



The Early Stages of Psychosis

Getting Help Early

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INTRODUCTION

About the authors

This short booklet has been written by Jenny Henry and Paul French. Jenny has experienced some psychotic symptoms in the past and was eventually referred to a team that works with people who are in the initial stages of psychosis or could be considered at ultra-high risk of psychosis.

Why I want to write this booklet (Jenny)

Well I wanted to write this booklet because I would like people to understand mental health particularly certain types of problems and relate this to my personal experiences.

Why I want to write this booklet (Paul)

I would like to share knowledge about something we call psychosis. Through this short booklet we will discuss what it is; how it can affect people; what can help; stages of psychosis; and reasons for accessing help early.

Definition of psychosis

The term 'psychosis' is generally considered to be associated with an inability to distinguish reality from unreality. The symptoms, which make up psychosis, are hallucination, delusions or thought disorders.

Hallucinations are an experience where a person will hear, see, taste, smell or feel something which is not actually there. The most common form of hallucination is one where the person hears something, most frequently this is in the form of words such as someone calling your name or hearing vague muffled sounds although some people can hear more complex sentences or hear a voice telling them to do something. Hallucinations can be considered as a normal experience, and research has shown that many people will have some form of hallucination at some point in their life.

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Hallucinations have also been linked to traumatic experiences and many people who have been traumatized will experience hallucinations relating to their traumatic experiences may be quite normal many people feel unsure about how to describe them and are fearful to discuss their symptoms with anyone. However, some people have hallucinations that cause them significant distress and will require assistance from specialist services.

Delusions are an experience where a person thinks something which when examined has little basis of truth. There are many different types of delusions but these just relate to the types of belief that are held, one of the most common is that of paranoia then this is generally accepted to be "a

state of mind where we believe that people may be after us in some way although there is little evidence to suggest this is actually the case". Some paranoia can be useful such as taking care at night if you are on your own in a vulnerable situation. However, too much can be unhelpful and again if things become too difficult this will require assistance from specialist services. Interestingly, unlike hallucinations, many people feel comfortable using the term paranoia and the term is incorporated within main stream language.

Thought disorder is an experience where a person has difficulties with their thoughts, and this may be in many forms. Generally speaking it is where an individual has difficulty carrying through a line of thinking in a way that makes sense to others. As with hallucinations and delusions many people experience times when they have difficulties getting their thoughts across to others. However, with someone who is developing psychosis this experience becomes more frequent and more pronounced.

Why psychosis?

In the early stages of development, a definitive diagnoses such as schizophrenia can be extremely hard to make. There are a number of potential diagnoses associated with psychotic illnesses, the most common being

- Schizophrenia
- Bi-polar affective disorder
- Psychotic depression
- Psychosis Not Otherwise Stated

It can be extremely difficult to make a distinction as to which of these diagnoses someone is experiencing in the very early stages. However, what are probably more important are the specific problems the individual is experiencing rather than attempting to categorise their difficulties in terms of fitting into a medical framework.

In general, people associate psychosis with Schizophrenia. Significantly, many people at risk of developing psychosis are concerned with the onset of "madness" and unfortunately the diagnosis of schizophrenia is perceived as encapsulating the essence of what the term "madness" entails. Schizophrenia is also frequently associated with long-term disablement; however 1/3 of people with a diagnosis of schizophrenia will have one single episode only although this fact is not widely discussed.

It appears that psychosis seems to be a more appropriate term when working with individuals in the early stages of symptom development.

How common is it?

Psychosis will affect approximately 3% of the general population over their lifetime, although the number developing psychosis at any one point in time is actually quite rare. Psychosis affects males and females roughly equally, although males tend to develop psychosis earlier. Rates of psychosis in the UK are increased in inner city areas compared to those who live in the country. This is by a factor of 2 for males and a factor of 5 for females. Generally psychosis will occur between the ages of 14-35 and this age group is most at risk, and approximately 80% of new

cases of psychosis will develop in this age group.

In terms of specific illnesses such as schizophrenia we know that there is an increased chance of developing schizophrenia if other family members have been diagnosed with schizophrenia.

In relation to schizophrenia the rates are

General population	1.1
One parent with schizophrenia	10.1
Both parents with schizophrenia	45.1

However only around 10% of new cases of schizophrenia will have one or more parents with the same diagnosis will not have a family history.

Stigma

The term Mental health can be very scary and just the word “mental” can frighten people off but I does not have to be that way. It is an illness that can be cured no matter how bad things seem at the time. It affects people for many different reasons it does not matter what sex age or religion you are, many of us will suffer with some form of mental illness at some point in our life. However, it does not have to be forever.

