A Conversation About… Schizophrenia, Quality of Life and Performing Arts

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Host (00:01):

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 (00:19):

Hello and welcome to this episode of MHPN Presents A Conversation About. This is a podcast series in which we've got the opportunity to chat informally about a topic of interest to us and of course, hopefully to our listeners. My name's Mark, Mark Creamer. I'm a clinical psychologist and a professorial fellow in the Department of Psychiatry at the University of Melbourne. My guest today, my co conversationalist as it were, is a passionate advocate for people with serious mental illness. Neil Cole, welcome Neil.

Neil Cole (00:50):

Good to be here.

Mark Creamer (00:51):

In this episode we're going to talk a little bit about schizophrenia in particular, and I'm very interested in Neil's perspective on this because he's been working alongside and with people diagnosed with schizophrenia for a very, very long time. I think over 20 years. And so I'm looking forward to hearing about the insights that he's gained over that time about how we might best support people with schizophrenia in particular, but perhaps also other serious mental illnesses. To start with, Neil, now you've got an extraordinary background and I'd encourage our listeners to go onto the website and have a look at your biography because it is really quite amazing. But for the purposes of this episode, I wonder if you could say something about how and why you became interested in schizophrenia and in community support models and in advocating for people with a condition.

Neil Cole (01:39):

I had an interest when I was a lawyer at the Flemington Legal Service, but it was actually very rare that you went to court for somebody who had a serious mental illness. It was very uncommon. It's different today for all sorts of reasons, but I had that interest when I was a member of parliament. I used to have people come to see me who clearly had florid psychotic symptoms. One of them used to come in and would have different uniforms on each time and there were others like that. But when I was diagnosed myself in 1993 with bipolar, I became really acutely interested in all forms of mental illness, and one of them that I studied and met with people and with carer groups, was to do with schizophrenia. When I started working after I left Parliament at the Mental Health Research Institute with Professor David Koff, I was researching a lot of topics and particularly I took a great interest in schizophrenia because so many people I met had it and so many carers, and I wanted to try to understand the nature of the illness and how people live with it.

Mark Creamer (02:57):

Fascinating stuff. I guess the question of diagnosis is, it's sometimes a bit controversial and certainly the diagnostic criteria for schizophrenia evolved over the years. What's your take on diagnosis generally? Do you think it's important in mental health?

Neil Cole (03:12):

I think it's crucial, but they're not infallible. I think in the case of schizophrenia, the psychotic symptoms, which can include paranoia, the police are after them or hearing voices internal or external. The symptoms are so floridly obvious. I think it's possible to diagnose people with schizophrenia. Where it becomes difficult is where psychiatrists jump into the trench of a particular diagnosis perhaps too quickly or the people don't have the severe symptoms of the illness. But by and large, I think it's probably relatively obvious if somebody's got schizophrenia and particularly with the psychotic episodes.

Mark Creamer (03:59):

Yes, quite, and diagnosis I think is really important even though as you rightly point out, the system is fallible, but the diagnosis is really what drives treatment, doesn't it? And I think you get the right diagnosis, you've got a much better chance of choosing a treatment that's going to work. But you were talking there about the sort of more florid symptoms. We sometimes talk, don't we, about positive and negative symptoms, schizophrenia, and so those hallucinations, delusions, whatever are the kind of positive symptoms, but we see a lot of negative symptoms as well.

Neil Cole (04:27):

Yeah, the negative symptoms is mostly what I deal with because our project or the work that I do is all based on people being medicated. The majority of them will take clozapine, which is very effective for treating the psychosis. But the problem is that they have secondary symptoms of lethargy. They're phlegmatic in the way they talk to you, they don't have any interest in things. They're uninterested and they just meander along without any contact or community. Often they have very poor hygiene, they won't wash. And it's a problem for depression too. It's not just schizophrenia where people don't look after themselves. So there is the negative symptoms which require a lot of work.

Mark Creamer (05:20):

And that are not really quite so responsive to medication.

