addressed appropriately. Of course, the role of being a carer can also be very satisfying and rewarding, but this is in parallel to less palatable consequences.

While people fulfil many responsibilities as carers, it is not a role that is sought voluntarily; no matter how dedicated and committed an individual may be as a carer, it is a role that is imposed; individuals may feel they have no choice other than to meet the responsibilities involved. While the role may be willingly taken on, it is also natural to feel resentment, anger and frustration at having to fulfil a role that has not been freely chosen.

### *What are some of the emotional impacts of being a carer?*

For an individual mental illness can have implications for behaviour, relationships, lifestyle and ability to function in everyday life. Mental illness can strike at any time, any age, and in any social class.

For family, friends and carers, coping with symptoms such as those outlined above can be distressing, traumatic and shocking; it can also leave people feeling helpless, angry and frustrated.

A sense of loss and grief is common for carers as they witness the lives of those they care for changing and providing challenges and difficulties that the individuals may not feel able to

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manage, while carers may also feel helpless and/or be rendered helpless by the mental health system, which does not always support or acknowledge the needs and feelings of carers.

## *Caring as a parent*

While the caring role can be difficult and challenging for anyone, it may be particularly so for a parent.

Parents may see their children – in their teens, or as adults – being affected by depression or anxiety; they may witness them experiencing psychotic episodes. Mental illness may mean an individual has difficulties in engaging in school, college or university, in holding down jobs, in engaging with friends or other social networks. Parents may also see the effects of such situations on other family members such as sons and daughters-in-law, and on grandchildren.

Severe mental illness may feel as though it has robbed parents of their children, and stolen the lives they envisaged for their children; parents may have to consider that their child may die before them. They may see their children making suicide attempts, self-harming, or using drugs or alcohol in a destructive way. Eating disorders bring their own distress and pain, with the knowledge that anorexia is the mental illness most likely to lead to the death of an individual.

Children may continue to live at home if they are not able to live independently; this can be very draining and difficult for all the family, particularly when symptoms are chronic and enduring, or during particularly difficult phases of an illness.

One of the effects of mental illness is that it can make relationships very difficult; the person affected may reject and push away those closest to them – this can be a feature of depression for example. This can be difficult for parents and other family members, particularly when they are trying to help and support the individual.

Children who are over eighteen may state that they do not want their parents to be informed of their treatment or care; they may express a desire not to see, or have contact with, their parents or other family members. This may be a feature of the illness and/or it may reflect pre-existing family difficulties; however, mental health professionals have a duty to respect such wishes, and it may leave families leaving distressed and helpless, particularly if they still have responsibilities as carers.

Depending on the mental illness, and the nature of it, and/or the effectiveness of treatment regimes and/or how their children choose to follow prescribed treatment regimes, parents may have to consider that this is a life-time condition they, and their children, have to live with; the illness may be of a more fluctuating nature, meaning that there are stable periods, with intermittent periods where symptoms are more distressing.

Such situations can be incredibly painful for parents; this is not the life they envisaged or wished for their child. Grief for the loss of their dreams; grief for the life not lived; grief for other family members who are also affected by the situation can all be part of the emotional impact of caring for a child with a mental illness.

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## *Caring as a husband, wife, partner*

Caring for a husband, wife or partner with a mental illness brings its own distress and pain. The changes wrought in an individual's behaviour and relationships can be particularly difficult, both for spouses and partners, and for children.

This may include being rejected or pushed away by the individual affected; it may mean witnessing someone experiencing psychotic episodes, which can be frightening and confusing; it may mean seeing someone lose interest in their lives, their jobs, their families, their children; it might mean seeing a previously competent and engaging individual lose the ability to function in aspects of their lives, as well as losing interest.

Such situations can be made even more difficult if the individual is not aware of how they have changed, or the effects of their symptoms either on themselves or on others. If this is the case, they may be reluctant to seek help, or not understand or accept that they need help. This can be very difficult for a spouse or partner, as they have to deal with the consequences of symptoms, but with no prospect of the individual being able to help themselves or gain insight into their situation.

Children may find it hard to understand such symptoms or changes in parents, and the parent who is caring for the individual may also struggle to find a way to explain the situation to children, in a way that does not cause unnecessary distress, fear or anxiety.

