

# How can we build a better world for people with bipolar?

Bipolar-friendly welfare.
Bipolar-friendly workplaces.



Beyond welfare reform, there is an urgent need to address failing mental health services. People with bipolar can only contribute to the economy when they have ongoing access to the appropriate support to stay well.



Simon Kitchen, Bipolar UK CEO

# Executive Summary | Building a bipolar-friendly welfare system

Bipolar is a severe mental illness characterised by significant and sometimes extreme changes in mood and energy, which go far beyond most people's experiences of feeling a bit down or happy.

There are over one million people with bipolar in the UK<sup>1</sup>. Millions more are impacted through close friends and family. The employment rate among people with bipolar is estimated to be between 40-60%<sup>2</sup>.

This is significantly lower than the average employment rate of 74% in the general population<sup>3</sup>. Given the high number of people who are living with bipolar without a diagnosis, this is likely to be an underestimate<sup>4</sup>.

There are currently 2.8 million people in the UK excluded from the workforce due to long-term health conditions<sup>5</sup>. Given that 1 in 50 people in the UK live with bipolar, it is safe to assume that people living with bipolar make up a good proportion of them.

A two-pronged approach to welfare reform is essential:

1. To focus on the benefits system itself to ensure it meets the needs of those with an episodic, fluctuating condition;

2. To eliminate the wider barriers that block people with bipolar from the workplace.

Addressing these challenges is essential, not only to improve the quality of life for those affected by bipolar but also to reduce the economic burden on society.

# **The Bipolar Commission recommends:**

- **Standardised basic bipolar screening** to reduce the diagnosis delay, ensuring early access to treatment and self-management.
- **Guaranteed access to specialist care** through a dedicated, lifelong care pathway focused on relapse prevention.
- Bipolar-friendly Work Capability Assessments that are person-centred, holistic and carried out by trained professionals.
- **A national awareness campaign** to promote the 'Access to Work' scheme, encouraging more people with bipolar to access workplace support.
- **Bipolar-friendly workplaces** that routinely implement reasonable adjustments like flexible work schedules, guilt-free time off for managing symptoms, and post-recovery support.

These measures will help reduce stigma, improve diagnosis and care and enable those with bipolar to thrive in both their professional and personal lives.



#### What is bipolar?

Bipolar is a severe mental illness characterised by significant and sometimes extreme changes in mood and energy, which go far beyond most people's experiences of feeling a bit down or happy. These are simplified using this Mood Scale. Manic episodes involve elevated or irritable mood, increased energy and a reduced need for sleep, while depressive episodes are characterised by feelings of sadness, hopelessness and a loss of interest in activities.

More than half of people with bipolar have been hospitalised due to their bipolar<sup>6</sup>. Globally, approximately 15–20% of people with bipolar disorder die by suicide, with another 30–60% making at least one attempt<sup>7</sup>. The Bipolar Commission found that 5% of our community had attempted to take their own life in just the last six months<sup>6</sup>.

There are over one million people with bipolar in the UK° and millions more are impacted through close friends and family.

### Bipolar in the workplace

While many people with bipolar can stay well for weeks, months and years at a time, a relapse can impair judgement, cognitive function and productivity, and wreak havoc in all areas of someone's life, including relationships, finances and the workplace. If someone experiences a severe episode, they can completely lose the ability to function and often need to be admitted to a psychiatric unit.

Addressing the challenges faced by individuals with bipolar is essential for welfare reform, not only to improve the quality of life for those affected but also to reduce the economic burden on society.

# The Bipolar UK Mood Scale

#### MANIA

#### **HYPOMANIA**

#### BALANCED MOOD

MILD TO MODERATE DEPRESSION

SEVERE DEPRESSION

Total loss of judgement, exorbitant spending, religious delusions and hallucinations		
Lost touch with reality, incoherent, no sleep, paranoid and vindictive, reckless behaviour		
Inflated self-esteem, rapid thoughts and speech, counter-productive simultaneous tasks	80	
Very productive, everything to excess (phone calls, writing, smoking, tea), charming and talkative	07	
Self-esteem good, optimistic, sociable, and articulate, good decisions, need less sleep and get work done	06	
Mood in balance, no symptoms of depression or mania	05	
Slight withdrawal from social situations, concentration less than usual, slight agitation	04	
Feelings of panic and anxiety, concentration difficult and memory poor, some comfort in routine		
Slow thinking, no appetite, need to be alone, sleep excessive or difficult, everything a struggle	02	
Feelings of hopelessness and guilt, thoughts of suicide, little movement, impossible to do anything	01	
Recurring suicidal thoughts, no way out, no movement, everything is bleak and it will always be like this	00	



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#### The bigger picture

There are 2.8 million people in the UK excluded from the workforce due to long-term health conditions  $^{10}$ , such as bipolar. This costs the treasury a substantial amount in health-related benefits and lost income tax revenue – and the bill is going up. The amount spent on Personal Independence Payments (PIP) – which help cover costs for disabled people – is forecast to rise by 60% from £22 billion to £35 billion by  $2029^{11}$ .

