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**First Person:
The role of lived experience in shaping
mental health services**

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Presentation by

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Thank you to the organisers for your generosity, particularly to Merinda Epstein and Flick Gray, who are a team inside Our Community who run a mental health initiative for people who use mental health services called Our Consumer Place.

I'm going to start with a song and some images. The song is by a friend of mine who has experienced mental health problems. I couldn't afford an ad agency to put these words and images together, I'm afraid, so I've got very rudimentary presentation. I do have some knowledge of PowerPoint though. Someone was having a go at PowerPoint this morning. I think PowerPoint's great.

[Song plays]

Well, those are just a few illustrations of what I think is a terrible history in the treatment of people who have been labelled 'mad'.

It's not just historical. Some of the images that you saw up there are still happening today – some of the same sorts of things are still happening today. They're not just happening in rich Western countries now. The pharmaceutical industry and psychiatry are doing the same sorts of things in developing countries.

Here's a little bit about myself. I used mental health services in New Zealand in the 1980s. Since then I've been working pretty hard to try and get the word out there about the human rights of people who have been labelled with mental illnesses.

I use the word 'mad' here. It's a controversial word. It's a reclaimed word really. It's a bit like gay people talking about being queer or black people talking about being niggers or something like that.

Not everyone likes it but one advantage of it is that it's a nice short word, and it fits very well onto PowerPoint.

I want to talk a little bit about the current situation of people who have been labelled with mental health problems. In summary, people with mental health problems tend to be poor, unemployed, isolated and unhealthy.

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I'm one of the lucky ones. I got out of there. And that's probably because I started off life quite middle class, privileged and well educated. But if you don't start off with those advantages and you hit the mental health system you're very likely to end up as one of these statistics here.

What we have is people who die 10 to 25 years younger than average, and that's excluding suicide.

Seventy-five per cent of us are unemployed – more than any other disability group.

We're three times more likely to be in debt than other people in the population, and we're not talking about mortgage debt here.

We're three times more likely to be divorced. Many people who have used mental health services are single. Fifty to 80% of us never have children.

When I first used services, the psychiatrist called me into his office and said, "You have a major mental health problem and you will really have to lower your horizons. I'm afraid you won't really have a career." In fact, he was grooming me for a career as a chronic psychiatric patient.

And he also said that I really shouldn't have children or I should think very hard about it because I might pass on my bad genes, the ones that you pass on when you're reproducing, not when you're swapping clothes.

There aren't many groups in the community that come up with statistics like that. I think probably Indigenous Australians are worse. But we're talking about a very marginalised, dispossessed group of people.

Many of you in your community organisations might have contact with people who have been labelled with mental illness. I think that we're one of the last cabs off the rank when it comes to claiming our human rights. I'll be talking a bit more about that soon.

We have a whole service industry, a very expensive one, designed to respond to our needs. This is how they respond: with meds, beds and if you're very, very lucky you might get something else.

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What we have in mental health services is basically a medical establishment. It's a medical project, really. The problem is that 80% of the funding goes into about 20% of the problem. What I mean by that is that if you talk to people with mental health problems, as those statistics show we experience multiple losses in our lives. To just medicate them and hospitalise people, to spend all your money doing that and not supporting people to regain the material and social opportunities they've lost seems to me a massive waste of money.

Every time people in mental health say, "We don't have enough money," I just see an incredible waste of money when it comes to cost effectiveness and mental health services.

So what sort of services do we have? Well, we have hospitals. You've still got quite a few of them in Australia. We've got less in New Zealand but we do have acute wards attached to general hospitals.

Internationally people experience these places as unsafe, neglectful and coercive. They're very distressing places for many people to be in. I haven't been a client or a guest in one for many years. I visited one in Sydney a couple of months ago and I was choking back tears. You wouldn't want to put your dog in there. Australia is a wealthy country with a democratic tradition. You take some pride in human rights, as do all Western democracies. The state of some of the hospital facilities is absolutely appalling.

Of course, as I said, the mainstay of treatment is drugs. It would be great if these drugs were experienced as helpful and they didn't have enormous side effects. But unfortunately some of the drugs are actually life shortening. These great new second generation anti-psychotics came out about 15 years ago and the drug companies pushed them and said, "These are fantastic. You won't get the bad side effects with these drugs."

