Introduction

This booklet is aimed at anyone involved in caring for a young person experiencing their first episode of psychosis. This booklet contains information about psychosis, how to relate to the person you are caring for, how long it might take for them to recover, information about the services STEP offer and information about how to take care of yourself.

What is psychosis?

Stressful life events and trauma can cause a range of mental health problems. Most people, at some stage in their life will experience a problem such as depression or anxiety. Another problem that some people may go through is psychosis.

Psychosis is a state where people have a heightened sensitivity to stimuli such as things we see, feel and touch, as well as events and thoughts, which can often make them feel overwhelmed. They also have difficulty working out what is real and not real, for example, confusing their own thoughts in their heads with what is happening in real life (a bit like a waking dream).

In psychosis a number of experiences or symptoms that happen together all create a loss of contact with reality. These may include:

- hearing voices
- having jumbled thoughts
- having frightening or unusual ideas
- having too little (or too much) energy

People may have any combination of these symptoms, not necessarily all of them. However, symptoms commonly involve
feeling unsure about what is real, changes in personality and changes in how the person views them self. These symptoms of psychosis may develop over weeks and months and can happen to anyone. It is most common for them to begin in people between the ages of 14 and 35.

Anyone can develop psychosis, regardless of age, culture or intelligence.

Approximately 3% of 14-35 year olds will develop psychosis and most people will recover fully from their first episode.

**Common symptoms of psychosis**

The most common experiences or symptoms of psychosis are:

**Delusions**

These are beliefs that the person feels to be true but others do not. When people hear voices or have other strange perceptions they often try to find an explanation for them. These odd beliefs are strongly held because they ‘make sense’ to the person, even though they may seem bizarre or illogical to others.

There are many different types of delusion.

- **Delusions of reference**: a belief that the behaviour and/or remarks of others on the street, on TV, radio, newspapers etc are meant for them.
- **Delusions of paranoia**: a belief that people are following or watching them or trying to harm or hurt them.
- **Experience of control**: a feeling or belief that they are under the control of an external force or power, e.g. aliens.
“Voices”

Also known as auditory hallucinations which are noises heard when there is nothing there. However, they seem real to the person. They often sound like a person or a group of people talking about the person or to the person. Sometimes people experience voices as coming from within their body.

“Voices” can be pleasant but are often nasty and may make the person distressed and uncomfortable.

“Voices” may be very loud and some people experience a number of different voices, sometimes all at the same time. This can make it very difficult for the person to concentrate or to focus on what you are saying to them.

A person experiencing a psychotic episode may also report other types of hallucinations, although these are not as common as voices. These can include:

- **Visual hallucinations**: the experience of seeing things that are not really there.
- **Tactile hallucinations**: the experience of being touched or touching something that does not exist.
- **Olfactory hallucinations**: the experience of smelling something that is not really there.
- **Gustatory hallucinations**: the experience of tasting something (often experienced as unpleasant) that is not really there.
Changes in thought

People with psychosis may experience a number of difficulties associated with their thoughts. The most common include:

- **Thought disorder:** problems with thinking, e.g. having trouble linking thoughts together.
- **Thought withdrawal or insertion:** a feeling or belief that their thoughts are either being taken away or put into their mind.
- **Thought reading:** a feeling or belief that other people can read their thoughts and know what they are thinking.
- **Thought broadcasting:** a feeling or belief that their thoughts are being broadcast out loud. This can often be very stressful leading to avoiding other people and not going out.

During a psychotic episode, people may also experience:

- A change in behaviour, e.g. becoming more isolated and withdrawn
- A loss of energy or drive
- A loss of interest and enjoyment
- A loss of emotions like not laughing at something they used to find funny
- Feeling “flat” e.g. feeling low and lacking emotion
- A reduction in their ability to concentrate or pay attention, such as being less able to read a newspaper or remember what they have watched on TV.

These last symptoms are often referred to as ‘negative symptoms’.
This list does not include everything – people can experience lots of other strange or peculiar feelings that are not mentioned here.

**Changes that you may have noticed**

You may have noticed some of these changes happening in the person you are caring for over the last few weeks or even months.

Often it is difficult to make sense of a loved one’s behaviour because they may not talk about how they are feeling or what they are experiencing. This can be frustrating and worrying.

It is useful to talk to others in the family (and the STEP care coordinator) about this and how these changes have affected you and other family members.

**Our thoughts and feelings**

It is common for people to ask: ‘Why and how did this happen? ‘Is it my fault?’ ‘Will he/she ever recover?’ and ‘Could it happen to others in the family?’

