



Psychosis

Psychological, Social and Integrative Approaches

ISSN: 1752-2439 (Print) 1752-2447 (Online) Journal homepage: <http://www.tandfonline.com/loi/rpsy20>

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Akiko Hart

To cite this article: Akiko Hart (2017): When we lose hope: experiences from Hearing Voices groups, *Psychosis*, DOI: [10.1080/17522439.2017.1363475](https://doi.org/10.1080/17522439.2017.1363475)

To link to this article: <http://dx.doi.org/10.1080/17522439.2017.1363475>



Published online: 14 Aug 2017.



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When we lose hope: experiences from Hearing Voices groups

Akiko Hart

Mind in Camden, London, UK

ABSTRACT

I often think that at the heart of a Hearing Voices group is hope: generating, renewing and offering itself, in a space where we share hope for the future and hope for recovery. It may therefore come as a surprise that for me, one of the strongest themes in groups, particularly in forensic settings, is in fact hopelessness. I'm interested in exploring what this hopelessness has brought up in me, how it has challenged me and what it has given me.

KEYWORDS

Hope; hopelessness; Hearing Voices groups; prisons; Immigration Removal Centres; forensic

One of the images I find particularly beautiful and compelling in recovery is the idea that we can hold hope for someone else, when they are at the end of their road and have lost all hope. For me, holding hope is saying or thinking – *I hear your hopelessness, and why hope might feel too heavy, or futile, or unbearable for you right now – so I will hold hope for you, because I believe in you.*

Sometimes I visualise this hope as something almost ephemeral I clasp in my hands – I have to be careful, or it will float away and I will never catch it again. Or sometimes it's a solid bean, compact and dense: it's small, but it could grow. And at other times, it's just a feeling deep inside me which I struggle to articulate. Maybe it's hope – and maybe it's love. I'm not sure.

There have been times in my life when I have lost hope for myself. I could not see any possible future for myself, or not any that I wanted. I was stuck – so stuck, and the thought of not being able to escape the misery I lived made me think of the only escape. It's hard to remember, but as dark as it was, it wasn't all hopelessness. I could still laugh, I could look at my daughter's face and wonder at her beauty – and also, in the same moment, want to die. It wasn't all or nothing. The hopelessness and hope were layered and intertwined.

When I look back on those days, I remember well-meaning friends telling me that things would get better and that they held hope for me. At the time, I felt deeply misunderstood, my experiences and feelings invalidated. Hope felt like a sack of potatoes they were dumping on me. *Here is all the hope I and everyone else have for you – please take it off us because it's too heavy for us to carry.*

I'm not sure that holding hope is about trying to instil or create hope in another. For me, in a Hearing Voices group, I'm not sure that hope even needs to be articulated with words. It's there in the room because the group exists. To me, that's what so powerful about Hearing Voices groups: the very fact that there is a group means there is hope. And sometimes within a group, we are able to hold hope together, briefly, in that hour, in that moment – and that feels somehow magical.

When I am on my own, however, I'm not always able to hold hope in a way that feels helpful. I have had friends who have struggled, who feel stuck and who want to die. And, against all my training, all my theory, my immediate response is to offer hope, to push it on them, to try and make them see it.

*You can make it, I believe in you, you are strong.
(Please live. Please live.)*

Why am I telling her she is strong, when she feels weak and broken? Why am I telling her she can make it, when she is telling me she is done?

It is, I think, because I feel helpless. I cannot help. I cannot will someone I love to live, however hard I try. I cannot wave a magic wand, and make the bad stuff go away. And there is so much bad stuff. Sometimes, even hearing her anguish feels too hard. There is a part of me that doesn't want to go to that dark place with her, that doesn't even want to look at it, because of what might happen to me. I've been to the edges of it and I've looked away. I don't want to go back. I can never walk in someone else's shoes, but even walking alongside sometimes feels more than I can bear.

I'm also acutely aware of how little of her pain I'm actually seeing. My friend loves me, she wants to protect me from the horrors she lives, because who could survive them? So I see a fraction, and even that fraction feels unbearable to me at times. It also feels complicit. If I hear your pain, and acknowledge it, am I giving you permission to die? (*Please live, please live*).

And sometimes I hear her, and I understand why she wants to die. She is stuck. It feels like it will never get better. She has suffered enough. The pills don't work. Therapy hasn't worked. The voices don't stop, they only get worse. There is just too much to fix, no human ever could. Too much suffering, already. The deck is stacked.

