

#9 Stories of loneliness and isolation



Many of the storytellers talked about loneliness, isolation or of feeling like an outsider or not fitting in. This was a strong theme throughout the narratives. For some of the storytellers, it was a dominant theme from the outset – loneliness and isolation wove their way through their lives and stories. Rather than picking one person's story to illustrate this theme, we present several facets of isolation and loneliness.

Loneliness and isolation could be a cause or a consequence of mental distress. In Chapter 2, we heard from a man born in South America how the death of his grandmother and his subsequent journey to England to live with his father had led to a homeless and rootless existence. In Chapter 6, we heard from a woman for whom cultural displacement and immigration caused her to be lonely and isolated in the UK.

The storyteller in Chapter 5 talked of losing friends and family when he started to become unwell and began to behave differently. Reflecting on the fact that he did not communicate about what was going on for him at the time, he gave advice to anyone becoming unwell to talk to others and make them aware of what is going on.

I had a lot of friends before my episode and before going to custody and before having issues with the police. But, over time, they hear stories and they don't really understand what's going on and they distance themselves from you and I've lost friends because of bad behaviour. So, I don't blame them. But, I would just say to anyone to make people aware of what is going on the best way you can. I didn't really explain too much, I didn't feel the need to. I just saw it as, "You get what's going on, why are we talking about it, let's not talk about it, can I stay at yours, can I have some money?" And, it's not really normal, you know. [Storyteller 6]

For the storyteller in Chapter 4, distress and isolation coincided as he struggled with paranoia and the idea that other people were following him.

This was really the beginnings of the paranoia where maybe had I discussed it with somebody or talked about it with somebody, maybe the rest of what happened wouldn't have happened but I didn't. I believed everything. When you're in psychosis, once you've been through it, it's easy to then know these are the symptoms but when you're going through it the first time you just believe everything is real. So yes, I believed I was somebody extremely important that was going to be launched as a celebrity and basically my reputation was very important and lots of people were out to get leverage on me. So I was scared. [Storyteller 1]

Consequently, he isolated himself quite deliberately, avoiding contact with people other than his close family.

That started to feed into my second set of paranoia where I started seeing codes everywhere and also, I have an ongoing preoccupation with others having leverage on me so I've really, really now isolated myself completely with only phone conversations to my parents and occasionally seeing them. I've had no friends now for years so it's completely just getting up in the morning, writing, eating, going to bed and I've been doing this for years, in fact five years so it's a very long period of isolation.

He was very clear that isolating himself had not been helpful to his wellbeing, and now had strategies that included remaining in touch with people:

Yes. I won't ever put myself in that isolated position again. I won't ever do the screen writing thing. I have done it now. Hardly any writers have written 34 screen plays so there's no point adding to it. My solution at the time was to cut myself off and write, well, now my solution is to get out there and network.

LONELINESS FOR CARERS AND FAMILY MEMBERS

Carers also talked of facing loneliness with the onset of their relative's mental distress. This was often due to the stigma attached to mental illness, causing friends and family to drop away or making the individual feel they had to keep their distress private. One of the carers we interviewed felt this so strongly in relation to her relative that she barely revealed anything in the interview.

I'm obviously being very careful what I'm saying because I don't want... even though they can't hear me. I could say a lot more but because my loved one is not aware that I'm doing something like this and... for me, the worst thing that could happen is my loved one becomes aware of it. [Storyteller 12]

The most common experience for carers and family members was loneliness caused by loss of support from friends and family, as illustrated by the extract below:

No, they ran away from us. We were lonely because everyone doesn't know what's going on... No, they

don't understand. They just run away, even relatives, they ran away from us... Yes, it's hard, yes. We feel lonely. [Storyteller 11]

A couple of the carers talked of the value of attending carers' groups, where they could talk to other people who were experiencing something similar and feel less alone as a result.

So, I engaged in [carer's group] and then when you start hearing the other carers' experiences, you felt like your problem has been shared, that it's not you alone. So, I find that really helpful because you find that if it's just... you get the feeling, but when you hear the carers that would experience it so, so similar, it's all so similar, you know? [...] because the first time I didn't know anything and one of the parents, when they talked, they told their history of what happened, her experience. I felt like the problem... [was shared] Yes, it's not only you. [Storyteller 15]

ONE STORY OF LONELINESS AND ISOLATION

Here, we share a story in which isolation became a major factor in one man's distress and the onset of his voices. None of the stories we heard fit easily into a single theme, and this man's story clearly illustrates this complexity. His story describes the interplay of threads of loneliness and isolation, stress and drugs, and the 'vicious circle' that resulted from using drugs to manage his distress. In addition, he carries a strong critical voice within him from childhood.

