

What is Psychosis?

The Early Intervention in Psychosis Service

Patient Information Leaflet

Shining a light on the future



Who is this booklet for?

This booklet is for people who have been referred to the Early Intervention for Psychosis (EIP) service. This booklet gives you information about what psychosis is and what the service can do to help you recover. Take some time to read the booklet. If there is anything you don't understand or you would like to know more about please ask your care co-ordinator.

What is psychosis?

The word psychosis describes a state of mind where a person has thoughts and experiences that are out of touch with reality.

Psychosis is a mental health problem (like depression or anxiety), which causes distress because of the way it makes a person feel.

Everybody's experience of psychosis is different but there are some common symptoms. You may have experienced some of these:

- **Delusions:** Strong beliefs that you hold but other people around you do not share. These beliefs can often be about threats from other people; these are called paranoid or persecutory delusions. An example might be that you believe that a group of people are out to get you, e.g. drug dealers. Some people have beliefs that they are very important or have special powers.
- **Hallucinations:** Hearing, seeing, smelling, feeling or tasting something that is not there. Sometimes these experiences can be pleasant but sometimes they can be upsetting. For example you may hear a voice telling you that you are a bad person who has done terrible things.
- **Changed feelings:** Experiencing hallucinations and delusions is very distressing and you may feel very anxious and down because of these experiences.

Some people also find ...

- They feel 'flat' or don't really feel anything
- Their feelings change very quickly
- That they are out of step with how other people feel.
- **Confused thinking:** These experiences make it ...
 - Hard to concentrate or remember things
 - Hard to follow things people say or that you read
 - Hard to link thoughts together and make sense of things
- **Changed Behaviour:** These experiences can make you behave differently and your family and friends may notice this change. For example you might avoid seeing people because you believe you are in danger.

Dan's story...

Dan was 17 when his Mum took him to his GP. She was worried about him, since leaving school six months ago he had stopped going out with his friends or to his part time job. He spent all his time in his room listening to music and smoking cannabis.

Dan was very scared about going to the doctor. He didn't like going out of the house because he believed that a local drug dealer was trying to kill him, understandably this made him feel very anxious. He also heard voices telling him that people were after him because he was a bad person.

The GP asked him some questions about how he was thinking and feeling. He then made an appointment for Fiona, a care co-ordinator from the Early Intervention in Psychosis Team, to visit Dan and his Mum at home. Dan told her about what was happening. He told her that a white van was following him as people thought he was a drug dealer and the police wanted him killed. His Mum got upset when he said this, which made Dan feel angry and guilty.

Dan was worried, sometimes he thought that maybe the voices were not real, but if this was true then it meant he was mad and a "schizo" and would have to go and live in a mental hospital. This made him feel very scared. Mum said that she was worried about this too. Fiona told Dan that if people become very unwell they might go to hospital for a while but never to live. She said that her team tries to prevent people having to go to hospital.

What is the Early Intervention in Psychosis Service?

The Early Intervention in Psychosis service works with young people who experience an episode of psychosis.

Research has shown that if someone receives support and treatment quickly once they have experienced psychosis, then they are less likely to have further episodes of psychosis.

The support you receive from this service can help you recover from your psychotic episode. It can also help you reduce the impact of psychotic episodes you may experience in the future.

The service is made up of a team of professionals (including nurses, psychologists and psychiatrists) who have lots of experience in working with people with psychosis. You will meet someone from the team who will talk to you and your family about what you have been experiencing. This person is called a care co-ordinator.

Will everything I tell the team be confidential?

All the members of the team work to very strict rules on confidentiality and everything you tell the team will normally be kept confidential and will only be shared among the professionals working with you. The only exception to this would be if we felt there was a risk to you or to someone else. If that happened, we might have to share information with other agencies but we would talk to you about this. If you have any concerns at all about confidentiality please speak to your care co-ordinator or another member of the team.

How common is psychosis?

- Approximately one or two people in every hundred experience psychosis
- It is more common in young people

Are there any myths about psychosis?

Being told you have psychosis can be a very frightening experience. There are lots of myths about psychosis that are untrue and these myths can frighten people even more. It is important to remember that people with psychosis:

- **Do not 'have to live in hospital for their rest of their lives'**

For every hundred people who experience a psychotic episode:

- Twenty people will never experience another episode
- Sixty people will have more than one episode. They will be able to lead a normal life the rest of the time
- Twenty will find their psychotic experiences get in the way of them leading their lives. They will need support but this is usually in their own home, not in hospital.

- **Do not 'always become violent or dangerous'**

People who experience psychosis are not generally dangerous to others. 95% of all murders are committed by people who do **not** experience psychosis.

What causes psychosis?

The reason behind why a person develops psychosis is unique to each person. It is down to a combination of lots of factors, not just one. But, research shows that some things increase the risk of someone experiencing psychosis

These are:

A family history of psychosis

Research has found that having a close family member (a parent or a sister or brother) with psychosis makes the chance of you having psychosis higher. This points towards genetics being involved in psychosis. But genetics are not the whole story as

- Most people who develop psychosis do **not** have a close family member with psychosis.
- The chance of getting psychosis when you have an identical twin with psychosis (i.e. you both have exactly the same genes) is only one in two (50 per cent).

Stressful life events

Everybody experiences events in their life that are stressful. Some events are stressful because they are unpleasant or difficult. Things like a relationship ending, or parents divorcing. Some events are stressful even though they are positive: things like leaving home to start college, or starting a new relationship. We know that stressful life events often happen just before someone has a psychotic episode.