Neil Cole (05:24):

Well, it's just when you're like that, you're like anybody, but they get depressed. So you take antidepressants, there's a very high suicide rate for people with schizophrenia. There's a lot of obsessions. There's what my observation has been, people get obsessed with particular things, shopping, gambling, sometimes obsessed about particular people and issues, you know, you can get very obsessed, which is a major issue for people.

Mark Creamer (05:52):

And these kinds of symptoms to state the blinding obvious really make it quite difficult to hold down a job or even sometimes a place of accommodation, for example.

Neil Cole (06:02):

Accommodation's the big issue, and we have to provide not only accommodation but support within that accommodation. So it's independent living with support. So it's a 24 hour thing. We've done with Professor Allen Fells and Richard Wynn who was then the minister housing, we've established a lot of housing places for people with schizophrenia. I think we're going to get up to over 400 places now. Housing is crucial for everybody, but it's even more crucial for people with schizophrenia, a lot of them end up on the street, unmedicated. So we've got to provide housing support services, an income stream. There's not many jobs, as you say, the nature of their illness doesn't really lend them to getting many jobs. Having said that, the prognosis for a person who's got a job is very good, much better than if they don't. It's about 50% improvement.

Mark Creamer (07:01):

Is it? That's a very important statistic, isn't it? I'd like to come back to those broader psychosocial issues in a minute. I guess first of all though, you mentioned clozapine. I think medication is likely to be a kind of foundational treatment in schizophrenia. I think when the Phenothiazines came on board in the late fifties, early sixties, they kind of revolutionised treatment and led to a lot of de-institutionalization, so on. They had a lot of problems with them. We've now got much better medications, I suppose, and atypical antipsychotics, olanzapine and whatever, risperidone. I guess most of the people that you work with would be on those kinds of medications.

Neil Cole (07:37):

Absolutely. Majority clozapine, overwhelming majority. And those who aren't worries me sometimes when they're put on particular antipsychotic drugs, when I think they shouldn't be on them, they should be on something else. That's a layman speaking. So I don't say to the person, don't do that. I say, look, go back and see your doctor or psychiatrist. So it's a huge issue medication, but because of its success in reducing psychosis, we support it. But it's by no means a magic bullet for schizophrenia, but it's been very successful with the psychosis.

Mark Creamer (08:13):

So it certainly helped. The side effects are certainly much less than they were with the old style antipsychotics, but there still are side effects today.

Neil Cole (08:21):

Oh, huge. The big one is putting on weight and some people put on 20 or 30 kilos. So that's seen as a sacrifice you have to make in order to get rid of the psychosis, which is the practitioner's argument, always, 'oh, well look, we won't worry about that because we resolved that'. But you say, 'no, no, no, you must look at that'. That's all part of the treatment. But they don't do that because they're too busy and often it's not, they just worry about that side of it. The other side of it is difficult. There's no question. It's hard. It's labour intensive working with people.

Mark Creamer (08:58):

Quite, quite, I think there's been an increasing interest in the last, I dunno, decade or two, couple of decades probably in the role that psychological treatments like cognitive behaviour therapy can play as an adjunct to the medication. But I am interested in moving on more into your area of interest and maybe kicking that off perhaps with the notion of perhaps a link between mental illness and creativity and whether that's something that we can use therapeutically in the broadest sense of the word.

Neil Cole (09:27):

It can be, and it's very important. There's always the old debate that you're saying people are creative, but there must be some other reason. Probably if you've got prior family involved and they had creative, and there's a genetic link there, which talent is that way, it comes through genes. So there's always a great debate about whether you should actually promote the idea of creativity and mental illness. But nobody's saying that it's good to have the illness or some people do, but that's inappropriate in my view. But empirically, we can show there's a very strong link between bipolar and unipolar disorder and creativity. I'm an example of that. I've written 35 plays and three books.

Mark Creamer (10:15):

And for the benefit of the listener, you've had a long history of bipolar disorder yourself.