I remember when I had my first episode; I was about 21 at the time. I didn't have a care in the world, I had my own house and a long-term relationship, and things couldn't have been more perfect. So when I found my self-hiding under the quilt adamant that my boyfriend was somehow trying to kill me, well as you can imagine, it's a very scary thought. Who could I tell without them thinking I was mad? I was even worried about discussing it with the people close to me at the time; after all I thought my boyfriend was trying to kill me. Maybe everybody else was, perhaps they were all plotting against me somehow.

This was just one of many irrational thoughts that came into my head and there were many more. Looking back on it now the things I thought then seem so silly now but of course they didn't at the time.

Reasons for early intervention services

There is a lot of evidence from research to suggest that the length of time between the start of psychotic symptoms and then getting access to treatment, Termed the Duration of Untreated Psychosis (DUP) or treatment lag) has been found to be approximately one year. What is important is that a number of studies have found that the longer it the delay in getting treatment then the worst the outcome and one local study found it to be the most important predictor of response to treatment. This is hardly surprising. We know that early detection of common physical problems such as cancer or heart disease is important and the earlier something is treated the better. This should also apply to mental health problems although typically mental health services offer a more reactive rather than preventative approach.

The main clinical implication from these findings is that minimizing DUP would be advantageous to the client, their family, and the treatment team. However, an average treatment lag of one year indicates that there are clear difficulties in getting treatment to people.

Why is there a treatment lag?

We know that in some cases the people undertaking the assessments may not be adequately trained or have enough time to recognize the developing symptoms of psychosis. This issue may also be linked with the fact that a young person may find it extremely hard to find the words to describe what can be quite unusual symptoms. Even mental health professional at times struggle to find words to describe these complex symptoms so for a vulnerable young individual who is frightened about what is happening this can be extremely difficult. However for others discussing the symptoms of psychosis may be too frightening because of fears associated with stigma or what may happen to them.

Experience of services

Some services can be quite unhelpful and even ignorant about these problems frequently responding with a prescription for medication. I just wanted answers or at least a listening ear; instead I was handed over a prescription of antidepressants and told there was basically nothing wrong with me. If there was nothing wrong with me what was the prescription for?

I made further attempts to visit the surgery and by this time things had got considerably worse for me. Months had passed and I now had a new theory maybe I had a brain tumour and this was the reason why I was ill. I had swapped one fear for another, and it was only then the doctor decided to refer me to someone else. At last I thought my prayers had been answered, however, yet again it proved a very difficult road ahead.

I was eventually referred to somebody who then referred me again to someone else and at this point I felt like the lost luggage you get at the airport, nobody knew quite what to do with me, this was quite unnerving for me.

I had now gone through several different services and each time it was getting harder. I was now becoming more withdrawn from this world and finding things extremely difficult to deal with.

Early Identification

Interestingly, some recent research has suggested that it is possible to identify people who have a high risk of developing psychosis (Yung et al., 1998). If this is the case then monitoring this high-risk group to see if a full psychotic episode occurs could be really important. If someone does develop psychosis then treatment could be started as soon as possible which would be advantageous in that this could reduce the treatment lag previously discussed. It may also serve to impact on engagement with this client group (French et al., 2001).

Finally, if it is possible to identify at risk groups, then intervention at this stage could potentially prevent the onset of psychosis, providing a primary preventative approach. This would be best suited to a psychological intervention such as cognitive therapy (CT). This could target many of the problems associated with the prodromal period, such as anxiety, depression, psychotic experiences and sleep disturbance, without the dangers of providing pharmacological interventions to 'false positives' (people identified as high risk who will never become psychotic). A recent local piece of research has demonstrated that such identification of a high-risk sample is possible within the NHS (Morrison et al., 2001), and interim data suggests that CT may be effective in reducing or delaying transition.

Services that are aimed at reducing DUP would be advantageous, and are strongly indicated in research and policy documents. In general practice, to make a diagnosis of psychosis can be extremely difficult, with it being even harder to ascertain whether someone is at risk of future psychosis. A specialist team with experience in this area could affect this process by providing screening.

What was happening to me? What was I experiencing?

At the time I didn't understand what was happening to me. All I knew was that strange things were happening to me. One day I would be fine and then the next day I would be in my own horror movie, that's the only way I can explain it.

I was to have many more experiences and each time I felt they were getting worse. I was experiencing panic attacks associated with these problems and these were becoming more intense each time. I thought I was surely going to die or have a heart attack, and all the while I was thinking why me I'm not a bad person why should I be punished in this way.

However, the worst was yet to come. I started hallucinating; hearing voices and seeing things. It was hard enough to explain the symptoms I was experiencing before so how on earth was I going to tell someone this. Things began to be very limited to what I could do all those things you take for granted like going to the shop or just even watching the television was a big deal for me because soon as I would start to do these normal things the voices would start they always did pick their times to start.

