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Carers information booklet on first episode psychosis

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Feedback

We welcome any suggestions you have, please send your **comments, concerns, complaints and compliments** to: Cheshire and Wirral Partnership NHS Foundation Trust, **PALS, Complaints and Claims Team**, 1829 Building, Liverpool Road, Chester, CH2 1HJ.

For more information see www.cwps.nhs.uk

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The early intervention in psychosis team works with people from the age of 14 who have experienced a first episode of psychosis or who are in the early stages of illness.

The team will complete an assessment and determine whether the episode of illness is related to a psychosis and if so tailor an individual treatment plan for your loved one.

The majority of people who experience a first episode of psychosis live with their families who are often the first to notice that something may be wrong. Families can play a vital role in helping people with psychosis access care and support.

Families and carers play a key role in the recovery of those with mental health issues and are entitled to help and support.

As a carer or relative you should not hesitate to contact the team if you are worried, need information or simply want to talk to somebody about the person you care for. The early intervention team will always listen to what you have to say.

What is psychosis?

The word psychosis is used to describe a variety of conditions which affect the mind, where there has been some loss of contact with reality. Psychosis is most likely to occur in young adults and approximately 1 out of every 100 people will experience a psychotic illness. Most will make a full recovery from the experience. Psychosis can happen to anyone and like any other illness it can be treated.

A psychotic illness occurs in three phases. The length of each phase varies from person to person.

Phase 1: Prodrome

The early signs are vague and sometimes hard to notice. They might include anxiety, depression, social withdrawal, or changes in personality and behaviour.

Phase 2: Acute

This is when clear psychotic symptoms are experienced, such as hallucinations, delusions or confused thinking.

Phase 3: Recovery

Psychosis is treatable and most people recover. The time to recovery will vary from person to person and can depend upon how quickly they sought treatment.

What are the symptoms?

The symptoms vary from person to person, and can consist of a variety of symptoms.

Psychosis can lead to changes in mood and thinking. Everyday thoughts become confused and thought patterns disrupted. Conversations may become random, switching from one subject to another or there may be a space mid-way through a sentence.

False beliefs

False beliefs or delusions are ideas that are out of context with an individual's background or circumstances. They are often paranoid in nature such as beliefs that someone is spying on them or wanting to harm them.

Hallucinations

Another symptom of psychosis is that a person may see, hear, feel, smell or taste something that is not actually there. This is called an hallucination and can affect any of the senses, however the most common are auditory hallucinations (hearing voices).

People may talk directly to the voices that they hear.

Families may notice changes in their relatives behaviour because of these symptoms. They may become isolative, spend a lot of time on their own, lose interest in college, friends or work, and not enjoy themselves as much as before.

People can also experience negative symptoms of psychosis which include feeling unmotivated, slowed down, and lethargic.

What are the types of psychosis?

Attaching a specific diagnosis to a psychotic illness is not always useful in the early stages. A diagnosis of a particular psychotic illness is usually given after a period of assessment is completed. The diagnosis is used to give a summary of symptoms, can indicate what may have caused them, and can inform a treatment plan. As time progresses the initial diagnosis may change as both the team and the client gets a better understanding of the nature of their illness.

Schizophrenia

Schizophrenia refers to a psychotic illness in which particular groups of psychotic symptoms have continued for a period of at least four weeks.

Drug-induced psychosis

This can be commonly triggered by the use of cannabis, amphetamines, cocaine, and M-CAT. Psychotic symptoms associated with intoxication with drugs can be brief and the effects will wear off as the drug leaves a person's system. However, if symptoms persist for up to a week then drugs may have triggered an illness that requires medication.

Symptoms of psychosis can occur as a result of alcohol use and commonly occur during alcohol withdrawal.

Acute and transient psychosis

Psychotic symptoms arise suddenly in response to a major stress. Symptoms can be severe, but the person makes a quick recovery in only a few days.

Delusional disorder

The main problem is a strong belief in things which are not true. A person may be preoccupied that there is a conspiracy against them, that people are talking about them, or that a person or organisation wants to harm them. People can also believe that they have special powers or are famous.

Organic psychosis

These symptoms may appear as part of a head injury or a physical illness which disrupts brain functioning, There are usually other neurological symptoms present, such as memory problems or confusion.

What causes psychosis?

There are many factors which contribute to psychosis developing. They all lead to imbalances in the brain's chemical messenger system which is what creates the psychotic symptom. The most common time for someone to experience a first episode of psychosis is when they are in their late teens or early twenties. Changes in brain development during this time can trigger a first episode of illness. Genetic factors can also increase vulnerability if there is a family history of severe mental illness. Drugs and alcohol misuse can also contribute to a first episode of psychosis occurring. Finally, stressful events can also increase the risk of such an illness developing.