Our feelings are closely related to our thoughts and this is why you may be feeling worried, stressed, upset, gloomy or depressed. You may blame yourself or others for things which you did or did not do prior to the illness. You may feel awkward about talking to others about what has happened because you are not sure how they might respond.

It will be helpful for you to talk about your feelings and get some perspective on your worrying thoughts.

Besides having these feelings, when we are under stress our own physical health and behaviour can also be affected. Common changes you might experience include:
• Difficulty sleeping
• Difficulty concentrating
• Loss of appetite
• Crying
• Feeling like acting out of anger, e.g. hitting or yelling.

There are many reasons why we feel or react the way we do. Our reactions are determined by:

• Our personality
• Our relationship with those around us
• Our own way of coping with stress

It is reassuring to know that these reactions are normal responses to stressful situations and they don’t last forever.

Later in this booklet, we identify a number of ways in which you can help yourself cope and adapt to the changes happening around you while coming to a greater understanding of psychosis and how it might affect the person you are caring for.

Psychosis and Families

Being related to someone who is experiencing psychosis or any other mental illness can be confusing and scary. Many people begin to worry that, because someone in the family is affected, they or other family members might also become unwell. Just because one member of the family has developed psychosis it does not necessarily mean that others in the family will also become unwell.

As with many other health problems, a family history of psychosis will increase the risk that other family members might have
similar problems. The risk will be higher than if there was no family history but the degree to which the risk will be increased depends on the closeness of the blood relationship to the person affected:

- If there is no known family history, the risk of developing psychosis is 1%.
- If a grandparent, uncle or aunt has psychosis, the risk of developing psychosis is 3%.
- If a parent, brother or sister (including a non-identical twin) has psychosis, the risk increases to 10%.
- If an identical twin has psychosis, the risk is 50%.

It is important to note that while having a relative who has experienced psychosis is a risk factor for developing psychosis, a combination of a number of different risk factors are needed to go on to develop a psychosis.

As you can also see below, the likelihood of a family member NOT developing a psychosis far outweighs any risk of them having a psychosis:

**Probability that others in the family will NOT be affected:**

- Grandparent, uncle or aunt … 97% probability of NOT being affected.
- One parent, brother or sister…90% probability of NOT being affected.
- Non-identical twin…90% probability of NOT being affected.
- Identical twin … 50% probability of NOT being affected.
How do I help myself?

Learn as much as you can about the experiences of the person you are caring for.

You will be given information by the care coordinator of the person you are caring for, who is also available to talk to you about psychosis, your experiences and to answer any questions that you or the family may have.

You may also discuss with the care coordinator any difficulties you are having in adjusting or coping with the changes.

Learning about what is happening can minimise some of those difficult feelings. It helps us understand what is happening and helps us to feel we can cope a bit better.

If it is a relative that is affected, it may also be helpful to talk honestly and openly with your family about your feelings.

Talking about things can ease the burden we feel when we carry around all the things we are worrying about.

By talking, things become a bit clearer which helps us to cope and adjust.

Make sure you have support in place in case things become too much. Being able to ask for and accept help when needed is important for your wellbeing and the welfare of the person you are caring for.

Be honest with yourself and others about how much you are able to cope with at the moment. In the long run, this will prevent a lot of frustration and misunderstanding.
Where possible stay involved with your regular activities, sports and hobbies and keep in contact with your friends.

Remember that putting aside some time for yourself is important for your health and happiness.

Talking with others who have been through similar experiences can also be very helpful.

Carers Assessment

As a carer, you are entitled to an assessment of your caring, physical health and mental health needs. The STEP care coordinator will offer you a carer’s assessment during the initial care planning process. During the assessment the care coordinator will discuss your needs with you and can refer you to a Carers Assessment Worker (CAW). CAWs specialise in assessing the needs of carers and can work with you to identify any support you might need and how to access this.

Questions that you may have

Why does he/she say and do strange things?

When the person you are caring for is saying “weird” things or acting strangely, they are most likely to be experiencing hallucinations or delusions.

Hallucinations and delusions can be very disturbing and may cause the person to feel frightened or threatened. They may become angry, frustrated and upset or say things which seem strange and don’t make sense.

Many people also say that their thoughts become all jumbled up and are racing around in their head at a million miles an hour. Racing thoughts can cause speedy speech or mixed up
sentences. It can also make it hard to concentrate on what people are saying and how to answer.

This can be frustrating for everyone because it might be difficult to understand each other.

**What do I say or do?**

The important thing to do is to try and be patient and to keep calm. Repeat what you have just said if you need to.

Saying a person’s name in a friendly way can help to get their attention before you start talking.

Please ask the care co-ordinator if you would like to discuss matters further.

