

In the First Person... Improving the physical health of people living with mental illness

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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 (<u>00:09</u>):

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

Russell Roberts (00:27):

Welcome to this episode of MHPN Presents In The First Person. It's a podcast series that provides you with the privilege of hearing people's stories in their own words and how multidisciplinary care helped or indeed impeded their recovery. In this episode, you'll hear firsthand about why people living with mental health conditions tend to have poorer physical health and what we can collectively do about it. My name is Russell Roberts. I'm the National Director of Equally Well Australia, and with me today is Fay Jackson and Paul Klotz. Welcome Fay.

Fay Jackson (01:04):

Hello everybody.

Russell Roberts (01:05):

And Paul, welcome to you.

Paul Klotz (01:07):

Hi Russell. Hi Fay. I am looking forward to our fireside chat we're about to have.

Russell Roberts (01:13):



It should be great. It won't be Trumpesque, but it should be great. Today what we're going to do is talk about why people living with mental health conditions have a poorer physical health and reduced life expectancy. Also, what mental health professionals can do to protect and support your client's physical health in the most effective way and the most effective things you can do to also enhance their mental health and wellbeing. And thirdly, some practical tips and insights and reminders to make you a better mental health professional. So to help us with that, we have Fay Jackson, Fay, tell us a little bit about yourself and your background in a couple of sentences.

Fay Jackson (<u>01:51</u>):

So I'm a person with lived experience. I hear voices. I see things that other people tell me they can't see, not convinced. And I have lived with PTSD and anxiety. I was sexually abused as a child and I think that that's the root cause of my mental health issues. Of course. Then there are other betrayals. As I went along in life professionally, I started work as a peer worker in a public mental health service. Then I was a manager of peer workers. Then I became the director of consumer care and community Affairs in that public service. Then I was so honoured to be invited to be the inaugural deputy Commissioner with the New South Wales Mental Health Commission. And I've also been working 10 years with Flourish Australia, which is a large not-for-profit specialist mental health service. And I do a lot of national advocacy from a lived experience perspective.

Russell Roberts (02:47):

Absolutely. And Fay and I are joined by Paul. Paul, tell us a little bit about yourself.

Paul Klotz (02:52):

A little bit about myself from a personal note. I'm the richest man in the world. I have four amazing sons and that's what keeps me going through the hard times. I spent 35 odd ideas in the corporate world before my life suddenly changed. And it changed mainly due to a fairly long period as a young child, of childhood sexual abuse, which then led from there to a whole range of mental health, mental illnesses, as well as a very detailed physical health in terms of cancer and heart attacks and a whole range of things. That's what motivated me to get off the sideline and join the team. So I work on probably about 15 plus different lived and living experience committees and a whole range of research projects, just trying to raise a profile and make a difference out there. And that's probably one of the reasons why I'm here today with these two wonderful people.

Russell Roberts (03:45):

Absolutely. And you can see Paul and Fay are here because they're experts by experience and decades of expertise and insight into their experiences of having contact with the mental health and physical health system. So why are we talking about this today? Why is this important? Well, just a few stats from our recent data report. Every year over 16,000 people living with mental health conditions die prematurely of a potentially preventable, get this preventable, not total preventable physical health condition. Just to put that in context, that's a massive number for just one of the scores of diseases in the ICD 10 category of diseases. Every week in Australia, 16 women living with mental illness die of breast cancer, 12, 12 of these 16, every week are dying of preventable, potentially preventable breast cancer through screening, early detection and or quality treatment. So this stat is repeated for just about every disease type. It is not right, it is unjust, and together we can do something about it. So that's why we are having this conversation. I think today's podcast could be one of the most important podcasts that you ever listened to. Maybe not for yourself, but for the people and the clients that you



work with today. You may do something which will save somebody's life and we've got the best people to talk about it and a really fascinating journey. So Fay, let's get into it. Tell us a little bit about your personal journey around this area.

