



In The First Person: Living with Bipolar

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Content warning (00:00):

This podcast discusses content that may be distressing. For some listeners, please refer to the episode description for details about the topics covered.

Host (00:09):

Hi there. Welcome to Mental Health Professionals Network podcast series MHPN's aim is to promote and celebrate interdisciplinary collaborative mental health care.

Mark Creamer (00:27):

Hello, and welcome to this episode of MHPN Presents In The First Person. In this podcast series, we have an opportunity and indeed the privilege of hearing people's stories in their own words. My name's Mark, Mark Creamer. I'm a clinical psychologist and a professor in the Department of Psychiatry at the University of Melbourne. And in this episode we're taking a look at the lived experience of a mental health condition, in this case, bipolar disorder from the perspective of someone who has lived with it for many years and indeed who has now become a passionate advocate for people suffering from serious mental illness. It's a great pleasure to welcome my guest for today. Neil Cole, welcome Neil.

Neil Cole (01:10):

Thank you. It's good to be here. Mark,

Mark Creamer (01:12):

Before we start discussing your experience of bipolar disorder, Neil, you've got a fascinating background. In fact, we could easily spend the whole podcast talking about that without even getting onto bipolar, but we're not going to do that. But what I would like to do, if you could, is if you could just give us a couple of minutes, a few sentences as a kind of thumbnail sketch of your CV.

Neil Cole (01:32):

Yeah. I graduated from law school at the end of 79. I worked as a lawyer in Box Hill doing my articles. Then I went and set up the Flemington Community Legal Service, which became the Flemington Kensington Legal Service as a lawyer. And then in 1988 I went into Parliament. I was the member of Parliament for Melbourne. I did that for 11 years. I was also the Shadow Attorney General for three of those years. I went public about my mental illness in 1995 saying that I had bipolar mood disorder. We called it manic depression back then. When I left Parliament, I started working at the Mental Health Research Institute in Parkville with Professor David Koff. And then I worked down at the Alfred Psychiatric Research Centre at the Alfred Hospital with Professor Jri Kani and Professor Paul Fitzgerald. And then I went back and I've been working for Professor Colin Masters on Alzheimer's and similar relations were there. But the big thing I've done since 1996 is I took up playwriting and writing in general. And I've written 35 plays now and three books. So it's been a major outlet for me because I enjoy writing obviously, and I enjoy production.

Mark Creamer (03:01):

It's a fascinating history and in fact, we are going to record another podcast with you, aren't we? We're going to have a conversation actually, about some of your work with people with schizophrenia, but that's not for today. Today we're talking about your experience of bipolar disorder. You've had it for several decades now. Can we go back to the beginning as it were? When did you first begin to experience signs or symptoms or difficulties? What were the first signs for you?

Neil Cole (03:27):

Well, the first sign for me was when I was 16. My mother took me down to the doctors. I was very depressed. It wasn't for the depression. I'd had a problem with my neck. And that was the first time that I'd actually sat down and there was something wrong. I proceeded to do well at school and go on to university where I struggled with depression throughout the five years I was there. And I had numerous, what you'd call breakdowns. So it's a regular event, yearly thing, right up until when I was diagnosed in 1993.

Mark Creamer (04:06):

So up until then, had you had any treatment?

Neil Cole (04:10):

I'd been to psychiatrists, counsellors, herbal medicine, Chinese medicine, acupuncture, I dunno, even tarot, reading cards, whatever I could do because it was so obvious I had something wrong. And the depression was really bad for me, particularly when I was in parliament very, very bad. And with the late nights and working weekends and the type of work that was involved. And then when my children arrived, the sleep wake cycle was disastrous for me, much as I loved having my kids. So that's the journey. But the big one was being diagnosed in 1993.

Mark Creamer (04:55):

1993. So you get diagnosed with bipolar disorder?

Neil Cole (04:57):

Manic depression, then took him 40 minutes after all the psychiatrists I'd seen. I'd seen a psychiatrist about six months before. With all the psychiatrists I'd seen, he just said, I think you manic depressive, and confirmed. I had to go and have special tests done to see whether I could go on the medications.

Mark Creamer (05:18):

And what was it like getting that diagnosis?

Neil Cole (05:20):

It was an enormous relief. It finally, it all fitted. He gave me a book to read called *The Ecstasy and the Agony*. It was just so obvious that what I had was bipolar disorder, manic depression as we called it.