Well it turns out, and they knew this of course at the time, that some of these drugs give you diabetes. They create huge weight gain. People are now acknowledging that these drugs actually shorten your life.

That's bad enough but often these drugs are used in compulsory treatment – people are forced to go on these drugs, sometimes for a long, long time. There's always been compulsory treatment in mental health services as long as the asylums have been around. But since the asylums have been very downsized they've been very clever actually. What they've done is to

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say, “Well, you can get out of the hospital but you have to have treatment. We’ll force you to have treatment when you’re living in the community.”

Now, that’s not for everyone. It’s for a minority of people by the time we get to Community Treatment Orders. But I think particularly in Australia and New Zealand there’s an alarming lack of worry about the infringement of human rights that goes on and the lack of legal protections, the farcical legal protections.

In Victorian and in New Zealand we have Mental Health Review Tribunals for people who want to get off these Community Treatment Orders. In New Zealand about one in 25 people who apply get off these orders. I think the figure is similar for Victoria.

So that’s an issue that is going on. That’s one response we had from mental health services.

People who have mental health problems often say the worst discrimination we get is from inside mental health services. And what we have, as I demonstrated with my own story and this still continues today, is very low expectations for our lives. So from the day I got a diagnosis I was being groomed to have a career as a chronic psychiatric patient. Fortunately I didn’t and I went on to have a more rewarding life. But I think it’s a tragedy that so many people get stuck in mental health services.

It’s very much a medical service and we have very little access to talking therapies, peer support, support to regain the material and social opportunities we’ve lost like education, employment, housing and other social inclusion stuff and very little genuine advocacy for people.

So why do we do this? Why do we respond to people in this way? Well here’s one answer: it’s tradition. But just because you’ve always done it that way doesn’t mean it’s not incredibly stupid.

I’m sure people here are interested in social change and social justice. How many times have you thought that about the way societies and governments and the state respond to people who are somewhat different?

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As you can see from those history slides at the beginning, the mistreatment of people with mental health problems has been endemic forever. At the beginning of the asylum era 200 years ago, when they started building those huge elaborate Victorian buildings, they were full of good intention and hope. In fact, they used to boast about the recovery rates of their clients. But of course the Victorian asylums filled up and of course conditions deteriorated.

For the whole time that people have been confined there have been elements of protest. Really, I'm talking to you today about the 'Mad Movement'. But I wanted to describe to you the conditions that created this movement.

As I said, people have been protesting. There are some very famous examples of people protesting about being put into mental hospitals.

There was a woman, for instance, called Elizabeth Packard in Illinois in the 19th Century who protested because her husband put her in there because he was sick of her.

In Sydney in 2010 I talked to two women in an acute ward who were saying the same thing, that they were really in there because of domestic abuse and their husbands didn't want them. So there's still plenty to protest about.

One of my favourite quotes is from a playwright called Nathaniel Lee. He lived in the 17th Century and he said, "They called me mad and I called them mad and damn them, they out-voted me."

You won't have heard of the Mad Movement because that's just my term for it. I do this, I just make up my own terms for things because I'm a free spirit. But, really, if you hear about the Consumer Movement, the Service User Movement or the Survivor Movement, we're talking about the same thing. It's the movement of people who have been through the mental health system.

Although there had been individual processes, it really started as a liberation movement in the 1970s. It really was riding on the same wave as feminism, the gay rights movement and the civil rights movement.

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It was very much about liberation from oppression – this was the language that was used, quite appropriately too for the time.

There are two main activities that the Mad Movement got into. The first one was peer support. In the early days they used to talk about consciousness raising in a similar way to the way feminists talked about consciousness raising. People were sharing the trauma, the feeling of oppression they had from being through the mental health system. It was very much about empowering the self and empowering each other. And that continues today in various forms.

The other arm of the movement, of course, was political action. It wasn't about changing ourselves and changing our own narratives. It's actually also about coming up with our own analysis of what had been going on.

In the very early days there was an enormous rejection of psychiatry. Like all movements there are much more moderate people around now who don't reject it. They reject parts of it but they see the benefit from psychiatry too. It was very much focused around campaigning around false treatment.

