

Information for friends and families

The Early Intervention in Psychosis Service

Information leaflet

Shining a light on the future



Who is this leaflet for?

This leaflet is for family members, friends or anyone who is worried about someone with psychosis. It can be very upsetting and confusing when you care for or know someone with psychosis. This leaflet is designed to offer some basic helpful information and advice. You may want to know more, so contact details of some local services are provided at the end.

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:

- Delusions: strong or unusual beliefs that others do not share.
- Hallucinations: hearing, seeing, smelling or tasting something that is not there.
- Confused thinking: these experiences make it hard for a person to concentrate, and for them to make sense of things. Sometimes it is hard to make sense of the things that people with psychosis say.

Things you can do to help

Get the most out of the services involved

You have probably been given this leaflet by someone from an Early Intervention in Psychosis service. They are here to help and support the person with psychosis. But they also work closely with families and carers. They can provide you with all sorts of practical support and advice. They can give you all sorts of helpful information about psychosis.

You can give them a ring if you have any difficulties or need some help or advice. They can also put you in contact with other groups and organisations that may be able to help.

Psychosis is different for everyone. It can be really helpful to understand the things that led up to your friend or relative's psychosis. This can help you understand what helps and what doesn't help them to feel well. Their care coordinator at the Early Intervention Service should be able to help with this.

Here are some general tips on things that you can do to help:

How to manage if the person with psychosis hears voices

For the person with psychosis, hearing and seeing things that are not there feels very real and often very upsetting. If you can learn to recognise and accept this, this can be very supportive for someone with psychosis. They often feel that they have no control over these experiences, so it's not helpful to try to force them to stop having them. They may find it helpful to talk about their experiences.

How to manage if the person with psychosis starts doing less and less

Often people with psychosis sleep more or start to do less and less. It can be helpful to offer to talk to them about this. This may help you understand what they are avoiding and why. It may also help to ask them what would be helpful and let them know that you're there if needed. It isn't always helpful to avoid them or to try to force them up and out. Gently encouraging them to start undemanding activities may be a good start and supporting them in this. It is difficult to try to remain patient as this can take time.

How to manage if the person with psychosis starts having strange ideas

People with psychosis often say or believe strange things. It can be difficult knowing how to react to this. Talking together can be helpful. Sometimes this can turn into an argument with the person, which often doesn't change their ideas. It can be helpful to acknowledge that you know that these seem real to them, but that you do not think it is real. Also, it can be supportive if you can show some understanding about how they feel. Some of their ideas may be very disturbing to them, and it can be very frustrating believing something that others do not.

Remember that recovery can take time

Recovery from a psychosis can be quick, but can take longer. This can be frustrating for someone who cares, but it is important to bear this in mind when trying to help. It is difficult, but try to gently encourage and support the person with psychosis in making small gradual steps to recovery.

Looking after yourself

Helping someone with a psychosis can be challenging and stressful at times, and can affect your mental health. So it is important to look after yourself. This is something that you can do on a day to day basis, not just when things are difficult or when you're feeling stressed. Here are some things that may help:

Talk to someone

Talking to someone you know and trust about how you're feeling can be a huge relief. Even if you're not feeling stressed, talking to someone regularly is more helpful than keeping it all in. This may be a friend or family member. However, sometimes you may feel that your friends and relatives don't understand what you're going through. It may be helpful talking to someone from your local Early Intervention in Psychosis service.

It may not feel like it, but there are probably many people in a similar situation to yourself. You may find local support groups more understanding. The Early Intervention in Psychosis service should be able to tell you what's around locally, and there are some helplines listed at the end of this leaflet.

Take time out

Make sure that you give yourself some time out, away from the person with a psychosis. Professionals may be able to help with this by offering practical support or respite.

Do things that you enjoy

Most people are happier when they do more things that they enjoy! This seems obvious, but it's an important point. Many of us don't do as many things as we like. This is for lots of reasons, for example, that we're too busy. It can be difficult, but try to get into a pattern of doing things you enjoy each week.

Try to live a healthy lifestyle

To feel well mentally, you need to take care of yourself physically. This can be difficult when you live a busy life, but sometimes a small change can make a big difference to how you feel, such as getting a good night's sleep or taking a little exercise.

Be realistic about what you can manage

It's very important to realise that you can't do everything. None of us can! Be realistic about what you can do, and try not to take on too much.

