



# **INFORMATION FOR CARERS OF PEOPLE WITH MENTAL ILL HEALTH**

A Carer is someone, who without payment, provides care and support to a partner, child with additional needs, relative or friend who could not manage without their help. They may be expected to be available 24 hours a day, 365 days a year. They can act as nurse, companion, taxi driver and financial advisor among all of the other roles they have in the relationship!

Carers are normal people who out of a sense of love, duty or compassion try to live their own lives and at the same time do their best to help a husband, wife, partner, son, daughter, family member or friend. The Carer may be the only person who is trusted by the person who they are supporting.

Carers ask for guidance, information and time to understand and learn how to cope with the challenging situations and emotions they may encounter.

Carers recognise the role of the professionals and it is important that professionals also recognise and value the role of the Carer. Carers ask that their expertise be recognised and that they are treated as “partners in care”, that people talk to them and keep them informed of what is happening but, most importantly, listen to them!

Living with or caring for someone with mental ill health can be tiring, worrying, stressful, upsetting and emotionally draining. It can be also be very rewarding, however in order for you to support them through the tough times and keep them on track you may need support and guidance for yourself.

## **CARERS RIGHTS**

Carers have only 3 statutory rights:

- ◆ Every Carer is entitled to a Statutory Carer’s Assessment, even if the person they care for does not wish to engage with services.
- ◆ Every Carer is entitled to their own Care Plan.
- ◆ It is a requirement that Carers are told, by any professional involved with the person they care for or themselves, of their right to a Statutory Carer’s Assessment.

However, there are good practices which most professionals should observe. Carers should:

- ◆ Be taken seriously when expressing concerns and treated with understanding and respect.
- ◆ Be informed about the illness of the person they are caring for, the diagnosis, treatment and possible side-effects of the treatment.
- ◆ Be included in care planning, implementation and review.
- ◆ Be included in discharge planning.
- ◆ Be offered support / referral to local Carers support services.
- ◆ Be informed of procedures for complaint and redress.

## CARERS ASSESSMENTS

Carers have the right to their own assessment even if the person they care for does not receive , or wish to engage with, services.

Durham County Carers Support are commissioned to carry out initial assessments in County Durham. The assessment will take the form of a discussion between you and your Carer Support Coordinator where you will discuss how your caring role impacts on your life, identify areas where you may need support and how you will get it. The assessment will look at 7 specific areas of the Carers life:

- ◆ Health
- ◆ The caring role
- ◆ Managing at home
- ◆ Time for yourself
- ◆ How you feel
- ◆ Finances
- ◆ Work

After a discussion around these areas you and your Carer Support Coordinator will discuss how any needs will be met. Durham County Carers Support can often meet the needs of the Carer. If not you will be offered a referral to Durham County Council for a full Statutory Carers Assessment which will be carried out by a social worker/care coordinator.

## LOOKING AFTER YOURSELF

As a Carer it is important to think about your own needs and how this role impacts on your own life, health and wellbeing.

Carers often say “If the person I care for has all the necessary help and services then I’m fine” but in reality this may not always be true. Carers still need to make time for themselves and get the support to have their own life alongside the caring role whether this is for leisure activities or work. All too often these activities, which most people take for granted, can be denied to Carers because of caring responsibilities.

Some Carers may only need information and occasional support to enable them to cope. Other Carers may feel they need a greater level of support. It is important that you have the opportunity to maintain your social networks, families and friends as caring can become a lonely or isolating experience. Carers of people with mental ill health can feel inhibited about talking to people because of the stigma associated with mental ill health. Talking in itself is a therapeutic exercise and a good place to start is by talking to your GP so that you are recognised as a Carer. This is also a good time to add your name to your GP Practice Carers Register. This will alert the GP to the fact that as a Carer you may find yourself in stressful situations which may result in your own health difficulties.