Here's a little picture for you [refers to PowerPoint presentation] – that's van Gogh there. He cut his ear off and posted it to his wife. He had some mental health problems. I'm not sure if he sniffed his paint or what happened. They don't really understand what was going on with him but he did some pretty drastic things. He did the self-portrait of himself looking pretty sad after he'd cut his ear off and posted it to his wife.

I found this other portrait of him on Google [refers to PowerPoint presentation]. That's entitled *van Gogh on Prozac*. The thing that really strikes me is he has a beautiful set of dentures there. But his ear has actually grown back. I don't know whether this is the Prozac or what it is, but it is quite magical.

I want to go into a little more detail about the thinking in the Mad Movement. Really, at the very core of discrimination against people with mental health problems is the view that madness is a forbidden experience, it's an experience that's very low on the hierarchy of human experiences. It's something that people are very fearful of. Since medicine got hold of it, it's been seen as a pathology and not a legitimate experience.

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In order to reduce discrimination it's my very firm belief that we have to change that fundamental view we have about madness. The Mad Movement really rejected the medical and deficits-based perspectives. Now, it wasn't just the doctor; the psychotherapists were pretty awful about it too, they were always looking for what your mother did when you were three and looking for problems and thinking you were pretty inadequate and all that sort of thing. We rejected that as well, that view.

Some of the views that people have come up with is that madness is a response to negative life experiences. There's a huge amount of evidence that people who have major mental health problems, not just the so-called minor ones, that we're responding to trauma, racism, income inequality. They are very powerful social determinants.

They used to say if you've got schizophrenia or bi-polar it's a biological condition. There's more and more evidence that they actually know that the social determinants of any kind of disturbance in your mind are pretty powerful.

I guess the closest approximation I would say to my own experience is that it was an existential crisis. People often talk about this very powerful, profound, disturbing, disruptive experience as a 'spiritual emergency'. Some people think of it as a protest against a so-called insane world.

We've tried to cast this experience as a legitimate human experience. It doesn't mean to say it's a nice one; most people don't enjoy it. We certainly don't enjoy all of it. But it's an experience that value and meaning can be derived from.

This conference is about power. As you can predict we've got some pretty strong feelings about power, that the mental health system in society has been pretty impressive and discriminatory and that we must claim our own power, our own self-determination. We've got to claim our own expertise and our full citizenship.

Merinda Epstein, who is one of the workers at the Our Consumer Place at Our Community, has done this. She very kindly gave me their original [refers to PowerPoint presentation]. It's called *Targeted Treatment*. You can see these injections being chucked. I said they never hit the bullseye so I don't know why you gave them the bullseye. The treatments are very imprecise. They don't really hit the problem at all. They hit the symptoms. Nice cartoon that one.

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I just want to talk a little bit about the developments in the Mad Movement since the 1970s because it really started out as a radical, unfunded protest movement, like most movements do, out of this grassroots rage and enthusiasm and a newfound belief and another way of looking at things.

But in the 1980s the mental health system started to think they wanted to start involving people in our services so that they could help make decisions. So there was a much more moderate element that came into it, who were much more prepared to work with the system.

Even those of us today who might have some radical roots tend to work with the system. That's where the money is, I suppose. I'm being cynical there.

There have been some people who have said, "Well, do we have a movement?" Yes, we do, but it's very diffuse, it's very fragmented and it's poorly resourced. I want to give you an indication about how poorly resourced and poorly documented it is.

There's no university department in the world that has a Department of Mad Studies. There may be one soon. So we don't have an intellectual infrastructure.

If you look at the woman's movement there have been plenty of rich women around who could help to fund it. And even the civil rights movement in the US in the 1960s was funded by some pretty wealthy churches.

We're a very scattered and very poorly documented and resourced movement. This is something that continues to pain me but I won't bore you with that. But I think it's an issue that I would like to see more resolved.

I've talked to young people, because as you can tell I'm middle aged. I've talked to young people about where this movement is going to go in the future because let's face it, young people aren't staying in institutions for as long but there's still a lot of young, middle aged and old people getting a terrible time inside mental health services. They need the same kinds of supports and opportunities to think differently and empowerment and all those sorts of things that we had.