In 2023-24, the overall cost of working-age health-related benefits in the UK was £48bn, compared to £36bn the year before the pandemic<sup>12</sup>. The Office for Budget Responsibility (OBR) forecasts that it will reach £63bn in 2028-29<sup>13</sup>.

Not only are the costs of economic inactivity surging, the Institute of Fiscal Studies (IFS) reports that the people claiming benefits are getting younger and the number of new awards primarily for mental health conditions is increasing.

It is difficult to say exactly how many people with bipolar are living on benefits given the low levels of diagnosis. The best assessment is the Adult Psychiatric Morbidity Study from 2014<sup>14</sup> which found that, of those who received an out-of-work benefit related to disability (then called ESA), 12.4% screened positive for bipolar compared with 2.0% who did not receive the benefit.

Having bipolar carries an enormous burden, both for the individual with the condition and for the friends, family, society and health service around them. The condition constitutes 17% of the total burden of disease for mental illness and costs the UK economy a massive £20 billion a year $^{15}$ . This includes both direct costs, such as medical appointments, hospitalisations and benefits, and indirect costs, such as lost productivity due to unemployment and sick leave.

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# The political landscape

The government has set a target to get the employment rate up to 80% (from its current 75%) to lower the benefit bill, increase tax revenue, raise employment, and help individuals with self-esteem and mental health. Their 'Get Britain Working' plans were unveiled in July 2024, with complex welfare and employment support reforms and a £240m package to include work, skills and health support for disabled people and those facing long-term sickness. The aim is to bring two million people back into the workplace<sup>16</sup>.

In November 2024, the government published the 'Get Britain Working' White Paper with topline details of the proposed welfare reforms. The aim is to move from a welfare-focussed approach to one 'centred on employment'.

The Minister for Employment, Alison McGovern, stressed that the welfare reforms need the market to provide better opportunities and that it is not down to the individual. However, for the million-plus people who live with bipolar in the UK, the conversation around welfare reform, with headlines like 'sick note culture' and 'worklessness', is leaving many feeling anxious and stigmatised.



# Members of the Bipolar UK eCommunity tell us:

'I feel dehumanised, and have overwhelming anxiety, depression and guilt for feeling like a burden on the economy.'

'The greatest problem is the uncertainty, as every day there are multiple non-news stories which are just speculation of what might happen, I had to stop reading them as they were making my suicidal thoughts a lot worse. I'm in no state to even try and work. I'm just about surviving by selling personal possessions, but I'm running out of things I can sell.'

'I'm still waiting to get an answer on my PIP application, been 3 months already. It's difficult to see a future as I don't see myself ever getting well enough to hold down even the most basic job without the NHS MH services doing what they are meant to, after a year of being regularly referred back and forth between GP and the CMHT and still no further forward in recovery.'

# Welfare reform

Welfare reform ideas often don't take into account the specific needs and challenges someone with bipolar commonly encounters during the course of this episodic illness. At the time of writing, these ideas include:

Idea	Why it can't work for people with bipolar
A change to Work Capability Assessments (WCA) that could see a multi-billion-pound cut to benefit eligibility, affecting 450,000 people.	Many clinicians who support people with bipolar don't fully understand this complex and much-misunderstood condition. It is unrealistic to think that the professionals carrying out WCAs will have the understanding to make informed judgements unless they have meaningful training.
Employment advisors into healthcare settings.	People living with bipolar who need admission to a psychiatric unit or support from secondary care are often not well enough to make use of employment support services.
A crackdown on fraud in the welfare system <sup>17</sup> to prevent 'illegal activity', including a mention of having "direct access to bank accounts to recover debt".	A common symptom of bipolar is paranoid thinking, so the introduction of this idea has the real potential to delay recovery, or even make an episode worse.