Fay Jackson (05:21):

So my personal journey is that I, as Paul, I spent two years in a children's hospital between the age of 10 and 12, I was sexually abused between the ages of four and eight. The most wonderful words I think I've ever heard is now she's eight, it's too late. And they left me alone. But I did spend two years in hospital between 10 and 12 and was very ill a lot as a child. I ended up then as a teenager, people didn't believe me. They didn't believe that I was sexually abused. When I went finally as a teenager, got to the police, they told me to just go away. They had other things that they had real crimes that they needed to deal with. I became very mentally unwell. I started hearing voices. The anxiety was extreme. I have never lived a day of my life without feeling frightened.

(06:18):

And of course that's going to lead to mental health issues. So the physical trauma is the reason I believe that I have mental health issues. I was then diagnosed, I'd been diagnosed with depression and anxiety and PTSD and that. But when I reached 38, I was diagnosed with bipolar or bipolar schizoaffective disorder depending on which psychiatrist I was seeing. And was forced to take medications that within two days the shaking in my body started and it was quite extreme. So they changed medications a few times, but ended up parking me on lithium and a few other things. And the shaking continued, but I wasn't allowed to come off the medications. I was on community treatment orders. And very quickly my kidneys, liver, thyroid all started to be impacted by these medications, but I still wasn't allowed to come off them. I ended up having my thyroid removed from cancer.

(07:23):

I've had five different types of cancer, seven different times I have blood clotting disorder. I'm not saying that that's caused it, but the issue that I had was trying to get people to listen to my physical health issues because of my mental illness. As soon as they see bipolar or schizophrenia or something, it's all in our heads and it can't be the physical health. The chronic illnesses that I've ended up with were avoidable and should never have happened. And five years ago I thought I was going to have to leave work, which would've meant we would've lost our home, my family would've lost their home. I was the breadwinner and there would've been no inheritance or anything because I wasn't believed. And it took moving to another area, another location to find a doctor that took my physical health seriously and believed what I was saying. And he gave me permission to come off the psychiatric medications and started treating my physical health seriously.

Russell Roberts (08:34):

And Fay what you've shared is an example of what we call diagnostic overshadowing.

Fay Jackson (08:39):

That's right.

Russell Roberts (08:40):

When you see a mental health professional, they focus on the mental health diagnosis and they forget the rest of the person. And this is why the chronic diseases, premature mortality and the poor health is so bad because they focus only on the mental health diagnosis. So the diagnosis to overshadows



everything else about that person and the data from lived experience Australia shows that half of people in contact with mental health professionals feel as though their professional doesn't listen to them. And only one in five feels that their professional takes them seriously when they raise physical health concerns. And so your personal experience just reflects what's happening for so many people. Paul, tell us about your story.

Paul Klotz (09:20):

Very similar to Fay. As a young boy, I was sexually, physically and emotionally abused by a number of Christian brothers whilst I was at boarding school. And basically being passed around, that led to my brain basically shutting down, fragmenting. So I spent the next 40 odd years hiding away. What I didn't realise at the time, this is what I call out to the medical professionals, is to look to the science. So for me, because of that shutdown, because of the fear factor, there's the thing known as general attachment syndrome, which is your fight and flight. So it's how the body reacts to those things. It's level one, level two, level three. So my body was basically running on level three. So I was living with cortisol, being pumped through my body 24 hours a day, seven days a week. And the tap couldn't be turned off because of the trauma that my mind and therefore the body was having to endure out there.

(10:15):

That's what I believe is the precursor to all of the things that I went through from a physical perspective, as Fay said, I mean I've had cancer four times through different types of cancer. I've had a heart attack, I've still got a cerebral aneurysm in the left hand side of my brain. I've had a stroke and I suffered a mini one about 10 days ago, which I've mostly recovered from. Now I've got FND, I've got epilepsy. There's a whole range of other physical health complaints. I was diagnosed late, although on reflection it was always there with borderline personality disorder, DID. So there's multiple personalities that I have. So all of these things were running in the background consciously and subconsciously I became aware of these things. And the frustrating thing for me is that, again, like Fay said, yourself, Russell is all of this, or at least a large chunk of it could have been preventable if doctors had just put two and two together rather than looking at my body from a mental perspective or just from a physical perspective, we need to have that collaboration between the two.