The process of recovery

The meaning of recovery will be different for each person. The speed of recovery varies from person to person and may take a number of months or sometimes even longer. They may aim to return to being able to achieve their potential before they were ill. It may also include making changes to their lifestyles to avoid another episode. This may mean taking anti-psychotic medication for a number of years, or avoiding excessive stress that triggered the initial episode. Recovery can be achieved by learning about the illness, its treatment, and the ways to prevent further illness episodes. Work can be done to recognise early warning signs or symptoms, how to manage stress, develop a social network, and become involved in work, school and leisure activities.

Treatment for psychosis

Psychosis is treatable and people do get better in most cases. It is important to seek help early. Initial contact begins with an assessment which can also include relatives to allow the team to have a better understanding of the issues. Medication is often the first line of treatment and is used in conjunction with talking therapies. Medication relieves symptoms of psychosis by acting on chemical imbalances in the brain and plays a critical role in preventing further episodes of illness. There are two types of antipsychotic medication. Typical (or first generation) antipsychotic medications have been available for 30 years.

Typical antipsychotic medications include:

Fluphazine, Flupenthixol, Haloperidol and Zuclopenthixol

Atypical or second generation antipsychotic medications have been available since the 1990s.

Atypical antipsychotic medications include:

Olanzapine, Amisulpiride, Quetiapine and Risperidone.

Each group are equally effective, but they do differ in terms of side effects. The role of the team is to discuss these with clients and make an informed choice about which may be the most suitable.

Treatment begins with a low dose of medication that is monitored closely for any side-effects. Annual health checks are also carried out by either the team or the GP. This will include monitoring weight, blood pressure and pulse and completing routine blood tests.

Some people experience no side effects, however common side effects include: tiredness, dizziness, weight gain, dry mouth, blurred vision, restlessness, stiffness, constipation and muscle spasms.

Atypical medications as a group are less likely to cause restlessness, stiffness and tremor, but are more likely to cause other side effects such as weight gain.

Clozapine is one of the atypical medications that has been proven to be effective for people who do not respond well to standard antipsychotic medications. It should be considered if two previous treatments have not been successful.

It is important to note that medication must be taken even after the symptoms have gone. When medication is discontinued too early, there is a risk that symptoms will return. This does not necessarily happen right away, and can happen a number of months after medication is stopped. It will be important to talk with the team to know how long you should remain on medication.

If symptoms settle on medication , a period without medication may be discussed with the team to see if it is needed in the longer term.

What are psychological therapies?

These are also known as 'talking therapies' and help people to explore and deal with their problems. They involve talking in groups or on a one to one basis which can include trying things out between sessions. Sessions are not indefinite and can range from one to six months. It can take time for people to notice changes during therapy.

A range of problems can be helped by psychological therapy including

anxiety, stress, depression, obsessions, traumatic life experiences, long term emotional problems and psychosis.

Cognitive behavioural therapy (CBT) is an intervention that research has identified as successful in helping people manage with anxiety, depression, phobias, and psychosis. CBT is based on the model that what we think affects what we feel physically and emotionally and what we do. What we do to manage distressing thoughts can sometimes be helpful in the short term , but become unhelpful in the long term i.e avoiding going out.

CBT is based in the 'here and now' and does not focus on past experiences. If a client agrees to engage with this approach it will involve providing them with information about thinking styles and automatic thoughts. Clients can be taught how to challenge intrusive thoughts and think about whether they are right or wrong.

CBT can be used to help manage voice experience and delusional beliefs. In some cases these may not go completely but they can become less distressing and the conviction in them may have lessened. The aim of this intervention is for the client to become their own therapist.

Families and carers

Family involvement

The onset of psychosis is a distressing time for families who may feel worried, helpless and confused. The involvement of relatives is important in the assessment and treatment plan towards recovery.

Many families describe having benefitted from learning how to develop coping strategies and effective communication skills to help them support their family member.

Individual family intervention, psychoeducation workshops and support groups can help develop these approaches. The groups can provide ongoing emotional and practical support, as well as education about the illness.

It is important that family members find a balance between supporting their recovering relative and finding time for themselves. This helps them prevent exhaustion and avoid becoming "burned out".

Groups for families also allow them to feel that they are not alone with their experiences.

What does the term 'carer' mean?

We use the term 'carer' to describe someone who provides regular, unpaid support to a person with first episode psychosis. You could be a family member, partner or close friend. You might also be a child or young person under the age of 18 who is caring for someone in your family.

Carers may need emotional as well as practical support. Emotional support may be as simple as having someone to talk to about the things that may be worrying you. Practical support might involve help with the activities of daily living including personal care and managing money or attending care meetings.

I don't see myself as a carer

We know that many people do not see themselves as a 'carer' in the formal sense. For example, you might see caring as your natural duty or responsibilities because the person you care for is a family member or partner. Regardless of who you care for, or how you see yourself, if you care for someone with a mental health problem you are entitled to help and support.