There are, however, several changes that are likely to be beneficial in the long term. One particularly important development is the start of the rollout of IPS (Individual Placement and Support) services in primary care settings. By integrating these services into primary care, individuals with bipolar will be able to access timely employment support as part of their routine healthcare.

We strongly endorse the expansion of IPS services within primary care as an accessible and effective way to support people in their recovery journey in the appropriate setting.



#### From welfare to workplace

People living with bipolar often face significant challenges when it comes to employment. In a 2024 Bipolar UK survey of over 1000 participants, respondents cited that the biggest barriers to staying and thriving in work are managing bipolar symptoms (76%) and managing medication (57%). Although bipolar is defined in law as a protected characteristic, 44% of the survey respondents reported experiencing stigma in the workplace because of their condition and 32% reported being actively discriminated against<sup>18</sup>.

It is a mistake to assume that people with bipolar don't want to work. Only 6% of respondents in this 2024 survey said they were both out of work and not currently looking for work. Many people with bipolar are in and do want to work.

In July 2024, our **Bipolar in the Workplace** report set out our recommendations for employers to create an environment where employees with bipolar can thrive. This included integrating a culture of compassion into workplace policies, training workforces to understand bipolar, implementing meaningful reasonable adjustments, supporting employees to utilise support schemes and signposting employees to bipolar-specific support.

While we hope this report acts as a roadmap to inspire employers to move towards best practice, workplaces don't exist in a vacuum. So what wider changes are needed to support the million plus people living with bipolar in the UK to both get into and thrive in the workplace?

# Personal account | Ted shares his story

Content warning: Ted's story includes mentions of suicide and A&E

I have had bipolar symptoms since I was 17, but only got a diagnosis in January 2024. I'm 37 now, so for nearly 20 years struggled with the highs and lows. I lost friendships, relationships and, recently, my job because of my inexplicable behaviour.

In December 2023, I held a senior leadership role at a large visitor attraction, and the work-related stress triggered a manic episode. I can't recall any of it, but others tell me I became convinced something big was going to happen and behaved in ways that were completely out of character.

Afterwards, my mood crashed and I felt mortified about what I'd done. I attempted suicide three times and was eventually detained in A&E. It was an horrendous experience, but ultimately started my journey to diagnosis and recovery.

In a disciplinary hearing at work, two consultants stated I was low risk as I now had a diagnosis of bipolar, and was managing the condition well. But in the September, I was dismissed. My relationship ended and I found myself on a friend's sofa.

Understanding how the benefits system works was impossible, especially when I was first in recovery. I didn't have a clue what to apply for but eventually applied for Job Seeker's Allowance.

Benefits forms don't cater to bipolar at all as the questions are skewed towards long-term physical conditions. For example, can you feed yourself? Do you need help preparing meals? How can I tick either of those boxes and get across that when I'm low I don't eat at all.



Because I had a month's salary and modest savings when I first applied, I didn't qualify for benefits. As these savings have now dried up, I'm currently reapplying, but keen to get back to work.

I've applied for more than 50 jobs, but even as a stigma champion, I'm cautious about telling anyone I've got bipolar. I don't think people understand it unless they have direct experience.

I feel angry about the situation I'm in and frustrated by the welfare system. Whilst I understand that it's impossible for a benefits form to suit every single long-term health condition, the system needs to understand mental illnesses better.

I do feel hopeful for the future, though. Now that I have a diagnosis and am starting to understand bipolar better, I really believe that I can live a full and purposeful life.



Understanding how the benefits system works was impossible, especially when I was first in recovery.

# Building a bipolar-friendly society | Recommendations for policy makers

#### 1. Standardise basic bipolar screening

It is estimated that 56% of people living with bipolar don't have a diagnosis. And, on average in the UK, it takes 9.5 years to get a diagnosis after first telling a healthcare professional about symptoms<sup>19</sup>. During this lost decade, people are unable to get access to the treatment, support and self-management that can help them stay well.

The Bipolar Commission recommends prioritising routine screening and referrals for suspected bipolar in all mental health assessments. We also need more psychiatrists who specialise in bipolar to ensure that secondary care is set up for accurate and timely diagnosis.

The sooner someone gets a diagnosis of bipolar, the sooner they can learn self-management techniques to understand the condition, its triggers and relapse-prevention tools. Once people are able to manage bipolar well, they are far less likely to become unwell and are far more likely to be able to find and stay in work.