Neil Cole (10:19):

Yes, I've had bipolar all my life and diagnosed in 1993. But I've exploited the concept that there is this link between creativity and there are two major studies done, one by Nancy Andreason, which was a 15 year longitudinal study of people with high profile successful writers. And the conclusion was that about 40% of them, of those writers had either bipolar or unipolar. And on top of that, Professor Kay Jamison did a study and she actually wrote a book called Touch with Fire, which was an inappropriate title because people touched with depression are also abnormally creative. It's outside of the range. So there's a link between creativity and mental illness. What I've done, aside from my personal things, is try to work out how we can use creativity with people with severe mental illness to improve them. Now, that was my hypothesis they say in science, and my hypothesis has not been proven.

Mark Creamer (11:32):

Right.

Neil Cole (11:33):

So it's very important to say that.

Mark Creamer (11:36):

Nevertheless. Let's talk about your program if we could. So you've got a program or involved with the program called Into the Limelight.

Neil Cole (11:43):

It's called Into the Limelight, and it was based on the theory that if you take somebody with a mental illness and you put them into a theatrical production and you devise their character; so if you are an actor, you get into the part of the character and you learn the character, you learn the part. So the theory was that I would get all of them, people with schizophrenia, as it turned out there was others, bipolar and depression, and give them their character and let them express that inner performance. We did that. So one guy had always had an idea that he wanted to be a cowboy. So I made a part for a guy who was a cowboy and he loved it. He enjoyed it very much. So we've tried to create a piece, and on top of that, we had professional director and a professional actor in the mix. It went really well, but it was disastrous for people with bipolar and with depression.

Mark Creamer (12:46):

Interesting.

Neil Cole (12:47):

Even though they were medicated, and that was the ruling, they had to be medicated. The people with bipolar often went high or got extremely depressed when it was over or during production. And people with depression got anxiety, had problems with getting to production phase. Now, if we'd had the resources, I would've gone ahead with people with bipolar and depression, but we didn't have the resources. But more importantly, what we discovered was that people with schizophrenia are happy in the moment. They don't vary. Now, my theory was wrong. I thought we could somehow improve them over time. And while I haven't researched extension, we did initial research for shows, it doesn't work. However, they've got a great in the moment feeling.

Mark Creamer (13:40):

I was just going to say, and that's not to be sneezed out or dismissed for a minute, is it? I used to have a clinical lecturer who used to talk about difference between making someone feel better and making someone get better. And there's nothing wrong with the former as long as we know that that's what it is. This is about improving their quality of life today and so on. And there's a lot to be said for that. Were you disappointed that it didn't produce some longer term effects?

Neil Cole (14:03):

I was, but I'm a writer and I'm producer, and I think we need something more professional. Somebody that does therapeutic drama or play. The workload for doing theatre, and also the problems of getting people to the starting gate to do it was a bit overwhelming as well. So we changed it from doing theatrical productions to doing videos. And so for the next, if we get the funding, which I think we will, the next one will be 20 jokes, and they're very small jokes that each one can tell and we can get their responses and we'll put it on at St. Kilda Film Festival. So technology these days is so good and so simple, it's easy to film, it's not a problem. Whereas with rehearsals, it caused a lot of stress for people, not necessarily the people with schizophrenia, but it was a hard process.

Mark Creamer (15:03):

And this new project, are you going to limit it to people with a diagnosis of schizophrenia?

Neil Cole (15:07):

Ever since we had the first bad responses, we've confined it to people with schizophrenia. And also the reality is that people with schizophrenia are probably the greatest need. And the seriousness of their illness is such that with the secondary symptoms, there's something to be gained by being involved in theatre, video projects. So look, it's a very worthwhile thing to do. The other thing is we do things like we go out to lunch and we have a pizza together, and the writing, they get a laugh out of it. I wrote them all, but you get a laugh out of 'em. But also sometimes you can draw unexpected things to be honest, that you draw out somebody, you discover, oh, they're a really good storyteller, and they just tell the story and you put it in. So the interaction is what's important, but it's also the hardest part because you've got to put time into people. And a friend of mine gave me $10,000 once to do a production with people with schizophrenia, and we did it. And the people with schizophrenia were fantastic. The actual actors we had in were problems. They were problematic as was the director. So it's interesting trying to bring it into a space. People get into the space of performing and they love it. You try to make it better by bringing, and it just complicates it.