The Care Programme Approach (CPA)

The CPA is a framework that all mental health services work within nationally. Therefore if somebody moves to a different area of the country they will still be under the same system.

If someone is under a CPA level of care it means that they have more than one mental health professional involved in their treatment. This can be an early intervention practitioner and consultant psychiatrist.

Elements of the CPA include:

A care coordinator: A professional who is your main point of contact with the team for both you and the person who is unwell.

Needs assessment: A full assessment of a person's health and social needs. As a carer you are also entitled to a carer's needs assessment

A care plan: A written agreement setting out the care and treatment that can be expected that the client is given a copy of.

Review meetings: With persons using our services, the carer and practitioners to see if the treatment plan is working well and if it needs changing.

With your relative's agreement, the care coordinator will involve you as much as possible in the programme of care.

- You can have access to a **carer's needs assessment** so we can find the most appropriate type of help and support for you
- Provide you with **information** about psychosis and information about how to manage it
- Give you information about the **services that are there to support you**. This may be services provided by other organisations such as **Making Space** and those in the voluntary sector
- Some early intervention teams have a **dedicated carer link** who will provide help and support

Hospital admissions

Although the majority of mental health problems are successfully managed in the community some people need a stay in hospital.

People are admitted to hospital either "informally" or on a Section of the Mental Health Act. An informal patient can leave hospital at any time and their movements are not generally restricted.

If a person is in hospital under a Section of the Mental Health Act they need medical permission to leave the ward (called Section 17 leave) and may be expected to take medication and treatment.

If you are the nearest relative you also have rights under the Mental Health Act. For example, you can ask that the person you care for has a Mental Health Act assessment. This can put a strain on a relationship, however it is not a carer's request that leads to any admission to hospital but an agreement between the two Doctors and an Approved Mental Health Professional who complete the assessment.

Most people do prefer to receive help at home rather than have to go to hospital which itself may be stressful for them.

In the event of an admission you can also talk to the team about your relatives' discharge from hospital, and with your relatives consent the right to information about treatment plans.

Before discharge from hospital, family and carers can be involved with the care team in drawing up a 'discharge plan'.

The Mental Health Act

If a person with a mental illness is unwilling to take treatment, or is unable to consent to treatment, then a decision could be taken to use special legal powers called 'sections' to detain them in hospital. These set out under different paragraphs of the Mental Health Act and are usually applied when there are risks evident of harm to self or others because of mental illness, and that there is no better alternative.

The main sections of the Mental Health Act are:

Section 2

This section lasts for up to 28 days. Two doctors and an approved mental health professional decide when someone is put on Section 2. A senior doctor known as a responsible clinician will be in charge of their care and treatment. This can be discontinued by the responsible clinician before 28 days or following an appeal.

Section 3

This lasts for up to six months. Again, two doctors and an approved mental health professional decide when someone is put on Section 3 – and a responsible clinician will be in charge of their care and treatment. The main purpose of Section 3 is to allow more time to effectively treat someone for a mental problem. This can be discontinued by the responsible clinician during the six months or following an appeal. A Section 3 can also be renewed if it is agreed to be necessary when the first 6 month period is due to expire.

Section 4

If someone comes to hospital under Section 4 it means the approved mental health professional assessing them was very concerned about them and needed to act quickly. Section 4 means only one doctor saw them and it only lasts for up to 72 hours. A Section 4 is usually followed by a Section 2 or Section 3, or that the Section 4 is allowed to expire and the person is regraded to a voluntary patient.

Community Treatment Orders (CTO)

Some patients under Section 3 can leave hospital and carry on receiving treatment in the community. A patient on a CTO needs to keep to particular conditions and can be recalled to hospital if there are concerns about them. A CTO lasts for up to six months and might be renewed.

If a relative is assessed for detention under the Mental Health Act an approved mental health practitioner will ask the nearest relative if they disagree with that decision.

Once somebody is admitted under the Mental Health Act they will be informed about their right to appeal. If this is requested a mental health review tribunal is arranged and the client is provided with a legal representative who specialises in the Mental Health Act. The panel is external to the hospital and has the authority to regrade a client to a voluntary status.

How do I get help in a crisis?

Part of the care plan will set out what should happen if the person you care for becomes unwell again.

Involving family members and carers in crisis planning is important as you are often the first to notice a problem. It is therefore important to think about how you might respond to a crisis before it happens. A crisis plan should also include information about what might increase the risk of a relapse i.e. stopping medication, or taking drugs, possible warning signs of a relapse, i.e. poor sleep or irritability, details of who will do what and contact information for support. The care coordinator will be able to talk to you about who should be contacted in a crisis and the type of support that you would prefer.

The crisis home treatment team is an extra service who can respond to psychiatric emergencies by providing intensive community based support. They aim to avoid hospital admissions being necessary or reduce the time somebody stays in hospital.

People who access our services are welcome to talk to the Team Manager if they are experiencing any problems with their care.