Days passed then months, some were good but there were always the bad but as time went on I began to learn how to deal with each episode as they came. I realized if looked out for the bad things I would find them.

I never in a million years thought this illness would ever end and it did. You just have to learn how to control it instead of it controlling you.

An alternative approach

I will never forget the day I met someone from the EDIT team I was very angry and upset with the whole system and how they had treated me so how could seeing them make my situation any better after all aren't all psychologists and doctors the same, so I thought but as time went on I was to realize they were not.

It took a while to find this team but when I did my life certainly started to look up they thought me so many things but most of all listened and did not judge me, this was what I was looking for all along I couldn't believe my luck.

At first I admit on my first interview I remember being quite rude but it just did not seem to matter they were actually there because they wanted to be and not because they were being paid for it, this was a big help.

I never thought this service was going to be of any help to me as all the rest had failed, I was now happy to talk about my experiences and not worry what any one was going to say. I began to learn how to control symptoms and how to deal with them with a clear mind and not have them all spinning out of control in my head. We tried all different methods of therapy to help me if one didn't

work we would try another there was never any pressure put on me and most importantly no medication. I can honestly say this service has helped me so much and I think it would benefit so many more people out there who are suffering with these types of symptoms.

How therapy kept me well.

Therapy kept me well because I had someone there at all times to discuss and work through my problems as they arose I could work through them one at a time and try to rationalize them. One of the things I found most helpful was to write things down so when I had one of my episodes afterwards I would write down what happened, how it made me feel and how I dealt with it. This was a very big help as I could slow my thoughts down and normalize them into what was real and what was not.

We would set tasks for me to do myself like just go to the shop on my own or get on some sort of public transport but all times there was never any pressure for me to do these things, it was just one way to introduce me back into society and to live a normal life as possible.

Therapy is a really good thing to have as it helps the individual to understand what is happening to them or at least break it down into smaller pieces so that they can understand it more easily, you can just sit and talk about anything you wish without worrying what anyone will think or if they will tell anybody else everything is totally confidential at all times.

I can't possibly imagine how my life would be now if I did not have therapy as it was the best and most positive and stable thing I had found to benefit my needs I know I would have not pulled through my illness without therapy and would advise it to anyone who is in need of help with these difficult times in their lives.

Drug use

We know that many people take recreational drugs at various points in their lives and get on with their lives with very few problems. However, some people may take drugs in order to combat some of the difficult experiences they are having. What seems to be the case is that various recreational drugs can help with some psychotic symptoms in the short term, although, in the long term they can seem to make things worse. If you are able to reduce your recreational drug use, you could monitor how this affects your experiences.

Self help

If you are starting to experience psychotic symptoms then possibly the most important thing you could do would be to get help early. Talk to someone you know and trust, ask their advice, if you have no one to turn to talk to your GP. As discussed if you are taking recreational drugs or alcohol in order to combat the distress of the experiences this can be helpful in the short term but can also maintain the problem so try and reduce your intake. If you are under stress then take steps to reduce this. Many people who are having these problems have difficulty sleeping, poor sleep alone can make us feel miserable and irritable and stop us seeing things clearly so take steps to improve your sleep, maybe get a few early nights.

Finally, think about what is happening to you as if you were a journalist who is only able to report facts. Look at these facts and start to consider their likelihood. Is there anything that stops you from

totally believing what you do, if so why? Start to ask yourself questions and also get others opinions.

Conclusions

There are times when someone may require medication in order to help with their difficulties. However, what we have found is that a number of people do not want to take medication, what they desire is a way of making sense of their experiences. If people have access to specific talking therapies such as cognitive therapy we have found that the process of making sense can reduce the distress associated with some of these difficulties even without medication.

If you feel that you or someone you know may be experiencing psychosis possibly the most important thing you can do is to get help early. Try and explain what is happening as clearly as you can in order that the people can understand and plan what needs to happen. Make it clear not just what is happening to you but also what you would like in terms of any help. It may be that these experiences will go away by themselves but if you have been experiencing them for more than a couple of days then it would be worthwhile talking to someone about them.

**Jenny Henry
Paul French**

If you are unsure of what is happening to you or someone you know and you want to discuss there are a number of alternatives.

www.nhsdirect.nhs.uk

Campaign Against Living Miserably (CALM)
c/o Room 621, Gateway House, Piccadilly South M60 7PI
Tel: 0800 585858

[Http://www.comcarenet.co.uk/trafford/therapy/calm.htm](http://www.comcarenet.co.uk/trafford/therapy/calm.htm)

This is a help line for 15-24 year old men at the onset of depression, to give advice, guidance, referrals and counselling. A free and confidential service.