Mark Creamer (16:43):

Well, it's all a learning experience, isn't it? And obviously you've learned a lot by the process, but I am struck by and sort of agree with your observation that the social contact side of it is very, very important, maybe equally important to the drama side, do you think?

Neil Cole (17:00):

I'd like to think the drama side's more important, but I'd like to think that, but I dunno that I'm right. I think that being with the people offering something different, going out to lunch with 'em, elevating them by mere talking to them.

Mark Creamer (17:17):

Exactly, exactly.

Neil Cole (17:18):

And getting them engaged is a wonderful thing. But it's labour intensive. It's hard to do. I sort of have become less communicative over the last couple of years just because I've been doing it for so long. It's hard to sort front up sometimes to do it. What I have done though, we made a little documentary about schizophrenia, and I handed over the whole thing to the people to do it themselves, and they did. The questioner had schizophrenia or the people had schizophrenia, and it was extraordinary. The quality turned out to be good, but it would've been different if I'd had somebody else come in to do it. It wouldn't have been a true representation of schizophrenia.

Mark Creamer (18:06):

Quite. That sounds like an extremely interesting project actually, and probably should be doing more in that kind of line of things.

Neil Cole (18:13):

Absolutely.

Mark Creamer (18:14):

The importance of us as health professionals understanding more about these disorders and what it's like, and this seems like a vehicle. We mentioned the fact that the negative symptoms of schizophrenia have a really potentially damaging effect on life and quality of life and functioning and so on. And we also kind of alluded to the fact that as people drop out of treatment or don't adhere to treatment, that we run the risk of seeing this downward spiral into loss of employment and then homelessness and so on. Obviously, adherence to treatment is a massively complex issue, which we won't get too much into now, but do you see programs like yours as being part of the jigsaw puzzle to help hold people together as it were?

Neil Cole (18:55):

Absolutely. I think social isolation, common, particularly in men and with schizophrenia, is a complex terrible issue because the nature of the illness means you probably can't get a job. You're relying on disability support and you've got to fill in your day. And I really think that the more interaction we have with people, the better it is. In the case of the project, and even with me because I'm bipolar and I'm on medications, I can say to people, look, you can't go off your medication. Look at me, I'm taking it. But for people with schizophrenia, it is so tough. It's such a hard, unrelenting illness to have. People can live good lives, but it requires a lot of work. And I think the more we engage with people with schizophrenia, the better it is for them, the more we have something to do with them. Like my project Into The Limelight, when we did it with the theatrical productions and I had two actors and a director, professional director, and a professional camera person, it was extraordinary. One of the actors, my mate, Don Bridges, they just loved him because he was there and is involved. And I think when you see them there and being involved, it elevates them too. And they love it.

Mark Creamer (20:30):

Absolutely. And that opportunity to be actively involved in something meaningful and something creative and so on, it's so important when, as you rightly point out the risk is that they're very socially isolated. They're living in low quality accommodation, boarding house accommodation or whatever, and it's not surprising that their quality of life is appalling really. And I'll just come back to that. You alluded to this earlier, but I just want to really emphasise how important these broader psychosocial interventions are. You talked about how important getting someone into jobs, for example.

Neil Cole (21:01):

Yeah, and I think I've often said to people, we don't just want upmarket basket weaving. That's why I said we got the actors in and the director, because you're giving them professionals, you're really involved. But aside from that, the access to psychology services has been improved dramatically, but usually not bulk build. But all of those social services, I still am the patron of Prahran Mission where you put on meals and that was something people could come and do and didn't cost them too much or anything. Or you had a coffee shop where everybody can come to. And also the place called TJ's, where I first started back in 2002, the first theatre project I did was a psychosocial rehabilitation place. It was pretty basic. It was in Footscray and they got rid of it. But I think the interactions between people are crucial, particularly other people with mental illness.

