Practice

Patient's journey My bipolar expedition

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Suzy Johnston, a writer, adviser, and author, takes us on the journey that is her life with bipolar affective disorder

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When I received my diagnosis of bipolar affective disorder (manic depression) I was relieved. Finally, and at the age of 22, someone had told me that I wasn't going mad, wasn't barking, and wasn't going loopy or any of the thousand other things that filtered into my overwrought mind at 2 00 am every night. No, I had an illness and, although I had a long and bumpy road ahead of me, at least now I had a hook on which I could hang my symptoms. That, to me, was progress.

Road: an open way for passage or travel, esp. one between distant points; a highway

I first stepped, blind, shoeless, and alone, on to the rough and winding road that is bipolar disorder 16 years ago when I was 16 and in my final year at school. I became hugely depressed and was horrified how destructive depression can be—not only does it leave the sufferer unable to feel any emotion other than intense misery, it also removes the ability to reflect the emotion of others—for example, sharing in someone's good news—and this can be desperately isolating (box 1). Bipolar disorder is characterised by episodes of mania (overly elevated mood) and depression, both of which can have horrific effects on the sufferer. When manic, people may behave entirely out of character and be extravagant in their behaviour—for example, spending huge amounts of money well beyond their means, driving erratically, becoming delusional, etc. When they are going through a depressive episode their mood can be extremely low, and they may have thoughts of harming or even killing themselves.

Many people experience only one episode of either mania or depression and then go on to lead perfectly healthy and, for want of a better word, normal lives. However, I was to find myself in the minority of people who discover that their roads are full of potholes and sharp inclines. My learning curve was steep but necessary, because ignorance and mood disorders are potentially lethal partners.

Opening my eyes

I found out that I had bipolar disorder really by accident, as I had been sent to see a psychologist and she read out the letter of referral to me. It began with the words "I am sending you Suzanne Johnston, who is

Suzy Johnston, who has had bipolar affective disorder since the age of 16

a 22 year old manic depressive." This was not the ideal way to find out that you have a major psychiatric illness, but, frankly, I was just glad to have a name to put to what was wrong with me. I had spent the preceding few months at university reading everything I could find about mood disorders, and I had come to the conclusion that, yes, I had bipolar affective disorder. When the psychologist read that letter to me the first thought to go through my head was "Right, now that I know what is wrong I can start to do something about it." However, it should always be remembered that for some people, such as myself, receiving a diagnosis can be empowering, whereas for others it is a disaster. Professionals should always be aware of this potential impact and offer as much support as possible.

I saw the psychologist once a fortnight for a couple of years, and at first I was a little unclear why I had been sent to see her as I had no problems in my childhood, got on great with my family, and, apart from when I was

ill, was pretty happy. Gradually I began to understand that she was teaching me how to cope with everyday situations, when bipolar disorder is thrown into the equation. For example, if I'm feeling depressed and someone makes some casual comment that I wouldn't normally think twice about, I can be oversensitive and give my self esteem a real battering. Also, I had been by nature a very private person, and the psychologist taught me to be more open and forthcoming about my illness so that it would be easier for me to discuss my condition with doctors, nurses, friends, and family. This is a positive and constructive use of resources that can help people with serious psychiatric disorders live a fuller, healthier life. After all, when someone has recovered from breaking their leg they may receive physiotherapy to help them walk again. In the same way, someone who is recovering from a severe episode of depression (box 1) might need a psychologist to help them accommodate their condition in society.

Walk with me

An area in which I have been hugely fortunate has been the medical treatment that I have received over the years. This started in St Andrews when I was a student and continued back in Helensburgh when I returned to the care of Dr Calder's practice. I can't say enough good things about the doctors there—I really owe them my life.

