



**UNDERSTANDING
PEOPLE'S
PSYCHOTIC EXPERIENCES**

**A brief guide for family and friends
from the INSIGHT team**

WHAT IS A PSYCHOTIC EXPERIENCE?

Our physical and mental health changes over time. Sometimes we experience illness or unusual events which upsets our usual pattern of well-being. We often find it much more easy to accept physical illness than mental illness, both in ourselves and in others. Physically we sometimes feel tired, uncomfortable or generally below par and it is not always easy to tell when this is a result of an illness. Similarly, mental health and illness shade into each other and it is not always easy to know which experiences are the outcome of an illness.

It is a part of our normal lives to experience extremes of emotion, (such as joy, anxiety or fear), to sometimes act irrationally or to build fantasy elements into our everyday thoughts and actions. It is normal to sometimes act very impulsively, to feel enormous like or dislike for people or on occasion to react aggressively to perceived threats or criticism. For some people the balance in some of these areas sometimes begins to go way outside their control or they begin to experience a different reality than others around them. The words '**psychotic experience**' simply offer a general description for when that happens. Problems arising may include hearing voices or other hallucinations, holding very unusual beliefs (**delusions**), difficulties in thinking clearly, not realising there is anything wrong with oneself and experiencing very strong fluctuations in mood.

In everyday language it is likely that you have heard the word 'psychotic' to mean something like 'really mad'. In psychological language it emphasizes a condition in which a person is not in contact with the same reality as most people. Healthy, well-functioning individuals sometimes have psychotic experiences. For example, 10 to 15 per cent of the population have heard voices or experienced hallucinations at some point in their life. Some people accept and accommodate to such unusual events. However, many people find psychotic experiences frightening or in other ways distressing. Others may not recognise

the effects of their resulting changed behaviour upon family, friends or the wider world. Psychotic experiences can become a serious mental illness such as **schizophrenia** which may call for a wide range of help and support services to be offered.

HOW COMMON ARE THESE EXPERIENCES?

In the UK today about two people in a hundred are likely to receive a diagnosis of a serious mental illness involving psychotic experiences at some point in their lifetime. Some people are seen to be more vulnerable than others when trying to cope with extreme stress in their lives. However, almost anyone could have psychotic experiences in when facing powerful and extreme distress.

DO PEOPLE RECOVER?

The course and outcome of psychotic experiences for any individual remain unpredictable. Some people who have a psychotic experience do so only once throughout their whole life. This is called a '**single episode**'. Other people may have similar experiences again and again (**recurring episodes**). Less than 25 per cent are permanently affected. Most people might reasonably hope to recover either completely or partially after a psychotic episode.

Many individuals who continue to have psychotic experiences still manage to sustain a high quality of life. Some people who have had long-term psychotic experiences have problems looking after themselves or getting on well with other people. Most professionals working with people who have psychotic experiences think that early intervention and helping them to avoid it happening again (**relapse prevention**) mean much better long term outcomes.

PEOPLE AND PSYCHOTIC EXPERIENCES

Adolescence and young adulthood is a time of life marked by change and conflicts. Between the ages of 14 and 35 people face many uncertainties, pressures and high and low points. They may have feelings of being totally at one with those of their own age or at other times being completely isolated from them. These are normal features of the change from childhood to adulthood. Similarly, in the move towards more independence from parents, other adults or previous friends, people at this stage may appear often challenging, self-centred, moody and to swing from elation to self-doubt at great speed. Again, these are normal patterns of feelings and behaviour.

Some individuals are more vulnerable than others to the stresses arising during this period of change, especially if there are other factors which trigger or exaggerate further levels of distress for them. This might include, for example, bereavement, examinations, separation of parents, homelessness, the use or withdrawal of alcohol and/or drugs, or being the victim of abuse.

It is possible that family members and many professionals shrug off the difficulties that a person is having as being normal, even when their behaviour becomes extreme or bizarre. Some people still see mental illness as something to be afraid of or ashamed about. This may prevent family and friends wanting to recognize that something is happening beyond the normal patterns of turmoil in the life of an adolescent or young adult. For the people involved, a psychotic experience is a severe and lasting shock (**trauma**) to their changing and maturing identity. It may challenge their sense of progress and development or their sense of control over their transition to adulthood. This may rapidly affect their relationships with their family, friends and educational, recreational or employment settings. On the positive side, with appropriate early help and support,

especially after a **first episode psychotic experience**, many people are usually very adaptable. They can learn a set of strategies to avoid developing a long-term sense of being permanently restricted by a mental illness (to avoid a sick-self image). Early intervention services help the person develop self-management strategies and to build on the idea of a being a normal person who may have some unusual experiences, rather than an unusual person who cannot cope with everyday life

WHAT KIND OF THINGS DO PEOPLE DO AS A RESULT OF PSYCHOTIC EXPERIENCES?

