

Acknowledgements

This booklet used information from and was based on the Young People Early Psychosis Intervention (YPEPI) 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.

This resource has been further adapted for use within Oxleas NHS Foundation Trust, with grateful thanks to South Worcestershire Early Intervention Service for their permission to use their booklet.

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Information about psychosis for brothers and sisters



Introduction

This booklet is for people whose sibling ie brother or sister has experienced or is experiencing an episode of psychosis. This booklet contains information about psychosis, information about how to help yourself, how to relate to your brother or sister, and how long it might take for them to recover.

What is psychosis?

Most people at some stage in their life will experience a problem with their mental health. Depression, anxiety and stress can happen to anyone. Another problem that some young people may go through is psychosis.

Psychosis is a word often used to explain a number of experiences or symptoms that happen together.

These may include:

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

Further information

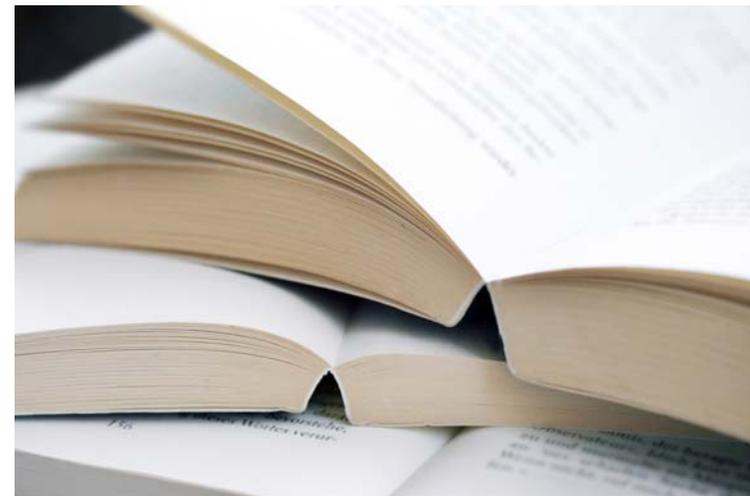
If you need more information about psychosis, you can ask your sibling's care coordinator.

The mental health charity Rethink has a section on their website dedicated to siblings. This webpage contains further information about mental illness, as well as an online forum where you can speak with other siblings.

Website: www.rethink.org/siblings

The charity Sibs has a generic website for siblings of people with an illness or disability. The website contains information sheets, a newsletter, sibling support, and training workshops for siblings.

Website: www.sibs.org.uk



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 your brother or sister will gradually improve.

It is common for people to experience some 'left over' symptoms throughout this time, eg they might hear voices occasionally or get nervous or worried when they go out in public.

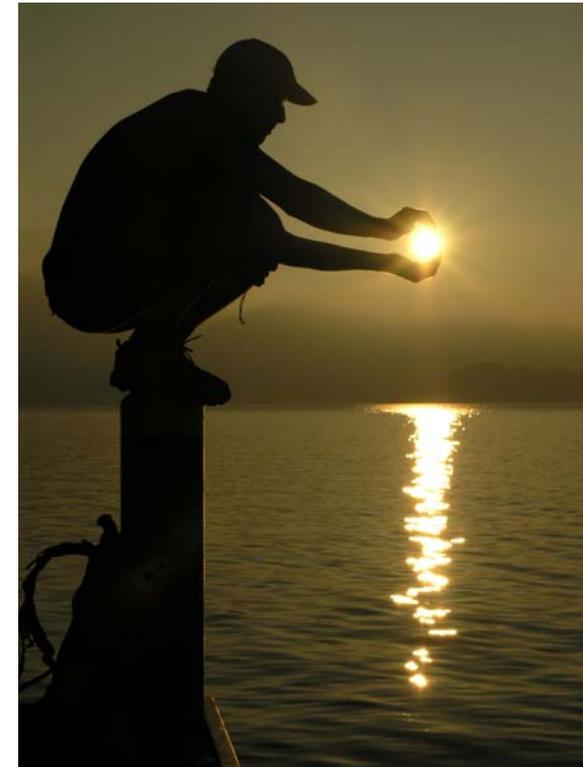
Many young people also feel down or depressed as they come to terms with what has happened and begin thinking about their plans for the future. You can be supportive and helpful by:

- **Being there to talk to**
- **Being positive**
- **Encouraging your brother or sister to do things they are good at**
- **Giving them genuine compliments**
- **Being yourself and showing that you care.**

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. It is an illness, which can be treated.

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. 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 you are under the control of an external force or power eg aliens.