## UNDERSTANDING THE JARGON

When people first come into contact with mental health services it can be confusing. Professionals may use terms and abbreviations that you do not understand. Always ask them to explain what they mean. Sometimes people forget that not everyone uses the same language.

Below is a list of some of the most commonly used terms:

**Affective Disorder** These are mood disorders, the most common are depression, anxiety disorders and Bipolar disorder. Symptoms can vary but typically affect the mood.

**Approved Mental Health Professional (AMHP)** Each local authority has a responsibility to provide sufficient numbers of social workers specifically trained under the Mental Health Act 1983. Their role is to assess people for admission to hospital and if there is no alternative, to authorise admission and make all necessary arrangements. This is an enhanced role and is different to the usual role of Social Workers.

**Atypical anti-psychotic medication** These are recently introduced forms of medication used to treat psychosis. Some of the more commonly prescribed are Amisulperide, Clozapine, Olanzapine and Risperidone. These drugs are thought to have fewer side effects than some of those previously prescribed.

**Bipolar disorder (manic depression)** This is an illness which causes excessive change in mood from deep depression to hypomania (elevated mood/hyperactivity). See section on Mental Health Conditions for more details.

**Care co-ordinator** This is the person who will be responsible for the Care Programme Approach (CPA) and act as the link for the Service User/Carer and other mental health professionals.

**Cognitive Behaviour Therapy (CBT)** A form of therapy used to help people to cope with stress and emotional difficulties by making connections between how we think, how we feel and how we behave.

**Community Mental Health Team (CMHT)** The providers of mental health services on a local basis. These teams include Psychiatrists, Clinical Psychologists, Community Psychiatric Nurses (CPN's), Social Workers and Occupational Therapists all of whom will be working together to develop a Care Plan which meets the needs of the person using the services.

**Community Psychiatric Nurse (CPN)** A qualified, specialist mental health nurse who will provide patient and follow up care when the person is living at home or in the community.

**DBT Dialectical Behaviour Therapy** was originally used to treat chronically suicidal people with borderline personality disorder. It is a therapy used to change unhelpful patterns of behaviour such as self harm and suicidal thoughts.

**Depot injections** Long acting medication given by injection which is often used when people are unable or unwilling to take prescribed tablets.

**Dual – diagnosis** This term is used to describe patients who have a mental illness or learning disability combined with problematic drug and/or alcohol misuse.

**Electro-convulsive therapy (ECT)** This treatment is most commonly used for severe depression when medication has failed. ECT is always administered under general anaesthetic and produces a mild shock to the brain. People are often concerned when ECT is discussed but, administered correctly, it can be an effective, life saving treatment.

**Emergency Duty Team/Worker** This team/worker provide social work cover outside normal working hours—evenings, nights and weekends.

**Forensic service** This part of mental health services deal with people who commit a criminal offence whilst they are mentally ill. Also known as secure service.

**Holistic** This means considering the whole person in treatment of the illness—physical, emotional, psychological, spiritual and social needs.

**Mental Health Act 1983 – amended by Mental Health Act 2007** This is the law in England and Wales which allows for people with a mental health condition to be admitted to hospital, detained and treated without their consent, either for their own health and safety or the protection of others. The act has numerous sections but the most commonly used are:

- ◆ **Section 2** A person is detained in hospital for an assessment of their mental health and any necessary treatments. This section will be used for people who have not been previously assessed in hospital or have not had a hospital assessment for a long time. It is a 28 day section but can be discharged before 28 days and the patient can be assessed for a section 3 at any point during the 28 days.
- ◆ **Section 3** Under section 3 a person is detained in hospital for treatment. They will be known to mental health services so there is no need for an assessment under section 2. A person can be detained for up to 6 months but can be discharged before this time is up. This section can also be renewed for a further 6 months in the first instance then can be renewed for 12 month periods if necessary.
- ◆ **Section 4** This section is used in emergency situations for short periods of time when a persons mental health needs to be assessed. They can be detained for up to 72 hours. A section 4 can be changed to a section 2.