Psychotic experiences can affect nearly every aspect of an individual's life. The person may respond or behave differently than expected by those who know them well. He or she may not really mean to be deliberately awkward or challenging. Their different behaviour may reflect the psychotic experience they are having. Some of the practical problems which arise may include: -

- ◆ Withdrawal from others or difficulties in talking to them. This is because they are preoccupied with trying to cope with unusual perceptions or feelings – or being afraid to talk to them about those perceptions or feelings. This can lead to troubled relationships with friends and family.
- ◆ Increased difficulties at school, college, university or work. The person may not be able to concentrate on one thought for very long and may be easily distracted and unable to focus their attention
- ◆ Increased difficulties taking decisions, dealing with problems or relating to people due to jumbled and unclear thinking. This may show in their speech, perhaps changing from topic to topic or showing a lack of logical connections between one part of a sentence and

another. This can make a conversation very difficult to maintain, and may lead to them to feel or to be isolated. This is simply because others can feel uncomfortable and end up avoiding the person.

- ◆ Lack of interest in leisure activities.
- ◆ Patterns of eating, sleeping and hygiene changing
- ◆ radically.
- ◆ Attaching great significance to everyday events. Examples of this may be a mistaken belief that television programmes or other conversations are about them and their personal life.

As explained earlier, some or all of these may be part of normal adolescence or early adult life. Most parents will have seen some of these things happening as their children approach adulthood. The difference is to do with how severe and frequent some or all of these things are and how far they are outside the persons control.

SO, WHAT CAN BE DONE TO HELP?

Prompt assessment and a comprehensive range of interventions at the stage when a person first has a psychotic experience will seek to:

- ◆ identify and address their current needs
- ◆ reduce pressures in their lives
- ◆ provide appropriate and minimal medication when necessary
- ◆ develop self-awareness strategies which can help to avoid or reduce the effects of further psychotic experiences.

The intensity and duration of support and treatment offered will reflect the needs of the person, their family and the stage of their illness.

WHAT KIND OF SUPPORT DOES INSIGHT OFFER?

The INSIGHT team at The Zone seeks to work in close partnership with:

- ◆ the person having psychotic experiences
- ◆ family and friends trying to understand and support that person
- ◆ all the other support teams within The Zone
- ◆ many other support agencies

Our service always looks at the whole person. We see all parts of their life as being important for their health and well-being. We work on psychological, social, physical and practical aspects of care. We try build realistic strategies with everyone concerned to anticipate and avoid a crisis arising rather than having to deal with it after the event. Our team of care co-ordinators, psychiatrists, psychologists and other staff work in a flexible way to engage the person and to take their views seriously.

Our work with people includes:

- ◆ individual discussion and counselling
- ◆ information, advice and help on housing, employment, benefits, education etc.
- ◆ Group work to help with social interaction
- ◆ supported individual and group activities in the community
- ◆ a focus on learning how to:
 - ☺ understand psychotic experiences
 - ☺ develop strategies to avoid their recurrence
 - ☺ share understanding with other people
 - ☺ access other support services
 - ☺ build self-awareness and problem solving strategies
- ◆ individual or group therapeutic approaches which build on people's strengths and promote a positive self-image
- ◆ the right kind of prescribed medication if necessary

Families and friends need to know that they are not alone in having to deal with the person. We see them as part of the team of carers for the person and work to support them in their understanding of all that is happening. We will develop parent support networks for those parents who wish to be in touch with other parents in a similar position.

We provide a 24 hour phone support service for our registered service users and their families.

The INSIGHT team has members from many professions working together. We see this to be a strength in our work with people. Being part of the broader Youth Enquiry Service means we are well placed in a setting which people in and around Plymouth see as easy to walk into and not to feel at all 'odd' compared to others. If you would like more details about the INSIGHT team please ask for the separate leaflet.

DOES MEDICATION LEAD TO PEOPLE LOSING CONTROL OF THEIR LIVES?

It is important to understand that medication to control psychotic experiences (**antipsychotic**) is only one part of the kind of interventions described above.

Minimal doses of antipsychotic medication are used to control what is happening in particular areas of the brain. This reduces the distress that the person feels when they are experiencing such things as:

- ◆ extreme changes in their perceptions and feelings
- ◆ a changed sense of control over events and people in their lives

A doctor skilled in understanding the effects of such medication (a **psychiatrist**) will carefully choose what he or she thinks is the appropriate type of medication, how much needs to be taken

(**dosage**) and how often. The psychiatrist will also closely monitor the effects of the medication over time and in consultation with the person and the family GP consider any side effects which may arise and when any change in medication becomes advisable. Good practice in prescribing such medication seeks to reduce the distress arising from psychotic experience while allowing the person to think, feel and act as normally as possible.

WHAT CAN FAMILY AND FRIENDS DO TO HELP?

A psychotic experience is often frightening, confusing and distressing both for the person concerned and their family and friends. It is helpful to learn what to expect and what to do. Each individual's ways of coping with the experience will be different. However, most people in this situation are likely to feel confused, afraid and lacking in self confidence. They can feel overwhelmed by the world around them and experience loss of control over their thoughts and feelings.

