Bipolar Diagnosis Matters

The early findings of
the Bipolar Commission

October 2021

bipolar UK

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

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

Why? 1 in 20 people who take their own life in the UK have a diagnosis of bipolar[1]. And this figure is likely to be a significant underestimate as it excludes people with bipolar who are undiagnosed or misdiagnosed, two factors that increase the risk of suicide.

The report also aims to provide hope: with the correct treatment and support, it is possible to live well with bipolar.

The Bipolar Commission brought together 22 Commissioners with academic, clinical, policy and lived-experience expertise to identify and review evidence on the current services and quality of life for people living with bipolar.

The research involved:

- a literature review
- stakeholder and lived-experience interviews
- a series of online surveys

This first report focuses on what bipolar is and what causes it and provides vital insights into the bipolar community's experiences of getting a diagnosis.

Over a million people in the UK have bipolar. The most comprehensive prevalence data is from the Adult Psychiatric Morbidity Study (APMS) in 2014, which found that 2% of the UK population aged 16 and above were living with bipolar[2].

Bipolar disorder is a severe mental illness characterised by extreme experiences of mood. Lots of people with bipolar can live a 'normal' life with a relatively stable mood for weeks, months or even years at a time. But mood changes can go far beyond most people's everyday experiences of feeling a bit down or happy.

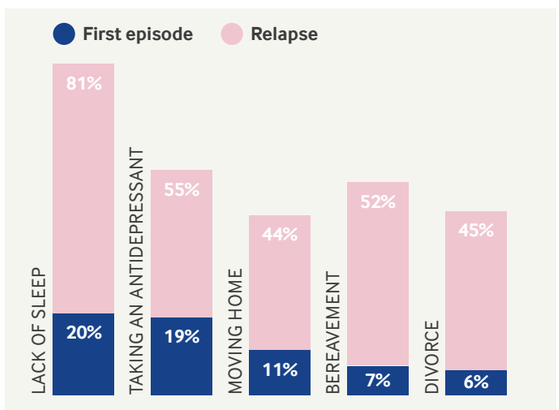
Bipolar UK uses a mood scale to rank mood from zero or 0 (low) to 10 (high). When someone living with bipolar goes above a 6 or below a 4, they are said to be relapsing. At the extreme ends of the scale, manic highs (10) and depressive lows (0) can be incredibility destructive – yet with effective treatment and support it is possible for people with bipolar to live well.

Mania	Reckless decision-making, rapid uncontrollable thought patterns and hallucinations
Hypomania	Less severe than mania; often very productive and energetic but also unusually irritable
Severe depression	Low energy, not leaving the house for months and, tragically, sometimes suicide
Mixed state	A combination of mania and depression called a 'mixed affective state' or 'agitated depression': this can be very serious and is a particular risk factor for suicide

Bipolar is a predominately genetic condition. If a twin has bipolar, their identical sibling has a 70% chance of developing the condition[3].

Yet heritability is variable, averaging out at 10%[4] - a parent with bipolar has a one in ten chance of passing it on to their child.

A number of environmental factors can trigger the first episode or, post-diagnosis, a relapse:



20% **even positive things like getting a promotion at work, getting married, starting a new relationship or going on holiday, had been major triggers**

19% **taking antidepressants was associated with a first episode of mania**

This reflects what our bipolar community tell us is a common pathway to diagnosis:

- Saw doctor with symptoms of depression
- Sometimes prescribed 'talking therapies', and/or diet and exercise changes
- Diagnosed with 'unipolar' depression and prescribed an antidepressant*
- Experienced manic episode
- Sectioned and hospitalised
- Received diagnosis of bipolar

* 'Unipolar' depression is about ten times as common as bipolar[5]: they can be very difficult to tell apart[6].

This chimes with an academic study reviewed by the Commission that found **around 10%** of UK primary care patients prescribed antidepressants for depression or anxiety have undiagnosed bipolar disorder[7].

However, getting a diagnosis of bipolar isn't straightforward because there are no physical tests for bipolar unlike other conditions, such as diabetes (diagnosed by blood test) or a stroke (diagnosed by brain scan). It does not show up on a brain scan. Instead, the diagnosis of bipolar depends on specific and sudden changes in mood and behaviour, not otherwise explained by something else (for example, drug or alcohol misuse or a thyroid problem). These changes may be puzzling at the time and their significance may only be evident in retrospect.