Mental illness in a spouse or partner can also have practical and financial implications, if the individual's ability to work is impaired over a period of time. Long term mental illness can seriously test a relationship and carer may feel they have to take an unfair share of household and family responsibilities where previously such responsibilities may have been shared.

As with all caring roles, emotions are likely to run the full gamut, from love, care and tenderness through to frustration, anger and resentment. It is helpful to recognise that all these feelings are natural responses to the situation, and it is unrealistic to expect that more difficult emotions won't exist alongside more apparently 'acceptable' emotions.

## **Coping as a carer**

Almost without exception, when speaking to others, either professional or social, carers will focus on the person they care for - their needs, their condition, their prognosis, treatment, medication etc. However, in order to truly cope as a carer, it needs to be recognised that there are two equal elements in the equation – the person being cared for, and the carer. While it can be difficult for carers to recognise or acknowledge, the needs of the carer are as great as, and as worthy of attention as those they care for.

This factsheet addresses both and, in the interests of attending to carers' first concern, it first addresses ways in which carers can help those they care for, before going on to attend to ways in which they can meet their own needs and get appropriate support for them.

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## **How can a carer help?**

### *Information*

Although each individual and carer will have their own experience of their illness, it is helpful for a carer to find out as much as possible about the condition once a diagnosis has been confirmed. This may help both the carer and the individual understand and accept that their symptoms are a normal aspect of the condition; it may also help them to understand how treatments and medications can help.

While such information may be available from doctors, psychiatrists or others involved in treatment and care of the individual, this is sometimes given at times when neither the individual nor the carer may be most receptive to it, so it is helpful to have factsheets about illnesses, such as those provided by SANE, as they provide a point of reference at times that may be more relevant for individuals, and allow information to be taken in over time.

Situations where there is no clear diagnosis, or where a range of diagnoses may be given over time are particularly difficult for both carers and individuals affected. In such situations, it may be more helpful to try to get information about specific symptoms and how to cope with them, even if they haven't been categorised into a specific diagnosis.

### *Relationship with mental health professionals*

If possible (and it's not always possible, depending on the wishes of the individual affected), it is helpful for carers to try to develop a positive relationship with the professionals involved in the care of the individual – doctor, psychiatrist, members of the mental health team etc. This can be particularly helpful when an individual may be unwell, or their condition has deteriorated.

### *Understanding / acceptance*

Depending on circumstances, an individual affected by mental illness may have relatively few people they feel they can talk to openly about their situation and circumstances. Carers can provide understanding and acceptance that may be difficult for individuals to find elsewhere.

This kind of open, honest conversation can be helpful; it can also be difficult and distressing for carers, for example if the person they are caring for is feeling very depressed or suicidal. This is another reason why it's important for carers to consider their own support needs, as providing this kind of support can be emotionally overwhelming.

It can be useful to learn some listening skills to help with this aspect of caring, as active listening does not mean simply absorbing everything the other person is saying. It enables an equal relationship that can include challenging as appropriate and being assertive, and therefore perhaps not so inclined to feel overwhelmed by the needs of the person affected.

### *Social activities / humour*

These are not necessarily the first things that come to mind when thinking about a role as a carer, but in fact, sharing social activities that are fun and enjoyable, and humour, can be important aspects of the caring role, for all parties.

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This might include watching films together, going out for walks, visiting the theatre, going to the cinema, sharing a hobby, or taking an interest in other people's hobbies and interests. This can help alleviate the difficult feelings that can accompany mental illness, and also serve as a useful reminder that people's identities, either that of the person directly affected, or their carers, are not entirely determined by mental illness.

## *Monitoring/ relapse / emergency*

As well as providing emotional support and encouragement, a major role for carers can be to help monitor the person's mental state, watching for signs of relapse, encouraging them to take their medication and to attend medical and/or therapy appointments.

If a carer is concerned about any deterioration in a person's mental health they can alert the doctor, psychiatrist or mental health team as soon as possible in order to prevent the possibility of a relapse.

A carer may become very concerned about the mental health of the person they are caring for; perhaps as there are major signs of deterioration, or threats of danger to themselves or other people.

## *Mental health assessment*

In these cases, the carer can contact their local Social Services department or Community Mental Health Team and request a Mental Health Assessment, if this has not already taken place. This usually involves two doctors and an Approved Mental Health Professional visiting the person at home to assess their mental health, and to see whether any other support services need to be put in place.