(11:21):

We need to have that conversation. They need to be able to help us. I mean, our cases are a little bit different because of the childhood abuse and the trauma. So we are not as open, we're not as forthcoming with what's happening in our lives. But from a GP perspective, if they are noticing that, geez, Paul, you're having all these physical problems, man, that's not normal for anyone out there. Do you want to talk about it? Can you give me some background? I mean, that's an obvious key to the door to say, let's have a different conversation. And for me it's not about the GP's having to solve it, it's about them just starting that conversation. Having someone that I can talk to, hopefully trust a safe place, safe person that they can then say, hey, I'm probably not the best person to talk to, but I can refer you to someone. So they've got skin in the game, they need to step up and start to look at the bigger picture, look at all the environmental factors that occur. So I'm sure we'll go through a lot more of that. But that's the background.

Fay Jackson (12:19):

I really agree, Paul. And I remember I had lung clots, lots of lung clots. I couldn't get anybody to believe me. I had them for months and months. It got to the place I couldn't even pick up a plate. And I had a six



week old grandchild that I couldn't hold because I was so unwell. But it was all in my mind because I'm mad.

Russell Roberts (12:43):

So what would there be advice, Paul, you mentioned GP's, but a lot of people listening to this podcast aren't GP's. They might be psychologists and social workers. They go, hang on, this physical stuff is outside of our normal remit. But what would your advice be to someone who doesn't have, like GP's, have clearly a whole of person remit, but people in other mental health professions. And also you've both talked about beginning and the cause being based in sexual abuse early, but also for those people who don't have a mental illness as a precursor of sexual abuse, when mental health professionals are working with them, what can they do? What would you be your advice to them when they are working with someone who comes with a mental health diagnosis?

Paul Klotz (13:26):

Yeah, I mean there's some key words that I sort of frame it around. First is observation. We've got these eyes and we've got these ears. We need to actually observe what's happening in that person's space. And then from there, what they need to do is listen. Listen to what's being said. Listen to what's not being said, listen to how it's being said. And then basically ask them questions. Give the invitation for the person to talk to them. And if they're not comfortable talking to you, ask them is there someone else that you think you could talk to? Whether it's a social worker, whether it's a peer worker, someone that else that they feel comfortable with. And then seek confirmation affirmation. So what you're saying to me, what I'm observing is X, Y, Z. Is that accurate? Yes. Okay. So as a course of action, these are the things that I think that I can help you with.

(14:16):

These are the things that other people could help you with. Would you like me to organise some referrals for you? So they're just some simple basic steps that it doesn't matter what role you have, not necessarily GP's. It could be the person, the triage nurse at the emergency department. It could be a social worker that you're talking to. It could be an OT that you're seeing because there's some damage that you had. There are obvious signs that are there. We may not be able to articulate that because of what we're going through. And when I say trauma, it's not just from childhood sexual abuse. If you are confronted with cancer, if you are confronted with some life event that's there, there is going to be a level of trauma. It may not be complex trauma, but there's going to be a level of trauma, which means you're not thinking clearly. So that's where we're dependent on the rest of the people. To pick up on those little signs and just start a conversation. For me, one of my favourite phrases is we need to normalise this conversation.

Fay Jackson (15:11):

Yeah, I agree. And I think the asking questions is the big thing, Russell, particularly even with the little children as well, normally like my mother was taking me to the doctors every week when I was little. I remember it very clearly and I was bleeding. I was in a lot of pain and no one asked the question.