The APMS estimated that 44% of people with bipolar have a diagnosis, (though it was calculated using a small sample size). Our survey results found many respondents had had a previous diagnosis:

DEPRESSION nearly 70%
(as explained above)

ANXIETY DISORDER 21.4%
(often overlaps with depression)

SCHIZOPHRENIA 2.8%
(symptoms of psychosis may initially appear similar)

There was an **average delay of 9.5 years** between people first contacting a health professional about symptoms and getting an accurate diagnosis of bipolar.

60% of people said this delay had a significant impact on their life.

> *"For years I took antidepressants but still struggled with low moods. And at times I was spending too much, irritable and angry."* **AT**

> *"I was diagnosed with depression and given antidepressants. Four months later I had climbed to the heights of mania and was sectioned. That experience irreparably damaged relationships and left me broke."* **GW**

1. Plans, L., et al. "Association between completed suicide and bipolar disorder: a systematic review of the literature." Journal of affective disorders 242 (2019): 111-122.
2. It conducted a survey of 7,076 people using the Mood Disorder Questionnaire (MDQ) – see appendix 1 (Demographic information). The questionnaire describes 13 manic symptoms. If respondent had experienced 7 or more symptoms at the same time and that caused them problems then they were considered to have bipolar.
3. Barnet, J. H. and Smoller J. W. 2009. The Genetics of Bipolar Disorder. Neuroscience. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3637882/.
4. Craddock, Nick, and Ian Jones. "Genetics of bipolar disorder." Journal of medical genetics 36.8 (1999): 585-594.
5. Hirschfield, R. M. (2014). Differential diagnosis of bipolar disorder and major depressive disorder. Journal of affective disorders. 169, S12-S16.
6. De Almeida, J. R. C. & Phillips, M. L. (2013). Distinguishing between unipolar depression and bipolar depression: current and future clinical and neuroimaging perspectives. Biological psychiatry, 73(2). 111-118.
7. Hughes, Tom, et al. "Unrecognised bipolar disorder among UK primary care patients prescribed antidepressants: an observational study." British Journal of General Practice 66.643 (2016): e71-e77

Bipolar Diagnosis Matters

Respondents accessed the survey through our website, newsletter, ecommunity or social media which means they are engaged with our services to some extent and may not be representative of the wider population/people with bipolar in general.

Nevertheless, the vast majority of people welcomed a diagnosis:

84%	diagnosis was either helpful or very helpful
80.5%	diagnosis gave an explanation for their past experiences
68%	diagnosis enabled them to get better medication
47%	diagnosis helped them be better understood, despite the stigma
2.6%	didn't want to get a diagnosis

A diagnosis makes it possible for someone to get effective treatment and support, and to live well with bipolar. The shorter the delay in diagnosis, the sooner someone can empower themselves with effective self-management and foster a virtuous circle with fewer relapses in both the short and long-term.

Self-management includes:

- access and good adherence to a range of medication
- lifestyle (good sleep, routine, diet, exercise)
- support (healthcare team and family/friends)
- avoidance of triggers where possible
- specialised psychological therapies

All of these protective factors are only possible if someone has a diagnosis of bipolar. Yet **only 48%** of respondents received any advice about lifestyle changes that would reduce risk of relapse. **This is the equivalent of someone who has a high risk of lung disease not being told to give up smoking.**

The full Bipolar Commission report due to be released in March 2022 will put forward recommendations to:

1. Make it easier and quicker for someone with bipolar to get a diagnosis
2. Improve access to specialist treatment for people with bipolar
3. Develop an evidence-based online screening tool for bipolarity to prompt someone to seek assessment from a healthcare professional
4. Fund more research into bipolar, including genetics and its ethical implications
5. Improve awareness of proven self-management techniques
6. Change the narrative around the public perception of bipolar to reduce stigma and encourage understanding

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 'Bipolar Diagnosis Matters' report at **bipolaruk.org/bipolarcommission**

Get in touch at:

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www.bipolaruk.org/faqs/mood-scale

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