

# Stand Up for Schizophrenia

Schizophrenia Awareness Week  
11-17 November 2013

<http://www.rethink.org/get-involved/stand-up-for-schizophrenia>

## Schizophrenia

People are often afraid of the unknown.

My name is Philippa but I prefer to be called Pippa. I love origami and puzzles. I like music by Linkin Park and Three Days Grace. I love butterflies and moths. In my spare time, I pick up litter after other people in my local area. Now you know a bit about me, I'll tell you that I have a schizophrenia.

Often, I hear things no-one else does. The teaching staff at my old school are poisoning my sleep. On one occasion, I couldn't find the front door of my house. I have difficulty crossing the road by myself. A force which contains all the words ever uttered puts pressure on me so that when I am sitting, I am made to lean so far forwards, my face touches my knees.

1 in 100 people will develop a schizophrenia in their lifetime but schizophrénias affect us all. Chances are you know someone with a schizophrenic disorder – you may not even know it.

Some people get well and never have another psychotic breakdown; others, like me, can have debilitating symptoms for the rest of their lives.

People with a schizophrenia die, on average, 15-20 years earlier than their mentally-well peer group.

Schizophrenias are NOT:

- a split personality
- caused by bad parenting, personal weakness, or demon possession

As a person with a schizophrenia diagnosis, I have never been violent to anyone, other than myself. In fact, those of us with a schizophrenia are far more likely to be victims of violence than perpetrators. A schizophrenia is a hard label to live with.

## What Does Psychosis Mean?

The word 'psychosis' is used when a person loses contact with reality in certain ways, mostly in hallucinations and/or delusions (false, but unshakeable beliefs). The schizophrénias are forms of psychosis.

As a person with a schizophrenia, I hear the voices of my long-dead Scottish ancestors who often say horrid things about me or, for example, tell me what clothing to wear. They sound as real to me as the voices of anyone else. They send painful Scottish chest pains on me if I do something wrong.



Sometimes I see maggots in my food, or people's faces at the upstairs window. I believe I have seen God. It seems to me that the phrase 'Star anise, Middle East' can achieve total world peace, if only it were fully understood. In my experience, psychosis is terrifying but can also be exhilarating.

I believe my conversations are recorded. On occasions, I have gone mute, and many days I have panic attacks if I have to leave the house. But I take an antipsychotic medication to help control my symptoms and with the help and support of my family and mental health team, I am able to get by in life.

### **How many people with schizophrenia does it take to change public opinion?**

You stupid slap-fat doggerel! (No, not you). This sort of comment is the stuff of everyday life due to the voices I hear. I am diagnosed as having a schizophrenia with mood variability.

In 2002, I was Sectioned under the Mental Health Act 1983. I am fortunate to be a petite female. The authorities don't tend to come down so hard on little women. I found you leave your dignity and identity at the hospital door along with your dangerous personal belongings, such as your toothbrush. Side effects of the medications ranged from losing my hair to gaining 25kg in weight in a matter of months. During that year, I did, however, learn the value of freedom.

I brought home a triangular road-works sign, so sure it was the Holy Trinity. I've stayed awake non-stop for a week. I've tried to outrun cars on a busy road. I have been paralysed with fear, felt such elation, and plunged into catastrophic depressions.

A schizophrenia is a hard master. But those of us with brain disorders are mostly just ordinary people with extraordinary experiences, trying to make sense of life.

How many people with schizophrenia does it take to change public opinion? Well, I hope I have made a small difference by getting you to think again about your own attitude to those of us with brain disorders. Maybe we all need to acknowledge our shifting places on the continuum of human fragility, and stop discrimination against people with mental illness.

### **A psychiatric diagnosis: the end or the beginning?**

I always suspected something was wrong ever since the age of seven. However, my schizophrenia diagnosis jolts me every time I hear it even now at the age of thirty-two.

My world had shattered long before I became 'psychiatrically labelled' but such a label brings with it hope and despair: hope that a future could still be salvaged with help and careful support; despair that discrimination and disability could jeopardise that very future.

Whilst I was under Section 3 of the Mental Health Act 1983, the hospital staff pushed a whole rainbow of psychiatric drugs on me and then blamed me for the side effects I suffered. As patients, we were given most of our care by the loud television in the day-room. But I count myself as one of the lucky ones.