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 about do things which can be harmful to them. Unfortunately, telling your brother or sister 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 mum and dad 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 by doing something really small like putting the rubbish out or going to the shops to buy bread and milk. They will be very thankful.

Be sure you don't over do it though because there are probably a lot of things you should already be doing like... homework, your regular chores, hobbies and spending time with your friends.

You need to make sure that you have enough time and energy to do these things as well. Your parents will feel less stressed if you are already doing what is expected of you.

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, teacher, church member, school counsellor, sports coach or the care coordinator.

It also helps to remind yourself that your brother or sister 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 your parent with you when you do this.

“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.
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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: eg 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.

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.

Oxleas has a series of fact sheets for families including 'Dealing with strange talks and beliefs', 'Dealing with inactivity and withdrawal' and 'Dealing with difficult behaviour' that contain further tips and advice on how to respond to someone with mental illness.

Please ask your sibling's care coordinator if you would like a copy of any of these fact sheets.



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, eg having trouble linking thoughts together.
- **Thought withdrawal or insertion:** a feeling or belief that your thoughts are either being taken away or put into your mind.
- **Thought reading:** a feeling of belief that other people can read your thoughts and know what you are thinking.
- **Thought broadcasting:** a feeling or belief that your 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, eg 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” eg 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.

Questions that you may have

How do I behave around them now, he/she says weird stuff and does strange things. Why?

When your brother or sister 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 your brother or sister 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.

You may feel more comfortable contacting groups yourself. If you are under 18, Bexley, Bromley and Greenwich all have a young carers' project that supports people affected by a family member's illness and disability.

Their contact details are:

Bexley Moorings:

Royal Park Primary School
Riverside Road, Sidcup, DA14 4PX
Tel: 020 8300 9742
www.bexleymoorings.co.uk

Carers Bromley:

28 Chislehurst Road
Orpington, BR6 0DG
Tel: 01689 898289
www.carersbromley.org.uk

Greenwich Carers Centre:

Suite 9
Gunnery House
Duke of Wellington Ave
Woolwich
London
SE18 6SW
Tel: 020 8301 8677/8678
Text: 07957 825 743
www.greenwichcarerscentre.org

Changes that I may have noticed

You may have noticed some of these changes, happening in your brother or sister over the last few weeks or even months.

It is useful to talk with your family and your sibling's care coordinator about these changes and how they have affected you and other family members.

Things have changed...But why do I feel like I do?

Change happens to us all the time. Some changes can bring us joy, happiness and excitement, like the birth of a baby or getting married. At other times, change may not be so welcome, like when someone close to us moves far away, or when someone becomes ill. These changes can cause us to have all kind of feelings and thoughts, which may not feel so good.

It is natural to experience these feelings in response to changes in our lives but sometimes it can seem a bit strange and even scary because we also feel different to our usual selves.

Our thoughts and feelings

It is common for people to ask: 'Why and how did this happen?' 'Will he/she become well again?' and 'Will this happen to me?'

Our feelings are closely related to our thoughts. 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.

You may feel sad and lonely because your parents seem to be spending a lot of time helping or worrying about your brother or sister.

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 eg hitting or yelling.**

Offer the amount of help that you feel most comfortable with.

Be honest with yourself, your parents 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.

Stay involved with your regular activities, sports and hobbies and keep in contact with your friends.

Avoid revolving your life around your brother or your sister. Your health and happiness are of equal importance.

Talk with others who have been through similar experiences.

The care coordinator may be able to link you up with other young people and support groups in your area.

How do I help myself?

Learn as much about your brother or sister's experience as you can.

You will be given information by your sibling's care coordinator, who is also available to talk to you about psychosis, your experiences and to answer any questions that you or your 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 not so good feelings. It helps us understand what is happening and helps us to feel we can cope a bit better.

Talk honestly and openly with your family about your feelings.

Encourage your family to do the same.

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.

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 your own brother or sister's illness.



What about me?

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 might be next. Being related to someone with a psychosis does not necessarily mean that you will also develop psychosis.

As with many other health problems, a family history of a 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 increase depends on the closeness of the blood relationship to the person affected:

- **If there is no known family history, your 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 a 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 you **NOT** developing a psychosis far outweighs any risk of you having a psychosis:

Probability that I will NOT be affected:

Grandparent, uncle or aunt ... 97% possibility that I will **NOT** be affected.

One parent, brother or sister...90% possibility that I will **NOT** be affected.

Non-identical twin...90% possibility that I will **NOT** be affected.

Identical twin ... 50% possibility that I will **NOT** be affected.