For relatives there is the option of meeting as a family to discuss the situation and ways forward. Please discuss this with the care co-ordinator.

**Why don’t they want to do the fun things they used to?**

There are many reasons why people experiencing psychosis might not want to do the activities they used to like doing.

They might:

**Feel tired:** because they are unwell and taking medication they might not feel up to doing too much. A bit like when we have the flu and take tablets to stop our nose from running, medication can make us feel sleepy.

**Find it hard to concentrate:** which makes it difficult to do things that normally would come quite easily to us.
Have fears or worries about certain things: e.g. going places where there are large numbers of people, like shopping centres.

It will help if you are aware of this so you don’t take it personally. Try to be encouraging and supportive and to be sensitive to how they may be feeling.

How do I know if I can trust him/her anymore?

Sometimes when someone is really unwell they may do or say things that hurt us, scares us or betrays our trust. This may be your experience.

You may find it helpful to talk to someone about what has happened. This person may be a friend, relative, parent, church member, counsellor, GP or the care coordinator.

It also helps to remind yourself that the person was probably very confused and unwell and didn’t have much control over what he/she was saying or doing at the time. They may not even remember doing these things or might be very embarrassed and feel very sorry for what they have done.

Try to be forgiving and maybe try talking to them about how you felt when they did those things. You might find this easier if you have the care coordinator or another relative with you when you do this.

He/she still uses drugs and every time this happens I can see how weird he/she acts. Can’t they understand that it makes them unwell?

It can be quite frustrating watching someone you care for do things which can be harmful to them. Unfortunately, telling them what to do doesn’t help much. What you can do though, is let
them know about your concerns and the differences you see in them when they use drugs.

You could encourage them to speak to their care coordinator about the impact that continuing to use drugs might have on their recovery from psychosis.

**I see how stressed out other family members get sometimes, how can I help them out?**

Talk to them about what you see and how you feel about it. Offer to help them out in some way – even if it is the simple gesture of taking time to listen and understand how they are. They will be very thankful.

Be sure you don’t over do it though because it is important you keep time for yourself to relax, do everyday chores, enjoy your hobbies and spend time with friends.

You need to make sure that you have enough time and energy to do these things as well. Being able to successfully care for yourself will make your care for others much easier and more effective.

**How long does recovery take? What can I expect to happen?**

Recovery times vary. Some people recover quickly, others may be slower. Most people who experience a psychosis for the first time can take up to 18 months to recover. During this time there will be a gradual but noticeable improvement.

It is common for people to experience some ‘left over’ symptoms throughout this time, e.g. they might hear voices occasionally or get nervous or worried when they go out in public.
Many young people also feel down or depressed as they come to terms with what has happened and begin thinking about their plans for the future. You can be supportive and helpful by:

- Being there to talk to
- Being positive
- Encouraging them to do things they are good at
- Giving them genuine compliments
- Being yourself and showing that you care

**How can STEP help?**

The STEP care coordinator will be able to offer advice to you and the person you are caring for. They work closely with clients and their families and can support recovery in a number of ways.

The care coordinator will be able to give you more information about the services below. Feel free to discuss these services with the care coordinator and ask any questions you might have.

**Family support**

When somebody experiences psychosis, we know it has an impact not only on that individual but also on the family. It can be difficult to understand and know how to help someone who is experiencing psychosis. It can also be very stressful living with someone who is experiencing new and sometimes frightening thoughts about themselves and others.

STEP care coordinators work closely with families and can support you to understand what is happening for the person you are caring for. We hope to involve the family in the care planning and review process and support you so that you do not feel stressed and know how best to support your loved one.
Family Service for Psychosis

Research shows us that people with psychosis are much less likely to have further episodes of psychosis when family members/supporters take part in family sessions.

The Family Service for Psychosis work with families in which someone has their first experience of psychosis. The STEP care coordinator can refer your family to the FSP if it is something the family would like and would benefit the person you are caring for.

Family and Friends Group

STEP runs psychoeducation groups for family members and friends of young people experiencing psychosis. The group is run by STEP workers and around six families will be invited to join each group. The group takes place over five sessions and aims to provide information about psychosis and mental health services, to support members in developing and sharing coping strategies, to help people with particular problems that families might be facing and for families to be able to support one another effectively.

The STEP care coordinator will be able to give you more information about these groups and when they are running.

**STEP will also support the person you are caring for in the following ways:**

Social Integration

Our support networks are important in keeping us well and helping recovery. Unfortunately, for some people, psychosis and other mental health problems can be associated with isolation, withdrawal and other social difficulties.
STEP workers aim to support social integration in a number of ways, for example, STEP runs a number of social activity groups which can be helpful for people who are isolated, have difficulties socialising or would just like an opportunity to spend time with others.