Mark Creamer (22:06):

Quite, and perhaps we can put some links to this in the resources page, but there are a number of organisations that strive to fill that gap, I guess, aren't there, that provide social networks for people with serious mental illness.

Neil Cole (22:19):

It's dropped off since the NDIS

Mark Creamer (22:22):

Has it?

Neil Cole (22:22):

Well, because there's the, generic services are just fallen by the wayside, and it's now individual, which is good and bad. It has its downsides. And one of them is there's not as much community engagement.

Mark Creamer (22:36):

If we're thinking about community support for people with serious mental illness, schizophrenia and others, presumably issues like awareness and particularly stigma are important. Are we doing enough, do you think, to reduce stigma? What more we should we be doing?

Neil Cole (22:51):

Well, it's very hard because when some incident occurs and to person with schizophrenia involved, which happens quite often, all your wonderful de-stigmatization programs go out the window and they suddenly start attacking people with schizophrenia. I think the important thing is for people to be educated about the illness, it's not that hard to find out about the illness. And when they find out about the illness, they'll realise that 95% of people are harmless. They don't do any damage. They're really good people, and they're in fact very pragmatic and easygoing because of the medications and the illness. So I think if they study it, they'll learn a lot about it and understand the nature of psychosis. But that's the best way to reduce the stigma. And it's equally important, I think, for people to be available to talk to people with schizophrenia, because the more we do that, more engaged, the better it is. There is a huge problem with suicide in schizophrenia, about 14%. It might've gone down, the suicide rate was declining. And then of course, you have people with terrible depression and other things, and they all need to be handled well.

Mark Creamer (24:11):

Absolutely, absolutely. And as you say, we were saying enormous proportion of our homeless population have serious mental illness, and they also are vulnerable in terms of a whole range of things.

Neil Cole (24:21):

And hard to treat.

Mark Creamer (24:22):

Hard to treat, hard to engage. Yeah, absolutely. Absolutely. Look, that's been a fascinating and very valuable conversation. Neil, do you feel we've covered the key points? Anything you'd like to add?

Neil Cole (24:33):

The key point is that we must concentrate on the serious mental illnesses. The reason we've got to do that is because mental illnesses become so broad, so wide, and really we need to put our resources into the serious ones, like people with schizophrenia. It is a labour intensive process, and we shouldn't baulk that issue, but we should make sure that people are aware that it is the serious illnesses we've got to address. Our public health system, our public mental health hospitals. They have to deal with the most serious cases, and that we neglect that area of public hospitals and public health. So that would be the big message that these are serious illnesses even when medicated, and it's a tough gig, and they need support.

Mark Creamer (25:27):

Yeah, exactly. As you say, increased awareness and understanding.

Neil Cole (25:31):

Absolutely.

Mark Creamer (25:32):

Yeah. Look, maybe that's a good note to end on. We've run out of time, but it's a fascinating topic, and thank you so much again for agreeing to have this chat with me, Neil, it's been a great conversation and I must say I'm really impressed with the work that you are doing and have done for so long in this area and your generosity in helping others with schizophrenia and other serious mental illnesses. So thank you very much, Neil.

Neil Cole (25:54):

Thank you, Mark.

Mark Creamer (25:55):

And to you, our listeners, thank you very much for joining us on this episode of MHPN Presents A Conversation About. If you want to learn more about Neil and his work, and we've touched on a whole lot of interesting things there about the program Into the Limelight or indeed about his recent book, go to the landing page for the episode. There's all sorts of links there. You can find out about me as well. And you can also find a link to the feedback survey. So please let us know what you thought of this episode and what kind of suggestions you might have to help shape the future of MHPN podcasts. To stay up to date with MHPN podcasts, please make sure you subscribe to MHPN presents. And I hope, and I'm reasonably confident that we will be hearing more from Neil in future podcasts, but for now, it's thank you very much again to my guest, Neil and to all of you for listening. Thank you very much, and bye for now.

Host (26:49):

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