Some people experience traumatic events in their life where they have been harmed, such as physical, sexual or emotional abuse or assault. We know that people who have had these kinds of experiences have a higher chance of developing psychosis.

But again stressful life events are not the whole story, as they do not trigger a psychotic episode in everyone.

Drug use

Research has shown that taking recreational drugs such as cannabis and speed etc increases your risk of developing psychosis. We also know that taking drugs after an episode of psychosis increases your chances of having another episode.

Stress and vulnerability

Your care co-ordinator will talk to you about the stress-vulnerability model. This is a model that professionals use to explain the cause of psychosis.

The idea is that a combination of vulnerability and stress leads to psychosis. The model helps to explain why some people develop psychosis while others do not, even though they have had very similar experiences.

Everybody has his or her own level of vulnerability or proneness to developing psychosis. This level is set by things we have inherited from our parents through our genes, and by experiences we have had growing up.

We have seen that stressful life events very often happen to a person just before a psychotic episode.

Some people will have quite a high level of vulnerability and so only a small amount of stressful experience will lead to psychosis.

On the other hand, some people will have a low level of vulnerability but if they experience a massive amount of stress they will experience psychosis.

One way to think about this is to imagine a bucket of water. The bucket might be small so only a small amount of water is needed to make it overflow. On the other hand it might be large but pouring in lots of water will make it overflow.

Everybody has their own unique stress and vulnerability model. Take some time to think about your own stress and vulnerability factors. This can help you understand more about your experience of psychosis and help you prevent future episodes by learning what your stressors are. Your care co-ordinator can help you to do this.

Susan's story...

Susan is 29 and a graphic designer last year she was under a lot of pressure at work. She and a colleague had started their own business and they were working really hard to make it successful.

Susan started to think people were watching her. She thought that she was in some kind of experiment and psychologists were soon going to reveal all they had learnt from watching her. She did not tell Chris, her husband, or anyone else as she thought it would sound 'mad'. Being watched felt a bit strange, but she also felt quite powerful and energised. She found she had the energy to work hard but also to socialise with friends most nights of the week.

One day Susan was travelling to work and she heard a male voice telling her she was 'an amazing person'. At first she found it hard to believe that no one else could hear it, but she had asked Chris and he said he couldn't. She continued to hear the voice more and more, and it began to interfere with her day. After six months the voice started to change, there was a female voice as well and the two voices talked about her as if she wasn't there. She began to feel frightened and stopped leaving the house. Chris was really worried about her and persuaded her to go to the doctors. It was difficult to get the doctor to understand the problem and she was glad that Chris was there to help.

The doctor referred her to the Early Intervention in Psychosis Service. They could understand the difficulties she was experiencing and help her understand them too. Susan started to feel less anxious and agreed to take some medication. Susan became more confident about going out and negotiated a return to work with her colleague. She worked hard with her care co-ordinator on understanding the causes of her breakdown and the early warning signs. She developed a relapse prevention plan to try to ensure she did not have a further relapse.

We hope this leaflet has helped you understand more about psychosis. If there is anything you don't understand or would like to know more about then please ask your care co-ordinator.

Where can I get help and more information?

If you or your family member with psychosis has a care co-ordinator then they should be able to provide you with further information.

If you, or your family member with psychosis, do not have a care co-ordinator then you could talk to your GP or ask them about your local EIP service.

This leaflet has been put together by Early Intervention in Psychosis services in the North East. Other leaflets you might find helpful are:

- Information for friends and families
- Psychosis: Support and Recovery

Some of these websites or helplines may also be useful

National Organisations

- **Am I Normal?**
www.aminormal.org Provides helpful information about psychosis
- **Hearing Voices Network**
www.hearing-voices.org Provides info about self-help groups for people who hear voices.
- **Rethink**
Advice line: 0300 500 0927 (Mon-Fri 10am - 2pm).
www.rethink.org Provides info on support groups and other services.
- **Eppic**
www.eppic.org.au Australian website that provides information on psychosis
- **Young Minds**
www.youngminds.org.uk/for_children_young_people/whats_worrying_you/psychosis
Provides information on psychosis specifically for young people.

What if I have a comment, suggestion, compliment or complaint about the service?

If you want to make a comment, suggestion, compliment or complaint you can:

- talk to the people directly involved in your care
- ask a member of staff for a feedback form, or complete a form on the Trust website www.ntw.nhs.uk (click on the 'Contact Us' tab)
- telephone the Complaints Department Tel: 0191 245 6672
- We are always looking at ways to improve services. Your feedback allows us to monitor the quality of our services and act upon issues that you bring to our attention.
 - **Points of You** - available on wards or from staff. Some areas of the Trust have electronic feedback touch screens, staff can help you to use these.
 - **Friends and Family Test** - available from staff or online at www.ntw.nhs.uk/fft

References

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- Schizophrenia: early warning signs. *Advances in Psychiatric Treatment* (2000), vol. 6, pp. 93-101. Birchwood et al.
- CG 178: Psychosis and Schizophrenia in adults: treatment and management. NICE guidelines, 2014.



Further information about the content, reference sources or production of this leaflet can be obtained from the Patient Information Centre.

This information can be made available in a range of formats on request (eg Braille, audio, larger print, easy read, BSL or other languages). Please contact the Patient Information Centre Tel: 0191 223 2545

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