This man was the only child of a single parent. He described his mother as critical several times during the interview, although he also appreciated the support she was able to give him despite her own struggles. He felt it was an effort to live up to her expectations, which then morphed into his own.

...my mum wasn't a bad person but sometimes you just need positive reinforcement and you need to feel that what you've done means something to someone. It was just always an uphill struggle. I think that's definitely where that comes from. [Storyteller 5]

He went to a school he didn't choose, a private grammar school, which his mother could only afford because there were reduced fees for single parents. He felt he did not fit in, partly because he was gay but also because the school placed a high premium on academic achievement and sporting prowess, neither of which he excelled at. He said he had low self-esteem and little self-confidence.

I am gay so at the time in an all boy's school, it was quite a formal grammar school that was all about sports achievements and rugby and various bits like that. That was the only recognised way that you would be seen positively almost in the school so you either achieved academically or you achieved in the sporting sense and if not, then you fell in between. So I fell into that bracket really where I felt that I didn't really belong in the environment and the pressure was coming from home to perform in certain ways.

He traced many of his subsequent difficulties back to this beginning.

So that's looking back as where do I think some of my issues in adulthood came from. So it wasn't putting the blame on mum or the time at the school because it was what it was. As a teenager you don't think of it like that but yes, I guess looking back, that could be the start of where I felt that my identity wasn't really what it wanted to be or I didn't feel that I was comfortable in my own skin, but didn't want to say anything or didn't feel that I could do anything about it because of the family unit and just because we're in a small village, that kind of thing.

He experienced a good period between the age of 18 and his early 30s, when he was working and travelling. However, he faced a major turning point when he was diagnosed with HIV in his 30s. This resurfaced the difficult feelings he had experienced as a teenager, causing him to isolate himself.

I think what that did was accelerate some of the negative things from my childhood, couple it with the status and where that then left me in the present day, with feelings such as denial about the diagnosis. For the first couple of years you live in a bubble of just questioning yourself, your place in society, stuff like that. You have this almost self-loathing element.

So the diagnosis just makes you feel very disgusting almost a) that you've got HIV and b) what does that mean for you and contact in the future? It makes you feel very insular again because you go back into your own little world because you wonder what people's reaction is going to be.

The diagnosis caused him to ruminate a great deal about what to do, whether and when to start taking medication, and who to tell. All this fed into the low self-esteem he felt he started with.

I think a lot of the issues to date when the same themes of self-esteem, not thinking very well of yourself, not placing yourself in the world in a decent way, you don't give yourself a break. You're very critical of yourself. All these things that are within yourself, and I'm a deep thinker as well so I go through this chain of not a lot of action but a lot of thinking too much about stuff and that can consume you sometimes.

Following his diagnosis, he also experienced a number of other stresses in his life. He began to take illicit drugs when things became very stressful and he felt the need for escape.

But yes, I think when I got to a point in my life where I'd had, unfortunately, a couple of close family bereavements, work was very stressful, there was some bad things going on at work, then I, at one point, turned to taking drugs. Very light stuff at the start but yes, that in itself is a cry for help I guess that you give because you're seeking something external or you're seeking some kind of release or relief that just takes you away from yourself.

After he began experimenting with illicit drugs his experience of hearing voices also started. During this time, many of his friends, who he had supported in the past, fell away when he reached out to them, leaving him to cope with these experiences alone. He experienced psychosis as isolating, in that he was unsure who to trust, and found it hard to work out what was real and what could be his mind playing tricks

on him. He described the distressing and isolating impact of the voices very eloquently:

So it was very scary stuff. You're not wanting to react to it because you're thinking, "What is this?" and you're also not wanting to let whoever or whatever this is beat you. So, you don't want to react because that gives them the advantage so you're constantly trying to keep one step ahead of something that either is or isn't happening.