#### 2. Guarantee access to specialist care

In its **Bipolar Minds Matter** report, the Bipolar Commission found that at least 50% of people with a bipolar diagnosis relapse each year, costing the NHS up to an estimated additional £1 billion annually<sup>20</sup>. Heartbreakingly, it is estimated that bipolar-related suicide costs between £436m and £872m a year due to service response, potential lost productivity and the value of the emotional distress to loved ones<sup>21</sup>.

What's needed is the development of a dedicated care pathway to provide specialist treatment and continuity of support over a lifetime – from first telling a GP about symptoms and receiving a diagnosis to getting ongoing specialist support from clinicians who focus on personal

recovery and managing triggers and relapse, with first-class inpatient care available if needed. This focus on relapse-prevention would mean someone with bipolar is more likely to stay well and in work.

The cost-effectiveness of this specialist support model is proven. The Kessing study in Denmark for instance found that by spending the equivalent of £2,550 per patient per year on specialist care, there is a saving of £2,715 from reduced hospital admissions, and dramatically improved outcomes for people living with bipolar<sup>22</sup>. Similar findings have been replicated in France and the UK.

#### 3. Make Work Capability Assessments bipolar-friendly

Welfare health assessments are usually carried out by a provider on behalf of the Department for Work and Pensions (DWP). All reforms to Work Capability Assessments (WCA) need to be coproduced with people living with disabilities, including bipolar. This will ensure that, rather than assessing outcomes by clinical and work measures, mental health recovery will be approached from a person-centred, holistic and strengths-based lens with a focus on symptom management.

Depending on an individual's specific needs, this would involve timely access to therapy, secondary care, self-management training, peer support and career coaching.

Crucially, the Work Capability assessments themselves need to be carried out by providers who are fully trained to understand bipolar, which is a complex and muchmisunderstood condition.

#### 4. Run a national campaign to promote support schemes

'Access to Work' is a government scheme that provides financial support for job seekers and employees who are living with a disability to cover various adjustments, such as specialist equipment, support workers, and other workplace adaptations.

Our survey found that although everyone living with bipolar is eligible to apply for the scheme, only a third of respondents had heard of it and fewer than 7% had applied for it<sup>23</sup>. This limited awareness shows there is an opportunity for employers to support people to get more support – both within the workplace and beyond. There is also an opportunity for policy makers to increase awareness of the scheme.

#### 5. Commit to bipolar-friendly workplaces

Creating bipolar-friendly workplaces is essential for supporting employees with the right conditions in which to thrive. We encourage workplaces to make a pledge to create bipolar-friendly workplaces by adopting the recommended adjustments outlined in **Bipolar in the Workplace**, including:

- Guilt-free time off for managing symptoms
- Flexible work schedules and environments to accommodate episodes
- Time out for medical appointments
- Regular wellbeing check-ins with managers
- Post-recovery support for reintegration after episodes
- Clear objective-setting to reduce stress
- Avoidance of known triggers such as excessive workloads or disrupted sleep patterns

These adjustments, combined with a culture of understanding and support, can help individuals with bipolar manage their condition effectively and bring their talents to the workplace.

# Conclusion

# Bipolar can significantly impact someone's ability to work and live independently, costing the UK economy £20 billion a year<sup>24</sup>.

By implementing targeted reforms that focus on early diagnosis, specialised treatment, and empowering individuals to manage their condition, the UK can reduce the economic burden of bipolar and improve the quality of life for those affected. However, this approach is only possible if there's a sustained, coordinated effort between healthcare providers, employers and the welfare system to create a supportive and inclusive environment for people living with bipolar.

So much suffering and waste of talent could be avoided – and money saved – if the emphasis were switched to prevention: prevention of relapse and prevention of premature death.

We need to move away from tick box exercises, increased frequency of contact and crisis management towards building long-term patient-clinician relationships that encourage holistic self-management and focus on prevention relapse.

We need to reward inclusive workplace environments that make meaningful changes that allow people with bipolar to thrive.

We need to create a compassionate welfare system that understands the specific needs of people living with bipolar.

Only then will the bipolar community be supported to reach their full potential in the workplace and be able to use their talents and resources to contribute to the UK economy.



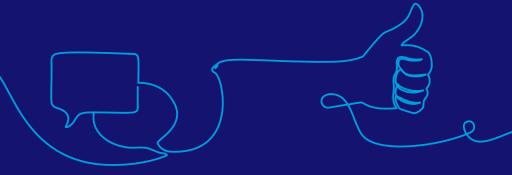
# **Get in touch**

If you would like to find out more about Bipolar UK, or to discuss ways in which we can work together, please get in touch.

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