

# Improving Carers' Experience

Information Booklet for  
Mental Health Carers

**East Sussex, West Sussex and Brighton & Hove**

# **Improving Carers' Experience**

## **Information Booklet for Mental Health Carers in East Sussex, West Sussex and Brighton & Hove**

**This booklet offers information to people who are concerned about a relative, partner or friend because they may be experiencing a mental health problem.**

**ICE (Improving Carers' Experience) is an independent Community Interest Company**

*Many thanks to:*

*Maggie for allowing us to use her work and for Deidre, Gordon, Stephen and Julie for their useful quotations.*

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*Sussex Partnership NHS Foundation Trust staff who helped with information, corrections and suggestions.*

**MH** will be used throughout for mental health and **MH issue** as a general description of a wide range of symptoms.

**'Service user', 'cared-for person' or 'patient'** are used for the person being supported.

**Local Carer's quotations are in blue**

Alan Stenning and Jane Lawrence

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*"I'm not sure what it is about Carers, confronted with a leaking roof, a heating system in the winter that's packed up, a broken down car and a main fuse blown in the house we would get someone in to fix them. When a family member or friend becomes unwell with a MH problem, possibly because we know them better than anyone else, or because we feel guilty in some way we're sure we can get them better, all without specialist training and support".*

*"Although I'm not a 'group' person the ICE Carers Information Course gave me the support I needed to build up my confidence, and learn a lot about treatment, medication, how the system works, problem solving, etc. Using this information as well as my own knowledge about the person I know and love has started us on the road to recovery and genuine laughter has come into my life again."*

Note: The original version of this booklet was compiled by the ICE (Improving Carer's Experience) Project who are no longer operating.

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## Introduction

This booklet has been constructed from a variety of different sources, including contributions from Carers locally and nationally, and from people who experience mental health issues themselves.

It is an attempt to gather useful information in one place both for people new to caring and those who have been doing it for a while. There are also quotations from local people who have found themselves trying to help someone through the 'journey' that begins when they develop a MH issue. It is clear that the family and friends who are offering help have to go through their own journey too.

The booklet has little information on dementia and related conditions but there are more specialist resources listed. Neither does it deal in detail with autistic spectrum, eating disorders or ADD/ADHD, which again share some common features but need a specialist viewpoint and information.

Reading this booklet may cause concern because it is unfortunately necessary to consider the worst possible situations, hopefully ones you may never have to deal with. But for Carers who do have very stressful times to cope with the hope is by being open about these difficulties they may feel less alone and more prepared to seek support. The booklet doesn't have any magical answers but it may help in some way to improve the quality of your life as a Carer, particularly when your patience and understanding are under pressure!

The main message to Carers is that looking after you is not a luxury, it is a necessity.

### Who is a Carer?

If you give unpaid support to someone with a mental health issue and they rely on that support, then you are a Carer. This applies even if the person doesn't live with you.

This term is confusing and not always a comfortable one to accept as it is also used for paid care workers.

It may be easier to see yourself as a parent, partner or friend.

However, it is the word used in official policies, law and generally accepted by professionals, so it is worth recognising that it applies to you even if you prefer not to use it.

It can be the key to recognising what help and resources are available to you.

## From the beginning

It is very difficult to know in the early days what is a MH issue and what isn't. You may notice some unusual behaviour and become worried, but of course there could be another explanation altogether.

Some physical conditions produce unexpected symptoms. Secretly misusing drugs, both prescribed and un-prescribed (including alcohol) could be responsible. This is not, by itself, a MH issue.

Other factors could be a life event, perhaps bereavement, redundancy, exams or maybe leaving home for the first time. Stressful events can cause temporary changes and worrying behaviour but this may only last a short time. For example recently bereaved people can be highly emotional, cry a lot, or be angry or withdrawn. With a clear recognisable reason relatives and friends often offer support until the crisis passes.

Hormonal changes can be responsible, adolescence and menopause being two key times. Our society expects teenagers to be 'difficult' and for people 'of a certain age' to act out of character, maybe buy a fast car or break up a long standing relationship. This behaviour can be fairly extreme.

Often people will deny they are behaving differently, especially if they do not acknowledge the cause. However if there is an identifiable reason then it may be a brief period that soon sorts itself out and the person returns to their more usual character and behaviour.

Children can have worrying behaviour from an early age; some develop these issues from late adolescence or early twenties. These may be identified through the educational system but sometimes they are merely considered withdrawn or 'difficult'. How can you judge what is normal

Two of the categories of carers that have specialist services are:

### **Young Carers**

(8-25 yrs old). These young people may have problems with their education or access to an 'ordinary' life because of their caring role, usually for a parent or sibling.

### **Armed Forces Families**

Ex-servicemen and women who may have been affected by their experiences often take several years to recognise that they are not adapting to life back home. This may involve a high incidence of alcohol and drug use. Families can bear the brunt of this.

For specialist services for these categories see the contacts pages at the end of the booklet.

adolescent behaviour? There is always the belief that a young person will 'grow out of it' and change with the onset of adulthood and often that is exactly what happens.

If changes do not fit with recent events, do not fade after a time or appear out of nowhere then it may be that another explanation is needed. How do you go about starting to get advice and information? This is especially difficult when the person themselves seems unconcerned and perfectly prepared to carry on, insisting that everything is fine or resenting your 'interference'!

## Causes

**Mental ill health can be caused by a variety of factors, most frequently it is a combination of more than one.**

**Inherited factors.** For many conditions there is a hereditary factor, which maybe has skipped a generation or two. It is noticeable that two people can go through similar experiences and one will be barely affected while the other reacts strongly and this may be due to genetic factors. Recent research has shown there are genes that relate to certain clusters of symptoms (and which don't always tie in neatly with the current way of classifying MH issues). This may create a 'predisposing factor', a sort of vulnerability within the family tree. It could mean relatives develop MH issues which do not always have the identical symptoms. However, many people could have a family tendency and not be affected at all. A useful explanation of this can be found in the book 'Introducing Mental Health', details on page 67.

**Social and environmental causes.** Events that an individual sees as traumatic can trigger a MH issue. Possibilities include leaving home, being made redundant, being bullied or abused. Many service users have had very traumatic experiences, but not all. Childhood environmental factors such as poverty, inner city living, inability to speak the local language, physical illnesses or social isolation may also play a part.

In the 1960s there was widely publicised research that held families responsible for all MH difficulties. A child who has been abused in any way will, of course, be more likely to develop issues but this is just not a factor in many cases. Stigma may remain when neighbours, friends and relatives fail to realise that a dysfunctional family is certainly far from the only reason for these conditions to arise.



**Childhood trauma** frequently comes up in explanations of why someone has developed these serious conditions. If you are a parent of the affected person this can easily become a real source of guilt. It's worth considering that these people are often particularly vulnerable because of inherent characteristics such as worrying more or being less able to 'self soothe.' The events may seem unremarkable to the rest of the family but important to that one person, or be out of anyone's control, such as bereavement or (social media) bullying which comes to light usually after the damage has been done.

MH Practitioners don't automatically presume that the family are abusive, in fact they usually presume that without their support the person would be far worse off! The number of situations where there is deliberate abuse from the family is very small, this 'childhood trauma' factor is not a reason for guilt!

**Psychological factors.** In recent years there has been a considerable amount of research around how people cope with their own mental health. It seems that part of a person's development involves creating coping skills to deal with life's difficult bits and that it is possible that over-thinking, worrying, constantly replaying awkward or embarrassing moments and seeing every small 'failure' as being evidence of your own lack of worth all contribute. So it is possible that one person may be greatly affected by an incident according to how they think about it, whereas another may be more resilient due to the ability to 'shake it off'. Most talking therapies focus on strengthening that resilience so, no matter what symptoms people may be living with, they can be less buffeted by everyday life.

### **Non-prescribed drugs**

Research indicates that certain drugs trigger some MH issues in some people, possibly those that are genetically or psychologically predisposed, and that this can continue even after the drugs are stopped.

It can be impossible to tell if the MH issue or the drug use came first for any particular individual, and therefore which is the 'cause'. Letting go of trying to find this out can be a struggle but in reality knowing probably won't make a great deal of difference to how things work out.

**In summary,** MH issues are spread through the population nationally and internationally. Extreme experiences such as those encountered in the Armed Forces can cause reactions in fit fighting troops. Universities have special services to work with their students because this is a vulnerable time even for the most academically intelligent people. As more celebrities and high profile figures go public with their diagnoses it is clear that given certain circumstances it could affect absolutely anyone.

## What is a MH symptom?

Being sure you are dealing with a MH issue is not as straightforward as with physical health problems. Symptoms are unusual changes in behaviour - what a person says and what they do - which in turn rely on what they are thinking and their mood. This is highly complex to diagnose and very individual to each person. As someone close you are in a position to see what is different and monitor changes. It will be very helpful when you see a doctor if you can have a clear set of ideas about what is causing concern and some factual examples. Statements such as 'he isn't himself' or 'she just seems a bit off colour' are too vague to help much.

### Getting a diagnosis

What can be frustrating is the apparent reluctance of doctors to give a label to the problem immediately. The delay may be caused by the time it takes to get an accurate assessment and a premature diagnosis could lead to the wrong treatment.

It is not always helpful either to be told you have MH difficulties; this can make someone feel a whole lot worse and make them less motivated to work on their problems themselves.

It can be frustrating feeling that no one seems to know what is going on but the delay is often for good reasons. It isn't unusual to wait months or even years for a firm diagnosis but that doesn't mean people won't get treatment in the meantime. And then it may often be changed!

For example

-She won't come out of her room and hasn't done all week. She used to go out and meet her friends but now she stays in all the time. I seldom see her.

- He keeps checking things, like locking the back door and turns the light switch on and off. Not once or twice but ten or more times and finds it hard to stop.

- He has scratched his arm quite deeply several times. He wears a long sleeved shirt to try to hide it but I have seen scars, including new ones over the last few weeks.

It is really useful for you and for any staff that get involved if you have kept a diary of basic facts. You can monitor changes and have a clearer description of what happened and when. These details are useful in trying to give them accurate information. This may seem obvious but doctors are looking for specific symptoms and factual evidence provides the best way of assisting them.

## Main categories of MH issues

If you suspect that the person you are worried about has a MH issue you may be able to convince them that they need a doctor's support. But it is important not to put a label on these changes too quickly or without professional help. This can cause misunderstanding and complicate an already tricky situation as well as possibly being quite wrong.

There follows a brief description of the major diagnoses, hints on how to cope with are under 'Day to Day Living.'

### Depression

Symptoms include low energy, waking early or struggling to sleep, finding it hard to get out of bed, eating a lot more or a lot less. People lose interest in things that used to be enjoyed, and are hard to motivate and impossible to cheer up. There is no magic line between a diagnosis called depression and the day to day lows we all experience except a matter of degree. If it lasts a long time and affects the person's life seriously enough that they need help from a doctor it can become a formal 'label'.

For many, depression can be temporary or mild and only a passing cause for concern. For some it can be severely disabling and long term. It may be in response to a life event or appear out of nowhere, in which case the cause may be more genetic? It has been described both as 'like having your head in a goldfish bowl, you can see the world but not take part in it', or the opposite of rose coloured glasses, everything is grey'. About one in 20 people will experience it at some stage.

It can be tempting to feel people are 'putting it on' and of course this is possible. But for most sufferers it is not an option and is very unpleasant and frightening. Most people would definitely not choose to feel like that. Like many MH diagnoses, depression is thought to have a genetic component but is often it is a response to a life event as well with the person's own coping skills also making a difference.

**New Mothers** may temporarily feel mild depression but a small percentage become very ill. They may develop *post-partum* psychosis and there are suggestions that some develop Post Traumatic Stress Disorder (See relevant sections).

**Seasonal Affective Disorder (SAD)** is the experience of depressive moods during the shorter days of winter and often includes craving carbohydrate-based foods. SAD relates to lack of daylight and can respond well to light treatment. In Northern Finland 9.5% of people experience this unpleasant response to winter.

Enthusiastic encouragement to 'stop feeling depressed and do something positive' will probably not result in change, but sensitivity is much appreciated even if the person cannot express their thanks until they feel better. Gentle support to try small challenges can be effective but if your cajoling, bribery, persuasion, ultimatums, pleas and patience are not having any effect then maybe there is nothing you can do for a while but wait.

Anti-depressants can be highly effective for many people and provide short or long-term relief. The chance to talk to someone such as a counsellor or therapist or learning self-help techniques may also be very useful.

## Anxiety

Many people worry a lot but at its worst anxiety can severely affect the way someone lives. If you consider what it would be like to have to face something you are really frightened of, such as putting your hand in a tank of snakes, it is a small insight into their constant tension.

Anxiety produces a physical reaction with rapid breathing, palpitations, nausea, sweating and sometimes chest pain. It seems that some people are born more prone to feeling anxious and are more likely to be affected by negative experiences, others may learn these behaviours or develop them in reaction to life events. Anxiety disorders can take different formats, the main categories being:

**Panic disorders** where extreme fear suddenly takes over a person, they may feel they are having a heart attack because of the overwhelming physical symptoms. This traumatic experience can lead people to avoid any situation similar to that in which the panic occurred, which then affects their ability to function day to day.

**Phobias** are the intense fear of something which leads to avoidance of specific situations or objects. Many people have a fear of something (heights, spiders, snakes) but for some it is a constant dread which leads to changes in behaviour and they will avoid any situation that risks being close to the 'trigger' object. Fear of vomiting may lead to difficulties in eating well, not all phobic objects are easy to avoid.

**Social phobia** is a common anxiety. This is a fear that they will do something inappropriate or embarrassing which will result in humiliation. This is based on an expectation that other people see them as odd, unworthy or stupid. For example:

*A woman is taken ill on her way home from the shops; she experiences both sickness and diarrhoea in her own street. She is panicking and unwell but eventually makes it home. The memory is*

*so unbearable, the fear of it recurring, the embarrassment that she might have been seen, that she feels terrified about going outside. So she stops going out altogether and becomes dependent on her family. This in time then becomes a hard habit to break even though the original memory fades.*

**Agoraphobia** is the term used for a fear of being in a place where there is no escape, such as a crowd, a shop, a bus or a queue. The person feels unsafe (and may also fear a panic attack.)

**Generalised anxiety disorder** describes a constant state of anxiety which can be focussed on a constantly changing variety of things such as money, health, traffic accidents or their children's wellbeing.

