

Psychosis: Support and Recovery

The Early Intervention in Psychosis Service

Patient Information Leaflet

Shining a light on the future



Introduction

This leaflet tells you about ways to recover from your first episode of psychosis and how to reduce the chances of it happening again. It suggests ways that may help you to cope and offers guidance on how you can find help.

What helps people to recover from a psychotic episode?

Research shows that there are four main things that you can do to help you recover from your first episode of psychosis and reduce the chances of it happening again.

These are:

- Understanding your experience of psychosis
- Taking medication
- Coping with psychotic symptoms
- Having a satisfying life

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 Dan 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 service, to visit Dan and his Mum at home. Dan told Fiona what he thought was happening. He told her that a white van was following him as people thought he was a drug dealer and the police wanted to kill him. 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 'schizo' so he 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 then they might have to go into hospital for a while, but never to live. She said that the Early Intervention Service tries to prevent people having to go to hospital.

Understanding your experience of psychosis

Research shows that people who look back on their psychotic episode and think about the things that led up to it are less likely to have another episode.

Understanding what happened can give you control over your psychosis. It can help you to understand what does and what doesn't help you to feel well.

This is called a formulation. Your care co-ordinator or the team psychologist can help you to do this. There are three parts to it:

- Your stress-vulnerability factors
- What makes you feel worse and keeps the problem going e.g. taking drugs; stressful relationships
- What helps you to feel better e.g. exercise; talking to friends; going to college

Together Dan and Fiona developed a formulation or an understanding of why Dan became unwell.

Vulnerability factors:

- Dan's grandfather had experienced psychosis
- Dan's father had left the family when he was eleven years old, Dan did not see his Dad; as a child he believed that his Dad leaving was his fault.

Stress factors:

- Leaving school and looking for a job
- Relationship with girlfriend had ended
- Smoking lots of cannabis

What makes things worse:

- Smoking cannabis – though this makes Dan feel calmer at the time he also finds it makes him feel more paranoid
- Staying in room all day thinking about beliefs

What helps:

- Talking about things
- Exercise – Dan enjoys going to the gym
- Taking medication

Why should I take medication?

Research shows that taking medication helps reduce psychotic symptoms like voices and delusions. There is also some evidence that it may also prevent those symptoms from coming back.

What medication will I take?

The team psychiatrist will talk with you about the medication he or she will prescribe for you. The medication that we use is called anti-psychotic or neuroleptic medication. There are lots of different anti-psychotic medications. What medication your psychiatrist will prescribe depends on two things:

- How much the medication helps reduce your symptoms.
- How much the medication gives you unwanted side effects.

The most common side effect is weight gain.

Everyone is different so the type and amount of medication that will help will be different for different people.

The psychiatrist will work with you to find out what is the best type and amount for you. You have a right to be involved in the decision about what medication you take, so please ask the psychiatrist about anything you don't understand or want to change about your medication.

For how long will I have to take medication?

Some people worry that having psychosis means they will have to take medication forever. This is not the case; the government guidelines say that you should take medication for one to two years after a psychotic episode. If you do not have another psychotic episode in this time then you can stop taking the medication.

But you should never stop taking your medication all at once. You should stop gradually and with the support of your psychiatrist and the team.

Can the authorities make me go into hospital and take medication?

We aim to work in partnership with you, so your views about what treatment and support you find helpful are very important.

Occasionally, the professionals may decide that someone who has psychosis is so unwell that they must have treatment, even if they say they don't want to take medication. This usually means they have to go into hospital for a period of time. This legal process is called a section, because the person is detained under a section of the Mental Health Act. It only happens when someone is so unwell that they are a risk to themselves and others, and all the professionals agree that they have to be admitted to hospital for treatment. This only happens as a last resort. Before this happens the EIP team tries to work closely with the person and their family to help them stay at home. If hospital is necessary then the EIP team will try and support the person to go into hospital voluntarily.