Mark Creamer (05:38):

Then it kind of validated your experiences really?

Neil Cole (05:42):

The experiences were pretty bad. It was a bit of a train wreck, particularly finances, sexuality, some of the morose states I'd been in, my intemperate responses at times.

Mark Creamer (05:56):

Yeah. Well, let's talk about that because for the benefit of our listeners, let's talk a bit about what bipolar disorder is or what it was like for you. We're talking about a mood disorder that's characterised by highs and lows. I guess people know that sort of thing. Can you talk about what it was like when you hit a low, when you have a period of depression?

Neil Cole (06:14):

I think the best way to describe it is the contrast between what it was like before to what it was like after I was taking medication. So for instance, the anecdote that I often give, although I give now, is I was watching a movie back in 1992 about Treblinka, the concentration camp. This woman said to the SS guard, the children went off one direction and she was going to go another, and she said, can I go with my children? Which meant she was going to die. And he said yes. And I had it in my head about this thing that I could go now if I could take my kids with me, because I didn't want my kids to live and see this terrible situation. Now I had that in my head for three months. It just wouldn't go away. Now, fast forward to 2004 when I'm on medication, I don't have depression. I wrote a play about the Holocaust called the *Trial of Adolf Eichman*. And in that all the time I was researching, including interviewing survivors from Auschwitz, I never had any depression. It was harrowing and it was upsetting, and I never had that depression I'd had, and in fact, I lived normal. I could read it and absorb it and write a play about something that 20 years ago had made me extremely depressed.

Mark Creamer (07:38):

Exactly. That's a pretty good indication of progress, isn't it? But let's go back to that time then. So it does sound like an awful period for you. Was it frightening to have those kinds of thoughts that you might do yourself and your children some harm?

Neil Cole (07:51):

No, it wasn't at the time. It just became more and more a feeling. It's like people have likened depression to having the flu. You just sort of got no energy. You're sleeping all the time. You want to sleep all the time, you're indifferent. So it was not good in politics because you have to be on your game all the time. And I wasn't.

Mark Creamer (08:14):

Exactly. So you were still trying to hold down a job, at least in the early stages?

Neil Cole (08:18):

Oh yeah. Oh yeah. Always holding down a job. But the depression was just overwhelming at times. Just go to the office and fall asleep and then the mania was different of course.

Mark Creamer (08:30):

Of course. Yeah. So let's talk about that. What's it like when you go through a manic or a hypomanic phase?

Neil Cole (08:35):

Well, the manic phase is very unpleasant. Some people say it's a good time. It's not for me, never has been. Your libido is out of control. You're totally sexually dysfunctional because of it. So you're driven by sexual matters, and it's not just a case of promiscuity. Everything comes back to you. Your brain is like a memory bank and all these things come back and there's no understanding of it. It might be something that happened when you were 17 or you saw something and it all comes back and it's all sexually orientated. So not just me, but people are driven by the libido issues. There's also, you talk very quickly, you become very anxious. You interrupt people all the time, talk over them. Your mind moves from one issue to another too quickly. One of the things is you become very good unfortunately at puns, but then you come across as a smart Alec.

(09:33):

The other problem was the spending of money, particularly on credit cards and giving money away. So one of the biggest symptoms of mania, particularly at the high level, is this abundance of empathy for people. You really feel for people and you can't normalise it. You look at something on TV where people are starving and you just feel terrible about it and what can I do? Or you meet people and you see what's going on, or you get caught up in all of the social issues. Often it's not to do with being a man and all the problems that men are involved in. Domestic violence, domination, men generally. I used to get very upset about being a man. So the empathy for people was very strong and very dangerous because you're out there and you can do things and be used up. The problem really was to be used up because of your empathy.

Mark Creamer (10:33):

Yeah, quite. It involves sometimes giving money away.

Neil Cole (10:38):

Oh yeah, big time. Particularly people who don't have any. I did. I did that a lot. I did that a lot.

Mark Creamer (10:45):

Now you've kind of alluded to this, but I'm interested in how it affected people around you. Let's take work first. Presumably your parliamentary colleagues would've noticed these ups and downs a bit.

