Hidden in plain sight

The second interim
report from the
Bipolar Commission

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Let's talk at bipolaruk.org

Introduction

The Bipolar Commission was launched in March 2021 with two aims for people with bipolar in the UK:

1. To improve the quality of services
2. To reduce the rate of suicide

The first interim report 'Bipolar Diagnosis Matters' was published in October 2021 and focuses on what bipolar is, and what causes and triggers it, and provides vital insights into patient experiences of getting a diagnosis.

This second interim report focuses on the lived experience of the bipolar community to paint a comprehensive picture of what it's like living with bipolar in the UK today. What's the journey to diagnosis? What are the treatments? What impact does the condition have on physical health? Which services are working well – and which aren't? What's the link between bipolar and suicide?

The full Bipolar Commission report collating all our evidence will be published in June 2022.

By empowering people with bipolar to live well, we will see benefits way beyond the individual and the family. The Commission at this stage is uncovering more questions than answers and opening up several cans of worms, but it's the start of a national conversation. We are determined to get the voices of our community heard, to bring the issues of living with bipolar into plain sight.

Melanie Perkins shares her story

“I struggled with periods of depression for years. When I was 45 I finally went to my GP and she referred me to a psychiatrist. I waited weeks for an appointment and then at the end of an hour-long assessment, the psychiatrist said, 'I think you just don't like yourself'. I just sat there feeling numb from my head all the way down and made up my mind never to see another doctor again.

I coped with difficult symptoms – sometimes finding it impossible to get out of bed and go to work - for another five years. Eventually I saw another GP who again referred me to another psychiatrist. This time I was heard, and diagnosed with bipolar type 2.

Getting the diagnosis was bittersweet. On the one hard I was terrified about taking psychiatric medication, and didn't like the 'bipolar' label. But there was also a sense of relief about the diagnosis, and from being believed, and understood.

The medication has lots of side effects, including slowing me down, and if I'm tired my speech becomes slurred. I found it really helpful to see the same doctor for three years. She helped me try difficult combinations and doses of medication before we got it right. Sadly she's retired now and I see various GPs and psychiatrists who don't know me.

After I got a diagnosis, the gap in healthcare services was significant. There wasn't any support in the community and the waiting list for psychological therapy was a year. All I got was the out-of-hours emergency number.

The diagnosis has had a huge impact on all my family and work relationships. I couldn't talk to anyone about it at first, including my husband. It took me almost a year to tell just one sister, who was devastated. She still won't speak about it to this day. And I'm too embarrassed to tell my work colleagues.

What helped me most was joining a Bipolar UK peer support group. It was amazing to feel so understood. We met online during the pandemic and hope to start up our in-person meetings again soon. The group feels like family to me now.

If I had to give some advice to a young person newly diagnosed with bipolar I'd say, 'You are not alone. There are services out there to help you. Just remember that no matter what, you have a voice, and you have every right to use that voice.

> It's likely that bipolar symptoms have been around since the dawn of time. The ancient Greeks referred to 'melancholy' and 'hypomania' and we can hypothesise that other cultures had their own terms.

In 1896 the symptoms were formally described as a condition by a German doctor, Emile Kraepelin, and the term 'manic depression' was first used. In the 1980s, the American Psychiatric Association renamed it 'bipolar disorder' to reflect what it called the 'bi-polarity' of the illness (the characteristic highs and lows). Today it's more widely known as 'bipolar'.

Whatever you call it, bipolar is a complex condition that requires specialist treatment and support. Living well with the condition is possible – the Commission has interviewed doctors, lawyers, film producers, policy makers, psychologists, app developers and presenters as part of our evidence-gathering process and they're all thriving. But unless the right support and treatment is in place, living well can be a challenge, if not impossible.

Sadly, the Commission has also met several members of the bipolar community who are far from thriving. They have poor physical and mental health and, statistically speaking, are significantly more likely to die of cardiovascular disease and suicide. In fact, the Commission estimates that at least 5% of all suicides in the UK are carried out by people who have the condition. And our research is uncovering many of the reasons why.

Diagnosis is taking far too long – there's an average of 9.5 years between someone first seeing a healthcare professional with symptoms of bipolar and eventually getting a diagnosis. This also excludes the thousands of people who live with, and die from, bipolar without ever knowing they had the condition. Yet the vast majority of our community (84%) tell us that a diagnosis is helpful.

Even when they finally get a diagnosis, little advice or no advice is given on how to manage the condition. This is astonishing as lifestyle changes, such as good sleep habits and avoiding triggers, can dramatically reduce the risk of relapse. It's the equivalent of someone diagnosed with lung cancer not being told to give up smoking.

Medication is a vital part of self-management, yet nearly two in three (60%) people with bipolar are not getting access to even basic medication. For those who are, some people are experiencing serious, extremely unpleasant side effects, many of which have lasting health implications. The gold standard treatment, lithium, is under-prescribed.