Coping with psychotic symptoms

Medication can help reduce psychotic symptoms. Some people still experience symptoms but they can learn strategies to help them cope with these. Some of these strategies are listed below. Your care co-ordinator can help you learn to use these.

Voices

- Remembering that the voices are not real and cannot harm you
- Understanding why you are experiencing the voices from your formulation
- Distracting yourself with other activities

Beliefs

- Taking time to examine the evidence for your beliefs
- Understanding why you are experiencing these beliefs
- Making sure you continue with your normal life – avoiding things will only help you to confirm your beliefs

The voice Dan heard was his Dad's. Sometimes the voice would come back when he was feeling stressed. At these times Dan reminded himself that it was not real but happened because of the feelings he had about his Dad. If the voice got really bad then Dan would listen to music for a while until it went away.

When Dan was outside he would sometimes get very anxious and worried as something would happen which made him think that he had been right and people were after him.

Here is an example:

- **Situation:** Walking to college, see three white vans in traffic
- **Thought:** The three vans belong to the drug dealer; they are all out looking for me

When this happened Dan took some time to examine the evidence. What other explanations could there be for this?

- White is a common colour for vans so bound to be a lot of them about.
- It's rush hour so a lot of traffic so likely to be a lot of white vans.
- I had a late night last night as went to pub after college. When I haven't had much sleep I feel more anxious, so more likely to have paranoid thoughts.

Having a satisfying life

We all need things in our life that make us feel okay. These include:

- A safe and secure place to live
- Enough money to be able to live
- A job or training that is enjoyable and rewarding
- Interests which are enjoyable
- Supportive relationships with family and friends

This is no different for people with psychosis. For some people who experience psychosis having these things becomes difficult. This is because having delusions and hearing voices can interfere with normal life.

Examples of how this can happen are:

- Believing that someone is out to get you would mean you were nervous about going outside and talking to people. This could mean you stopped going to work and lost your job.
- Family and friends can be very concerned about the changes to a person when they are experiencing psychosis. They can find it difficult to understand what you are experiencing. This can make you feel very alone.

Research has shown that people who have satisfying lives are less likely to have another psychotic episode.

The EIP service can help you to make your life satisfying. Some examples of this are:

- Helping you get back to work or to start some training
- Helping you find a flat to live
- Helping you to talk to your family about what you are experiencing so they can support you

Everybody's own idea of a satisfying life is different and there is no right way for everybody – it's what works for you.

Dan and Mum often argued which made them both feel angry and upset. Fiona helped them to talk to each other about how they were feeling. Dan's mum found she got less annoyed with him now that she knew the reasons behind his behaviour.

Dan had left school but not been able to find a job. He had enjoyed computer studies at school but did not have any qualifications. Fiona helped him enrol on a part time computing course at college. This made Dan feel better about himself and more hopeful about the future. Being busy distracted him from thinking about his beliefs. Going to the college made him feel very anxious at first, but this had got better as time went on. Going to college and feeling safe helped Dan to find evidence against the belief that people were out to harm him.

Preventing relapse

Having another episode of psychosis is called a relapse.

Before psychotic symptoms come back there can be early warning signs that psychotic symptoms are back again.

Examples of these are:

- Feeling anxious
- Feeling low
- Feeling confused
- Racing thoughts
- Finding it hard to sleep
- Finding it hard to get on with normal life

Recognising and working on early warning signs can help to prevent psychosis returning. Your care co-ordinator will help you work out what your early warning signs are. They will also help you make a relapse plan. This is a plan of what to do if you have some early warning signs of psychosis.

We hope that you have found the information in these leaflets helpful. If there is anything you don't understand or want to know anything about then please ask your 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 team working with you. We will also ask you whether you want to receive copies of any letters that we write to the professionals involved in your care.

The only circumstance in which we might have to share information beyond this, is 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.

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:

- What is Psychosis?
- Information for friends and families

Some of these websites or helplines may also be useful

- **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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