(15:35):

And when I was in hospital in Sydney for two years as a little kid, they must have seen the damage. No one asked any questions about that. So this is sounding like it's about childhood abuse, but as Paul said, it is about any trauma. If a woman is being abused by the husband, ask questions. If somebody is being abused at work, ask questions. If people are coming to you with lots of physical health issues, there's



something going on, there's something behind it. So ask what's going on and then try and work it out from there. But don't jump immediately to let's treat the person for their mental health issue and forget about what the consequences of that treatment are to our physical health. Paul and I are unlikely to live into our older age. The stats say, depending on what research, 17 to 25 years younger, I've already outlived that 17 year mark. But everything that I live with, the chronic illnesses that I live with could have been avoided. That even if they weren't avoided because of the medications, they still should have been taken seriously and managed carefully over the course of a lifetime. Because now I've got Parkinson's and that didn't need to happen.

(<u>17:01</u>):

And the other chronic illnesses that I've got didn't need to happen or didn't need to be so bad if they were treated early and if I was respected, rather than denied what was actually going on in my body as a result. Not just of the trauma betrayal and gaslighting, which really affected my mental health, but also because of this unwanted side effects of the medications.

Russell Roberts (17:31):

And I think Fay, you've both mentioned about the importance of listening and Fay being aware and alert to the signs. And also you've talked about ask, and I think one of the things mental health professionals should do as one of our mantras is ask, assist, advise and advocate. So ask and there's a checklist on the equally well website, ask about sleep, ask about cigarette smoking, ask about have you visited GP to have your cholesterol and blood sugars tested? Ask about alcohol use, ask about urinary function, ask about diet. These are the things that are really important, not just for your physical health, but also looking after the physical health is one of the best treatments for good mental health and wellbeing. I think that's the two things that you guys have really captured. I'd be really interested about someone where you think that's been a good interaction, that mental health professional, that's stuff they want to see more of. Is there anything of that in your personal experience of your physical health and mental health journey?

Fay Jackson (18:29):

I have to be honest with you, Russell, I haven't had a psychiatrist or a psychologist care about my physical health to be honest. I know now that there are some psychiatrists that are really taking care of people's physical health. They make that a part of the whole way that they see the person, which is amazing. But that wasn't my experience. My experience was the opposite of that. Even when I've raised within all these issues, it's just not important. I think it's all about, oh no, we've got to keep the community safe when in fact people with mental health issues are four times more likely to be assaulted than people without mental health issues. So there's a very wrong way of thinking about people with mental health issues. So a physician, health physician that I'm seeing, who is the person that allowed me to go off the medications and everything, he cares about my mental health as well. So he's looking at me holistically and he taught me about the importance of microbiome and the gut and the gut brain connection. And so I changed my diet a lot and that has helped my physical health so much that the most important thing is that he sees me holistically and he treats me holistically and he recognises that I've got a past and he recognises that I want to have a future and that he's helping me have that future, not making decisions about fear for if I become mad again. And it's wonderful and beautiful, and that's not just helping me, that's helping my whole family.

Russell Roberts (20:15):



Yeah, Fay, that's a great point, which we'll come back to in a sec, is a lot of people in the system, it's so crowded and they're so busy, they go, oh, this is my little job and I'll just do that for someone else to do the others. And the problem is our system, there's a shortage of mental health and physical health, primary health workers, and also it tends to be a bit fragmented. So I'm going to come back to that. It's a how do mental health professionals work within that context. But before we go to that, Paul, I just want to throw to you in terms of your experiences of a clinician mental health or others or professional, that it's been a good experience, like that you'd say I'd love to see more of that in contact with clients.

Paul Klotz (20:52):

If I go back probably 10, 12 years ago when I suffered the really big collapse, I was referred to a suicide watch clinic in Fortitude Valley, and they put me onto a really great psychiatrist who basically her standing point was that we're not going to worry about the past. My focus is to keep you alive. If I can keep you alive, then we can start to unpack the rest. So she really looked at it from a holistic perspective. She then referred me to a psychologist in Brisbane who started that same conversation. He wanted to look at the mental health side, the physical side. He noticed over probably a three or four month period that I went from a plain weight, ya know when I was fit of 105 kilos up to 162 kilos in less than six months. He said, man, what's happening? I said, look, I eat well.