**Obsessive compulsive disorder** has two elements. Obsessions are the constant unwanted thoughts that predict that the person will do something terrible or something awful will happen to them or their loved ones. The most common obsession is that they will contaminate others. Usually these terrible fears are linked to compulsions, which are behaviours that try to reduce these threats. This may be a mental or a physical ritual such as counting, putting things in order, cleaning themselves and/or their surroundings or checking that things are exactly as they should be.

**Post-traumatic stress disorder** is a response to a highly traumatic event - which may have been apparently coped with well at the time. People may develop periods of intense fearfulness which involve having 'flashbacks' of the event in nightmares or in thoughts and images that they cannot control. They may go to great lengths to avoid anything that might remind them of the trauma and become cut off from those around them who 'cannot possibly understand'.

They may also feel very jittery and jumpy, constantly alert for danger and unable to sleep well. They experience the physical symptoms of anxiety for prolonged periods which is exhausting for them. This may also produce irritable and sometimes aggressive behaviour. This anger can be directed towards others or themselves. Using drugs or alcohol to cope with these issues is also not unusual.

**Eating disorders** are often anxiety based but because of the complexity and risk to physical health it is vital to get specialist advice.

B-eat are one of the leading organisations, helpline 0345 634 1414 or [www.b-eat.co.uk](http://www.b-eat.co.uk).

Generally medication may help with anxiety issues but mostly treatment is through talking therapies. This tries to break the cycle of having a thought

(everyone thinks I am stupid) which creates a mood (fear and self-loathing) and then behaving in a negative way (so I have to stay at home all day so they don't see me). This is called 'changing negative thinking patterns' and is the basis for **cognitive behavioural therapy (CBT)**.

There are lots of self-help strategies including relaxation, breathing control and yoga, meditation and mindfulness. These are readily available and can be really helpful, but it is never easy to change. As a Carer it may help to consider how easy you have found changing your own unwanted habits! Supporting someone to change is a delicate process, often including everything between 'nagging' and 'giving up on them' and patience can be hard to maintain over weeks and months when progress seems slow.

### Self-harm

This is not in itself a MH diagnosis but may occur as a result of someone's high levels of distress. It is a frightening discovery that someone you care about is hurting themselves. Although many of us do take risks or are careless with our wellbeing, self-harm usually refers to deliberate acts like cutting, burning or drinking harmful substances.

The person is usually suffering a high level of emotional distress and they are trying to retain control. The pain acts as a distraction and also releases chemicals into the body which are immediately soothing. In short it is a coping strategy which enables people to keep going in very difficult circumstances. It can be confused with suicidal behaviour, but self-harm often is a means to avoid suicide - a crucial point in understanding it.

It is frequently not attention seeking as many people harm themselves where they can hide the effects and don't tell anyone. It may be comforting when treatment is given and you are looked after, but accident and emergency department staff can be unsympathetic with repeated visits, sometimes seeing self-harm injury as a waste of valuable nursing time.

If you find out someone is self-harming it is not always necessary to treat it as an emergency. If they are at risk from their wounds the first step is clearly to get medical help, otherwise it may be a priority to ensure that razor blades or similar tools are sterilised and the wound can be disinfected and covered with a clean bandage or cling film. It may sound drastic to support this behaviour but aggressive pressure to stop could contribute to the need to seek a release and make it more likely to occur.

*A service user said: 'the situation only improved when I finally realised I was the only person well enough to do things differently. Me finding ways to reduce the tension eventually made a big difference.'*

## Addictions

This is not in itself a MH diagnosis either but can be a response to one (although not everyone who takes unprescribed drugs or drinks has a MH issue). Carers can try to support the person to get help but crucially can't just make them stop, only the person themselves can do that. It can be heart-breaking to accept that your power to control the situation is very limited. Practical and emotional support may encourage the person to give up; it is strongly recommended that you avoid giving any help in getting their drugs/alcohol (i.e. giving money) no matter how desperate they appear. Sometimes 'tough love' and saying 'no' is the best help in the long term. As a Carer in this situation it is even more important that you get support for yourself. (See Useful Contacts)

## More unusual behaviour

Depression, anxiety and the need to blot out bad feelings are all experiences that most of us recognise to some degree. However, there are MH issues that appear very different to 'everyday behaviour'- although increasingly it is recognised that many people have some mild 'symptoms'.

## Psychotic conditions

Psychosis is the experience of **hallucinations**: information received through sight, sound, smell, taste or touch that would be described as 'unreal'. It must be petrifying not just to have these experiences but then to have others say it is not real when you know it is! Alongside this people often develop unusual views or belief systems (**delusions**) - which may be strongly linked to their unusual experiences. For example:

*A man lives alone and is watching TV late at night. He turns it off but then hears a voice speaking to him which is threatening and unpleasant. This is repeated several times. Seeking a rational explanation, he decides that it must be the TV talking to him, nothing else in the room 'speaks'. So as it is turned off it must be being controlled from outside, perhaps by criminals, spies or aliens. The person will then pay attention to things that back this up (as we all seek evidence to confirm our own beliefs). There may be a strange car outside or a piece of wire not previously noticed coming through the wall. This becomes a frightening view of the situation, that people are out to harm him and help doesn't happen because no one believes him.*

People experiencing hallucinations won't have them constantly. They can be reasonably open to communication sometimes and at others seem withdrawn, may talk to themselves or stare at a spot on the wall. They may

be very grandiose and see themselves as hugely superior to others, or be extremely fearful and withdrawn.

## Schizophrenia

This is the most well know psychotic condition, but it also has several other symptoms besides hallucinations. These include having intruding thoughts that are repetitive and often very negative, harassing and belittling the person. It may include feeling that people can read your mind or you can read theirs. It may impair thinking skills and make a person noticeably lacking in anymotivation.

Hallucinations and delusions are a major symptom of schizophrenia but may occur also in severe depression and bipolar affective disorder; conditions which share much in common and seem to be genetically related.

Just under half of people newly diagnosed will experience few long lasting effects, especially with early treatment. Some will have occasional relapses but the remainder will have long lasting issues. There may be a genetic factor but often the person has experienced traumatic or stressful events too. The theory is that these experiences are an attempt to represent and cope with the person's sense of being overwhelmed. Ability to deal with mental stresses - 'resilience'- is also a major factor. It is becoming clear that children may show early signs although may not fully develop until adolescence or early twenties or sometimes later.

## Bipolar affective disorder

This is well publicised these days and most people are aware, as the name suggests, that this produces extreme mood swings. The lows are depressions with all the problems that brings, while the highs produce elation with feelings of being powerful and special – and can be very enjoyable. The high bit brings irrational behaviour that can be extreme, including spending, reckless sexual behaviour, unrealistic schemes and risk taking, often making people very vulnerable. They may also experience 'pressure of speech' which means talking fast or being unable to be quiet. It is far more extreme than the moods most of us experience and can be very disabling. The pattern of these changes is a very individual one although depression occurs more frequently than mania.

The person may also be convinced that people are holding them back or are against them because they are 'special'. These delusional beliefs may be reinforced by hallucinations such as voices telling the person they are superior or capable of impossible feats, although these voices can be punishing and critical as depression sets in.



Medication is crucial in treating this condition because it works well in controlling the causes of the mood swings, but unfortunately the mania can be so enjoyable that the person will not comply with treatment until they come to realise that there is a high price to pay for those wonderfully exciting feelings. Often all a Carer can do is to act as a reminder that medication is necessary, often a very difficult and thankless role.

### Personality disorders (PD)

These are a difficult group of diagnoses to really understand as it seems to label someone's personality as an 'illness'. The person seems to think differently, have unpredictable moods and react in a way that seems unusual compared with others. They break the normal cultural and social rules and can be extremely demanding, needy, highly insecure, and lacking in empathy. It is not a trivial issue and it can be a cause of great distress. Self-harming can be a frequent feature and it is unlikely that relationships and jobs will remain unaffected. About 6% of the population seem to have some traits; a great many are undiagnosed, although they may live on the edges of society particularly regarding drug and alcohol use.

As yet, no clear cause has been identified although some signs are often visible in childhood and increase gradually over time rather than a sudden onset. Many sources of information refer to childhood trauma and this may be present but there is also a growing awareness of potential genetic factors particularly in regard to **emotional instability** where there is a rapid change in extreme moods.

There are three 'clusters' of PDs.

#### **Emotionally Unstable Personality Disorder (EUPD)**

was Borderline Personality Disorder (BPD) is one of the most frequently diagnosed. This comes under Cluster B and involves impulsive behaviour, which is often emotionally erratic, and with a focus on suicide and/or self-harm. People report frequent feelings of emptiness.

They may find it impossible to consider the feelings of others and be very detached. This makes it difficult to sustain a relationship with them as they can be demanding and really hard to please.

Cluster A results in being socially withdrawn, not forming relationships and maybe being (unusually) suspicious of others. Cluster B involves extreme reactions, both positive and negative. So they may be wildly enthusiastic or terribly angry in quick succession. They may behave impulsively and

take risks, and are hard to live with because of these intense reactions. Cluster C are people with high levels of anxiety who avoid new people and experiences. They have low self-esteem and may be very dependent on others.

A very, very small number of people with specific types of PD can be dangerous and violent.

A Carer needs to be firm under pressure and put boundaries in place which are kept consistently, not an easy task when the reactions can be extreme. It is also helpful to point out where a reaction has had a negative consequence and to consider options: 'maybe this happened because you did that'. This may be a bit of a challenge! The book '**Introducing Mental Health**' is helpful in describing approaches to Personality Disorders (see useful resources).

Recently there has been a much better chance of getting effective support and there is a new programme specifically targeted at getting people to work with practitioners on these issues. These therapies include Schema Therapy and the STEPPS programme which are worth researching. Treatment can be a very slow process as people may be very suspicious or resentful of 'help' and the use of drugs or alcohol greatly hampers any progress.

## Dementia

This is a brief introduction to a complex topic as it is not covered in this booklet. The causes and the way the condition develops are different from other MH issues although they can occur together.

Dementia occurs when the brain is affected by a disease, which can cause a wide range of symptoms. Dementia can affect a person's normal character and daily routine through forgetting things, repeating themselves and misunderstanding what others say. There are many different types of dementia, with Alzheimer's disease and vascular dementia being the most common.

Everyone responds to dementia in different ways. It is normal to think back to the person and how things were before the diagnosis. It is common to experience a range of worries and emotions during the course of the dementia. You may find that others do not understand the diagnosis or what you are going through. The person may present with unusual behaviours and it can be difficult to know how the brain changes have caused this or what the most helpful coping strategies.

You will need to make practical changes to how you live your lives. Central

to this is the need to help the person live their life in stimulating and meaningful ways which make the most of their abilities and enable them to maintain and develop relationships with others. Research shows that people with early stage dementia can still learn new skills and start new activities.

Many Carers benefit from talking with people in a similar situation. The Alzheimer's Society has information for people with different types of dementia. You can go to their website [www.alzheimers.org.uk](http://www.alzheimers.org.uk) or call them on their helpline (freephone) on 0300 222 11 22. They have a comprehensive information guide called 'Dementia Guide: Living Well after Diagnosis' plus useful factsheets on particular behaviours. They can also supply details of your local Alzheimer's Society branch.

Local Carers support organisations can offer information and advice. Contact details can be found in the 'Contacts' section from page 68.

## SUMMARY

Diagnoses are not firm; they may change over time or people may end up with several. Individuals may be rated on a variety of symptoms which defines what treatment is offered. The family may be frustrated not to get an immediate 'label' but this is a normal part of the process.

## Getting help

Of course there are as many different stories of Carers' and cared-for people's 'journeys' as there are people who become mentally unwell. There tend to be a number of stages that have to be passed through and it is generally unlikely that there is a short cut, things unfold at their own speed.

Carers are often so focussed on the wellbeing of the cared-for person that they can ignore their own issues and emotions until the situation calms down, if then. So there is a higher incidence of stress related ill health in Carers than others. The message is always 'look after you.'

There is no benefit in two people becoming unwell.

## Early days

The main obstacle to getting advice quickly often is that the person concerned does not feel that they need help. They may be embarrassed or unwilling to admit that they are not coping well. It may be that they feel fine and believe that the problem lies with others. If they cannot be persuaded to see a GP and, just as importantly, tell them honestly what is happening,

then this stage prior to getting help can last a very long time. You are convinced that there is something significantly wrong and they are convinced that you are exaggerating, misled, troublemaking or unhelpful.

This is a frustrating situation. It may be a question of accepting that you are waiting either for this to go away or to get worse, in which case treatment will be less easy to avoid. **If you feel the person is at serious risk, please see the 'Crises and high risk situations' section on page 26.**

### Going to the GP and getting treatment

MH services are accessed through a 'gatekeeper', the GP, who has to do an initial assessment. The patient may find it helpful to run through their thoughts and rehearse or even write a list out before they see them. If they are happy for you to be there then that could be useful too, but it is necessary that the doctor has an opportunity to find out what his/her patient thinks about it all. It's a fine line between you being too involved or not involved enough.

If you make statements to the GP that the cared-for person disagrees with it can be the cause of friction, so it is good to get these issues sorted out first wherever possible. If you really feel that the crucial factors won't get heard, then ask to speak to the doctor separately or write a note for them.

During this time you can face difficult decisions about offering help which may not actually be helping! For example, if they are highly anxious about going out they may just stay home. If you get all their shopping does this prevent them facing the issue? Caring for someone involves supporting them when they can't manage, but what if that stops them facing that they need treatment?

There may come a point where there is a need for negotiation. Maybe 'I will carry on helping you, but in return I would like you to see the GP even though I know you don't want to.' In real life of course it can be very complicated, but there is a need to recognise if your support is preventing them from facing up to reality.

Crucially, there needs to be a clear and preferably brief statement from the person or yourself about the behaviour or feelings that are causing concern. What is vital is to communicate any risks in the situation; the finer details can be shared over time.

You can see the GP alone if the person just won't go, but unless there is a current serious risk they may be able to do little but offer general advice.

## What treatments can a GP offer?

**Medication.** GPs vary in their response to MH problems; they may well prescribe medication as a first line of treatment. Reading the leaflet in the packet or looking on the internet can prepare you to spot side effects if they occur. These lists can be very frightening! It is worth remembering that these side effects do not affect everyone and often they are worse in the first few days/weeks and then fade as the medication becomes more effective, which is why it is often necessary to give it a fair trial. Some medications take several weeks to really kick in. If you have questions a pharmacist is accessible and very knowledgeable.