Neil Cole (10:55):

I think in the context of the nature of politics, as they say, a week's a long time in politics, well, 10 minutes is a long time in politics. There's always something going on. So they just thought it was me and I just thought it was me. It wasn't at the workplace. Where it was really bad was when I was working at the legal service, and 1984 was the worst case of burnout. It was melancholic depression, and my friend Richard Wynn and my other friend who was the nurse, Maureen Fanning, they were very upset, but they didn't know what to do. And we thought it was because I'd had a girlfriend that I'd broke up with that I'd been going out for two months and also work stress. So I went to see a counsellor and talked about all sorts of gobbledygook about my past and nothing about the need to be on antidepressants. So seeing the depression was hard on my work colleagues. But equally hard was the fact that they couldn't do anything about it. And we just thought, oh, it's the pressure of work.

Mark Creamer (12:03):

And family or friends outside work? Did they?

Neil Cole (12:06):

No, no, no, no. Nobody said anything. I would tell people, oh, it's actually interesting because in 84, Lindsey Tanner who became the federal member of Parliament and I were close mates and he used to ring up and take me to the football. He backed for Essendon and I barracked for North Melbourne. I used to go to the football with him, even though it wasn't my team, and he knew how sick I was, and they didn't know what to do about it either. They just thought you'd come out of it, you'd get better and go back. So it was really difficult for people who were close to me, but it was explained by burnout rather than some sort of genetic illness called manic depression or depression. And I think in a way, that was the other problem. When I did come out of depression, I really came out of it. So I was up there, but there was no problem at all. I'm better now, which I wasn't, and I was just high.

Mark Creamer (13:02):

Yeah, sure. Absolutely. Be interesting to see what would happen today. I mean, I'll talk about that later, but hopefully we have come at least some way eventually. Then 1993, I think you said that you get diagnosed and you get introduced to treatment. And presumably the kind of foundation of treatment for bipolar has traditionally been lithium invented by an Australian psychiatrist, wasn't it John Cade?

Neil Cole (13:23):

Yeah, I've written a play about him called Dr. Cade.

Mark Creamer (13:25):

Have you? But it kind of revolutionised the treatment I think of bipolar or manic depression as it was then. And deinstitutionalized many people. So were you on lithium?

Neil Cole (13:35):

It's an interesting story. I was put on lithium and it changed me almost immediately. I wasn't driven by sexual desires anymore. My racing thoughts went markedly down. My loquaciousness stopped. And on top of that, I just started to feel relaxed, almost. The lithium, which I'd been on for 30 years, I had to go off it because of the damage to the kidneys. But as a drug for people, it's fantastic. It's the best.

Mark Creamer (14:08):

Yeah, it's an extraordinary drug, isn't it? So it dampened down the highs. Did it also make depressive phases also less serious?

Neil Cole (14:16):

No, it didn't. I had huge problems with depression after I was diagnosed and I've been on just about every medication possible and nothing worked, even though times I thought I wasn't depressed when in fact I was. And it manifests itself in very strange ways.

Mark Creamer (14:34):

So we'll come back to other medications. Just sticking on the lithium for a minute. So you had to come off it because of liver damage?

Neil Cole (14:39):

Kidney damage.

Mark Creamer (14:40):

Kidney. Kidney damage. Did you notice when you came off it, did you lose the impact of -

Neil Cole (14:45):

No, it was disastrous for me. I went on to, I won't say the drug because it's good for some people, it just wasn't for me. And I had quadruple bypass heart operation, and then I got really sick and started to,

even before the heart, I was falling over and all these things, just total loss of muscle. Anyway, it came to a head, worst of all when I was over in Edinburgh Festival for a play that we had on there, and I had to fly back and I was so sick. My ex-wife, Rosalie came up and got me from Singapore, and it was all due to the drug I was on. So it was pretty disastrous. So we changed that drug and went on to another one. And that's been very successful for me. I do suffer highs. I shouldn't say suffer, but you do. They're not good for me. No. Some people say they're good, they're not for me. They're terrible. I had a high just prior to Christmas, which was not good. I gave away a lot of money. But there are medications for the mania, which work and which are really very good for the depression. I think it's a lot harder, and that's what I've found.

Mark Creamer (15:57):

So for the mania, people would call them mood stabilisers would they?

Neil Cole (16:00):

They are mood stabilisers and they're very effective. They also can in some cases help you sleep.

Mark Creamer (16:08):

But depression, nothing. Now we got a raft of antidepressant medications of all types. So none of them you found particularly helpful?

Neil Cole (16:16):

Oh, some of them were damaging too. They caused anxiety or sleeplessness didn't work. One other drug that I was on for 12 months was useless, but it helped you sleep. And I was told by a professor that drug was no good. And so I changed it. And then I've been good for 20 odd years.