**Occupational Therapist (OT)** An occupational therapist will work with a person to improve their ability to perform tasks in daily living during their recovery. They will use purposeful activities and interventions to restore the highest possible level of independence and mental well being. They will look at both practical tasks and coping strategies.

**Psychiatrist** A medical doctor who has trained and specialised in the branch of medicine which is concerned with the diagnosis, treatment and prevention of mental, emotional or behavioural disorders. A psychiatrist can prescribe medication.

**Psychologist** A psychologist will look at the way a person thinks, behaves and interacts. Their interests are around thought processes and behaviours and they will explore concepts such as perception, cognition, emotions, and personality. A psychologist cannot prescribe medication.

**Psychosis** This is a broad term used to describe a severe mental disorder in which thoughts and emotions are so impaired that a person loses touch with reality. Two main symptoms can be hallucinations or delusions.

- ◆ **Hallucinations** This is when a person hears, sees and in some cases, feels, smells or tastes things that aren't there. A common hallucination is hearing voices.
- ◆ **Delusions** This is when a person believes things that, when examined rationally, are obviously untrue. An example of this could be thinking your neighbour is planning to kill you.

A combination of hallucinations and delusional thinking can often severely disrupt thinking, perception, emotions and behaviour.

Experiencing the symptoms of psychosis is often referred to as having a psychotic episode.

**Schizophrenia** A specific term for a mental illness where symptoms include psychosis. See section on mental health conditions for more details.

## CARE PROGRAMME APPROACH (CPA)

The Care Programme Approach is a way that services are assessed, planned, co-ordinated and reviewed for someone with mental health issues or a range of related complex needs. People will be offered CPA if they are:

- ◆ Diagnosed as having a severe mental disorder.
- ◆ At risk of suicide, self harm or likely to harm others.
- ◆ Likely to neglect themselves and don't take treatment regularly.
- ◆ A "vulnerable" person e.g. likely to be a victim of physical or emotional abuse, financial difficulties because of mental illness or cognitive impairment.
- ◆ Someone who has misused drugs or alcohol.
- ◆ Someone with learning disabilities.
- ◆ Someone who relies heavily on the support of a Carer or has their own caring responsibilities.
- ◆ Someone who has recently been detained under the Mental Health Act.
- ◆ Someone who has parenting responsibilities.
- ◆ Someone who has a history of violence or self-harm.

The person will be involved, along with the care co-ordinator (a nurse, social worker or occupational therapist), in the assessment of their needs and the development of a plan to meet those needs. A formal written Care Plan will be issued that will outline any risks and include details of what should happen in an emergency/crisis. The plan will have the name and contact details of the care co-ordinator whose responsibility it is to manage the plan and ensure it is reviewed on a regular basis—at least once a year.

## MENTAL HEALTH CONDITIONS

**Anxiety Disorders** Anxiety is a feeling of unease, such as worry or fear, that can be mild or severe. Everyone has feelings of anxiety at some point in their life, usually as a reaction to stress e.g. when taking exams, seeing a doctor or before a job interview. During these times feelings of anxiety are perfectly normal. However, some people find it hard to control their worries and the feelings are more constant. There are many types of anxiety disorder including panic disorder, social anxiety disorder and Post Traumatic Stress Disorder. One of the most common is **Generalised anxiety disorder (GAD)** A long term condition that causes people to feel anxious about a wide range of issues rather than just one specific event. People with GAD may feel anxious most days and struggle to remember the last time they felt relaxed. It can often affect their daily lives to the point where they cannot cope with day to day activities. It can impact on their ability to work, travel to places or even leave the house. It can cause psychological as well as physical symptoms including feeling restless or worried, inability to concentrate or sleep, become tired easily, increased heart rate, tension and pain in muscles, inability to relax, sweating, rapid breathing, dizziness and bowel disturbances.