It is normal for medication to be tried and then changed. It is not easy to get it right first time and often people will end up on more than one. This is a common situation and not a cause for concern as long as there are reviews now and again to make sure it's all necessary.

There is a long standing resistance to MH medication from a lot of people and of course, it is better to find another way if at all possible. However only medication can act relatively quickly, reduce distress and risk or restore some sense of control. It is a fine balance.

**Talking treatments.** Currently there is an option for GPs to refer people with mild to moderate anxiety or depression symptoms to an organisation which offers talking therapies - both one to one and in groups. You can self-refer to them, but a GP referral is preferable. The contact details are listed on the local pages in this booklet from page 74.

These organisations (there is a different one in each area of the county) offer cognitive behavioural therapy, CBT, a process which looks at how someone can help themselves to change repetitive, unhelpful patterns of thinking. There is a lot of information about CBT available and it can be a useful tool, with or without medication.

Another option may be to see a counsellor through this organisation or other sources, this is also a talking treatment but different from CBT. Counsellors allow the person time to talk over important events within a neutral, safe space and work things out for themselves. This can be extremely helpful, but is not for everyone. Those with more severe conditions who find it hard to concentrate or work rationally through problems may not benefit at certain stages of their condition.

Talking treatments have side effects as they produce emotional reactions which can be tough on families who are trying to help and on the person themselves.

The vast majority of MH problems fall into the mild to moderate category. When you live with someone it may not feel mild but treatment can often be obtained fairly quickly through local organisations and GPs. Sometimes there is a need to persist, to find a sympathetic GP or to change a medication that isn't right but many recover fully given time and support. More severe conditions need similar but specialist interventions.

## Secondary care

Complex and severe conditions are referred to secondary care by GPs, which in mental health is offered by **Assessment and Treatment Services (ATS)** rather than a hospital outpatient department. There are centres housing teams of psychiatrists, community mental health nurses, social workers, occupational therapists, psychologists and other support staff.

**If it is an emergency, then a GP can make an urgent referral to secondary care / ATS.**

The initial assessment for a new referral may be with a psychiatrist, psychologist, senior occupational therapist or senior mental health nurse. Families are often asked to contribute information, but a lot depends on whether the person accepts your participation.

Many of us when faced with a doctor may minimise our symptoms or say we are 'perfectly fine, thank you' and this is a frequent frustration in MH! If you feel they are not being totally honest and are covering up it is important that you give your information - in confidence if necessary. If you are not offered this option, then ask for it!

The cared-for person may be prescribed medication and/or a referral to a different practitioner, such as a psychologist, occupational therapist or a mental health nurse. The treatments available are medication and/or talking treatments and/or opportunities to work on life /coping skills.

Very occasionally **ECT** is offered but this is in extreme circumstances and for severe situations in which all other approaches have been tried. It is a much less intimidating procedure than it used to be and has to be agreed by the patient who is encouraged to talk to a family member or advocate about this decision. No one seems to quite know how it works. The majority of people feel some benefit and for some it literally saves their life - but there are side effects. The MIND website has some good information.

“It is very confusing when first coming into contact with the services to understand what service your relative has been referred to and why.”

Those with more complex needs will eventually have a **care programme approach** (CPA) plan, or **care plan**. This document details treatment, frequency of appointments, agreements with the service user and emergency contacts. As a Carer you should have an opportunity to contribute to this, but again this can be difficult if the person doesn't want you involved. Requesting an appointment or phone conversation for yourself should be an option if you have concerns about the plan.

### Making a relationship with the professionals

“Many Carers feel helpless and abandoned, being pushed from pillar to post without any one able to help and the situation deteriorating. I think this is made worse because Carers, perhaps because of being under stress, do not understand the system and often professionals do not take this into consideration. It all seems such a fight and Carers can feel so isolated and helpless in seemingly unsolvable situations.”

Many Carers report that initially they feel rather excluded and overlooked by professionals and it takes time to develop a working relationship. Hopefully this is improving!

Professionals have to prioritise their relationship with the unwell person to establish a sound basis for treatment. They need accurate information and you may feel you have that, but they do not yet know you or how you are involved. So appearing calm and quietly assertive may help your case more than losing your temper (because you are frustrated and desperate for help). That is always valid advice whatever stage you may be at - but it's easy to say and hard to do!

If you find yourself becoming upset or agitated towards the professionals, you will not be alone. You are emotionally involved and they are not, tensions will arise. As time passes it is important that you can respect each other's viewpoint and try to make a good working relationship. This will be easier both for you and the person you care for.

“I sometimes wonder, when waiting with xxxxxx to go into a meeting, how the doctors would feel if they had to wait for an interview that would decide their fate, month after month, year after year. They don't let patients get angry, or family, you are either put down as ill or over-emotional. Considering the build-up of pressure before one's monthly trial, I feel that both of these reactions are normal.”

“I turned to the out-patient's mental health team and all they would say

was 'He can come and see us'. He wouldn't even go out of his flat! Or they said 'We went to see him and he wouldn't let us in'. That let them off the hook. I felt really isolated."

Family and partners have found themselves regarded as difficult, demanding, hysterical, irrational and a source of pressure on the patient.

Staff seem occasionally to misunderstand a natural reaction to extreme worry and a desperate need for help which families understandably feel. This can make communication tense and frustrating and lead to 'getting off on the wrong foot'.

Staff still vary in their willingness to give time to support Carers but often better understanding develops over time and good working relationships are formed. There is far more sensitivity to these issues nowadays and a recognition that involving Carers is a good investment of time for MH teams.

Despite the need for a good working relationship there is no reason not to pursue issues, being calmly assertive and asking 'why, when, and how' questions.

"Never accept no for an answer, no matter how unpopular you become! Look at what you want from the situation and work towards those goals".

## Carers and confidentiality

Many Carers struggle with the apparent silence that may happen as soon as the cared-for person starts to get appointments with the MH team. One day you know everything that is going on, while the next they are seeing people and being offered treatment, and you feel excluded. This is frustrating when you have all the history and often a more detailed knowledge of the situation, possibly more than the person themselves.

A professional is trained to consider a patient's confidentiality as very important because it demonstrates respect for the person and their right to have control. It also helps form a successful relationship with them where they can be honest and this will help with diagnosis and treatment. But a Carer also needs to know information which will enable them to offer appropriate help both on a practical and an emotional level.

The system is that individuals are asked to sign a consent form to confirm what information can be shared with their carers – if they will identify you as that!



If your experience varies from the statements below then it may be worth asking staff to check what their policies are or bringing these issues to their attention.

All patients can decide what information is shared about them unless:

- They are incapable of making that decision or
- Not sharing could lead to you as a Carer or someone else being at risk.

They can decide to share everything, nothing, or just some things. (For example they may be fine with you knowing about their appointments and who they are seeing but not with you knowing about their drug use or sexuality).

This can only be overridden if it is justified by risk or if required by law. Decisions about consent to sharing are recorded in a patient's health records. However:

**It is not a breach of confidentiality to talk about information which a Carer already knows.**

**Staff can also listen to what a Carer has to say about the person they care for even if they cannot answer specific questions.**

**Anything you tell staff is also confidential (but do remind them of this!) unless you tell them it is all right to discuss it with another person**

**Just talking making conversation with staff does not breach confidentiality**

**Where consent to share information has been withheld** staff should discuss the implications of that decision with you and with the patient. What can be particularly tricky is when the person decides not to share information with you on the basis of a delusional or mistaken belief. However they may still be judged as having 'capacity' to make that decision because their confusion is a temporary state.

Decisions about sharing information are not fixed for ever. They should be reviewed, especially where a Carer's level of involvement or the patient's mental health situation changes.

Whatever level of privacy the person you care for wants, as a Carer you should get information about:

- mental health problems /where you can go to get more information
- what treatments are available generally, how they work and what the potential side effects are
- what services are available for you as a Carer
- what to do if you are concerned about the person you care for
- who to contact in an emergency, including out of office hours
- how best to cope with the effects of mental health problems at critical times, such as home leave and after the person has been discharged from hospital

Staff should be aware of these principles, but it can still be a struggle to get time with a busy professional. It can be frustrating that your 'life or death' crisis is a daily occurrence for them and they may not appear to be giving it the attention you feel it needs because they see many similar 'emergencies'. Being calm can be tough when you are worried sick, getting angry and no one seems to want to talk to you!

Making it clear to any professional that you are a major source of support is very important. This can be tricky if the unwell person themselves denies your relationship, but persist. You are their Carer and have different rights and privileges to other people who are acquaintances or who are just visiting.

You can attend appointments with the cared-for person if they want that, but it can be good not to go every time. There needs to be sensitivity about them forming helpful relationships directly with staff. Ask for time alone with professionals if it is difficult to talk freely with the cared-for person present, maybe their lead practitioner/named nurse if they are in hospital or their named worker/keyworker if they are at home. Many psychiatrists will sometimes see Carers alone too; it is always worth asking.

## Mental health teams

This is a more complex topic now as areas are choosing to design their services to meet local needs so the teams defined below may no longer exist in this format in all areas. For example some areas now have a team specifically working with people with psychosis to support them

over time as they recover. Some have new crisis response arrangements. However it is worth finding out how the local services operate and what you can expect as the situation changes.

The **Assessment and Treatment Service (ATS)** usually does the initial assessment and may continue to be involved for a time or refer on to other specialist resources. The team may be subdivided. One part may focus on more complex situations that require several professionals to be involved and have care programme approach (CPA) plans to ensure this care is coordinated. Other teams work with less complex situations where people need less input.

**Assertive outreach teams (AOT)** work to engage and maintain relationships with 'high risk' people who are suffering with psychosis and are chaotic and not willing, or able, to keep regular appointments or cooperate with medication programmes. This team may step in after others have been unable to maintain a treatment plan.

**Early intervention service (EIS)** works with other teams to offer specialist help to younger people (under 35 years old) experiencing their first psychotic episode. This early treatment has been shown to greatly improve the long term outcome.

**Crisis resolution home treatment team (CRHT)** offers frequent intensive contact to try to prevent an admission to hospital or to speed up being discharged home safely. They can visit or call several times a day and will assess anyone who might be admitted to hospital to see if they can offer an alternative through support at home.

There are also specialist services for children (known as **CAMHS** - child and adolescent mental health service) and for older adults there are specialist older adults MH services for both organic conditions such as dementia or with other MH conditions.

## Crises and high risk situations

For someone known to the services already, periods of acute distress are usually dealt with by offering increased input from the team and this may involve treatment from the CRHT for intensive home treatment or admission to an acute unit in hospital.

If they are not 'open' to a MH team you can only access emergency MH services via a GP, A&E or the Police if the situation is high risk.

A **GP** can refer to the ATS team and rate their referral as very urgent, fairly urgent or lower risk. This will result in an appointment within a few

hours to a month. This can be useful for an urgent referral and a good GP can cut out a lot of stressful experiences.

**Accident and Emergency (A&E)** offers talking things over with someone which may help in itself. Medication may be suggested or admission to hospital. However, the wait for this can be several hours. The advice is often to go there, although when you are a 5ft woman alone with a 6ft son who is unwell and unwilling to go, and unwilling to stay, this is definitely not an easy option.

There are now alternative '**Urgent Care Lounges**' which are always worth asking for. These are quiet spaces away from the main department but these rely on having staff available to cover them.

**Ambulances** can be called especially if the person is hurt (self-harm or overdose perhaps) but crews cannot make a person go with them. If there is any hint of aggression the police may also be involved.

Calling the Police may anger the cared-for person and leave them furious with you after the event. However, if there is a risk of harm to you or to them it is the fastest response and demonstrates that you will call for back up if you feel you need to - which is a positive message when boundaries are needed.

**Police** can take someone against their will who is clearly very unwell, highly agitated or violent to a special '136 Suite' at the hospitals or to sit with them in A&E. This power is used in public places rather than people's homes (See MH Act for more detail). They can be held for up to 24 hours until assessed by MH practitioners. If the person is in a private house the Police presence alone can calm the situation but they will need to get a court order to remove them, which takes time.

The Police sometimes have a MH Nurse on duty with them which is very effective as they can access the person's NHS records, have an expert immediately available and get things done faster.

**MH hospital acute services** are listed on the contacts page in this booklet however you cannot go directly and ask for a bed. If someone is assessed as needing admission and the nearest unit is full people will need to go to the nearest vacant bed in the Trust area or further afield. This is often very inconvenient for family who want to visit, but the person is usually brought to the closest service as soon as possible.

## So when are people admitted to hospital?

No one is admitted to an acute unit unless they are in a severe crisis -they are currently at serious risk themselves or a risk to others.

What can be confusing is the difference between physical health treatment which often includes being admitted for planned treatment and mental health where admission is primarily to provide a place of safety while assessing and starting / changing treatment.

What is sometimes difficult for family to understand is that what may be a critical situation for a family may not be seen that way by MH practitioners. Suicidal ideas are not always enough in themselves to ensure admission. Talking about suicide is often a sign of distress rather than a statement of intent, but is still highly stressful if they are not offered a bed and you are left at home with them and highly unsure of their safety.

'At risk' usually means that there is clear evidence from the person themselves or other people, of which you may be one, that their behaviour is likely to result in serious harm to themselves or others in the near future. The Mental Health Act is the only law which can take someone's liberty away without them having committed a criminal act. It is used with great care, as misuse can lead to major repercussions for the professionals involved. It is always a last resort.

The **CRHT** (Crisis Team) is usually part of an assessment to see if they can keep the person safely at home by offering intensive support - which again may be hard on the family.

Your relative or partner may be very angry if you 'collude' with professionals in their forced admission to hospital in a crisis, but this may be necessary for their own wellbeing, even if they cannot recognise that fact until later on. It is important to be very clear that the family/carer does not make the final decision.

Being on a unit with other highly distressed people is not always restful or therapeutic, but it offers safety and time to observe the issues in order to understand the symptoms better.

## Missing Persons

Within MH there are lots of different circumstances in which a person may go missing. They may be wanting some peace and quiet or be lost and

unable to get home or setting out with the intent of committing suicide. The Police are the obvious service to call. They need information which will help them to assess whether this is an urgent situation or not. Whoever calls them needs to be clear if there is a level of risk (to the person or to other people) or vulnerability. Being diagnosed with a MH issue definitely counts as a vulnerability.

It would also be very helpful to have details which would help the Police find someone quickly. What have they taken with them? A car registration number, social media details or whether they have a passport can be very helpful as can a photo. Have they taken their bank cards and do you have the account details so any usage can be traced?

