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Website gives service users the chance to say what psychosis really feels like

The truth about psychosis - the often-frightening experience common in people diagnosed with schizophrenia and bipolar disorder - is finally revealed by the real experts. A total of 34 people (31 service users and 3 carers) talk in detail online about their experience of hearing voices or having persistent and unusual thoughts or beliefs in a new section on Experiences of Psychosis on the website www.healthtalkonline.org.

The comprehensive picture of the experience of psychosis and the treatment received has been widely welcomed as a much needed resource - that will combat 'the huge amount of ignorance and fear in society about psychosis,' according to comedian and former psychiatric nurse, Jo Brand.

The insight into the experience of psychosis is so valuable, according to the National Institute for Health and Clinical Excellence (NICE) that it is using the resource to inform NICE's Service User Experience Guidance, due to be published later this year and intended to help influence future service provision.

'Taking patients' experience into account is now recognised as a key part of improving the quality of healthcare - and this is especially the case with severe mental illness where the experience of psychosis has such an impact on so many aspects of people's lives,' said Professor Tim Kendall, Director of the National Collaborating Centre for Mental Health and medical director at Sheffield Care Trust.

'This online resource provides a really comprehensive picture of patients' experiences of psychosis and the treatment they receive that is invaluable for service users, carers, the public and professional - as well as NICE. Failing to place patients' experience at the heart of the way we provide mental health care is now an unacceptable omission.'

He said healthcare professionals should pay attention to the robust criticism of healthcare provision for severe mental illness contained within the website: 'This website is not an ideological mouthpiece but an evidence-based scientific resource. If that includes criticism of what we as psychiatrists are doing, then it's important that we listen carefully.'

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Service users have welcomed the website as an opportunity to break down stigma surrounding mental illness and give patients a better understanding of the care pathway - and thus greater power over their treatment and recovery.

‘I am one of hundreds of thousands of people who has been excluded from society as a result of being labeled as being schizophrenic.’ says Peter Bullimore of the Hearing Voices Network who describes on the website how his first psychotic episode followed the experience of being sexually abused by a child-minder. ‘The stories on this website will help to break down the stigma of having psychotic experiences and gets across the positive view that people can recover from the experience of trauma to which psychosis is so often a response’.

The Royal College of Psychiatrists has also welcomed ‘this ambitious and well evidenced website featuring testimonies and different perspectives of a group of conditions known as psychosis’. The College’s Director of Public Education, Dr Peter Byrne, said he recommended the section as ‘an excellent resource for users, carers, students and health care professionals’.

On the website, contributors, diagnosed most frequently with schizophrenia as well as bipolar affective disorder, talk in detail about their diverse experience of:

- trauma, including bullying and sexual and physical abuse in childhood
- hearing voices, seeing things and having unusual beliefs - with examples of how aspects of how life from religion to technology feature in these types of beliefs
- taking medication, sometimes under duress, that often has unpleasant side effects such as substantial weight gain
- hospital and community services, including being detained under the Mental Health Act
- alcohol and drug abuse
- failing to be taken seriously by health professionals
- being marginalised and stigmatised by their diagnosis
- spirituality
- prison and police

The contributors also express strong opinions on the key experiences involved in suffering from psychosis including:

- the causes and triggers for their mental health problems including the emerging label of ‘trauma-induced psychosis’
- the approach to recovery - and why there is no single model of how you can feel better
- advice on how to live ‘your dream’ - even if you are still hearing voices

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Dr Laura Griffith, the senior researcher at the Health Experiences Research Group at Oxford University, who carried out in-depth interviews with a cross-section of people with psychosis and analysed the results, believes the new website section will ‘humanise experiences that are too often dehumanised’ as well as support planning for improving services.

‘At a time when psychiatrists, psychologists and others in the health service are looking at developing ‘outcome measures’ to assess whether mental health services have been successful, people with direct experience of psychosis should play a key role in deciding what these outcomes should look like.’ she said. ‘In this context, it’s important for mental health professionals to understand more about the person behind the diagnosis and the views that person may have about recovery and how to improve their quality of life.’

Notes to editors:

Interviews with Dr Laura Griffith, Professor Tim Kendall, Pete Bullimore and case studies with experience of psychosis are available on request.

About DIPEX/Healthtalkonline/Youthhealthtalk

DIPEX has created two websites – www.healthtalkonline.org and www.youthhealthtalk.org – of people’s experiences of nearly 60 different illnesses and health conditions. The websites are aimed at patients, their carers, family and friends, doctors, nurses and other health professionals, and are based on in-depth qualitative research carried out by the Health Experiences Research Group at the University of Oxford.

Users of the websites will find accounts – presented through video, audio and written material – of issues such as reaction to diagnosis, consultation with their doctor, effect on work, social life and relationships, decisions on treatment options and side-effects.

To date, www.healthtalkonline.org has covered illnesses including cancer, heart disease, neurological conditions (Parkinson’s, epilepsy and autism) chronic health issues (HIV, diabetes, rheumatoid arthritis) and mental health. We also provide experiences of women’s health, dying and bereavement. and publish young people’s experiences (including epilepsy, sexual health, teenage cancer) on our dedicated youth website – www.youthhealthtalk.org.

Supporters include Jon Snow, Dawn French, John Humphrys, Ian McEwan, Dr Jonathan Miller, Jenni Murray, Michael Palin, Philip Pullman, Libby Purves, Thom Yorke and many others. The actor, Hugh Grant is patron.

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