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But they don't want to label themselves as part of the 'consumer' or 'survivor' movement. It's quite interesting, I think, that we labelled ourselves too tightly. In fact, in the 1980s anyone who'd gone to the GP for a bit of Prozac who came along to one of our meetings we were very suspicious of because they weren't depressed enough, they hadn't been through the system enough.

In fact, we labelled ourselves very much in the way that we'd been labelled by the institution. And it was a very bounded identity that we had.

I think there has been a little bit of progress in mental health services and people aren't so locked into the institution in the way that they were 20 or 30 years ago. I think the identity I have is also less bounded than ours.

But certainly the issues are remaining. It's great to see younger people coming up and doing this work.

I just want to give you some examples of the kinds of things we do. There are just a few labels. We do a bit of branding too, actually. That's interesting isn't it? We probably do it mostly on our own. The World Network of Users and Survivors was done by me. I couldn't afford an agency to do that either.

So what we have here [refers to PowerPoint presentation] are peer support methodologies and organisations, global advocacy networks. We've got the National Nutters Conference in New Zealand that we had a few years ago. That was the best conference I've ever been to. It was fantastic. We have festivals – the Bonkers Fest happens in London. We have Creative Roots – that's the evolution of humankind and it starts off with a chimpanzee and it ends up with a person, a nut case. It's got a peanut head. We have Mad Pride, there's been Mad Pride in Australia. They've tried to trademark it but we're resisting that. There have been online groups. Right down the bottom there you can see the ourconsumerplace.com.au, if you want to visit it. That's the initiative within Our Community that is by consumers for consumers. So there are a huge variety of activities.

Now to the changes since the 1970s. Well, they've been mixed and isn't this true of life. When I started this 25 years ago as a very young woman, we had this notion of progress. We have this great notion of progress, don't we, in all our narratives? The politicians talk about "We're

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going to crack this problem” – it doesn’t matter that it’s been going on for 30,000 years – “We’re going to crack it in the next term of government.” There’s this idea of progress. Unfortunately life doesn’t work out that way. Some things get better and some things get worse, which is bloody annoying if you’re an activist but that’s just the way things are.

So we’ve had the downsizing or closing of old institutions. You haven’t gone nearly far enough in Australia. You still love your hospitals too much and look at the state of them.

And of course there have been more community-based services. There are more opportunities in community-based services – it doesn’t mean to say they’re any good but there’s more scope for delivering what we call a recovery-based service.

I’ll just tell you a little bit about what recovery means in mental health. It’s a term I’m very ambivalent about but basically it’s a post-institutional philosophy. The most paramount thing about recovery is hope. You saw on those images the loss of hope. You can see in the statistics the loss of hope. The experience for me as a young women was being told that I probably wouldn’t be able to have a career and I should think twice about having children. There’s been a lot of pessimism in mental health. So one of the great things about recovery is hope.

Of course, another foundation stone of recovery is self-determination for the person who is labelled with mental illness.

A third one is having a broad range of services. As I said, we’re putting 80% of the funding into 20% of the problem. We’ve got to turn that around and actually put in far more funding, get it away from those expensive hospital beds that cost as much as a five-star hotel per night into resources and opportunities and services that assist people to get their lives back.

Also involved in recovery is the idea that we’re full citizens; the nice term that often is used by governments is ‘social inclusion’.

So that’s really what the whole recovery approach is based upon. It’s very diametrically opposed or different, in a way, to the traditional service delivery, which is based on pessimism, paternalism, meds and beds, pills and pillows and segregation from our communities.

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There have been anti-discrimination campaigns in some Western countries. I think probably the best one has been in New Zealand. Some anti-discrimination campaigns can actually have the opposite effect if they're based on a medical understanding of mental health problems.

At the same time in the last 30 or 40 years we've had the resurgence of biological psychiatry. They've really been palled up with the drug companies. The drug companies have had an enormous invisible influence on the way mental health services are delivered.

But also 30 years ago things like depression and bi-polar were relatively rare conditions. And now every third person you meet is on anti-depressants. How many people here are on anti-depressants? I'm just off mine, bloody hell, but honestly half my family are on them. They're not even depressed. I don't know why they're on them. Eighty per cent of it is a placebo effect, if you really want to know. The placebo effect, it's an effect, but there might be other ways of dealing with these problems.