There is a form online under the '**Herbert Protocol**' which was originally developed for people with dementia but can be equally useful if someone is prone to running off and is at risk (as was the original Mr. Herbert). This enables the family to record all this useful information and either have it to hand or actually lodge the form with the local Police so the search can be triggered in the quickest way.

If the Police assess the situation as high risk they will take immediate action, medium risk will also be acted on but less urgently. However it is worth noting that when the person is found they are not automatically returned home if they choose not to be. Unless they are acting in a way that causes the Police to suspect that they are at risk, maybe they are on Beachy Head or in the middle of the road for example; there are no legal powers which can be used to make someone come home. If they are potentially at risk, vulnerable or aggressive then the Police can use Sect. 136 to get a mental health assessment.

If you live separately from the person and are worried about them because you have evidence that they could be in trouble in their home then the Police may also help. Perhaps if you usually heard from the person regularly and this suddenly stopped or a neighbour let you know that the curtains had been drawn for several days, or they had put worrying messages on social media and this was unusual. In these circumstances the Police will call round and do a 'Safe and Well' check which could include breaking into the house if necessary. Again there has to be evidence that the person is at real risk.

## The Mental Health Act

This law is divided into different segments, a particular section can be used in specific circumstances to admit and treat a person. This has resulted in the term 'being sectioned.'

Two doctors are involved in the process, usually psychiatrists or occasionally a GP, and an **Approved Mental Health Professional (AMHP)** who can be from a range of professions, usually but not always a specially trained social worker.

The MH Act is a complex law, it is worth knowing the basic outline even if you cannot imagine it ever being used with someone you know. If this did happen you would be given information during the process but it is still helpful to have a rough idea so you are prepared.

- People who agree to be admitted will not be 'sectioned'. There are sections which can prevent a person leaving hospital even if they are a voluntary patient, if staff consider there is still a risk.
- Being sectioned may have repercussions (job applications, visiting some countries) but it does not have any criminal implications.

The **Care Quality Commission (CQC)**, who assess the quality of MH services, did a recent report on how the MH Act is used (June 2019) and they recommended

'Promoting the use of the guiding principles to improve practice and enable meaningful engagement with families and carers.' So expect to be heard.

The most frequently used sections are outlined overleaf

Section	What does it allow?	Length	Needed to enact
<b>2</b>	Period of assessment which may be followed by an offer of treatment - often used first.	Up to 28 days	2 doctors 1 AMHP
<b>3</b>	People can be made to accept treatment, although agreement is always sought first. Includes medication + other treatments but not <b>ECT</b> which requires further doctor's agreements)Can be renewed by the Consultant Psychiatrist. Usually follows a shorter Section, maybe 2	Up to 6 mnths, may be renewed for 6 mnths and then yearly.	2 doctors 1 AMHP Nearest relative must be consulted.
<b>135/ 136</b>	Police can keep a person in a Place of Safety, this can be a 136 Suite but these may be busy. In Sussex Police cells are no longer used so often the option is an A&E dept with a Police escort. Technically a person's home or a family home is acceptable but this is rarely used as it is too complex to manage.	24 hours (used to be 72)	Police
<b>CTO</b>	Community Treatment Orders. Can be used after a Section 3. It sets conditions such as taking medication regularly but allows people to live in the community. If the person does not comply they can be returned to hospital immediately.	Up to 6 mnths, may be renewed for 6 more mnths and then yearly.	Psychiatrist in charge of care and an AMHP



The first time someone is admitted it is usually under Section 2 for up to 28 days.

A person can be discharged as soon as they are considered well enough, even after a few days, regardless of the length of their section.

## NEAREST RELATIVE (NR)

### Patient Confidentiality:

The patient still has a right to withhold consent to give a NR information about them, they have no more rights here than any other carer.

This is a legal term which gives certain rights under the Mental Health Act. **The NR is not the same as the next of kin and not the same as the Carer.**

Of course, one person can be the next of kin, Carer *and* nearest relative which makes life more straightforward!

The person closest the top of this list is the nearest relative:

1. Husband, wife or civil partner
2. Son or daughter
3. Father or mother
4. Brother or sister
5. Grandparent
6. Grandchild
7. Uncle or aunt
8. Niece or nephew

They must be over 18 years old. If partners (including same sex) have lived together for 6 months or more this counts, partners/spouses who are permanently separated have no NR rights. With two 'equal' people, perhaps father and mother, the eldest would be appointed and similarly full blood relatives over 'step' ones. Those who live abroad are discounted.

There are other more complex rules which are best researched on reputable websites like [www.mind.org.uk](http://www.mind.org.uk) or ask the AMHP.

An AMHP can also apply to the county court to have an NR removed when they have a health problem themselves or are seen as being unsuitable. This removal can be challenged in court.

A NR can delegate someone else, but they have to put it in writing to their chosen person and to the NHS Trust involved. The AMHP is the best source of information in these situations. The patient can also apply to have their NR removed but this is also a county court process. They can also nominate

someone if they don't have a NR, or one that is prepared to get involved, but again, this has to be agreed by the court.

This may seem unnecessarily complex but not all close relatives have the best interest of their cared-for person at heart and this helps to protect those who live with damaging relationships or with abuse.

### Nearest relative rights

Most importantly a NR can request that a person is assessed under the Mental Health Act. This doesn't mean they will automatically be admitted, it still has to be agreed by an AMPH and two doctors, but it can start the process. You can request an assessment by letter or verbally by contacting the duty social worker in the assessment and treatment team. Other NR rights include:

- To be *informed* if your relative is detained under Section 2.
- To be *consulted* if Section 3 is being considered - which may happen after a shorter section and perhaps where treatment needs to be enforced (although staff always prefer to persuade someone than make them as it works better in the long term).
- The NR can request discharge under Sections 2 and 3 and under CTOs. This involves presenting a case to a psychiatrist that a safe alternative is available such as caring at home, but they have the final decision. If the psychiatrist refuses a NR request to discharge, then it goes to the hospital managers who hear evidence from professionals and the patient themselves.
- NRs should be given notification of the end of a section as often this will mean coming home, unless the patient is required to and willing to stay in informally.

The NR or any other carer is never solely responsible for someone being sectioned. They will always be assessed by professionals who will take the final decision. But if you play any part it will almost certainly cause tension with the cared-for person in the short term.

All people detained under the Mental Health Act have the right to an **independent mental health advocate (IMHA)** and should be offered this fairly promptly. A NR can request this for the patient, but this doesn't stop them seeking independent legal advice too if they want to.

## Discharge from hospital

Sometimes this happens with little notice whether the person is in under a section or in informally. It can be presumed that the family is willing to offer a home or their support again on discharge. If you feel you can no longer offer this then state it clearly and frequently, preferably before going home is even mentioned.

It can be hard to stay firm when the alternatives are to stay in hospital until accommodation is found - frequently a lengthy process. Emergency accommodation is often pretty basic and less than ideal. But it is important if you are concerned about your own or others wellbeing to hold out if you feel it is necessary. A suitable alternative is often found but it takes time.

Professional support will be available at home after discharge, but the Carer is often alone for long periods. If it is the first admission the person may seem different now they are taking medication and you may need to adapt to their new ways.

## Making complaints

The NR can complain about the way the Mental Health Act was used. Contact Sussex Partnership's complaints service or the Care Quality Commission (CQC) - see useful contacts.

Complaints about treatment go through the NHS procedures. Going directly to the relevant service manager first can help avoid a formal complaint and be quicker. A formal complaint can take a time to be answered, so won't produce urgent results. If the patient doesn't consent to their files being used then the complaint can get stalled and it may be better to present the evidence from the Carer's perspective: it could be useful to get advice first, 'Carers UK' website/phone line can be helpful here.

For complaints about adult social care services phone the direct social care contact line or visit their website. See local contacts.

## Day to day living

MH problems are not just about crises, often they are about ordinary life. There can be gradual or sometimes dramatic changes in behaviour which can make you feel very unsure how to react and which settle into a regular routine. Guidance is not always easily available. MH staff can be hard to reach when you need advice and other sources take time to find. Carers often look for a 'right' way to respond, but there are few rules.

"Often one feels that you are fighting the system rather than trying to resolve the illness. There will always be those who will get in the way; bypass them and get what you want and deserve."

Below are some suggestions that are based on sources offering Carers' or service user's advice, but they do not come with a guarantee. If a certain response always worked the NHS would use it and the MH teams would be out of a job. Remember that you haven't had any training for this and will need time and experience to develop the most helpful responses for your individual situation. Learning is bound to be by trial and definitely by error!

**Not all the issues covered in the next section are part of every MH diagnosis - ignore the ones that are not relevant!**

### Staying in their rooms.

If your attempts to get them out don't work, it may be better to leave them to it for a while. Constant encouragement only wears you out; if it's not working then it's not working! There is no point sitting worrying and blaming yourself. When they do come out, try to speak to them positively: "It's really nice to see you" and offer a drink or snack. They may need to sleep a lot - both the condition and the medication can cause lethargy and it can be hard to understand what they are dealing with mentally. Try to offer opportunities to do low stress activities they might enjoy.

A lot of people seem to develop an alternative life online. This is a wider problem not just with people with MH issues; the online life seems (understandably) so much more appealing than the real one. Apart from sabotaging your broadband you have very little immediate power to change this.

You need to avoid a showdown or a battle of wills, so the calmer you can stay the more likely that they will feel able to come out when the time is right for them - although it is all too easy to beat yourself up about not feeling calm. Try to keep the environment quiet, avoiding too many people especially if they have come to 'have a word with the patient'. You cannot drag the person out or force them to do anything, the struggle is to accept there is little you can do.

If you feel able and they are safe , then go out and have a social life - preferably one where you can relax!

### Low self-esteem

This can be part of or another layer to any MH issue. Not only is there the condition to deal with, there is often a sense of failure in not reaching 'normal' goals and the stigma of being seen as 'different'. This feeling of being less worthy than others can increase loneliness, anxiety, depression, drug use and suicidal ideas. So the lack of self-esteem reinforces the MH condition and creates a vicious circle.

It is very difficult supporting someone to work on their low self-esteem. Carers report that it can be hard not to adopt a parental, patronising tone: "Of course no one thinks you're stupid!"

Doing things that are enjoyed, finding ways to spend time that are productive and satisfying, and choosing to be with people who are encouraging and supportive all help. If the service user can help other people this is very rewarding, either in the family or as a volunteer. Maybe you could be ill and need help occasionally?

A useful skill is assertiveness, so working up to challenging people who make negative statements about them is a major step. A Carer could help by rehearsing what might be said and supporting the person to say "no", or to say how they are upset by that person's remarks.

The crucial part, however, is to understand that it is a habit to think negative thoughts and filter everything through this process. So if a person sends a text to a friend but gets no reply they may presume it is because they don't want to be friends anymore. Alternative explanations such as a flat battery, being busy or not hearing it arrive are not considered. So a Carer can help by gently pointing out other explanations for events and emphasising when

positive things do happen and goals are achieved.

It is useful if people can become aware that they often are far more negative and unhelpful in their own 'self-talk' than they would ever be to anyone else. This includes Carers!

The challenge is to support someone to not see themselves as weak and socially outcast, but as a resourceful person with strength and skills who is doing their best to cope with the challenges of a MH issue - which was not their fault.

There are lots of useful resources online and in self-help books when the person is ready. Many talking treatments, including CBT cover this area.

### Low motivation

People can lack motivation to help themselves or to get help from others. They can be highly resistant to trying anything, even old activities they used to enjoy. This may become an indicator of how well/unwell they are.

As before, there is little point in nagging, persuading or bribing if it's not working. Progress may be slow and all you are doing is wearing yourself out.

The question "what do you want to do?" may well be always met with "don't know", but if they have any ideas, support them if you can. Keep it simple and direct with, "Let's go down the garden and see if the daffodils are out", rather than the confusing, "Let's go for a walk. Where would you like to go? The town? The woods? McDonald's? Or somewhere else?"

The crucial point is to make sure that the long term strategy to keep them going isn't going to make you unwell.

You are the one who has to look to the future as they may be firmly stuck in the present.

**"Meanwhile be aware that the service user is anxious and trying to make order out of chaos. Reassure them and realise that their brain may be like spaghetti!"**

None of us like being asked to do things that frighten us. It is unrealistic to expect that people will do activities that make them highly anxious. They may need to get more confident socially but trying to force them to

go to the neighbour's New Year's Eve party will leave your nerves in tatters and possibly damage your relationship with them as well.

It is helpful to set a regular routine, maybe ask for assistance with small jobs that are predictable and short. Give clear instructions such as "can you clean the kitchen worktops with this cloth and this spray", rather than "clean the kitchen". Set small tasks and expect some co-operation. Concentration can be an issue and they may wander off and make mistakes, but try to stick to praising positives rather than criticising negatives.

If they will not eat regular meals, then it may be useful to have accessible healthy do-it-yourself snacks. People can become quite nocturnal and it is crucial to avoid a diet of crisps and chocolate, especially if the medication gives them the permanent 'munchies' as some does.

There is no clear line between 'can't do' and 'won't do'. You may suspect that they are doing less than they could, but the only guide is what they do, rather than what they say. If they can make a sandwich once, there is a good chance they can make one again. They may be more motivated if you do less, even if you are aware they may be getting pretty hungry?

In an ideal world you will slowly withdraw your help at a pace they can cope with and increasingly leave them to cope alone, even if they are not always getting it right. The other alternative is to do everything for them because they never get it perfect or they leave a mess. Doing too much for them for too long can be unhelpful as it gives the message 'I don't expect you to be able to do this' and over time they lose skills.

It is very easy to get frustrated and angry and to start thinking of them as (or calling them) lazy or unhelpful. It will be difficult not to lose your temper sometimes, but again, if you can, find a way to reduce your stress levels that doesn't involve getting mad at them. You may have to change your own attitude and just learn to live with a messy kitchen for a while!

## Lack of insight

Some people seem to grasp quite quickly that they have a MH issue which they will accept treatment for and work to 'self manage.' Some really struggle with this.

There may be several reasons why they cannot either understand or refuse to accept this, there are still major social/stigma and career implications after all.

There is a possibility that some people, particularly those with psychotic symptoms, actually are unable rather than unwilling to understand what is going on. The brain may simply not be capable of updating and sticks with the person's view of themselves from before they became affected. This symptom is called 'Anosognosia'.