Research indicates that acceptance and support from family and friends is crucial in aiding recovery. This can be an extremely challenging time for family and friends and it is often difficult to accept what appears as irrational, insensitive, hurtful or simply self-centred behaviour on the part of the person.

We would like to offer some practical suggestions that we think will be helpful to you. **We recognise that some of these may feel impossible to achieve in the short term.** We will be happy to talk through with you some of the practical steps you could take to follow the suggestions. They are:

- ◆ Try not to blame yourself for what is happening to your son or daughter. Many parents feel a mixture of guilt and self-blame – not just for their child's illness but in thinking that by seeking help they are somehow giving away control of their children's lives to 'others'.
- ◆ Other parents who have been in your situation say '*Ask for help as soon as possible*'. Accepting the need for some medication as part of an early package of help can be a positive move.
- ◆ When you talk to doctors or others, don't be afraid about explaining what is happening to your son or daughter.
- ◆ Mental illness is nothing to be ashamed about. Avoid trying to keep it a secret or not telling other people in your family, friends or at work.
- ◆ Remember that your child is the person behind the illness, even though some of his/her behaviours may upset you greatly.
- ◆ Try to live family life around the illness. Be honest with your son or daughter about the illness. Don't be afraid to ask them what it's like for them. You may be the only people they feel they can trust during the difficult times they are experiencing.
- ◆ Reassure him or her that you will always be there for them as their parent. Try to take the pressure off them if they are anxious about things such as keeping up with school or college, finding a job, having to leave home, or managing relationships with their own partners or children.
- ◆ Try to set some boundaries so that they are not talking about their psychotic experiences all the time. Keep them busy and suggest activities to divert their attention away from being

preoccupied with the illness. Sometimes you may have to tell them to calm down and to explain your own needs.

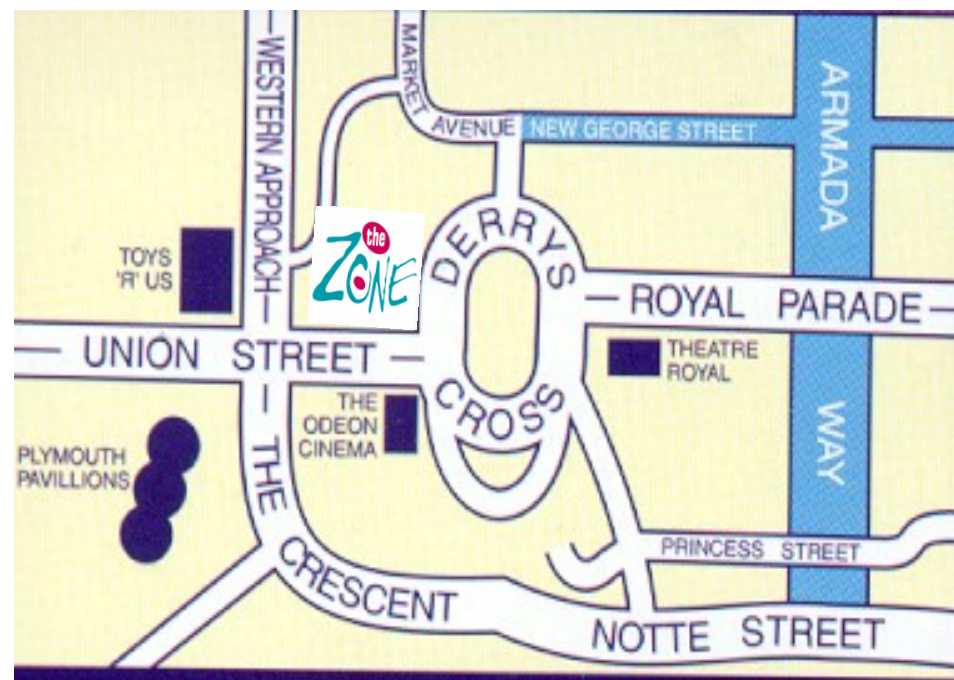
- ◆ Remember that they are trying to hold on to moving to being an independent adult, no matter how dependent they may feel at some times. Avoid criticism if you can and recognise that for much of the time they may not want you to be too involved with some of their lives.
- ◆ Be alert to the 'triggers' that can lead to them feeling stressed or anxious (and remember it may be things that you say or do). Plan with them how to avoid some of those triggers.
- ◆ It's hard to deal with their illness by yourself – especially in the early days. The INSIGHT team will work with you as part of the care team for your son or daughter. Please talk to us openly about your thoughts and feelings. We may also suggest that it could be helpful for you to talk to other parents in the same situation, if you wish to do so.

We know this may appear to be a very daunting list and nobody gets everything right all the time! Family and friends of a person with a psychotic illness face some very difficult periods of time.

IS THERE MORE INFORMATION AVAILABLE?

If you would like to talk to us about any of the information in this leaflet, please contact us on 01752 265775.

We can also help with book references, journal articles, web-site addresses and other information points should you wish to explore things further.



Where to find us...



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To find out more just call....
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