In New Zealand since the 1970s there's been an increase of people under compulsory treatment. This is really due to the introduction of Compulsory Treatment Orders in 1992 and you have those too in Victoria. That's worrying. I thought we lived in an era where we were having increasing respect for people's human rights.

So people's life chances haven't improved much in the last 40 years. That's the summary version of what's happened. There have been some good things happening, there's been some not so good things, but basically our life chances haven't improved that much.

Here's another cartoon from Merinda and this is about changing the culture. Any of you who have been inside a mental hospital will know that nobody goes up to you and says, "Medication, Madam?" Well, not unless they're being terribly sarcastic. So this is a cartoon about changing the culture.

So what needs to happen? Well, first of all we need changes to the service systems. We're not just talking about mental health services. One of the unfortunate things is that everyone's got dumped into mental health services when in fact we need services from multiple sectors and we're not getting a fair deal from these multiple sectors, I don't think.

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First of all, the community, the services, they need to see madness as a legitimate human experience that meaning and value can be derived from. In my own experience it's a very powerful experience. You can relate to having an existential crisis most of you, or a spiritual crisis. These are very powerful experiences.

If you're having huge sensory shifts and cognitive shifts at the same time, as you do when you're labelled psychotic, it's an even more overwhelming powerful experience. It deserves respect. It does have meaning and value can be derived from it.

So that's the first thing – services have got to get away from this pathology/tragedy view and give this experience the respect it deserves.

Next, we need to complete the process of deinstitutionalisation.

Of course, there needs to be an expectation from services that people can recover and can return to full citizenship. Actually, not 'return' – you should be a full citizen while you're a person using services.

As I've said, we need a broader range of holistic responses – support to get into employment, education, housing, relationships. You could run a dating service. There's the old saying that people have said, "I just want a job, a house and a date on a Saturday night." I think that's a very powerful little statement. In fact what we want is just what most other people want.

So it's about a broader range of holistic responses.

We also need a diverse, respectful workforce – we don't want just doctors and nurses. We want a lot of people working in the mental health system and in other kinds of social services who have lived experience of mental health problems.

We need service user leadership. I'll explain a bit about this. If we're on a platform of self-determination as I talked about, well we need to lead our own recoveries as individuals and not be under the thumb of the doctor or the nurse but to make our own decisions.

As a collective, we need to take up leadership roles. I was a Commissioner in the New Zealand Mental Health Commission. That was a leadership role, obviously. I was amazed at the power of position, which is quite ridiculous. I'd been an advocate and nobody took any notice of me,

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and as soon as I became a Commissioner everyone got offended with what I said. I was saying exactly the same thing!

So there are all sorts of leadership but I think we need 'position power' in the mental health system. Very few of us have it.

Of course, we need to reduce compulsory treatment. Nobody's talking about that but that's something that we need to do. There is a start happening in Australia and New Zealand, a very lacklustre start, in trying to reduce and eliminate seclusion or solitary confinement, but we need to go further than that.

The changes we need in society? Well, again, it's not just mental health professionals who need to reframe madness. It's the whole community.

We need to challenge community expectations of services because what happened to the asylums over 200 years ago was that communities abdicated responsibility for mad people to experts and institutions. Of course, this hasn't just happened in mental health. This is a well-known phenomenon. We're still doing it.

It's very interesting, I find it fascinating that every time there's a so-called 'incident' that gets into the media, the services are fully to blame for it happening. There's very implicit discrimination in that. The implicit discrimination is that the person who did the offence or the anti-social act or decided to end their lives had no responsibility at all because they're not capable of it.

I think that we need a much more nuanced understanding of responsibility and shared responsibility for things that go wrong. For those of you who are familiar with mental health services, they're obsessed with risk. They're just totally obsessed with it. We've never lived in a safer environment. If you walked down the road in the Middle Ages you'd just get clobbered. But we're just obsessed with risk in our culture which is really interesting because it's never been safer.

Of course, people with mental health problems are about as likely as an 18 to 25-year-old male to do anti-social acts and so on. But perhaps we should lock them all up. I don't know.