The result of this is that the person will refuse medication, contact with MH practitioners and/or blame the family for mislabelling and persecuting them. A Psychologist called Dr Xavier Amador has researched this symptom after spending eight years trying to persuade his brother to take medication and only making their relationship tense and argumentative- and still not taking any medication. He suggests an approach called the 'Leap Model', this is described in his book 'I am not sick, I don't need help' VIDA press 2012 or on You Tube. If you are supporting someone who cannot 'see' clear evidence that there is something not right then it is definitely worth looking up Dr Amador and seeing what you think!

## Regaining independence

The more they take back responsibility and rebuild their independence the better for both of you in the long term. This requires stepping back from being in 'protective' mode, doing as little as possible day to day and taking small positive risks. This can be hard to do alone, a professional may offer advice but this is not always available, especially when the crisis has passed.



Help more if a person is unwell and less if they seem to be ok.

Making changes in your behaviour needs confidence that the time is right / the risks are low. Use as many sources of support as possible.

Support the person to work on changing any unhelpful behaviour if they will accept this.

Encourage any interest or skill development - in small steps.

*Example: Your son has been through his first psychotic episode and is much better but still highly anxious most of the time. He hates being alone in the house but won't go out. He doesn't really trust anyone but you, but he is often angry and depressed by his situation. Result? You stay in most of the time, you get frustrated and angry as well, and your relationship with him suffers. He never has to deal with his fears and so remains anxious.*

Try a plan? If you tell him you are going out for 10 minutes at 10.50am promising to be back by 11am you may well find him angry and anxious on your return. You reassure him that you will always be back by the time you say (except in real emergencies and then you will phone) and repeat this exercise several times until the anxiety lessens. Then you increase to 15 minutes, then 20 minutes. If this works you can end up having several hours out and spend more quality time with him because you are less stressed.

This gradual build-up of trust and working on independence works in many ways but it can be hard to pursue, especially if you get 'threats' for going against their wishes. Service users may be scared or angry that you are leaving them. Nevertheless, for both of your sakes it is important that you have consistent boundaries, limits and routines.

If you always cook and clean you may need to support them to relearn, but avoid taking over just because standards are low - no one died from eating sandwiches for a month! They have lost confidence and feel highly uncertain about doing anything new. In addition, medication can make people feel less energised and more confused - as can the MH problem itself. Family are often left to assess that the time is right and of the long-term benefits of change to work on this.

'Tough love' is the process of acting in their best interest even though it may not be what they want.

Recognising any situations that cause distress ('triggers') and what helps at these times is useful. If they learn their own vulnerabilities and coping strategies, then they are taking back control of their own lives as much as they can.

There are several services offering support to people to get training, voluntary or paid work, or increased social contact. Often these organisations take self-referrals. However the availability of these often varies with funding so ask the professionals or local voluntary organisations such as Mind or Southdown.

"I mourn what might have been. While others of xxxx's age have married, split up, had children, got jobs, travelled, bought houses, gone to university, xxxx has been in stasis. He hasn't moved forward. I would visit him in hospital and the only subject he had to talk about was his childhood. Sometimes we would just sit in silence as he would say 'I do nothing, so I have nothing to say.'"

### Living with delusional beliefs

Some psychotic conditions produce strange ideas which may result in unusual behaviour. Sometimes people can feel paranoid and have a high level of anxiety about being pursued or watched. They can take steps to protect themselves (such as covering the windows with tinfoil). They may get very agitated with you if you don't believe them. If you knew for certain that someone was outside with a weapon you would get very agitated too!

In this situation the most difficult question is "you do believe me don't you?" Agreeing with the person may reinforce their ideas and not help them to distinguish what is real from what is not. Disagreeing results in conflict and heightened anxiety. The general recommendation is to say that you cannot agree with them but that you accept completely that they believe it. Some people choose to avoid even this response as it is still a (gentle) way of saying "You are mistaken".

This response may be more acceptable as time passes or the situation calms. You may even be able to use humour in time but this has to feel appropriate and not 'mocking'..

Crucially, you can always respond to the feelings that these ideas produce. If the person is highly distressed or anxious, then ask them if anything helps with this. Some people feel safer under a duvet - perhaps it reduces stimulation and is calming. Perhaps you could distract them and offer an activity which could lead away from this train of thought? Try to build up a range of options that may help, such as favourite music or film, or a change of subject. However, if they want tinfoil at the windows this may be necessary for a while. It is important that you acknowledge that what they are experiencing is utterly real to them. Hearing voices, for example, does cause activity in the region of the brain that processes speech so it is undoubtedly 'real' whether it is a cognitive malfunction or a response to overwhelming distress.

The ideal situation is to be able to say "I think this particular idea is because of your MH, your mind is making a mistake or misreading the situation and there is no threat from anyone, but I know it feels like there is."

Of course this is only possible if the person accepts that they have MH issues. This response will only enrage people who don't yet accept their MH status.

It can feel like walking on eggshells but a calm reassurance and recognition of their distress alongside a gentle message that you don't think they have any reason to be afraid can be very helpful in the long term.

Whenever possible avoid confrontation or arguments about these ideas. If they constantly repeat them then change the subject or tell them that they have explained this already, you have said all you are going to say and you really don't want to keep going over it. It's easy to just 'turn off' and nod absent-mindedly. You may be the main source of reliable information as to what's real and what isn't so it's important to be consistent. If the conversation gets incomprehensible, then it is worth reflecting that back by saying "I really can't understand what you are saying right now". Say you will come back to it later and then try to change the subject. You can just agree to differ, but it is helpful if you can to stay

calm, unflustered and matter of fact. See also 'Lack of Insight.'

If having visitors at home is a **trigger** and produces an increase in agitated delusional behaviour, then can you meet people elsewhere? If they need to go back to their room or home or if they become anxious in a social situation, then discussing this and agreeing a sign which means 'I need to go - NOW' may help them cope. If they get upset when the phone rings, then turn it off for a while or put it on silent? As time passes you may build up a set of agreed actions in certain circumstances and these can be reassuring if used consistently.

### Self-harm

This is a complex topic and getting appropriate information is important. Crucially the main 'rule' is that trying stop it happening is not the first priority. Working with the cause and negotiating safer alternatives are much more effective in the long term.

Pressure to stop can increase the likelihood of self-harm happening.

The National Self Harm Network website [www.nshn.co.uk](http://www.nshn.co.uk) also offers quite a few distractions and alternatives. A few examples are:

- Drawing on yourself in red marker.
- Snapping an elastic band on your wrist.
- Making ice cubes with red food colouring to rub where you want to self-harm.
- Squeezing ice cubes.
- Thinking about not wanting scars in the summer.
- Thinking about not wanting to go into hospital.
- Biting into a chilli.
- Set yourself a target, say 10 minutes, promise yourself not to harm in this time. Once you get to this target set a new one of 15 minutes, and so on.

Experienced Carers advise allowing the person to take care of the self-harm injury themselves whenever possible.

"It was suggested to me after several cutting incidents that I should not always help clear up the mess, dress the wound etc. – this idea horrified me at first, as being against all a mother's instincts, but it did actually help to stand back – it seemed to take some of the drama out of the situation."

Cling film is useful for cuts as it keeps them clean until treated. Burns should be cooled in tepid (not ice) water and again covered in cling film until treated. The overall feeling is that **it is safer for the person to have a kit with sterile blades, plasters and bandages available** - hard as it may be for you to accept this. Having the kit readily available decreases stress levels and, hopefully, the self-harming too.

The National Self Harm Network outlines some do's and don'ts:

Things to do	Things to avoid
Use different ways to talk (such as texting)	Don't force them to talk about it.
Give them the option to come to talk to you if they want to.	Don't imply this is something that should be kept secret and wrong to talk about.
Do they want to talk about what led to this individual episode (if anything)?	Don't assume every episode of self-harm is for the same reason.
Ask them what if anything they would like you to do to help?	Don't assume what they need/want or act without discussing it and be sure they are comfortable with it.
If they are willing to talk encourage them to seek professional help, learn coping strategies and use support groups and support forums.	Don't force them into getting help or take control away from them. If they are not ready this may cause them to withdraw from you.
Let them remain in control as much as possible (many people who self-harm feel they have a lack of control over their lives and feelings).	Don't try to make them stop (e.g. by removing tools), give ultimatums or do things that they aren't ok with. Never ask them to promise they won't harm themselves. This only adds pressure.
Learn all you can about self-harm.	Never jump to conclusions.
Try and be understanding.	Don't judge them by saying what they doing is wrong .

Show them that you care and can see the person beyond the self-harm.	Don't change your perspective of them as a person. They are an individual, not a 'self-harmer'!
Be positive. Try to focus on their strengths.	Avoid negativity; self-harm does not change everything about them.
If they have just self-harmed, stay calm, ask if they want to talk about it or need any medical help. Despite how you may feel, try not to show anxiety.	Try not to get angry with them, shout, or show shock after self-harm. You may feel this but expressing it may cause more harm and make the individual feel guilty
Get help for dealing with and understanding your own feelings.	Don't blame yourself or take it personally.
Only help as much as you feel able too. You need to look after your own wellbeing too.	Don't blame them for making you worry, or talk about how much this is impacting on you. This may make them feel even more guilty and lead to further self-harm.
Offer distractions. Talk about things not related to self-harm, watch a film together or go for a walk, but respect requests for time on their own.	Don't assume they always need to talk about the self-harm if they are low, or not allow them any time and space alone.

### Aggressive behaviour

This is a rare occurrence and most people with MH issues are more likely to hurt themselves than others, and are far less dangerous than very drunk people! They are also much more vulnerable to other people's violence. But if you are spending time with someone who becomes aggressive then you need to have a plan, for their sake and for yours.

**There is always a reason for challenging behaviour.**

It is useful to spend time trying to identify the particular **triggers** that produce this response and then work to reduce or remove these if possible.

The suggested reaction to being threatened or to destructive behaviour is to ask them quietly but firmly to stop. Acknowledging their mood and point of view ('I can see that you are very angry and want me to listen to you') can diffuse a situation quicker but don't get into an argument about detail - now is not the time.

If this doesn't work then get out of the immediate area, leave the house altogether if necessary. If it happens frequently could you create a safe space? This may be the bathroom as a locked door is not out of place here. Consider stashing supplies including a bottle of water, a snack, a book and a mobile phone that works.

Leave them until they have calmed down and, if possible, speak to them on the phone to check out their mood and to warn them before you return. You may feel concerned about leaving them but being alone may ensure a quicker 'calming down' - having an audience may increase the agitation.

You may have to call the police. The MH team need to know what is going and deal with the crisis, but their response time will be much slower and they won't confront a violent person without the police anyway. You may be reluctant to call them, but Police are used to spotting MH issues and responding without arresting them in most circumstances using their powers under Sect. 135 /136 instead.

Suspicions of being harmed or poisoned happen sometimes if people's taste or smell is affected as part of a psychotic condition.

Maybe they see you in that moment as interfering, over protective or unsupportive.

Maybe they want you to do something for them that they know you don't want to do.

Maybe they feel threatened by visitors or loud music.

Maybe they have just seen a killer in a black car outside and you just aren't listening.

They may also be using violence and threats to achieve their own goals and have no recognition of the consequences.

Identifying **early warning signs** that things are about to 'kick off' is helpful. If you feel there is an outburst coming, it is better to leave and come back to some damage to your furniture than stay and run risks with your own welfare.

They may be taken to a place of safety, a special 136 Suite at the hospital or to A&E. There they will be assessed by a qualified professional and offered treatment and/or to be sectioned under the Mental Health Act.

After it has all calmed down it may be useful to have a conversation with the person in which you are clear that this aggression is unacceptable behaviour, no matter how angry or upset they felt, and that you will always call the police as you have to keep yourself safe. Tell others who may spend time with the person to do the same.

The message is, "I know you feel really agitated and angry, but you need to find a safer way to deal with it".

Don't feel you have to protect them from their behaviour. If you both enter into some kind of secret contract of silence, then you will be left to deal with it alone and they may resent their dependence on you.

It isn't helpful if the behaviour has no negative consequences either.

You walking away and leaving them when they are aggressive may be the best thing you can do. It isn't betraying them to tell MH teams who need to know if they are to be effective.

Get out, tell people, get help.

### Threats of suicide

If the person is about to make or has made a suicide attempt seek immediate help via ambulance, police or A&E. If they seriously want to die, or at least desperately escape from their current distress, it can be really difficult to stop them and there are no guaranteed safe responses. You'll become the best judge of their intentions, learning over time what helps them but call for help (and tell them you will call for help) if you are at all uncertain that they are safe. There may be high risks but there is no sure way to keep them safe, it's a best guess based on experience.

It can be traumatic but you cannot take responsibility for the outcome when it's not you who has ultimate control of the situation.

After a time some family carers may feel that suicide threats seem to be an attempt to scare you, or make you do something you don't want to



do. When this happens your sympathy and understanding may begin to dissolve into anger, resentment and confusion.

Perhaps it feels as though the person is handing responsibility for their decision to you. "If you really wanted me to live you would come round now". There can be a handing over of blame: "It will be your fault if I kill myself". It is crucial to remember that you are not threatening to kill them – it is their action. Buying time by doing what they want works in the short term, but not if the situation is going to improve.

These situations can be intense and there often doesn't seem to be a 'right' decision. Suicide (or self harm) used as a threat is a no-win situations for you! Whether you go along with them or not, the risks should not be your responsibility alone, so talk to someone and get support as soon as you can.

The BPD Central website suggests that you refuse to take responsibility and that you:

- show you care and that you will support them.
- maintain your personal limits.

It is possible to do both even if the other person says you can't. Hand the responsibility back while offering support and being clear you want them to choose not to commit suicide.

*I'm not doing this to be cruel, I'm sorry that this hurts you. If I were to do what you want now, that wouldn't solve the problem. I know you realise our relationship shouldn't be based on me being afraid of you dying, and you thinking you can't make it without me.*

#### **AVOID**

- Arguing and long discussions about whether they are serious. You can escalate a situation to where they have to prove you wrong.
- Accusations of manipulation and power struggles over who 'wins'.
- Giving in to threats. This won't prove that you 'really care'. A relationship based on threats will not be fair on either person. The Carer will be angry and resentful and the unwell person still unwell and likely to repeat the behaviour, often many times.