**Bi-Polar Disorder (Manic Depression)** This condition affects the mood, which can swing from one extreme to another. People will have periods of depression when they feel very low and lethargic and elated periods (mania) when they feel extremely high and overactive. Unlike simple mood swings each extreme episode of bipolar can last for several weeks, or even longer, and some people may not experience a “normal” mood very often. The low and high phases are often so extreme that they interfere with everyday life. Episodes of highs and lows may occur directly after each other or there may be periods of stability. The depression phase is often diagnosed first. During an episode of depression people may have overwhelming feelings of worthlessness which can lead to thoughts of suicide. People can also feel overwhelmed by despair and guilt as well as feeling apathetic and totally unable to do even the simplest task. During the high (manic) phases people will feel extremely elated and have ambitious plans and ideas. They may spend large sums of money on items they cannot afford and would not normally want. During this phase people may not feel like eating or sleeping, talk rapidly and become annoyed easily. During this phase people may experience symptoms of psychosis where they see or hear things that are not there or become convinced of things that are not true.

**Depression** We all go through times of feeling fed up or miserable but these feelings don't usually last for long, they don't interfere much with our lives and we usually cope. However with depression these feelings don't lift after a few days, they can go on for weeks or months and are so bad that they interfere with a person's life. Depression affects people in different ways and can cause a variety of symptoms including: feeling down most of the time, loss of interest in life and no enjoyment, difficulty making decisions, inability to cope, feeling tired, restless and agitated, loss of appetite and weight, disturbed sleep pattern, loss of libido, loss of confidence, feeling useless, inadequate and hopeless, avoiding other people and having suicidal thoughts. Physical symptoms such as pain, constant headaches or sleeplessness can sometimes be the first sign of depression and people may not realise themselves. It sometimes takes a partner or friend to point out the problem and encourage a person to speak to their GP.

**Eating Disorders** are characterised by an abnormal attitude towards food that causes a person to change their eating habits and behaviour to the extent that it has a negative affect on their mental and physical health. A person with an eating disorder may focus excessively on their weight and shape, leading them to make unwise and unhealthy choices about food with damaging results to their health. Eating disorders include a range of conditions that can affect someone physically, psychologically and socially. The most common disorders are **anorexia nervosa and bulimia nervosa**.

**Anorexia Nervosa** is a serious mental health condition and eating disorder in which people keep their body weight as low as possible. They usually do this by restricting the amount of food they eat, making themselves vomit and exercising excessively. The condition develops out of an anxiety about body shape and weight that originates from a fear of being fat or a desire to be thin. Many people with anorexia have a distorted image of themselves, thinking they are fat when in reality they are not. Many people with anorexia will go to extreme lengths to hide their behaviour from their family and friends by lying about what they have eaten or pretending to have eaten earlier. Some signs of anorexia (or other eating disorders) can be:

- ◆ Missing meals, eating very little or avoiding fatty foods.
- ◆ Obsessive calorie counting.
- ◆ Leaving the table immediately after eating so that they can vomit.
- ◆ Taking appetite suppressants, laxatives or diuretics.
- ◆ Repeatedly weighing themselves or checking their body in the mirror.
- ◆ Physical problems such as dizziness, hair loss or dry skin.

Anorexia can also be associated with other psychological conditions such as depression, anxiety, low self-esteem, alcohol misuse or self-harm

**Bulimia** is an eating disorder and mental health condition in which people try to control their weight by severely restricting the amount of food they eat, then binge eating and purging the food from their body by making themselves vomit or by using laxatives. As with anorexia, this condition is associated with an abnormal attitude towards food or body image and people tend to use their eating habits to cope with emotional distress. People with bulimia tend to have periods of excessive eating and loss of control after which they will make themselves vomit or use laxatives. This purging is usually due to the fear that the binging will cause them to gain weight and people often feel guilty and ashamed of their behaviour. This is why these behaviours are usually done in secret. Some signs can include:

- ◆ Obsessive attitude towards food.
- ◆ Overcritical attitude to their weight and shape.
- ◆ Frequent visits to the bathroom after eating, after which the person may appear flushed and have scarred knuckles from forcing fingers down the throat to bring on vomiting.