Handling everyday life with a schizophrenia is a hard challenge whether it has been officially diagnosed or not. It is not merely the paranoia, the incapacitating depressions, the over-elated states, the sheer panic, the hallucinatory voices, the bizarre thoughts, or that no-one ever believes you. The older I get, the more I become aware of the cognitive dysfunction of my schizophrenia, too: I can no longer read books; watching a film is beyond me; I fight hard to follow directions; and I am baffled by the steps involved in tasks like sorting laundry.

People with schizophrenias and other brain disorders often have much to give, though not always in the way society expects; we are individuals, and not illness labels.

### **Mind Your Language**

I can be ignorant, flippant and lazy with language. I also know what it is to have a diagnosis of a schizophrenia. Severe brain disorders can be deadly, they wreck lives, and that is no joke.

"Bipolar", "schizophrenic" and "OCD" are commonly used to glibly describe personality traits, the weather, even political opinions. Is this a welcome, more relaxed attitude to talking about serious medical conditions, or just slack use of language? For me, any offence taken is minor compared to the way it reflects the general ignorance level. "Today's been really manic." I wish whoever said that lived in my skin for an excruciating, terrifying sleepless week of a manic episode.

The underlying problem is of greater concern. In UK culture, it is still a struggle to get people to acknowledge that these diseases are real, and not merely personal weakness, laziness, or the latest trendy 'fashion accessory' label. The recent incident of some of the big stores insensitively and ignorantly selling Halloween costumes labelled "mental patient" and "Psycho ward" seemingly did not realise how wrong, inaccurate and misjudged the names were. This is the main issue.

On the flipside, such illnesses are at least being mentioned. A facetious joke can be turned into a talking point. Humour, unless meant hatefully, is a great social binding agent. Indeed, it is important to be able to laugh at ourselves. The voices I hear of my Scottish ancestors are sometimes a complete hoot: "Hoity-toity dainty-do."

Perhaps it is because those with brain disorders are often unfairly discriminated against which makes it a difficult area. People with schizophrenia, for example, are stereotyped as dangerous or stupid. In reality, we are mostly ordinary people with courageous lives just muddling through like anyone else.

### **The Hidden Symptoms of Schizophrenia**

In addition to the more florid, headline-catching psychotic symptoms, schizophrenias also come with a range of other debilitating symptoms and thought problems.

People with a schizophrenia, like me, can suffer a severe loss of motivation, which includes a deterioration in self-care. Without reminders, I have gone weeks without washing or changing my clothes, and forget to eat if left alone. Withdrawing from company is also a symptom and leads to social isolation that can be compounded by fear of other people's attitudes to those of us with these disorders. I sometimes cannot make it out of bed on bad days.

My thoughts are often muddled which can make my speech confusing and difficult to follow. Thoughts can jump from one topic to an unrelated one in one breath. Sometimes I cannot find the right word, so I make one up. When I am in a manic episode, I talk a great deal; rhyming words and my sentences follow the sounds of words rather than any logical subject route.

Since becoming ill, I am no longer able to tell when it is safe to cross a road, and have been beeped at for walking out in front of a car on a guess. At times, I find the stages involved in sorting laundry or in performing multi-step tasks overwhelmingly beyond me.

You may know someone with schizophrenia – you may not even know it. We do not always realise the difficulties others have in their lives. So, be kind and patient and show some respect!

### **Famous People with a Diagnosis of a Schizophrenia**

As the schizophrenias typically tend to strike people in adolescence or early adulthood, there are relatively few examples of famous individuals with such diagnoses because most people at these ages are just beginning their professional lives after finishing school or university.

However, John Nash (mathematician and a Nobel Prize winner in Economics), Syd Barrett (of the band Pink Floyd), Antoin Artaud (artist and dramatist), and Vaslav Nijinsky (dancer) are some examples of people who have achieved note in history in spite of a diagnosis (historical or actual) of a schizophrenia. Did you know that Einstein's son, Eduard; James Joyce's daughter, Lucia; and Tennessee Williams's sister, Rose, also had or were thought to have had the disorder?

Some have thought that although the schizophrenias may be too disabling to allow a person to achieve greatness on the world stage in their own right, the capabilities of the immense creativity that is associated with full-blown brain disorders is fully realised in close family members who are unaffected by the disorders themselves.

In this Schizophrenia Awareness Week, 11-17<sup>th</sup> November 2013, be mindful to Stand Up for those with Schizophrenias, for their times of great distress and possibly just as great untapped potential.