Remind yourself of the things that you are doing well

It can be difficult trying to care for or help someone with a psychosis. It's no reflection on you if you're finding things hard - most friends and family find it stressful and confusing at times. If you're finding it difficult, remind yourself that it can be a tough situation. Try to remind yourself of the things that you are doing well. Sometimes it's easy to forget that you're doing simple but important things that are really helping.

Nicola's story...

When John was 22, he was sacked from his job as a labourer for always being late. He lived with his mum, Nicola, and his younger sister, Amy, who was 15. John knew all his mates through work, so when he was sacked he lost contact with them. He began sleeping all day and watching TV through the night.

Nicola was really worried as this had gone on for months now and was getting worse. John started eating only tinned food and drinking cans of pop. He said that he didn't trust anyone to make his food as it could be poisoned. When Nicola had tried talking to John about it, this just made him angry and he would lock himself in his room. Also, Nicola was finding it difficult to understand what John was saying. Sometimes he talked about aliens which didn't make sense to her at all.

Nicola was upset and confused about what was happening to John. She wondered if it was her fault, and she felt guilty a lot of the time. She stayed in all the time to make sure John was alright, and she saw her friends less and less. She was also worried about the effect that this was having on Amy. Nicola didn't know who to turn to. She was too embarrassed to talk to her friends about it, and her own mum had never been very supportive or understanding. Understandably, Nicola felt all alone, and became really stressed and depressed. Eventually, she went to her GP, who arranged for them to meet with, Sarah, a care coordinator from the Early Intervention in Psychosis Service.

John did not want to speak to anyone, including Sarah. But little by little he learnt to trust Sarah and they talked each week. Sarah helped John understand what was happening and helped him get out and about a bit. He started eating some of his mum's food and sleeping a bit better at night.

Nicola was upset when she met Sarah and felt that she should be able to cope on her own. She was worried that Sarah was going to think that she was a bad mother. Sarah explained that all these worries were normal and that Nicola was coping really well under very difficult circumstances. Nicola was relieved to finally talk to someone about John. Over the next few months, Sarah gave Nicola some information about psychosis and practical advice on how best to help John. Twice a week, Sarah also went out with John, which gave Nicola the chance to get a break from looking after him all the time.

Sarah offered Nicola some appointments to talk to someone at the service about her own feelings of stress and depression. Nicola did not want this, which was fine. With encouragement and support from Sarah, Nicola met with her closest friend, and told her what she had been going through. Nicola was surprised that her friend was so understanding and how much better she felt for talking to her. They now meet each week for a drink.

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?
- Psychosis: Support and Recovery

Some of these websites or helplines may be helpful

National organisations about psychosis

- **Am I Normal?**
www.aminormal.org
Provides helpful information about psychosis
- **Hearing Voices Network**
www.hearing-voices.org
Provides information about self-help groups for people who hear voices
- **Rethink**
Advice line: 0300 500 0927 (Monday - Friday 10am - 2pm)
www.rethink.org
Provides information on support groups and other services
- **Eppic**
www.eppic.org.au
Australian website that provides information on psychosis

National organisations for carers

- **Carers UK**
Tel: 020 7378 4999 Advice line: 0808 808 7777 (Monday - Friday, 10am - 4pm)
Email: advice@carersuk.org
www.carersuk.org
Provides information on government services for carers.
- **Young Minds Parent Helpline**
Tel: 0808 802 5544 (Monday - Friday, 9.30am - 4pm)
www.youngminds.org.uk
Free, confidential online and telephone support, including information and advice, to any adult worried about the emotional problems, behaviour or mental health of a child or young person up to the age of 25.

Local organisations

- **Carers Counselling Service**
Mental Health Matters, Boldon Lane Clinic, South Shields, Tyne and Wear, NE34 0NB
Tel: 07749 182 648
Provides confidential emotional support.

- **Sunderland Carers Centre**
Thompson Park, Thompson Road, Sunderland, SR5 1SF
Tel: 0191 549 3768
www.sunderlandcarers.co.uk
Offers a confidential advice, information and support service to carers throughout Sunderland.
- **Carers Association South Tyneside**
1 Beach Road, South Shields, Tyne and Wear, NE33 2QA
Tel: 0191 454 3346 Email: castadultteam@yahoo.co.uk
www.stcarers.org.uk
Offers support, activities and information to carers. They also run a Young Carers Project.
- **Gateshead Carers Association**
John Haswell House, Gladstone Terrace, Gateshead, Tyne and Wear NE8 4DY
Tel: 0191 490 0121
E-mail: enquiries@gatesheadcarers.com
www.gatesheadcarers.com
Offers confidential support, advocacy and information.

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



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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