**Obsessive Compulsive Disorder (OCD)** is a mental health condition where people have obsessive thoughts and compulsive activity. An **obsession** is an unwanted and unpleasant thought, image, urge or doubt that repeatedly enters a person's mind and causes feelings of anxiety, unease or disgust. These thoughts recur and persist despite efforts to ignore or confront them. The obsessions interrupt other thoughts and cause people to feel anxious and distressed. A **compulsion** is a repeated behaviour or mental act that someone feels they need to carry out to temporarily relieve the unpleasant feelings brought on by the obsessive thought. Some people with OCD may spend an hour a day engaged in obsessive –compulsive thinking and behaviour but for others the condition can completely take over their life. People with OCD are unable to control either the thoughts or the activities and most are aware that their thoughts and behaviours are not rational but they feel bound to comply with them otherwise they will experience significant psychological distress. They may also feel that complying with these actions will prevent something dreadful happening to others.

**Personality Disorders** are conditions in which a person differs significantly in terms of how they think, perceive, feel or relate to others. Common features include:

- ◆ Being overwhelmed by negative feelings such as distress, anxiety, worthlessness or anger.
- ◆ Avoiding other people and feeling empty and emotionally disconnected.
- ◆ Difficulty managing negative feelings without self-harming or, in rare cases, threatening others.
- ◆ Odd behaviour and difficulty maintaining stable and close relationships.
- ◆ Sometimes periods of losing touch with reality.

There are several types of personality disorder which can be broadly grouped into one of three clusters, A, B or C, which are summarised below:

**Cluster A Personality Disorders** : A person with a cluster A personality disorder tends to have difficulty relating to others and usually displays patterns of behaviour that would be regarded as odd and eccentric. They may be described as living in a fantasy world of their own. An example of a cluster A personality disorder is **Paranoid Personality Disorder** where people are likely to:

- ◆ Find it very difficult to trust other people, believing they will take advantage.
- ◆ Find it hard to confide in people, even close family and friends.
- ◆ Watch others closely looking for signs of betrayal or hostility.
- ◆ See threats and danger—which others don't see—in everyday situations.

**Cluster B Personality Disorders:** People with cluster B personality disorders struggle to regulate their feelings and often swing between positive and negative views of others. This can lead to behaviour patterns that are seen as dramatic, unpredictable and disturbing. An example of a cluster B personality disorder is **Borderline Personality Disorder**, where a person is emotionally unstable, has impulses to self-harm and has intense and unstable relationships with others.

## Personality Disorders - continued

People with **Borderline Personality Disorder** are likely to:

- ◆ Suffer from mood swings, switching from one intense emotion to another very quickly, often with angry outbursts.
- ◆ Have brief psychotic episodes, hearing voices or seeing things that others don't.
- ◆ Have episodes of harming themselves and thoughts of taking their own life.
- ◆ Have a tendency to cling on to damaged relationships through fear of being alone.
- ◆ Act on impulse and later regret their actions.

## Cluster C Personality Disorders

A person with a cluster C personality disorder struggles with persistent and overwhelming feelings of anxiety and fear. They may show patterns of behaviour which others regard as being antisocial and withdrawn. An example of a cluster C personality disorder is **Avoidant Personality Disorder**, where a person appears painfully shy, socially inhibited, feels inadequate and is extremely sensitive to rejection. The person may want to be close to others but lacks confidence to form a close relationship.

People with **Avoidant Personality Disorder** are likely to:

- ◆ Avoid work or activities that mean being with others.
- ◆ Expect disapproval and criticism and be very sensitive to it.
- ◆ Worry constantly about being rejected, ridiculed or shamed by others.
- ◆ Avoid relationships, friendships and intimacy because of fear of rejection.
- ◆ Feel lonely, isolated and inferior to others.