*I care about you and I want you to live. But doing this won't help you find what you are looking for, and I need some time to myself now and again for my own wellbeing.*

*I want you to find your own way forward; I will support you all I can but I cannot make it all ok by myself. Whatever I do won't be enough. You have to work on this yourself- use the help that's there. Maybe you need other people in your life, how can I help with this?*

These high risk situations can get worse before they get better, but entering into some kind of 'pact' with the person is not sustainable long term and is likely to postpone professional help being accepted. Getting support for you is absolutely vital. Would it be helpful to talk about it together with a third party, a MH practitioner or trusted relative perhaps?

Whatever you say should acknowledge that you take the suicide threats very seriously, offering to go with them to A&E if they are that distressed. The message is that you are very concerned, you care a great deal but can't cope with it alone, you don't take responsibility for their actions and you intend to get professional help for you and preferably for them.

## **Managing medications**

A lot of people feel well on their medication and conclude that it has made them better and stop taking it. They don't feel any different for a while as it takes time to leave the body just as it takes time to build up. Eventually it is possible they will become ill again but not necessarily connect this with stopping the medication.

For a lot of people, particularly with severe symptoms, medication can seem necessary to keep 'ok,' but managing without it is their choice. No one can be forced to take anything without using certain Mental Health Act sections.

This often creates a dilemma. It may be necessary to monitor a person's medication without being intrusive, pressurising or sneaky. (Sneaky may well be ok, just in times of crisis. If you happen to see tablets floating in the toilet, then that will help the MH team know what's going on, hopefully while keeping it quiet that you told them if that's possible).

Medication can be a very touchy subject. Carers may find themselves trying to point out the connection between not taking it and getting unwell. A daily battle of will is hard to win in the short term. People can settle into a routine quickly or fight against it for several years. You may find yourself an observer as they go round this circle for a long time. Advice from their peers may be more persuasive than any you can offer! (See Lack of Insight)

“Having had time to think, the best advice I could offer is once the service user and Carer have visited the GP do not start taking any prescribed medication until you have read around the diagnosis, looked at why the medication was prescribed and the side effects. Ask if there are alternatives, combinations of drugs at lower doses to reduce side effects and be as informed as you can; you can then ask the right questions to get the right answers.”

### The recovery model

GPs or psychiatrists will probably not give a prognosis during the early stages, as it may well be impossible to tell with any certainty exactly what will happen or how long it will last. Some recover and go back to their old lives, but the more severe the condition the more likely there will be some long lasting effects.

Most medication controls the symptoms rather than removing the cause.

Recovery usually means complete restoration of health and a return to the life before the illness, yet the MH professionals who work with people over long periods often use this word. Is this unrealistic?

The long term aim is to lead a life which has real meaning for the individual, including feeling positive and hopeful about themselves and their identity.

Crucially, it involves developing their independence, which means taking as much control and responsibility for their own wellbeing as possible. This presents a balancing act between taking risks of setbacks, distress and harm, while offering maximum opportunity for development. E.g. managing their own medication can feel risky but in the long term gives them both control and responsibility which improves their self image..

The concept of recovery has a different meaning within MH and this can cause confusion. Recovery is often defined as 'living well with a disability or illness'. Historically patient care involved medicating, monitoring and little else. Long stays in hospital resulted in loss of skills, low expectations of a fulfilling life and institutionalisation.

It has been clearly demonstrated that someone who remains or becomes part of a community by being involved with people, learning skills and self-managing as much as they can will have a better quality of life.

This may feel a risky process after the person you care about has been through such a traumatic experience, but too much looking after can be unhelpful and sets up long-term tensions and frustrations. A teenager has to be given the opportunity to develop adult skills despite the obvious risks. This may feel similar - handing back responsibility and encouraging self-care, often when your first instinct is to protect. In the long term this approach, although sometimes nerve racking, will result in a better quality of life for them and for you.

It helps for you to appear positive and hopeful about the future. Service users can become very introverted, depressed and lacking confidence. Remarks that imply you believe they will make progress and meet new challenges in the future can be encouraging. Pressure to move too quickly, or unrealistic goals, can do just the opposite. It's a fine line!

### **Wellness recovery action plans (WRAP)**

People with MH issues may find it helpful to complete a 'wellness recovery action plan' or similar. This is a detailed plan about how to stay as well as possible. It includes treatment they would prefer during relapses and other relevant self-management information. This plan often includes recognising the need to sleep and eat regularly, and avoid triggers such as alcohol or other drugs.

People who develop and sustain strong strategies to maintain their wellness may succeed in reducing (rarely, even giving up) their medication, but may need occasional higher doses at times. This progress requires great self-discipline by sticking to a very ordered, quiet life, being constantly aware of

their mood and behaviour. But even if this stress free life is never achieved anything that may reduce the number of distressing relapses, or the amount of medication needed is definitely worth investing time in.

**It has to be their plan and designed only by them (maybe with support) or it will not have any meaning for them.**

You and the cared-for person need to become expert on the details of your unique situation. Carers can be a real help in feeding back and discussing issues, "I don't know if you have noticed, but every time you stay up all night on the computer you have two or three bad days afterwards? Is there a way of working around this?"

There are also WRAP plans for Carers, planning to keep well both mentally and physically, especially under pressure. If you want the service user to plan to look after themselves then it can't hurt to set an example! A shortened version is included in Appendix A. The local Carers Centre will also have details (see useful contacts).

### Peer support workers

People are sometimes offered opportunity to work with a peer support worker who has lived experience of MH issues themselves and can offer support to improve self-management skills. Sometimes family can be 'too close' to be involved in this highly personal process. Someone who has been through it themselves is in a good place to help and can have a really positive influence. Some organisations accept self referrals.

### Expressed emotion

Most MH conditions are made worse by stress and improved by a relaxed environment. So family members who can remain calm, matter of fact and unruffled are directly contributing to the person's wellbeing. Shouting, crying, arguing, being too involved or over protective are unhelpful in the long term. Calm is demonstrated by tone of voice, posture, stillness and giving space.

This doesn't mean you should deny your negative feelings when they (inevitably) arise. It just means, whenever possible, that you vent them elsewhere!

The book, 'Mental Illness: A Handbook for Carers,' says: "Mental health professionals recommend that the four most important needs of patients that family members should meet are

- predictability
- reduced stimulation
- appropriate expectations,
- sensitivity to a person's self-esteem."

Mari Anne Harty (p. 266)

Denying those feelings are more likely to lead to a distressing incident than a smaller daily 'letting off steam' in a way that suits you, maybe by running, writing, yoga, gardening, going to the shed and hammering or whatever activity allow you to focus on something different for a while. See someone sympathetic and moan or have a good pillow bashing/crying session if it helps.

Being human means that the odd outburst is going to happen and adding guilt because you got angry isn't helping you either. It's just a case of bearing it in mind and doing the best you can from day to day.

## Friends and family

Family and friends can be both incredibly helpful and incredibly unhelpful. They may not see the person as much as you do and may be slower to accept what is going on. They may put pressure on you to get it fixed. You should tell the person to stop their behaviour and pull themselves together or put pressure on the vulnerable person themselves, "Look how you are worrying your poor Mother!"

Others, particularly siblings, can be very upset and jealous because of the attention given to the patient, especially when they are too young to really understand. They may need someone outside the situation to offer them extra time and support. Could they get support as a young Carer? (see contacts)

Honesty may be the best policy overall in talking to family and friends, but you may also have to face that some will simply not be able to cope with it, whereas you have to. The stigma associated with MH problems doesn't help, along with the often held but completely wrong presumptions that MH issues are:

- A weakness of weak people that can be overcome with determination.
- Caused by poor parenting or lack of a 'firm hand'.

You may have to be patient and wait for those who remain unconvinced or seek help among those who do understand. You may lose contact with those who cannot accept the situation, and come to rely on those that do offer you support.

### Long term planning

You may not be able to support the cared-for person for the rest of their life, perhaps because you are older or because of your own health and wellbeing. This can be a real source of concern for Carers.

This is another reason to encourage maximum independence so the withdrawal of your support results in as smooth a transition as possible.

If the service user is very reliant on you it is important that the MH services are given warning, if possible, that you are about to withdraw your support. They will step in and provide services up to and including residential care. However whatever is offered will be dependent on their assessment at that time and is unlikely to be a firm offer arranged in advance. It will also depend on current policy and what resources are available. Discussing it in advance can give an opportunity to give your opinion so it is worth doing even if there are no firm plans made.

You may also find yourself no longer being a Carer at some stage for a variety of reasons. Despite the fact that it has probably been an exhausting and worrying experience, you may find it leaves a large gap in your life. If you feel this is a problem for you then counselling or support from a Carers' Centre may be helpful. The end of a caring role can be very difficult to work through.

There is specialist help for those bereaved by suicide if this applies to you. GPs or Carers Centre should be able to refer you to counsellors or give information.

### Wills: property and money

This is a tricky issue as inheriting even a small amount may cause chaos with means tested benefits. It might also result in a spending spree with

wasted money, large amounts of alcohol, or unhelpful interest from a sudden group of new 'friends'. If you fear any unpleasant consequences but want the cared-for person to have some benefit it would be reassuring to plan ahead.

Both property and money can be left in a Trust and when the person is vulnerable and may not manage well (even if they are officially not assessed as lacking capacity) a **discretionary trust** is recommended. This allows finances and property to be managed by **trustees** who will oversee all expenditure. Often these are siblings of the cared for person. A regular allowance can be fixed at a level which has minimum impact on any benefits and occasional requests or property maintenance left to the trustees discretion.

It is important to consider the impact of the trust terms at a personal level. The relationship between the cared-for person and the trustees may be under strain if money issues get in the way and tensions arise. Solicitors will act as trustees, which avoids this problem but inevitably means paying a percentage of the money to them on an annual basis.

## What help can you get as a Carer?

### Benefits

The criteria for claiming benefits are constantly changing and it is helpful to get expert up to date advice particularly as other benefits may be affected. Specialist national Carers' organisations can be very helpful here such as Carers UK [www.carersuk.org](http://www.carersuk.org) or the local Carers Centre. The Department for Work and Pensions (DWP) has a good website: [www.gov.uk/dwp](http://www.gov.uk/dwp) or there is always the Citizens Advice Bureau. Generally it can be a real pain waiting for appointments or on phone lines but in the long term it can save many problems.



## Carers Assessments

“You don’t know what you want until you have it!”

These are offered by the Local Authority/ Social Care. Despite the title this is not an assessment of how capable you are as a Carer but an opportunity to consider your own needs and to look at what help there may be available for you. It also makes your status as the Carer more formally recognised.

The person who carries out the assessment is likely to be a social worker or resource officer, although in some areas they are completed by workers from the NHS or from a voluntary organisation such as the local Carers Centre. Most are done online these days (available on the East Sussex, West Sussex and Brighton & Hove website) and then responded to if they flag up a need that meets the (rather tight!) criteria. It may be helpful or upsetting to review your situation on a form!

The assessment is not a crisis plan, the wait for one can be long, it is more a means to evaluate your situation and offer help if it looks like you are really struggling.

The form itself covers topics such as your health and wellbeing, whether you are managing any risks or high levels of stress or anxiety, your options to pursue work, training or leisure activities, and other topics that may affect your ability to continue as a carer.

Practical, is available only when there are very high level needs so don’t expect too much. Other more available resources may include a referral to voluntary organizations that offer emotional support, counselling, or Carer support groups.

There is a small grant for carers who identify a need for something to help them keep going, perhaps a gym membership or

meditation classes, but at the time of writing this grant is subject to increasing restrictions.

Other useful tools available (through the Carers' Centre) are:

<b>Carers Card</b>	This identifies you as a Carer, carries CRESS details (see below) and can be used to claim a discount in some shops / parking in hospitals!
<b>Carers Respite Emergency Support Service (CRESS)</b>	This scheme allows an emergency plan to be activated at any time with one phone call. You, or a professional who finds your card, could trigger it if you cannot get home. It may mean a relative/neighbour stepping in, or if necessary a social care worker making sure the cared-for person is all right. This is available out of hours and at weekends. It can be reassuring, especially if you are the sole Carer.

## Respite

One of the most problematic issues for Carers in MH is that there are few options for respite unless you have family or friends that will help. It is particularly important if you have a healthcare appointment for yourself - funding is available for respite so you can go if you have an arrangement available.

Several voluntary organisations offer someone to stay with a person while the Carer goes out for a few hours. If the person you support won't be alone but is prepared to have a new face in the house it is worth asking through the local Carers Centre. However, if the cared-for person objects to this arrangement it can't happen.

Usually the 'sitter' is a volunteer and cannot be expected to cope with complex or risky situations either.

This means that Carers most under pressure from stressful situations are least likely to get respite.

In many places there are MH resource centres that offer one to one support and options for the service user to socialise/ learn skills. If they would like to be more sociable but are not ready for the wider community would they try these? The MH team may refer, check on **1space** website or pick up leaflets!

## A Carer's Journey

Being a MH Carer is a life of trial and error. Things may settle down when the initial crisis has passed and go back to 'normal' - or be radically changed. It may feel like adapting to a completely new person.

The first part is usually the most traumatic, dominated by the need to get help for the unwell person. When some stability returns it is time to take stock and recognising that ignoring your own wellbeing is likely to result in problems for both of you at some point. Taking care of yourself is not selfish behaviour - it is role modelling what the cared-for person also needs to do, which is to take as much responsibility as they can for their own wellbeing.

A Carer will often be pushed to their limits. They will be frightened for (and sometimes of) their cared-for person. They will be angry that help seems so hard to find at times and that their crisis is not always seen as that by professionals. They will be exhausted. They may be frustrated by the lack of progress, or the need to keep trying new medications with withdrawal and side effects. They will probably alternate between caring deeply for this difficult and changed person,

and just wanting them to go away. The journey is a roller coaster of despair and hope.

Monitoring how they are at any moment becomes second nature. Carers come to recognise good days and bad days. You look at them and just know how things are that day, maybe through a change in their routine, or 'their eyes'. Being aware of reliable clues becomes vital because on a good day you can do less and have more time to yourself, and when things are tough you can lower expectations and be more supportive. Establishing this awareness takes time and a degree of professional detachment.

Identifying any situation that increases distress and what helps with this is useful to the service user and to you. If they learn their own **triggers** and coping strategies, then they take back control of their own lives as much as they can. But helping them requires that you are on top of things.

It's easy to skip this bit about your wellbeing, as it can be upsetting to realise how your life may be at the moment. You may be struggling to accept that all the effort, time and worrying in the world cannot turn the clock back.

To be able to cope as a Carer make contact with local Carer groups and make sure you find time for you. This is so important otherwise you will not be able to cope."