Mark Creamer (16:40):

Really. So has your medication been stable for 20 odd years? More or less?

Neil Cole (16:44):

Yeah it was. The change for the lithium, and also there was an attempt to put me on another drug, which I won't mention because I don't want people to think it was bad, but it was disastrous for me. I just went as high as a kite. And an indication of the level of a high could be, I was watching a video about dad's army and I was laughing my head off with watching it, but I was laughing for about three hours. When I looked at it six months later, it was good. It was funny, but it wasn't that funny. So the high is not a good thing. You're dysfunctional, you can't write, can't do anything. But medications are good, but they're not a one size fits all.

Mark Creamer (17:30):

No. Sure. And so I was going to ask about adjunctive kind of treatments, more sort of psychological psychosocial kind of stuff. And I suppose you touched on there your early warning sign, for example, perhaps in that case was laughing excessively at this thing. But did people sit down and talk to you about helping you identify what your early warning signs were and how to manage them, give you skills to manage them and so on?

Neil Cole (17:54):

Not really. My psychiatrist, Rosie was always very good. She's retired now. She was more worried about the depression because she always felt she could treat the mania fairly well and that I was more on the depression side. But look, reading as much as I've done and talking to her and talking to everybody else about bipolar, there are certain warning signs for mania. One is uncontrollable libido, which just hits you, you can't believe.

Mark Creamer (18:26):

What about sleep?

Neil Cole (18:27):

Shocking, big problem. I just would get a book and read and read. I read a lot. I would read it all night. I think the best things for the mania, knowing that you're good at, is apart from the libido, is that sort of sense of elation and feeling. But what happens with me, which is the real one, is I become extremely anxious. When I say anxious, I'm not scared, anxious, but I'm always in a rush to do things and I get frustrated and I lose things. I can't find my keys and it just to the power of 10 of what it should normally be. So there's that.

Mark Creamer (19:04):

So it's pretty unpleasant actually.

Neil Cole (19:05):

Very unpleasant. Very unpleasant. It's not a good state for me.

Mark Creamer (19:08):

And you did talk about the fact that some people seem to quite like their manic states or whatever, and I wonder if it's linked with creativity. Do you write better or more when you are going through a high phase?

Neil Cole (19:19):

It's a controversial issue, but there's three phases. There's mania high, there's depression, melancholia low, and there's one in the middle called stability. It's the one in the middle where I'm most creative. And the reason is the bipolar mind has certain creative aspects to it. There's no question. But you don't have to be high. In fact, I believe you're dysfunctional. So if I go high, which happens, I never do writing. If an idea pops up, I just write a word for it or a couple of words. And then when I back out of that state, then I can start working properly. When you're melancholic, you're extremely aware of things. However, it's a very depressive negative awareness. But you can still have great insight, which helps with writing, believe it or not. But nobody talks about that because everybody talks about the happiness of the high because they think it's some joyous experience and melancholy isn't, but they forget.

(20:25):

But in a state of melancholia, you can be insightful and creative. The best example I have ever had is Samuel Beckett who wrote *Waiting for Godot*. If you look at something like that and how depressed he was when he wrote it, you see this whole idea of what is the point of existence. But just quickly on the signs and what you can do with mania, you don't know you're in it until you're in it. That's a big problem because it creeps up on you. And the same with depression. You don't know that you're depressed, you get certain signs, then you start to realise, oh gee, I am. But it's not as simple as just saying, oh, here's the sign, do it. The other thing that I've done, which has been fantastic is I took up running. But running itself is a great thing for low mood depression. If I go high and I'm running, I can run too fast and can do damage. My body is behind the mind.

Mark Creamer (21:28):

Yeah, very interesting. I'm a big fan of aerobic exercise generally, and I think we've got more and more data now, especially in treatment of depression, how effective it can be in helping to manage depression support groups of any kind. Did you ever join any support groups?

Neil Cole (21:43):

I don't like 'em when I say that. I love when I meet with people with bipolar or talk to people with depression or schizophrenia. I enjoy being amongst people with similar illness. I dunno, it's just the way it is. But I found groups they often get dominated by, 80% of the time it's done by 20% of the people. And I also found that when you go to those groups, some people tell you horrific stories and it can be quite upsetting. But I've also tried to keep a little in reserve to help people with mental illness as much as I can. And that takes up a lot of time. So I'm always talking to somebody who's not well.