Now, if that's in your mind then you're never going to win. This is your life now because whatever it is in your mind that does this to you, it feels like it's always going to be one step ahead because it knows your thoughts, it knows your movements, it knows your conditioning. But because it felt so real and it felt external that people were doing this to me, then I thought that I could get the better of it, I could get control back so it just sent me potty really, that I was doing things to mask what I actually wanted to do to stop them making comments on it. Yes, you could spend hours just doing things that you didn't want to do to create... it's almost like acting within your own home.

Eventually he sought help and was referred to the Early Intervention in Psychosis service. He was appreciative of the opportunity to talk things through and try to understand his experiences. For the first time, he felt able to share his experiences and difficulties with someone – the psychologist.

So she is the only person almost really, in the world that I can sit there and could, if I wanted, say anything to. Is it because she's a neutral person or is

it just because she knows everything that I feel more comfortable? At the end of the day, if I say something to her, I know that the stuff is private and confidential but I know that I can say it and I'm not having to mask a part of the story or act part of it.

Despite having support from a trusted psychologist, he was not yet ready to give up taking drugs so he still felt stuck in a vicious circle that he could not break out of.

The aim is that I want to stop the substance abuse but while I'm stuck in this vicious circle and things aren't, I feel, going right for me, I feel that if I take that away, the only piece of relief, even though it causes me problems, at least I get a moment of relief. If I don't turn to the substance abuse, I feel like there's nothing in my life.

In our interview, he described the ongoing impact of the voices on him, and at times was critical about how he reacted to them.

I still, even though I'm very rational, I'm about 95% at the moment, believing that it's me, it's myself, I'm creating these problems myself or involuntarily creating these problems. But there's still this 5% that when I'm sat in my flat and I hear a voice and it's being aggressive, it still puts the fear of God into me, even though it's only 5% and I'm questioning all the time that 5% but that 5% controls me. It takes away all rationale and in that moment it just panics you, it makes you feel you're going to be sat in a chair for two hours not moving because you think if you're doing something, it's going to get commented on. It just immobilises you. It freezes you. Before you know it, 12 hours have gone by and you haven't

slept, you haven't eaten, you've missed your medication, all these things that then start to have an impact on your life and you're just not doing yourself any good. But where I'm at at the moment is I'm still trying to chase answers to this 5% because when I'm in that moment it feels so real. To me, for it to feel so real, I think to myself, "I can't be making this up. There's got to be something in this that's real," and I'm still chasing that reduction. I want to get myself to the point where I can believe that it's me.

He has found this experience isolating, as outside of his meetings with the psychologist, he felt unable to talk to people about his unusual experiences. At the time of the interview, he had not been able to talk with other people who had had similar experiences, and expressed a need to meet other people who had heard voices.

I think I need to be speaking and be surrounded by people who are experiencing the same things. I think there's some kind of solace in being able to talk to people who can say, "Yes, I experienced that and I know exactly how you feel in that moment."

[...] I think the only thing that can, at the moment for me, take [that feeling] away is speaking to people who have been through it because they know those frustrations, they've felt it. Maybe I can ask them what they did to get beyond it because at the moment, I feel like I don't have the answers.

REFLECTIONS ON ISOLATION

Alison

“ For me, this last story illustrates the power of isolation to create or sustain madness, not just from a mental health perspective in this case, but also this man's identity as both gay and HIV positive. The latter exacerbated his low self-worth; a sense of self-disgust had complicated his sense of identity which had fragile origins. There seemed to be an emptiness that he was still filling by using drugs. The story also describes the value (and the absence) of what is often referred to as 'peer support', but which might simply mean meeting other people who share some aspect of your experience through services or groups. He expressed an awareness of this need towards the end of his story. An obvious example of this would be a Hearing Voices Network group, where people share their experiences as well as strategies for managing voices. ”

Dolly

“ I had no friends for over 15 years due to having psychosis and there being no support to make friends. I remember one time sitting on a bus and seeing people having picnics together in the sun. I started crying because I felt so lonely and jealous. When a mental health coffee morning started up, that was my first step to breaking my isolation and meeting people. Now I am blessed with lots of good friends. When I am at my most distressed, I become paranoid and I have lost friends because I have pushed people away. Those who stuck around realised what was happening and although I pushed them away, they came back to me when I got better. I wish I could find a way to deal with my paranoia so I don't push people away in the first place. ”