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But, really, we've got to get a much more sophisticated understanding of what risk is and who's responsible when things go wrong. I mean, it's just ridiculous to put it all on services. It's totally ridiculous. It's just not an accurate picture of the world.

The best way to reduce discrimination is to be in contact with people who have been labelled mad, or whatever the discriminated against group is. Hopefully some of you will go away today and think, "Those mad people, they're not that bad." You might have a different idea after seeing me up here talking.

Exposure to mad people, the discriminated against group, is terribly, terribly important. And it's not just about people getting up at conferences and talking. It's about having neighbours. It's about people being in the workplace and not being segregated off in little ghettos, whether they're ghettos in communities or in institutions.

I think anti-discrimination campaigns are important. It would be great if you had one in Australia, but you've got to be careful about how you pitch those.

You're probably aware, some of you, that there's been a huge resurgence and interest in wellbeing in Western democracies in the last 15 years – happiness or social capital or positive psychology, all that cluster of things is about how we create a community or a society where we create the conditions where people can have optimal wellbeing, a very reasonable question since we know that economic growth and affluence hasn't increased wellbeing.

The whole recovery approach that I was talking about, with the platform of self-determination, social inclusion, a broad range of services and hope, feed very well into the population wellbeing agenda. I don't think we should be left out of that. We're a group in the population whose wellbeing is most under threat and we should be very much included in the population wellbeing agenda.

Because traditionally, if you know anything about this, if you see these charts that people write, these continuums, they have mentally ill people at one end and mentally healthy people at the other end. The mentally ill people get treatments and services and the mentally healthy people get promotion and all those nice things. What we're saying is that actually we need promotion and actually the recovery approach is in a way mental health promotion for people who have mental health problems.

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So we need allies, and we need you as our allies. If you take away one message please take that message away.

I like this cartoon [refers to PowerPoint presentation]. It's the National Alliance of the Morally Inexcusable. He's saying, "Better that 10,000 homeless eccentrics be doped up than one dangerous whacko goes unmedicated."

I've got this sign hanging on my door. I love it. "Blessed are the cracked for they let in the light."

I'm just going to end with a funny story. Have you heard of *Onion News*? It comes from the US. It's a sort of take-off. This is from *Onion News*. I thought we'd just end up on a humorous note because it was a slightly heavy start.

[Video runs:]

The first ever prescription depressant hit the shelves today. Approved by the FDA last month, Despondex is intended as a treatment for the approximately 20 million Americans who are insufferably cheery. Tests prove the drug is effective at reducing a range of symptoms, from squealing loudly when a friend calls to use of the phrase, "Cool beans," and excessive hugging.

Dr Alman Way calls the drug a huge step forward in the battle against exuberance.

"If you're in a good mood every so often well that's fine, that's normal. This is for those that have a persistent positive outlook on life."

Eva Henry of New Haven, Connecticut, began participating in a clinical trial of Despondex six weeks ago.

"I was always telling people how cute their outfits were and bringing them little gifts and beam at anyone who made eye contact with me. I didn't realise that life didn't have to be like that."

Eva said she never knew how her annoyingly chipper attitude was affecting those around her.

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“Over and over again I’d ask Jeff to ride his bike down to the botanical gardens with me, no matter how many times he said no.”

“And she was always smiling. But I didn’t know what to do to help her.”

“I used to think, ‘Why am I the only one trying to set up single friends with each other?’. Now I realise it, I was sick. I needed treatment.”

Eva says the drug may have saved their marriage.

“Now Jeff and I can just waste a night sitting on the couch, watching a TV show neither of us enjoy like a regular couple.”

Not everyone is convinced that Despondex is the cure-all for perkinsess, however. In this week’s Time Magazine Michael Polosic of USLA argues that many patients get similar results from natural remedies, something as simple as a diet of corn syrup and white bread and a total lack of exercise.

*But Dr Way disagrees. “We have to erase the stigma attached with getting chirpy people help, real medical help. I mean, do you what it’s like to be around these people? It’s pretty f***ing annoying.”*

Doctors estimate the new drug could reduce the number of costume or theme parties in the US by up to 40%.

OK, well thank you very much for listening.

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