Coming to terms with the reality of the situation and taking extra care of yourself is a long term investment. Can you make things happen that will keep you going so you can keep them going? Perhaps this may mean putting yourself first sometimes, but that needs to be acknowledged by both of you - that you have needs too and sometimes they come first.

They may be remarkably helpful if you are unwell or taking time out. They can be the Carer for a while – which also helps their view of themselves?

Talking to experienced Carers it is clear that things do change; people become better at managing their problems and the crises are less overwhelming. Often the extreme symptoms found in young people mellow as time passes. Medication is constantly being improved and other treatments made more effective. Although life is likely to stay a bit stormy occasionally, it is certain that you and your relative, partner or friend will adapt and reach 'calmer waters' in time.

### A Coping Strategy- Problem Solving

This is useful as a structured approach to dealing with an issue, it can reassure you that you are doing everything that you can. It's worth practicing until it becomes second nature! Stick rigidly to the process with no skipping bits! The steps are:

1. Define the issue exactly and clearly, e.g. he won't leave his room.
2. List every possible solution you (and anyone else you ask) can think of without 'censoring' them. Include silly or impractical suggestions - they may start new thought processes. So the list may go
  - a) Ask him to come down for a meal
  - b) Talk to him about how unhealthy it is
  - c) Tell him you miss him being downstairs
  - d) Throw a stink bomb in the room
  - e) Promise him a treat if he comes out for an hour,
3. Only when you have exhausted all possible ideas, go through and score the suggestions on how likely they are to work. Then try the highest scoring one first, if it doesn't work try the next one

This approach increases the chances of coming up with a new idea rather than repeating actions which are not working.

## Vital questions for Carers

Am I doing more than I need to? Could I do less on their 'good days?'

Am I helping to make them as independent as possible, even though it feels a bit risky sometimes?

If some basic boundaries are needed, am I setting them clearly and keeping them consistently in order to help me (and them) in the long term?

Am I acknowledging that this is emotionally draining for me? The trauma of the past, accepting the present and the future all needs some grieving time. Am I being patient with myself?

Am I creating (and holding onto) a sense of hope even though it may seem unrealistic on some days?

Am I looking after myself - food, sleep, exercise, interests, friends, other Carers, creativity, relaxation and not being too proud to ask for help?

Am I taking breaks? Is there someone out there who may be more supportive when it's calmer? Will they walk, swim, paint or shop alone while I have 'time out'? Can I go out safely while they sleep?

Am I working to build a relationship with professionals, being clear, honest and assertive, but also aware of their job and time limitations?

Would a carers' assessment give me opportunity to review my situation and find out if there is any help available?

## Getting involved

When the situation is less volatile and more predictable you may find you have more time. With the experience you have gained you could be very helpful. You could get involved in developing and planning local MH or Social Care services by offering the Carer's perspective.

Or you could you help other Carers?

If you would be prepared to help in any way, please contact your local Carers Centre and find out what is involved.

If you feel there is a need for change, then be part of that process!

## Appendix A Carer's wellbeing plan

Being a carer may be a daunting task, but like every job it's easier if time is taken to plan and understand it. This is a much shortened version, check the website [www.sussexpartnership.nhs.uk/your-health-and-wellbeing](http://www.sussexpartnership.nhs.uk/your-health-and-wellbeing) if you would like the whole document.

### My strengths and supports

**What are my strengths and what do I value most about myself?**

**What do I do to support my relative or friend with mental health challenges?**

**What are the particular things I want to communicate with the MH team, or others, about how best to support the person I care about?**

**How does the person I care for also help me sometimes?**

**How do other people help me and what I have found helpful about them?**

**Who I can talk to when I feel stressed?**

**What other resources do I have?**

**My health and wellbeing maintenance plan**

**What things do I need to do every day or week to keep on top of things?**

**What things are important to me outside of my role of supporting the person I care about?**

**How am I going to fit these in and what help might I need?**

**When will I do the things I need to do and the things that are important to me?**

**Do I need any help to do this? If so, what and from whom?**

**My health and wellbeing 'first aid kit' - my plan for what to do when everything is getting too much for me:**

**Things I can do to stay OK**

**How I can tell if things are getting too much for me?**

**Things other people can do to help - what? who?**

**My plan for managing difficulties and things that upset me**

**Things that happen which make me feel hurt, angry, discouraged, stressed out.**



**What I will do to stop it getting to me too much when this happens.**

**Things I can do to get myself back on an even keel when I feel upset, angry, discouraged or stressed out.**

- **My plan for what I can do if I am in a total panic/crisis:**
- **When the person I care about is in a crisis**
- **People I can phone (and their numbers)**
- **Other things I can do**
- **When I am in a crisis myself**
- **People I can phone (and their numbers)**
- **Other things I can do**

**NOTES**

## Appendix B: Checklist for life!

This is about life in general, but worth a look in case it inspires you to tackle old problems in a new way.

### **Get organised**

List, plan, take notes and keep records. Having a daily list of what you expect to do will help you stay on top of things.

### **Do it now**

Do the most unpleasant or difficult task at the beginning of the day when you are fresh, thereby avoiding the thought of it for rest of the day. The worse stress gets, the greater the tendency to leave things.

### **Know your limits**

Be realistic about what you can accomplish in a day.

### **Develop a sense of humour**

Laugh whenever you can! When we laugh, blood flow to the brain is increased and endorphins are released.

### **Relinquish control**

Go with the flow. Many events are unavoidable and beyond our power to control. Stewing over these just drains the energy we need while, achieving no change.

### **Rehearse**

When you are going to face a stressful situation, rehearse how you are going to handle it. Picture yourself succeeding. Create a mental 'video' that you play over and over in your mind. This is what an athlete does prior to competition.

### **Learn to say no**

Sometimes in order to have time and energy for yourself you need to say no to other people. You don't have to say no every time, just when you know in your heart that you don't want to, or you have too much to do anyway, or saying "yes" would mean you miss quality time for you.

### **Socialise when possible**

Don't be a loner. Isolation has been tied to higher stress levels and greater chance of physical illnesses. Give, as well as accept compliments, this helps to connect to people. There is company online if you can't get out and help to get online if needed.

### **Deep breathing**

Deep breathing calms and relaxes your body. Slowly breathe in (through your nose) filling your lungs (from bottom upwards) as full as possible, and let your stomach expand on the in-breath. Hold your breath for a few seconds then slowly exhale until your lungs feel empty. This is a short cut to a calmer life and you can do them on the bus or in a queue!

### **Get enough sleep**

Lack of adequate sleep can make you moody, angry and more vulnerable to illness and daily stress. Get help with sleeping if you need it, there are self-help methods available.

### **Slow down**

Try moving, talking and behaving in a relaxed, slower manner and see if it helps some of your stress ebb away. For instance, drive 10 miles per hour slower, pause at the table before you eat or think for a while before you speak.

### **Encourage yourself**

If you're inclined to blame yourself for your problems, even when they're not your fault, you are using negative self-talk. Those who accept mishaps as normal in life, and who talk to themselves in positive terms about these events, have much lower stress levels. Be your own best friend.

### **Reward yourself**

Those who reward themselves by engaging in something pleasurable boost their immune systems for several days. Get pampered or spoil yourself every time you can. Do you really not have time or is it about your priorities?

## Useful resources

The Selfish Pig's Guide to Caring by Hugh Marriott

Old but still relevant!

"Get a copy of [The Selfish Pig's Guide to Caring](#); brilliant book."

Introducing Mental Health: A Practical Guide ( 2nd edition 2015) By Caroline Kinsella and Connor Kinsella

Particularly good on personality disorders

Mental Illness – A Handbook for Carers (2001)

Edited by Rosaline Ramsay, Claire Gerada, Sarah Mars and George Smukler.

Our Encounters with Madness (2011)

Edited by Dr Alec Grant, Francis Biley and Hannah Walker.

Anthology of personal life experiences of Mental Health Services, including a chapter by a local Carer (available on Amazon).

'I am not sick, I don't need help' Dr Xavier Amador VIDA press 2012 or [www.LEAPInstitute.org](http://www.LEAPInstitute.org)

**YouTube** has some great films and it is worth searching for MH topics, although some are personal and therefore worth vetting before sharing them with the cared-for person. There are really effective reconstructions of hearing voices and negative intrusive thoughts, but definitely not for people who feel vulnerable already. They can be hard to 'shake off'.

A good place to start is '**Simon Says Psychosis**' which was made locally and is very encouraging for Carers and service users. Visit [www.youtube.com/sussexpartnershipns](http://www.youtube.com/sussexpartnershipns)

You Tube **TED** talks usually has topics of MH interest.

## Useful contacts and information

<p><b>Sussex Partnership NHS Foundation Trust</b> Headquarters: Swandean, Arundel Road, Worthing, West Sussex, BN13 3EP</p>	<p><b>General enquiries:</b> 0300 304 0100 info@sussexpartnership.nhs.uk www.sussexpartnership.nhs.uk</p> <p><b>Complaints:</b> 0300 304 2198 pals@sussexpartnership.nhs.uk www.sussexpartnership.nhs.uk/complaints-and-views</p>
<p><b>Sussex Mental Health Line</b> Out of hours support and information on local crisis services for service users and Can be difficult to get through to at some times</p>	<p>0300 5000 101 Monday to Friday 5pm-9am 24 hours weekends and bank holidays (24 hours a day in West</p>
<p><b>NHS Direct</b> For urgent medical information and advice if 999 not necessary</p>	<p>111 Open 24 hours a day, seven days a week.</p>
<p><b>Police</b></p>	<p>999 or 101 if not urgent Emergency text 65999</p>
<p><b>Samaritans</b> Freepost RSRB-KKBY-CYJK, PO Box 9090, STIRLING, FK8 2SA</p>	<p>116 123 jo@samaritans.org www.samaritans.org for local branches offering face to face Support for them or you!</p>

## NATIONAL RESOURCES

**Websites with information on diagnoses, medication and treatment.** Many of these organisations have Twitter/Facebook accounts.

Royal College of Psychiatrists  
Health Advice section with high quality, comprehensive and easy to understand information [www.rcpsych.ac.uk](http://www.rcpsych.ac.uk)

Rethink  
National charity with a wide selection of leaflets, information and support options. Specialist information for carers  
0300 5000 927 [www.rethink.org](http://www.rethink.org)

Mind  
A national charity with comprehensive information and leaflets, particularly strong on legal/rights issues.  
[www.mind.org.uk](http://www.mind.org.uk)

MindEd Hub  
This is a free educational resource on children's and young people's mental health for any adult  
[www.minded.org.uk](http://www.minded.org.uk)

Sussex Partnership NHS Foundation Trust  
Information leaflets (search for 'leaflets')  
[www.sussexpartnership.nhs.uk](http://www.sussexpartnership.nhs.uk)

Triangle of Care "Working together with family and friend carers to improve the care we provide."  
[www.sussexpartnership.nhs.uk/triangleofcare](http://www.sussexpartnership.nhs.uk/triangleofcare)

Substance misuse information  
[www.talktofrank.com](http://www.talktofrank.com) 0300 123 6600 txt 82111

[www.drugs-info.co.uk](http://www.drugs-info.co.uk)

## **National Carers support - (see local pages for local centres)**

### Carers UK

Information on everything from benefits and tax credits, employment rights, Carers' Assessments, how to complain effectively and challenge decisions.

0808 808 7777 [advice@carersuk.org](mailto:advice@carersuk.org) [www.carersuk.org](http://www.carersuk.org)

### NHS Carers Direct

'Helpline providing information to help you make decisions about your personal support needs and the needs of the person you're looking after, including benefits, direct payments, individual budgets, time off and maintaining, leaving or going back to work or education'.

0300 123 1053 9am–8pm Mon to Fri, 11am–4pm weekends  
[www.nhs.uk](http://www.nhs.uk) (search 'carers direct')

### Carers Trust

Information on your rights and benefits as a Carer, online discussion boards, Carers' blogs and links to local support.

[info@carers.org](mailto:info@carers.org) [www.carers.org](http://www.carers.org)

## **Websites with MH information, forums and self-help tools**

[www.moodgym.anu.edu.au](http://www.moodgym.anu.edu.au)

A Cognitive Behaviour Therapy (CBT) based programme designed to help with depression, low mood and bi-polar disorder.

[www.moodscope.com](http://www.moodscope.com)

A means of monitoring your moods and letting selected other people know what's going on.

[www.getselfhelp.co.uk](http://www.getselfhelp.co.uk)

Information on a wide range of emotional difficulties.

[www.moodjuice.scot.nhs.uk](http://www.moodjuice.scot.nhs.uk)

Helps you to think about emotional problems and work towards solving them. Covers many conditions including anxiety, depression, anger and stress.

[www.thesite.org/mental-health/self-harm](http://www.thesite.org/mental-health/self-harm)

Self-harm help for people 16-25 years old including apps and other tools.

[www.bigwhitewall.com](http://www.bigwhitewall.com)

A social networking site where people can talk about their feelings with professionals offering advice and monitoring the wall to ensure safety and anonymity. A small charge for use but not to people who have served in the armed forces.

### **Specialist mental health websites with phone and email contact**

Anxiety UK

Factsheets, links, downloadable magazine and resources including magazine to download. Small payment for some resources.

08444 775774

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

Alzheimer's Society

National charity leading the fight against dementia.

Lots of useful resources.

0300 222 1122

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

Bipolar UK

Information and support including online community and local groups. 0333 323 3880

[info@bipolaruk.org.uk](mailto:info@bipolaruk.org.uk)

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

BPD

Borderline Personality Disorder information plus help for families. Small charge for some services. [www.bpdworld.org](http://www.bpdworld.org)



### Hearing Voices Network

Information and support, some local groups available.

0114 271 8210

[nhvn@hotmail.co.uk](mailto:nhvn@hotmail.co.uk)

[www.hearing-voices.org](http://www.hearing-voices.org)

### No Panic

Advice for carers and people with phobias, anxiety and OCD.

0844 967 4848 (10am-10pm daily) [www.nopanic.org.uk](http://www.nopanic.org.uk)

Youth Helpline (13-20 year olds) 0330 606 1174, weekdays  
4pm to 6pm

### Sane

Information line with trained MH volunteers, Carers welcome to call.

0300 304 700 6-11pm daily

[info@sane.org.uk](mailto:info@sane.org.uk)

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

### Self-Injury Support

Information line, text and email support for girls / women who self harm.

0808 800 8088 7-10pm Mon-Fri, 3-6pm Thurs.