The NHS is delivering a model of episodic care and support provided by both primary and secondary care, yet most of this support is only directed towards a core group of individuals who are at highest risk of relapse. In spite of this, the system is failing to prevent high levels of relapse, physical health issues and suicide.

This model of episodic care isn't working either for people living with bipolar or for the NHS. NICE guidelines expect GPs to provide specialist support for people with bipolar, but the primary sector is under immense pressure with limited time and resources. It's not surprising, then, that only half of respondents have an ongoing relationship with their GP and about a third have gone private. Support in the secondary sector is provided by those who appear to have the lowest levels of knowledge of bipolar (care coordinators and CPNs).

There is very little focus on prevention with only a minority receiving support on improving their knowledge of bipolar, and barely half receiving care plans and safety plans. The most helpful services are the bipolar specialist ones which are being used by only 14% of respondents.

Inpatient care is a vital element of care on the bipolar care pathway, yet two in five people describe the hospital they were in as a place of hurt rather than of healing. Basic legal rights aren't routinely observed, people are missing out on treatment like ECG, they stay on mixed-sex wards and are vulnerable to sexual predation and abuse from other patients and staff. People are often discharged too early and only a minority are offered a medication review when they need one or are supported to produce a care or crisis plan aimed at reducing relapse and readmission.

This is against a backdrop of fewer inpatients beds and rising detentions under the Mental Health Act. The hospital system is under pressure and people with bipolar are bearing the brunt of it.

The urgent need for specialist services

There are specialist healthcare services for people with cancer, arthritis, asthma, diabetes – the list goes on. However mental health conditions are often lumped together under one umbrella service for 'severe mental illness'. Decision makers talk about moving towards a parity of esteem but imagine the outcry if there was an umbrella service for 'severe physical health'.

In the same way that someone with cancer has different needs to someone with heart disease or asthma, someone with bipolar has different needs to someone with schizophrenia or an eating disorder. The high level of comorbidities complicates the picture (see page 8 of our 'Bipolar Diagnosis Matters' report) and some needs overlap just as they do with physical conditions, but the overwhelming consensus of clinicians, academics and people with bipolar themselves is that bipolar-specific services are significantly more effective.

The NHS is providing services for people with bipolar. The frequency of contact with healthcare professionals is fairly high. While this may tick boxes and look like it's working on paper, it is not working. Relapse rates are shocking. What's needed, then, isn't just frequency of contact but efficacy of contact. People with bipolar need to be supported by specialist clinicians who understand their very specific needs – medication, comorbidities, psychological therapy, self-management, physical health.

Whether counting the cost to the individual (in terms of lost income, jobs, relationships, opportunities) or the cost to the state (the high level of intervention that's needed to support someone when they relapse alongside the lost productivity over a lifetime), it's a no-brainer.

The system urgently needs to look at ways to significantly lower the average 9.5-year delay in diagnosis. It needs to introduce integrated specialist bipolar services that focus on relapse prevention and long-term strategies that lower the risk of someone with bipolar dying 15-20 years earlier from heart disease. Stakeholders told us that early intervention services for psychosis provided a useful model.

There remains an ongoing debate about the relative merits of the medical and social model for mental health – should people receive medical treatment or social support for their mental health issues? The Commission has found that people with bipolar need both.

We don't believe we've found all the answers. As we've already said, our aim is to start a conversation, to get bipolar on the agenda. We welcome research, studies or viewpoints that support or challenge any of our findings. This is just the beginning, and we'd love you to get involved. Email us at commission@bipolaruk.org

The bipolar community is asking for:

01 Significantly easier and quicker bipolar diagnosis

02 Improved understanding of bipolar triggers and symptoms so people can recognise the condition in themselves and those close to them

03 Universal access to specialist treatment for people with bipolar, including psychological therapies and peer support

04 Improved access to a named psychiatrist who provides ongoing (not episodic) care

05 Holistic medication and lifestyle reviews that take into account the physical side effects of medication, such as weight gain

06 Increased prescribing of lithium

07 More beds and higher quality care in psychiatric wards

08 An evidence-based online screening tool for bipolarity to prompt someone to seek assessment from a healthcare professional

09 Improved access to psychoeducation to help prevent relapse and lower suicide rates

10 Fund more research into genetics and treatments for bipolar

These asks will be refined into recommendations for the final report due in summer 2022.

Bipolar UK is more than a charity – we're a community. Our mission is to empower everyone affected by bipolar to live well and fulfil their potential.

Read the full 'Hidden in Plain Sight' report at bipolaruk.org/bipolarcommission

Read the 'Bipolar Diagnosis Matters' report at bipolaruk.org/bipolarcommission

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