(21:42):

I walk six to 10Ks every day. To me, it's got to be the meds. So we did a meds review back with the psychiatrist and yeah, that's what was causing it. So all of that extra weight then put pressure on my knees and I'm waiting to have knee replacements done. That put pressure on my gut. I suffered with diverticulitis and IBS, so I had to look at the diet. So they were really proactive. They didn't operate in their little silo event. And that's one of the challenges that I see out there is to encourage these people to take a broad viewpoint. If I present with mental health concerns, just don't go to the medications. Try and look at what are the alternatives, what is the impact that this may have on your social life? What impact may this have on your emotional life, et cetera.

(22:28):

Is giving the medication actually only going to consolidate the mental health issues? I went, as I said, from 105 to 162 kilos. I'd walk past and see a reflection and go, my God, who's that fat bugger? And I realised, my God, that's me. So that actually worsened my mental health, which meant I became more isolated. I didn't want to go out. I didn't have clothes to wear. So if we take that whole mystic approach that maybe that's not the way to go. I mean, I had a emergency surgery two years ago with a perforated bowel because when I went in there with stomach pains and all the rest, they looked at my file and said, oh, borderline personality, DID. So they were focusing on that saying, is this what's causing the gut pain? I'm going, no, it's not that, I think it's this, this and this.

(23:09):

Cut a long story short, yeah, I had a perforated bowel and then ended up dying twice on the table because they didn't take that holistic approach. They didn't say what other factors may be there? So just don't think that medication is the way forward. It may be part of the solution, but it's not the total solution. I ended up having shock treatment or ECT as a consequence, I've lost over half of my teeth, so that now impacts the way I eat. So that means I don't have as healthier diet as I would like. Again, it's just having that broader conversation.

Fay Jackson (23:43):



To think holistically too. It's not just about the person with mental health issues. It's also as a mother, both my daughters almost died because I wasn't believed that they had something physically wrong with them, and one of them almost died as a baby. The other one with gangrenous appendicitis, I took her to the doctors three times trying to get them to listen. They didn't even examine her. They just thought it was all in my head. So it's holistic about our health, but it's also about our whole lives and our relationships.

Russell Roberts (24:15):

Yeah. There's three things I want to quickly take up with what you both said. One is about the role of suicide risk assessment. So important, but 40 times more people will die early of chronic preventable diseases than suicide. So yes, you'd need to also worry about premature death from heart attack and cancers two thirds of all premature deaths incorporated in that second. The other thing you talked about, Paul, is about medication and some of the antipsychotics and their propensity to put on weight and refer you to Jackie Curtis's team at Mind Gardens and the awesome resources they have for clinicians to watch that. The metabolic syndrome, we call it, with some antipsychotics. And Fay, the point you raised is you talked about impact on families, but it's also working in partnership with your client and with their family. And family members often feel as though they're distant and separated from that and they're not part of their recovery team and they have expertise.

(25:10):

They have decades of expertise on everyone. And I just want to say that yes, it's a real challenge for mental health professionals, and yes, we need to change the system and have more mental health services and better connectedness between services, and that's the thing that every professional should advocate for. But what you have as a person in front of you when you work as a mental health professional and the importance of listening and dealing with their current circumstance, given the service context, we're not going to change that overnight. But what you can change is by listening and asking the right questions, you can save someone's life. Now, we're just getting close to time, so I'm just going to ask you both based on all your experiences, if there was one change, one thing that a mental health professional would do different that would enhance your journey and your experience of care, what would that piece of advice be to that mental health professional? I'll switch it around this time. So I'll let you go first this time, Paul.