Accommodation and independent living skills

Some people experiencing psychosis can find that they have difficulties with managing their accommodation and with daily living skills. STEP care coordinators can support clients to retain current accommodation or find more appropriate accommodation if current accommodation is not suitable. We can also help clients to develop skills to allow them to live independently such as shopping, cleaning, budgeting and planning their days.

Finance and benefits

STEP care coordinators can support clients to ensure they are claiming any benefits they are entitled to in order to make sure they have enough money to live on and look after themselves.

Drug issues

Some people experiencing psychosis or other mental health problems say that they take drugs or drink alcohol to help them cope with symptoms. However, drugs and alcohol can make the symptoms of psychosis worse and make treatment less effective. STEP care coordinators work with individuals experiencing psychosis to encourage them to think about how drugs or alcohol could be impacting on their mental health. In some cases, individuals may require work around substance addiction and the care coordinator can discuss this with the individual and refer to the right services.
Medication management

For some people, one of the most effective treatments for psychosis is medication. STEP care coordinators may arrange for their clients to meet with a psychiatrist to discuss whether medication would be beneficial for them.

If you or the person you are caring for have any questions about medication, you can discuss this with the care coordinator or the psychiatrist, who will be able to advise you. STEP care coordinators also work with their clients to support them to take medication as prescribed and to monitor for any negative effects of the medication.

Coping with symptoms

The person you are caring for will be able to discuss their symptoms with their care coordinator, who will have experience of working with people who have had similar experiences. Care coordinators work with their clients to find strategies that help them to cope with their symptoms and identify any things which might be making symptoms more difficult to manage.

Relapse prevention

Many people who experience psychosis fully recover and only ever have one episode. However, some people may experience more than one episode. When a person who has recovered becomes unwell again this is known as a relapse. In many cases there will be warning signs that an individual is becoming unwell again, which means steps can be taken to prevent this.

Care coordinators work with individuals and their families to discover what these warning signs are and will support individuals to make a personalised action plan so everyone
knows what to do and who to contact if they notice any of these warning signs emerge.

**Employment Support**

The Employment Support Service work with people with mental health difficulties to protect existing employment or support individuals to find work once they begin their recovery. If the person you are caring for requires support around employment, the care coordinator will be able to refer to the Employment Support Service.

**Other Psychological interventions**

Psychological therapy (sometimes known as talking therapy) aims to help people make sense of their difficulties by understanding how their thoughts, feelings, behaviour and environment interact and influence each other. The STEP care coordinator can discuss psychological interventions with the person you are caring for and can make a referral if this is needed.

**Further information**

If you need more information about psychosis, you can ask the care coordinator. The following websites may also be helpful.

**Rethink**

The mental health charity Rethink has a section on their website dedicated to carers. This webpage contains further information about mental illness, as well as advice and other practical support on dealing with unusual thoughts and behaviour.

[www.rethink.org/living_with_mental_illness/caring/](http://www.rethink.org/living_with_mental_illness/caring/)
Mental Health Care

The website ‘Mentalhealthcare.org’ is designed for families and friends of people experiencing psychosis. The site contains helpful information and advice for carers, guidance on living with psychosis, as well as links to useful resources and websites.

www.mentalhealthcare.org.uk/support_for_carers

Carers Trust

Carers Trust is a new charity which was formed by the merger of The Princess Royal Trust for Carers and Crossroads Care in April 2012.

Carers Trust works to improve support, services and recognition for anyone living with the challenges of caring for a family member or friend who is ill, frail, disabled or has mental health or addiction problems. They provide information, advice and practical support to carers across the UK.

The Carer’s Trust website contains lots of useful information about caring for someone with mental health difficulties and has links to local carers support groups.

www.carers.org/help-directory/mental-health-conditions

Acknowledgements

This booklet used information from and was based on the Young People Early Psychosis Intervention (YPPI) centre’s booklet entitled ‘For brothers and sisters, information about psychosis’, edited by Deb Howe and written by Kristine Horn. It was adapted for use in the South Worcestershire Early Intervention Service by Caroline Maynard and Jo Smith. It was further developed by Oxleas NHS Foundation Trust.

This resource has been adapted for use within Somerset Partnership NHS Foundation Trust by Rebecca Nee and Frank Burbach.
This leaflet is available in other formats, including easy read summary versions and other languages upon request. If this would be helpful to you, please speak to a member of staff.

Date Issued: January 2014
Review Date: January 2016
Impact Assessed: January 2014
Author: Consultant Clinical Psychologist and Assistant Psychologist
Ref: SS STEP 002