07800 472908 to text 7-9pm Sun-Fri

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

### Young Minds

Works with younger people and their parents to support mental health

0808 802 5544 9.30am-4pm Mon-Fri

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

### Armed Forces Personnel (and family members)

#### Combat Stress

Support for serving personnel, reservists, veterans and their families

0800 138 1619 (24hrs)

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

Royal British Legion  
Practical, emotional and financial support for veterans and  
serving personnel. 0808 802 8080  
[www.britishlegion.org.uk](http://www.britishlegion.org.uk)

SSAFA  
Armed forces charity offering lifelong support to veterans.  
Helpline 0800 731 4880 9am-5.30pm Mon-Fri  
0845 2417141 10.30am-7.30pm [www.ssafa.org.uk](http://www.ssafa.org.uk)

Sussex Armed Forces Mental Health Network  
[www.sussexarmedforcesnetwork.nhs.uk](http://www.sussexarmedforcesnetwork.nhs.uk)

### **Benefits (also see Carers' Support - national)**

Department for Work and Pensions (DWP)  
Information on Carers' benefits. [www.gov.uk/dwp](http://www.gov.uk/dwp)

Citizens Advice Bureau  
Advice available online (webchat), email, phone or face to  
face in local offices.  
03444 111 444 (for local contact details)  
[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)

### **National policy and monitoring organisations**

National Institute for Health and Care Excellence (NICE)  
Provides guidance and advice to improve health and social  
care services [www.nice.org.uk](http://www.nice.org.uk)

Care Quality Commission (CQC)  
The CQC checks whether hospitals, care homes and care  
services are meeting national standards.  
*CQC National Customer Service Centre, Citygate, Gallowgate,  
Newcastle upon Tyne, NE1 4PA*  
03000 61 61 61 8.30am–5.30pm Mon to Fri  
[enquiries@cqc.org.uk](mailto:enquiries@cqc.org.uk) [www.cqc.org.uk](http://www.cqc.org.uk)

## Patient Opinion

Independent website where people can share their experience of NHS services, good or bad. Comments made on sites are public.

0800 122 3135

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

## LOCAL SERVICES

### East Sussex

#### East Sussex County Council: Social Care services

The local authority is responsible for providing social care services to those who need them and who are eligible for them.

Carers Assessments – complete online or organize an appointment to have your needs assessed, or contact 'Care for the Carers' (below) for help.

Safeguarding issues- use this number if you are concerned that a vulnerable person is at risk of financial, emotional, physical or sexual abuse or serious self neglect.

Childrens' services – for special educational needs support and child protection.

0345 608 0191

[www.eastsussex.gov.uk/socialcare](http://www.eastsussex.gov.uk/socialcare)

online contact form

### Mental Health Services (East Sussex)

Assessment and Treatment (Community) –extra services in rural areas.

Cavendish House

Breeds Place, Hastings, TN34 3AA

01424 726553

Millwood Clinic

Uckfield Community Hospital, Uckfield, TN22 5AW

01825 761177

Newhaven  
Hillrise, Church Hill, Newhaven, BN9 9HH 01273 616440

Grove House  
Crowborough Hospital, The Grove, Crowborough, TN6 1NY  
01892 669393

St Mary's House, 52 St Leonards Road, Eastbourne, BN21 3UU  
01323 747224

Avenida Lodge, 3 Upper Avenue, Eastbourne, BN21 3UY  
01323 749970

#### Acute services (Inpatient)

Department of Psychiatry - Eastbourne District General  
Hospital Kings Drive, Eastbourne, BN21 2UD  
Amberley ward 01323 435650  
Bodiam ward 01323 435651  
Heathfield ward 01323 435652  
(Place of Safety if taken in by Police) 01323 417400

Conquest Hospital - The Ridge, St Leonards on Sea, TN37 7PT  
Woodlands Centre (Abbey and Castle wards) and St Raphael  
Wards 0300 304 0252  
(Place of Safety if taken in by Police) 0300 304 0252

#### Health in Mind

Group or one to one talking therapy support for depression,  
anxiety, stress and low self-esteem. Referral from G.P or self-  
refer. 0300 003 0130

[spnt.healthinmind@nhs.net](mailto:spnt.healthinmind@nhs.net)

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

#### Substance misuse services / alcohol services

Hastings and Rother community service 0300 303 8160  
Eastbourne, Wealden and Lewes community service  
01323 410092 [www.changegrowlive.org](http://www.changegrowlive.org)

## Carers' services

### Care for the Carers

The Carers Centre in East Sussex, supporting unpaid carers aged 16 and over, through the following services:

- 'Gateway' helpline – information, advice, support & access to other services
- One-to-one support and advice sessions
- Support to complete Carers Self-Assessments
- Carers groups, including specialist groups for carers of people with MH issues and for young adult carers
- Counselling service – 12 free sessions
- Support to access grants – e.g. for respite, equipment, white goods
- Carer engagement opportunities, such as forums and consultations
- Events and activities – e.g. pamper days, theatre trips, wellbeing walks, afternoon teas
- Young Carers - support for 8-19 year olds 01323 738390 (9am-5pm Monday-Friday)

01323 738390 or text 07860 077300 (9am-5pm Mon-Fri)

[info@cftc.org.uk](mailto:info@cftc.org.uk)   [www.cftc.org.uk](http://www.cftc.org.uk)

Highlight House, St. Leonards Road, Eastbourne, BN21 3UH

### East Sussex Young Carers

Supporting the most vulnerable young carers aged 5-18 who care for a family member with a long term disability or illness.

0300 777 2011

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

[info@eastsussexyoungcarers.org.uk](mailto:info@eastsussexyoungcarers.org.uk)

### Association of Carers

Support through free volunteer-led services including time to talk, respite, befriending and help to use a computer at home. Also offers young Carer befriending (Hastings and Rother only). 0300 330 9498

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

[info@associationofcarers.org.uk](mailto:info@associationofcarers.org.uk)

### British Red Cross (South East)

Offering respite, help and support for Carers in South East England. 01622 690 011

[ILCR\\_SouthEastAdmin@redcross.org.uk](mailto:ILCR_SouthEastAdmin@redcross.org.uk)

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

### East Sussex 1Space

Directory of local services and voluntary groups offering care or support. [www.eastsussex1space.co.uk](http://www.eastsussex1space.co.uk)

### Coastal Wellbeing

Wellness recovery action plans for Carers and service users.

[www.coastalwellbeing.co.uk](http://www.coastalwellbeing.co.uk)

07598 323254 [lucy@coastalwellbeing.co.uk](mailto:lucy@coastalwellbeing.co.uk)

07507 734370 [molly@coastalwellbeing.co.uk](mailto:molly@coastalwellbeing.co.uk)

## West Sussex

### West Sussex County Council Social Care services

The local authority is responsible for providing social care services to those who need them and who are eligible for them.

Carers Assessments - organize an appointment to have your needs assessed.

Safeguarding issues - contact if you're concerned that a vulnerable person is at risk of financial, emotional, physical or sexual abuse or serious self-neglect.

Children's services - special educational needs support and child protection.

[www.westsussex.gov.uk/social-care-and-health](http://www.westsussex.gov.uk/social-care-and-health)

01243 642121 or online contact form

### Mental health services

Assessment and Treatment Centres (Community) - extra services in rural areas.

16 Liverpool Gardens, Worthing, BN11 1RY      01903 843530

Chanctonbury, Swandean, Arundel Road, Worthing, BN13 3EP  
01903 843000

The Bedale Centre, 1 Glencathara Road, Bognor Regis, PO21  
2SF      01243 841041

Chapel Street Clinic, Chichester, PO19 1BX      01243 623400

Glebelands Mental Health Centre, Middle Road, Shoreham by  
Sea, BN43 6GA      0300 304 0055

Linwood, Butlers Green Road, Haywards Heath, RH16 4BE  
01444 416606

New Park House, North Street, Horsham, RH12 1RJ  
01403 223200

Springvale, 72-74 Moat Road, East Grinstead, RH19 3LH  
01342 326928

Midhurst Community Hospital, Dodsley Lane, Easebourne,  
Midhurst, GU29 9AW      01730 811300

### Acute services

Meadowfield Hospital, Swandean, Arundel Road, Worthing,  
BH13 3EF

Maple and Rowan wards plus Larch ward for older people.  
01903 843200

Langley Green Hospital, Martyrs Avenue, Crawley, RH11 7EJ  
01293 590400

Opal, Coral, Jade Wards and Amber Ward (Psychiatric  
Intensive Care Unit or PICU).  
Place of Safety if taken in by Police.

Chichester Centre, Graylingwell Drive, Chichester, PO19 6GS  
Secure Unit, Pine, Fir and Hazel wards 01243 791925

Oaklands Centre, Graylingwell Drive, Chichester, PO19 6GS  
Oaklands ward 01243 791898

Harold Kidd unit, Blomfield Drive, Chichester PO196AU  
Orchard ward 01243 791836

#### Time to talk

Group or one to one talking therapy support for conditions including depression, anxiety, stress and low self-esteem. Self-referral or through GP.

- Adur, Arun, Worthing and Chanctonbury: 01903 703 540
- Bognor and Chichester and surrounding area: 01243 265967
- Crawley and Horsham: 01403 227048 or 01293 843300
- Mid Sussex: 01444 251084



## Carers' services

### Carers Support West Sussex

Information, emotional support and practical advice. Includes:

- Support groups, both general and specialist
- Specialist MH, drug, alcohol and dementia carer wellbeing support workers
- Carers' rights
- One to one support including telephone call back service
- Events and activities
- Access to funding and equipment to enhance your wellbeing
- Counselling service
- Access to low cost alternative therapy
- Carers Assessments
- Skills Training
- Separate team for young adult Carers (18-25 years)

0300 028 8888

[info@carerssupport.org.uk](mailto:info@carerssupport.org.uk)

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

### West Sussex Young Carers

Support for Carers 5-18 years old, help to develop a support plan.

01903 270300 (ask for duty worker)

[www.westsussex.gov.uk/youngcarers](http://www.westsussex.gov.uk/youngcarers)

[youngcarers@westsussex.gov.uk](mailto:youngcarers@westsussex.gov.uk)

### Worthing Rethink

Providing support and education via monthly group meetings (which take place on the third Monday of the month at Meadowfield Hospital in Worthing, between 7pm and 9pm).

[www.facebook.com/groups/worthingmentalhealthcarers/](https://www.facebook.com/groups/worthingmentalhealthcarers/)

07763 082094 229900.

### Mind

Practical information and support for service users and carers, with local bases.

01903 277000

[www.coastalwestsussexmind.org](http://www.coastalwestsussexmind.org)

[info@coastalwestsussexmind.org](mailto:info@coastalwestsussexmind.org)

## Change Grow Live

Adults, young people and families whose lives are affected by substance misuse, homelessness, poverty, unemployment, domestic abuse, mental health issues and offending.

[www.changegrowlive.org](http://www.changegrowlive.org)

## Brighton & Hove

### Brighton and Hove Social Care services

The local authority is responsible for providing social care services to those who need them and who are eligible for them.

Carers' Assessments - can provide or direct you to an appropriate contact.

Safeguarding issues - contact if you're concerned that a vulnerable person is at risk of financial, emotional, physical or sexual abuse or serious self-neglect.

01273 295555

[www.brighton-hove.gov.uk](http://www.brighton-hove.gov.uk)

Children's services - including MH services for children

01273 295920

### Mental health services

Assessment and Treatment (Community)- extra services in rural areas.

East Brighton Community Health Centre Pankhurst Avenue,  
BN2 3EW

01273 621984

Hove Polyclinic, Nevill Avenue, Hove, BN3 7HY

01273 696011

Lighthouse, 60 Sackville Gardens, Hove, BN3 4GH

01273 770104

Royal Sussex County Hospital (emergency access to Mental Health Liaison Team) A&E, Western Road, Brighton BN1 2BE  
01273 696955

Mill View Hospital (Community Team) 01273 621984

### Acute (Inpatient) Services

Mill View Hospital, Nevill Avenue, Hove, BN3 7HZ  
Regency, Pavilion, Meridian and Caburn Wards.  
Place of Safety when taken in by Police.

01273 621984

### Brighton & Hove Wellbeing Service

Group or one to one talking therapy support for conditions including depression, anxiety, stress and low self-esteem. Self-referral or through GP.

0300 002 0060

[BICS.brighton-and-hove-wellbeing@nhs.net](mailto:BICS.brighton-and-hove-wellbeing@nhs.net)  
[www.brightonandhovewellbeing.org/](http://www.brightonandhovewellbeing.org/)

Pavilions drugs and alcohol advice and support services.  
Information and advice available.

0800 014 9819 (24 hours, seven days a week)

[www.pavilions.org.uk](http://www.pavilions.org.uk)      [familyandcarers@pavilions.org.uk](mailto:familyandcarers@pavilions.org.uk)

### Carers services

The Carers Centre 18 Bedford Place, Brighton, BN1 2PT

Information, emotional support and practical advice  
Pre-bookable face to face appointments available.  
Services include:

- Meditation group
- Book group
- Counselling services

- General and specialist support groups including eating disorders, LGBT (Lesbian, Gay, Bisexual or Transgender), BAME (Black Asian Minority Ethnic), male Carers, substance misuse, mental health)
- Young Carers Support Team (8-25yrs)
- Boys and sibling groups
- 01273 746222
- [info@thecarerscentre.org](mailto:info@thecarerscentre.org) [www.thecarerscentre.org](http://www.thecarerscentre.org)

#### Mind in Brighton & Hove

Information, training, support and advocacy service for people experiencing MH issues and their Carers. Appointment based service, please call first.

01273 66 69 50

[info@mindcharity.co.uk](mailto:info@mindcharity.co.uk)

[www.mindcharity.co.uk](http://www.mindcharity.co.uk)

#### Changes Ahead

Supporting Mental Health Families, Friends, Carers.

Offering 1-1 appointments, speakers, groups and events.

07511 858722 / 07935 302838

Mon/Tue alternate 12-8pm or 9-5pm (late evening appts available)

[janehowardchangesaheadoakleaf@gmail.com](mailto:janehowardchangesaheadoakleaf@gmail.com)

[changesaheadoakleaf@gmail.com](mailto:changesaheadoakleaf@gmail.com)

#### Sibling Link

A peer support group for adults who have or have had a brother or sister living with mental illness

07930 473130

[info@siblinglink.co.uk](mailto:info@siblinglink.co.uk)

[www.siblinglink.co.uk](http://www.siblinglink.co.uk)