Paul Klotz (26:07):

There's a whole range of things, but I'll try and make it short and succinct. Have the conversation now, not later. So if I go back to the points that I made about observing, listening, asking affirmation, working on an action plan, a referral plan, I don't expect that person to have the answers. I don't expect them to try and solve it. What I would like to expect is that they have that conversation now. They look for alternate paths that I can then go down and they can make those referrals. If I hadn't gone through the last 45 years, I may have a longer life. I may have had a more balanced life, a more enjoyable life. So for me, have the conversation now, not later.

Russell Roberts (26:51):

Great, thanks Paul, and Faye?

Fay Jackson (26:53):



For me, I really wish that my psychiatrist had acknowledged the trauma that I'd been through, and there was things that my husband had done and really serious things that if those things were acknowledged, and if I was told, no wonder you are responding like this. This is within a normal range of responses to the kinds of terrible abuse and trauma that you've experienced, that would've helped me feel better about myself for a start. So not pathologizing trauma or grief or betrayal or gaslighting, recognising it and building our confidence around managing those sorts of experiences. But the other thing that's really important I think, is for psychiatrists to be doctors again, not just psychiatrists. Why didn't they tell me about my gut biome? Why didn't I know that the same neurotransmitters are in my gut, that are in my brain, and that they talk to each other?

(27:57):

Why didn't I know that my thyroid could be and my hormone imbalances and that, could be what is really undermining my mental health as well. I've got six different specialists trying to help me at the moment take care of me. But if my psychiatrist had really focused on my physical health and had spoken to my GP and other specialists that needed to come in, then I think the quality of my life would've been so much better and the quality of the lives of my children and my husband and my grandchildren would've been a lot better, and my future would be longer than what it's going to be.

Russell Roberts (28:37):

That's a great point, Fay. And just to note that the Royal Australian New Zealand College of Psychiatry has made physical health, people living with mental health a priority, so they've just got to get that to cascade down to all the people in the profession. So has the Royal College of Psychiatry in the UK. In fact, they've appointed a rapporteur around physical health and mental illness. But what you say about psychiatrists also applies to any mental health professional, hear the middle word there. Health and see this last word professional. No matter who you are and what your profession is, you are a health professional in the system linked to the system with resources, supporting someone who's often under distress, whose personal resources are depleted and maybe don't have the sort of personal supports that they would normally have because of that personal pain and psychological distress. You are a health professional.

(29:27):

You can really help someone work through that system. It doesn't have to be just the cognitive side, it's the whole wellbeing. Taking from this, I think there's three key messages that I'd like people to take away. Firstly, the link between physical health and mental health. You cannot separate them. They go together, hand in glove. You can't be a mental health professional unless you attend to both of these things. Secondly, listen, watch the person with you, with your client and also ask questions, key questions that you should ask about their physical health. And finally, partner. Partner with your clients, partner with their family and supporters as appropriate and importantly, partner with other people in mental health, primary care, and physical health care. You're part of the same system and you're a health professional, and you've got that opportunity to connect and advocate. If you want to learn more about Fay, Paul, or me, or more about Equally Well, or you want to access the resources we've mentioned, please go to this episode's landing page and follow the hyperlinks or go to equally well and look at the links and the resources there.

(30:34):

We'd love to hear about what you thought about this episode On the landing page, you'll find a link for a feedback survey. Please fill it in. Let us know whether you got what you needed from the conversation and any comments or suggestions about how the Mental Health Professionals Network might better



meet your listening needs. Thanks so much for your commitment and engagement to quality, equitable, multidisciplinary mental health care. Stay tuned for the next Mental Health Professionals Network presents podcast that will be released Wednesday fortnight. In the meantime, please take care of yourself and those that you work with. Thank you.

Fay Jackson (31:08):

Thanks, Russell. Thanks Paul. Thanks everyone for joining us.

Russell Roberts (31:11):

Thank you.

Host (31:13):

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