Mark Creamer (22:29):

Almost all our listeners, Neil, are health or mental health professionals, have you got a message for them? What do you think they could be doing better? What should they do?

Neil Cole (22:38):

I think the best way to reduce the stigma of the illness and to be a good practitioner is to go and just look up what is bipolar mood disorder, to perhaps listen to a person with a lived experience. Because the difference is that a psychiatrist can tell you what happens. The lived experience can tell you what it feels like and what it's actually like. When we talk about low libido in depression, we're talking about no libido. It's gone completely, which is a disaster for relationships of course. And for the person. So my main message to people is just go and learn what the illness is. We don't have enough people, everybody say's "Oh, there's highs and lows", but it's got nothing to do with it. It's the symptoms. And it is about how do you deal with an illness like that? How do you handle people? And the best way to do that is to look up what the symptoms are and how they treat it.

Mark Creamer (23:38):

Yes, absolutely. Okay, so find out more about it. And I did like your comment about talk to people who've got it. I think that as mental health professionals, it's something we don't really do enough, so short of time. But if you've got the time to sit down with someone, and I hope this podcast of course will go some way to achieving that, but to talk about what it's actually like to go through this is a very important lesson for us.

Neil Cole (24:00):

And lived experiences become such a broad concept. So what I would say is for people that have listened to this podcast and people who are practitioners go away and learn as much as you can about bipolar, it's not that hard to do. It's not that hard to read on it. And so I would argue strongly for people to, when they're talking about lived experience, be specific, lived experience, bipolar or lived experience, schizophrenia rather than just a broad brush of lived experience.

Mark Creamer (24:33):

Absolutely. And particularly when in something like bipolar, we do have treatments that they may not be perfect, but they do help an enormous amount.

Neil Cole (24:41):

Obviously they do. And the only other thing I'd say is don't jump into the trench too quickly. People will look at somebody and say, oh, there are highs and there are lows, therefore they're bipolar, got nothing to do with it. They've got to be assessed properly and diagnosed properly. But in a general sense, to know and understand about bipolar is the important thing in a community level.

Mark Creamer (25:02):

And I was going to ask also about whether you'd have any advice for people who perhaps are suffering from bipolar or indeed their loved ones. I suppose similar in certain ways it would be to find out more about your illness.

Neil Cole (25:13):

I think that's crucial. But if you are caring for somebody with bipolar, it's pretty bloody obvious. It's not as if it's a mystery. There's there, with these symptoms, I would think for people caring for them to actually know what the symptoms are and how you can be supportive. It's very hard. Of course, it's very, very hard. Relationships are really damaged by depression, and mania, it's just a given. So it's very hard for carers. But with people with bipolar, we've at least got treatments that can work. And as you said before, it's not just the medications, it's running, it's aerobics, it's watching what you eat, don't drink alcohol. They're all same things as if you had cardio problems. But it's just manifestly bad to do things like drinking alcohol.

Mark Creamer (26:08):

Absolutely. I agree entirely. And those so-called common sense kind of things are actually so important in our mental health and our physical health and so on. And they're all things that in theory are within our control. Look, maybe that's a good note to end on, Neil. And we could easily have kind of talked for another hour, but thank you so much for agreeing to do it. I find it fascinating. And I do think that hearing about the lived experience of this condition is really important for us as health professionals and so on. So thank you very much indeed. Appreciate it enormously.

Neil Cole (26:38):

Thank you. It's good to be here.

Mark Creamer (26:39):

And to you, our listeners also, thank you very much for joining us on this episode of MHPN Presents In The First Person. If you want to learn more about Neil or myself, our bios can be found on the landing page of this episode. And in fact, you'll also find a link to Neil's recent book, the Trials and Tribulations in Community Law, which I'm sure is well worth having a look at. You'll find a link also to the feedback survey. So please let us know what you thought of this episode. And indeed, any suggestions you have about how MHPN can better meet your needs to stay up to date with future episodes, make sure you subscribe to MHPN Presents. May I also take this opportunity to say that Neil will be joining me again in an episode of MHPN's, A Conversation About series when he will talk about some of the stuff he alluded to today about working with people who have schizophrenia, helping people with serious mental illness to reach their full potential. But for now, it's thanks very much again to my guest, **Neil Cole** and indeed to all of you for listening. Thanks again and bye for now. Bye.

Host (27:42):

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