People with severe symptoms may require hospital admission for a period of assessment and treatment. Hospital admission can provide levels of care and attention that would not be possible at home. It can also give medical staff the opportunity to accurately assess a person's condition over a period of time, and to provide a broader range of treatment than might be possible otherwise.

## *Hospital admission*

Most people who are admitted to hospital go voluntarily; however, in some extreme situations a person may be admitted to hospital compulsorily under the Mental Health Act 2007, England & Wales (or equivalent in Scotland and Northern Ireland) commonly referred to as *sectioning*, or *detention under section*.

## *A & E*

There may be occasions when a carer may feel that the person they are caring for needs urgent psychiatric help, and mental health services are unable to arrange an appointment soon enough. In this situation, if practical, a carer could take the person to their local Accident and Emergency Unit where they can be assessed by the Duty Psychiatrist, or contact the person's Crisis Team if they have one.



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## *Police*

In extreme situations, for example if the person is presenting as an immediate danger to themselves or other people, a carer could call the police and explain the situation. It is possible for the police to take someone to a place of safety, either a police station or a hospital, where they will be assessed by a psychiatrist. This option should be seen as an action of last resort as it can be a very distressing situation for the person involved and their carer.

## **What needs may carers have?**

Being a carer can be an extremely satisfying role, however, it can also be extremely challenging, physically and emotionally demanding, stressful, exhausting and isolating. Carers can have a variety of needs depending on their individual situation.

Some carers may feel they need emotional support while others would like practical assistance. Some may want information and advice while others are looking for financial help.

Some people may want recognition of the hard work they do, others may need time off from their caring role. Some carers are desperate to find some type of support service for the person they care for, others would like to become involved further in the planning of care programmes.

Carers are usually fiercely protective of those they care for, and work very hard to provide support themselves, as well as seeking out external sources of support and treatment for those they care for. However, they are often less concerned about their own needs and may neglect their own health and other needs.

There are often very practical reasons for this, as caring for someone with severe mental illness can be very time-demanding, eg hospital and other appointments, hospital visits, ensuring the safety and well-being of the individual etc.

## **Support for carers**

There are sources of practical and other support for carers. However, the availability of such services may be inconsistent, and dependent on where an individual lives.

## *Carer's Assessment*

One way of assessing what support may be needed and available to a carer is through requesting a Carer's Assessment.

Carers are entitled to have a Carers Assessment to have their own support needs assessed by either their local social services or mental health services. However, this option needs to be viewed realistically as many local authorities do not have the resources to provide for these needs, even where clearly identified.

Carers can request a referral for a Carer's Assessment from their own GP, or they can contact the Care Co-ordinator of the person they care for, their local Social Services Department, or if the person they care for is in the care of mental health services, they can request a Carer's

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Assessment from the local Community Mental Health Team. Carers can also request a Carer's Assessment independently of whether the person they care for is receiving services or not.

## **What does a Carer's Assessment involve?**

Carer's Assessments aim to identify what support needs you may have, and to arrange ways to meet your needs. The assessment will usually look at how you are coping generally, whether you need emotional or practical support, what social or support networks you may have, whether your health has been affected by your role as a carer, how you might cope in an emergency, and whether you need information about benefits.

After the assessment you should receive a written support plan detailing how any needs that have been identified will be met. If the local authority is unable to provide any or all of the services you have been assessed as needing, they may put you in touch with other local voluntary organisations that can help you.

In certain situations where the local authority has assessed you as being eligible for a particular service they may not provide themselves, they may decide to give you *direct payments*. This is a means by which you can buy in the support you need from private agencies. This type of arrangement can be complicated, so it may be wise to contact your local social services and ask to speak to a *direct payments* specialist advisor.

## **What rights do carers have?**

Carers have recognised legal rights as set out in the Carers (Recognition and Services) Act 1995, the Carers and Disabled Children Act 2000, and the Carers (Equal Opportunities) Act 2004.

## **What kind of support may be available?**

### *Respite care*

This is designed to give you a break away from caring for a time. It might be a one-off break, or a regular service depending both on your needs and the needs of the person you are caring for. This often involves the person you support staying in a mental health respite centre to give you a break or allow you to go away for a holiday.