**Schizophrenia** is a long term mental health condition characterised by abnormal social behaviour and failure to recognise what is real. The mental processes of thinking becomes distorted making it hard to distinguish reality from what is imagined. Schizophrenia is a psychotic illness where symptoms can include hallucinations, delusions, muddled thoughts and changes in behaviour. The symptoms of Schizophrenia are usually divided into 2 categories—positive symptoms and negative symptoms. These can occur together, separately or they can alternate.

**Positive symptoms** generally refer to hallucinations, delusions and disorganised thinking.

- ◆ **Hallucinations** can involve any of the senses so can be auditory (sound), visual (sight), tactile (touch), gustatory (taste) and olfactory (smell). The most common is hearing voices. Hallucinations are very real to the person experiencing them.
- ◆ **Delusions** are beliefs held with complete conviction even though they are based on a mistaken, strange or unrealistic view. It may affect the way people behave and can begin very suddenly or develop over a number of weeks or months.

## Schizophrenia - continued.

- ◆ **Disorganised Thinking** is where people have difficulty keeping track of their thoughts and conversations. They can find it very hard to concentrate and making conversation can become difficult and hard for others to follow due to jumbled thoughts and speech.

**Negative Symptoms** represent a withdrawal or lack of function and contribute to poor quality of life and functional ability. The symptoms can include:

- ◆ Loss of interest and motivation in life and activities including relationships and intimacy.
- ◆ Lack of concentration, not wanting to leave the house and changes in sleep patterns.
- ◆ Being less likely to engage in conversations and feeling uncomfortable with other people.
- ◆ Lack of eye contact and reduced emotions.

**If you have any concerns or need any further information you could speak to a member the Community Mental Health Team who support the person you care for, a member of the ward staff if the person is admitted to hospital or your GP.**

| ORGANISATION                                | WEBSITE  |
|---|--|
| Durham County Carers Support                | <a href="http://www.dccarers.org">www.dccarers.org</a>               |
| Carers Trust                                | <a href="http://www.carers.org">www.carers.org</a>                   |
| Carers UK                                   | <a href="http://www.carersuk.org">www.carersuk.org</a>               |
| Mind  | <a href="http://www.mind.org.uk">www.mind.org.uk</a>                 |
| Rethink Mental Illness                      | <a href="http://www.rethink.org">www.rethink.org</a>                 |
| Mental Health Foundation                    | <a href="http://www.mentalhealth.org.uk">www.mentalhealth.org.uk</a> |
| Mental Health North East                    | <a href="http://www.mhne.org.uk">www.mhne.org.uk</a>                 |
| National Institute of Mental Health England | <a href="http://www.nimh.nih.gov">www.nimh.nih.gov</a>               |
| Schizophrenia . Com                         | <a href="http://www.schizophrenia.com">www.schizophrenia.com</a>     |
| Anxiety UK                                  | <a href="http://www.anxiety UK.org">www.anxiety UK.org</a>           |
| Bi Polar UK                                 | <a href="http://www.bipolaruk.org">www.bipolaruk.org</a>             |
| Eating Disorders                            | <a href="http://www.b-eat.co.uk">www.b-eat.co.uk</a>                 |
| Combat Stress—Veterans Charity              | <a href="http://www.combatstress.org.uk">www.combatstress.org.uk</a> |
| Royal College of Psychiatrists              | <a href="http://www.rcpsych.ac.uk">www.rcpsych.ac.uk</a>             |

Information in this booklet has been taken from the following websites:  
www.mind.org.uk, www.nhs.uk https://en.wikipedia.org, www.rethink.org,  
www.b-eat.co.uk, www.nimh.nih.gov, www.rcpsych.ac.uk  
Personalitydisorder.org.uk, www.carers.org www.mentalhealth.org.uk

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

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