I have been admitted to my local acute psychiatric unit many times, but I have the unshakeable belief that it would have been many more times had it not been for the superb care of my community psychiatric nurse, general practitioners, and psychiatrist. There are many examples of good practice to choose from but one that sticks in my mind is when my community psychiatric nurse sent me to see my general practitioner because I was tremendously depressed. We talked for a while, and she told me that as I was on the maximum dose of antidepressant she thought that she couldn't increase the dose, and putting me on another variety would take two to three weeks to become effective. We were both unhappy at this turn of events, so she told me to go home and that she would phone me in a couple of hours. She kept to her word and called me to tell me that she had spoken to my psychiatrist who, in turn, had phoned the manufacturer of my particular antidepressant to ask them if it was safe for me to be on an increased level. The company replied that there should be no problem and gave the go ahead. The consequence of all this was that I was put on an increased dose of antidepressant and, probably because of this, managed to avoid being admitted to hospital. Thus, a few phone calls and a willingness to go that extra mile to help the patient, probably not only helped me but made a saving of thousands of pounds. My general practitioners, community psychiatric nurse, psychiatrist, and I are part of a team. We all work hard and effectively to keep me well and out of hospital and, more importantly, to keep at bay those terrible thoughts that sluggishly circumnavigate my brain at times. These thoughts can be so demanding and viciously destructive that sometimes inpatient care is the only option. However, the human spirit is a remarkable thing. Sometimes it is possible to be in the

Box 1: The dark side

Breathing. In and out. In and out. This makes no sense—it doesn't seem possible to be alive and yet feel so miserable, so wretched. I feel death parading through my body, calling out to me and mocking my feeble attempts at resistance. A black liquid oozes from my pores and covers my skin in a slick, disgusting sheen that only I can see. Darkness creeps through my veins and launches a visceral attack on my soul. I am helpless and floundering, lost in this relentless hammering of depression, with psychosis scraping its talons sickeningly against the inside of my skull. This is not "feeling a bit down" or "a bit low"; this is full blown clinical depression with psychosis riding on its coat-tails for kicks.

Have I felt like this many times? Yes, often, and every time feels like the first time. These "potholes" that I fall into vary in depth, shape, and difficulty of escape. It is tempting to curl up and pretend that everything is okay. I wish. Running from yourself is hard to do.

Imagine that you are watching television and that the sound and pictures are your thoughts and emotions. To start with, everything is fine, and you have no difficulty in making out what you are watching. However, then a little interference appears on the screen, and it becomes harder to make sense of what is going on. This is what it is like when psychosis begins—you can still feel and understand your thoughts and emotions, but it takes a little more concentration than normal. When the psychosis takes over completely the "television screen" is completely overwhelmed by "interference," and it becomes impossible to make out any thoughts or feelings of your own as the psychosis dominates. Part of the problem I found with this is that I became unable to differentiate what was real and what was psychosis. I lived in a world for six months where I strongly believed that I was the most evil person on the planet, nurses and doctors were planning to kill me, and my parents, with whom I lived at the time, were plotting to throw me out of the house and I would have to live destitute and alone in London for the rest of my life. This was my reality.

darkest of places and yet see light in the most unsuspecting of corners. There is always hope (box 2).

An increasing gradient

In this frustrating world of stigma and fear, it is encouraging that the National Programme for Improving Mental Health and Wellbeing (www.wellontheweb.net) is making such progress in Scotland. Have I encountered stigma? Yes, and my worst experience of it

Box 2: Some light and laughter

One evening, when I was feeling a lot better and gearing up for discharge from the Christie ward, my Dad dropped by and offered to take me to the nearest McDonalds for a bite to eat. I thought that would be good and said that I would just pop into the "smoke room" to see if anyone else wanted anything. Sure enough, as I went along the line of occupied chairs people called out "Big Mac," "McChicken Sandwich," and "Cheeseburger." As I reached the end of the line I realised that one person hadn't asked for anything; he was a new patient who had hardly said two words since his arrival the day before after an unsuccessful suicide attempt. I debated whether to ask him and then thought "Sod it; why not?"

"James. Would you like something from McDonalds?"

No response. Try again.

"James. I'm off to McDonalds and wondered if you'd like anything?"

I was met with a glare from James and after what seemed like aeons of silence he came out with the immortal words "Happy Meal."

We all burst out laughing, everyone, nurses and patients—even James when he realised what he'd said. Laughter is a great equaliser, and suddenly we weren't nurses and patients anymore, just people enjoying a good joke.