### *Domiciliary care*

This usually involves a paid care worker taking over caring responsibilities for an agreed time each week, giving you a break from caring and allowing you space and time for yourself or to look after other responsibilities. Domiciliary workers can also help with tasks you might find difficult to do yourself, for example helping bathe someone.

### *Befriending services*

Befrienders can visit people with mental health problems in their own homes, or go out with them. This can give the service user the opportunity for more social interaction, and allow you to have time off from caring. Befriending services may be offered by local voluntary organisations, but availability may be patchy.

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## *Day care services*

There are a range of day centres, drop-in centres and day hospitals that service users can be referred to. These can offer a variety of services including social groups and therapeutic activities. These can be offered for anything between a few hours and a few days per week depending on assessed needs.

## **What financial support may be available?**

*(This section is under review; an updated version will be made available as soon as possible.)*

Carer's Allowance is the main state benefit for carers so it's important to find out if you can receive it. Carer's Allowance is currently worth \*£58.45 a week. To qualify you need to meet all the rules:

- You must be 16 years old or over
- You must look after someone for at least 35 hours a week
- The person you look after must receive a qualifying disability benefit
- If you work you must not earn more than \*£100 per week after deductions
- You must not get one of a list of other benefits, contact your local CAB for details
- You must be living in the UK when you claim Carer's Allowance
- You must not be a full-time student

You may also be able to get the Carer Premium - an extra amount of money included in the calculation of Income Support, income-based Job Seekers' Allowance, Housing Benefit and Council Tax Benefit (Rent Rebate in Northern Ireland). An amount equivalent to the Carer Premium is used to calculate Pension Credit.

It is important to be aware that if you are eligible for the Carers Premium payment this will mean that if the cared-for person is receiving Severe Disability Premium they may lose this benefit. So it is advisable to inform the cared-for person that you will be making a claim.

\*NB: SANE will endeavour to keep the amount up to date, but to be sure of the latest details of these payments, check [www.directgov.gov.uk](http://www.directgov.gov.uk) or contact the Citizens Advice Bureau.

## **Where can I find help and support?**

### *Support groups*

Many people find it helpful to meet with others in a similar position. It can be very useful to share experiences with those who may be going through the same thing you are. There are opportunities for mutual support, and you may get ideas of what things other people have found helpful to them. Above all, it is an opportunity to help you realise that you are not alone in your situation.

### *Care for yourself*

When you are caring for someone else it is extremely important that you look after yourself too. You will feel better if you are able to rest, eat properly, pay attention to your physical appearance, and don't abuse alcohol or drugs. Be kind to yourself, allow yourself treats, and try to keep up a social life of your own. This will help you to reduce your stress levels.

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If you are starting to feel that the impact of the caring role is affecting your mental or physical wellbeing it is important to seek support. It may be worth informing your GP surgery that you have caring responsibilities as they may be able to provide information about support available to carers.

## *Counselling*

It can be very stressful caring for someone with mental health problems, indeed carers may be service users themselves. Sometimes it may help for you to have someone to talk things over with. A referral for counselling can be arranged by your doctor. However, frequently there are long waiting lists for treatment on the NHS. Free or low-cost counselling is also provided by a number of charities and voluntary organisations and, for those who can afford to pay, there are many private practitioners.

## *Other support options*

There is a wide a range of services available that can help provide support, advice and information to carers. You may find some of the following useful:

### **SANE Services**

1st Floor Cityside House, 40 Adler Street, London, E1 1EE

SANE Services offer emotional support and information to anyone affected by mental illness, including family, friends and carers.

Helpline: 0845 767 8000 (6pm – 11pm every day)

SANE email: [http://www.sane.org.uk/what\\_we\\_do/support/email/email](http://www.sane.org.uk/what_we_do/support/email/email)

SANE Support Forum: [http://www.sane.org.uk/what\\_we\\_do/support/supportforum/](http://www.sane.org.uk/what_we_do/support/supportforum/)

The Support Forum provides a space where you can offer and receive mutual support through sharing your thoughts, feelings and experiences of the difficulties and challenges that can arise from living with mental illness. There is a space on the Forum dedicated to Family, Friends and Carers.

Website: <http://www.sane.org.uk/home>