

PETER BUTLER
SIZE 9.5

Audio Producer: Olivia Humphreys

My name is Peter Butler, I'm aged seventy three. I live in a granny farm and, sorry, I live in a retirement home for independent living. I was born in Newcastle, left to become a chemist, then decided to become a hippy, now I'm a geriatric hippy, I suppose. I have travelled quite extensively, went over to Canada, for a while, I was delivering sail boats round the Pacific. Started teaching up in, just below Alaska, came up here and then, that's nearing retirement, and that's when all your body goes to bits and everything starts going wrong.

Right now, I'm sitting back, getting over the effects of a bad delirium session, which was four weeks ago. I've had bad experiences or extended experiences of delirium at least three times. The thing is with delirium, is it's an infection of bacteria that gets into the brain, and it alters the brain working. It's as simple as that. My experiences in delirium have always been linked in with a trip to the hospital, and I had a bad session at the end of 2010. In that one, I had delirium from the moment of waking up after the operation. I first of all figured "Right, well, I'm going to hide it from the nurses and hide it from everybody else." I used to just pick a point on the wall and stare at it, and people were going past and everything, thinking "Ah, you know, he's all right, you know." Meanwhile, what they didn't realise, I was staring at the wall and it was an amazing thing that was going on in my head. Spiders coming out, you know. Rats coming out. It's always your worst nightmares and when I looked out of the windows where I was, at about two o'clock in the afternoon I would see a little train coming running along the rooftops and then you'd have all these people suddenly appear and those people would be saying "Come on Peter, come and join us," and so I get across there to the place, and I'd shove me a bed up and wind it up as high as it would go. So I could try and get out the window towards them. Of course you can't get out the window because they're all sealed. And then they'd start singing and so you joined in the singing. The singing drove everybody else bloody nuts, totally off-key. So there were other times when I imagined that I was in a castle, you know, and I was defending people. That time they got security in to restrain me, because I was, I was getting a bit violent, and it was the nurses who were suffering. The big thing that really got me was these seagulls who had rose tinted sort of bodies and they only had one wing. And they were flying everywhere, I couldn't understand how they were doing it, and I would puzzle away for ages of cause and effect - how is it possible for them to do that? The colours, when you've got delirium, are so vivid, yet you can't believe that such colours can exist, and, I mean, even on the little sandcastles you get inside of your room here. You know, some of them, when the water's coming up, and sprinkling out, it's, you know, the prismatic effect on the water sprinkler's just beautiful. It's like diamonds falling down all the time. It's almost as though your brain opens up and the memories come flooding out and it's say, you know, twenty, forty, fifty years ago - only they take on a twist which is perhaps, you could possibly call it sinister.

Yeah, you can have horror. And you can have beauty in a delusion and it can switch between the two just like that. This time, it, it really had a negative effect on us, it did. It's the worst one I've had. I was stuck in a bed, couldn't move around and I lost all my muscles. I have no balance, and so what they said was, they said "You can't go anywhere unless you're accompanied because we don't want you to fall down in the hospital." You try and find someone to accompany you in the hospital. It's impossible and I had delirium. You can only take so much of that without getting a bit upset. I had a major depression. Right at this moment I'm getting over that depression. I would say that delirium in any form, any level, can be really, really, frightening, and unfortunately the persons who really suffer the most are your friends and your relatives who are around you, because they're seeing you in a totally different situation, where you're not in control of what you're doing. You're not in control of what you're seeing, and, plus the language which comes out. I mean it is really basic. One time my son was there and I suddenly picked on him. And I was just the most vicious, horrible person there was. What happens is afterwards, when you come out of this and you realise

what you've said to your son. That guilt is incredible and there were times I would sit, when I was on my own, you know, and I'd cry for a whole day. Just because of the guilt I had, of how nasty I had been. And I still, to this day, feel guilty about those incidents. I don't know if it brought us any closer together. I think it probably did. Because they had seen me going through a really bad patch, and I had seen them looking after me while I was going through this bad patch. And we'd come through it and they didn't disown me, they said "Glad to see you're through it," and they knew what to expect the next time I went in the hospital. If I was going to go into delirium, they knew how to handle it.

I'd had the experience. And I realised there wasn't much information about it. I wanted to give something back. I've done a video which explained my experiences and that's with the International Delirium Association out in Brussels. And now, when I go into a hospital, it's quite often that the junior doctor recognises me, or the nurse will recognise me, because one of the videos I made is now standard play there. Everybody has to watch it. About talking about delirium. Because sometimes it is hard for medical professionals to recognise that you might be in a just a state of quietness and just staring straight ahead, you know, but it's there. When you've got delirium, you don't trust anybody. At least I don't, and I wanted to hide it. Just because I didn't want them to think that I was doo-lally. And I didn't want to be sectioned, you don't want to get locked up. That is why you hide it.

And I don't think that delirium was very high on the priority of hospitals a few years ago. It has increased. My own experience is that it could do with a bit more reinforcement, especially with health care people, you know, nurses and auxiliary staff, and I don't think they were being nasty about it. I think they were just, I don't think they understood it, and so they just took the Mickey. Because they didn't know how to handle it. When I first started doing the education work, which was going out giving lectures, you know, to professionals and to interested groups. It's amazing how many people come up to you afterwards and say "I figure over this, that's what my mum had in her final days." It was like a relief for them, because they could put a handle on what was going on and their parents weren't insane. It was a chemical imbalance in the brain produced by bacteria, and it's a question as well, as you start going into hospitals, and different hospitals and you see different conditions in them and you think "How do I know I can pick the right one?" The NHS is a great place. It's a great foundation. But it's getting carved up and you don't know what sort of service you're going to get in different sorts of areas of it. I raised the awareness and made, you know, made it possible for professionals to recognise that delirium is real and I feel as though I've contributed to society, giving something back for all the care I've received out of the NHS, there's a lot more I can do but I've got to get the strength back. I wake up in the morning and I touch out and I think "Right. I'm not in a pine box today!" and I live for that day. I don't plan ahead too far, because I never know what's around the corner. Going for holiday I would be looking at the last minute, you know, I'm happy to be able to live today.