I feel it's important to remember instances like this as it is not only patients who can become institutionalised but also nurses and doctors. After all, as patients we may spend a considerable time in hospital but the staff spend year after year there, and there is a very real danger of them becoming entrenched in their ideas and approaches to the patients.

was at my local accident and emergency department, where I was told that I was a “waste of time” because I was worried that my lithium level was too high. I also recall, on a separate occasion, being asked to leave the hospital canteen because I was a psychiatric patient. It is because of these and other instances that I believe that one of the biggest harbourers of stigma is general medicine in hospitals. To the patient being told to “Pull yourself together” after a suicide attempt. That isn’t going to help anyone, and it is crucial for those in attendance to be willing to listen to the patient and act responsibly in a caring and supportive manner. Staff in accident and emergency departments especially must learn how to deal effectively with psychiatric patients as they are often the first port of call for those in acute mental distress with the same being applicable to police forces and general practitioners.

Finding some shoes

Do I have mental health problems? Hmm, yes, I suppose so—but I prefer to bring the terminology into the 21st century and call them mental health

Further information

Johnston S. *The naked bird watcher*. Helensburgh: The Cairn, 2004.

Scottish Executive. *National programme for improving mental health and well-being*. www.wellscotland.info (accessed 17 Dec 2005).

challenges. Now that I seem to be on the correct medication, I am, for the most part, able to lead a full and varied life. I play hockey, I’m the lead guitarist in a rock band, and I write and advise on mental health issues. My life, albeit as a person with bipolar affective disorder, is far from over. I’m certainly not giving up on myself, and even when I’m ill I gain reassurance from those around me that this is not the end and that I will regain the life that seems to have shattered into a million pieces during this particular crisis. Life is like balls being thrown at you from all sides of a tennis court. I’m still working on my backhand. How good is yours?

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Commentary: Bipolar disorder—services need to catch up with rapidly developing evidence base

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The article above powerfully describes the misery and anguish that bipolar disorder causes.¹ Bipolar disorder is characterised by disabling swings of mood between mania (and mixed mania and depression) and depression. In the Diagnostic and Statistical Manual of Mental Disorders, fourth edition (DSM-IV), it is subdivided depending on the severity of the manic symptoms: bipolar I disorder is diagnosed when episodes of mania or mixed episodes occur with or without episodes of depressive illness, and bipolar II disorder is diagnosed when depression occurs with less severe episodes of elevated mood (hypomania) that do not lead to dysfunction or disability.^{w1} The lifetime prevalence of bipolar I disorder is around 0.5%; including bipolar II and less severe bipolar spectrum disorder increases this to around 5%.² The aetiology of bipolar disorder remain uncertain. It is strongly familial, although the precise genetic causes remain elusive.³ After the first diagnosis of mania, most patients achieve symptomatic recovery, but relapse is common, and after four years only about one third recover to premorbid function.³ Bipolar disorder is now recognised to be one of the commonest causes of worldwide disability especially within the 15–44 age group.³ Despite that, the needs of patients with bipolar disorder are almost completely ignored by UK policymakers, which makes service development very difficult.^{w2} Compared with schizophrenia, bipolar disorder is under-researched.^{w3}

Management of bipolar disorder includes specific treatment for the acute manic or mixed and depressive phases of the illness and long term strategies for relapse prevention. Historically, most effort has been put into researching pharmacological

treatments for acute mania. Antipsychotics and other drugs, including lithium and valproate, are effective in the acute phase of mania.³ There is very little evidence that psychosocial interventions are effective in mania. There is still limited evidence for interventions in the depressive phase of the illness, despite the fact that this accounts for the most substantial disability associated with the disorder.^{w4 w5} although this situation is rapidly improving. Antidepressants such as selective serotonin reuptake inhibitors seem to alleviate symptoms of depression, although trial data are scarce,^{w6} and the risk of precipitating manic or mixed episodes and mood destabilisation means that combination therapy with an antimanic drug is advised when there is a history of mania (such as bipolar I disorder).² For that reason, other drugs such as mood stabilisers (lithium, valproate, lamotrigine) and, increasingly, atypical antipsychotics, for example, quetiapine, are often recommended as first line therapies.^{2 4 w7} The current draft NICE guideline amply demonstrates the substantial uncertainty that currently prevails about the most appropriate first line treatment for bipolar depressive episodes,⁴ and the BALANCE 2 trial currently in development seeks to address this (<http://cebmh.warne.ox.ac.uk/balance/balance2/index.html>). Very little evidence currently supports the use of psychosocial interventions in acute depressive episodes in bipolar disorder.³

Bipolar disorder is often a relapsing illness, and many patients will need long term chronic disease

See web references w1–w9 on bmj.com