I understand that she has lost hope and wants to die. But I don't want her to die, I haven't lost hope. I cannot get past this seeming contradiction. Again, I feel helpless.

So for me, hopelessness usually engenders in me complex feelings of both hopelessness and helplessness. And yet, I work in mental health, where hopelessness is a daily occurrence. And isn't mental health about helping people?

Sometimes, I wonder how many people who work in mental health are there because they want to help people. I wonder how many of us are there because we couldn't help someone we loved.

For me, my journey into mental health has many beginnings. My journey starts with monsters. When I was a child, they stood in doorways, sat in corners and hid in rooms, until no space felt safe, least of all my own head. Sometimes they would step from my dreams into my room. They were hideous, inhuman creatures who wanted to harm me. One of my strongest childhood memories is being frozen in bed, not daring to open my eyes because of what was there in the room. I remember thinking – this is what petrified means, I have indeed turned to stone.

My journey starts with me, aged nine, thinking that if I told anyone about the monsters, that I would be locked away in an asylum forever.

My journey also starts with days on an acute ward visiting someone I loved. I thought diagnosis and medication were the answers. I would chain smoke with the other patients whilst waiting for the clinical psychologist or the psychiatrist to arrive. I thought they had the answers, and I wanted to be like them. I desperately wanted a white coat.

It starts with me working on a locked ward and realising that the people there weren't in fact scary – and that more often than not, they were scared, distressed or angry.

It starts with me facilitating a Hearing Voices group in Richmond, London and discovering that voices, visions and beliefs could have meaning.

I think I started off in mental health because there was someone I couldn't help, so I thought I'd help others instead. I'm not sure it's why I'm still there. Now, I don't know that people can or should be helped. I think that I now work in mental health because I'm angry, and because I have hope. There are many things that I want to change, and I believe that we can change them – both within and beyond services.

So hope is also at the heart of my work: it is partly why I do the job I do. I don't think I'm alone in this. And whilst in mental health and in recovery we talk so much about hope, I wonder how much we talk about hopelessness.

Hope is the currency of mental health. It is what we offer people who are on their knees. Here is hope, in these pills, in this therapy, in this treatment. You can get better. You can recover. You can become well again. Your life will have meaning again. Hope is one of the reasons why people who have been on every pill under the sun and who have experienced terrible side effects because of their medication, will say – *Yes, I will try this new pill which may be the one that works and makes me better.*

But whilst hope is so central to the mental health system, if I think of all the times I have been on acute wards, I have felt deep hopelessness all around me and within me. Ten years ago, I thought being diagnosed with a “severe and enduring illness” was a life sentence. I remember feeling slightly optimistic about younger people and their prognosis, and depressed about older ones, who kept on returning to the ward – and then feeling guilty, for not holding hope for the latter. What is it like to look into the eyes of someone who doesn’t hold hope for you? I have been on both sides of that divide. You would think that having experienced it from one side, I would never inflict it on another. But I have, and I’m ashamed of it.

Once, I remember feeling disapproval because a senior nurse told me that a specific person would be back on the ward not long after being discharged. She was right, and I didn’t like her being right. It felt like she was always right about these things – but of course, if someone did recover and move away from mental health services, she would probably not be told. It seemed to me sometimes that where I was locating hopelessness within a person – a service user, or a member of staff – it was actually in the air, emanating from the built environment, embedded and continuously reinforced into the structures of the service. Is it even possible to really hold hope on an acute ward, working within the strict parameters of diagnosable lifelong, debilitating illnesses?

In my experience, one of the pervasive themes of Hearing Voices groups in forensic settings is hopelessness. I find it hard to untangle this hopelessness from the experience of imprisonment itself. The men and women I meet are deprived of their freedom and autonomy in small and large ways. They don’t choose when or what to eat; they live apart from their children, partners and friends. Many feel powerless.

I’ve witnessed the despair of people who had just been sentenced, as well as the darkness of those who still had a decade to serve. I’ve met people in secure forensic units who didn’t know when they would be released, because it was contingent on their recovery as determined by psychiatric team, and not on a fixed sentence. I met people who were on their fourth or fifth offence, and who said that even with the best will in the world, they would end up back in prison not long after they were released. I heard the hopelessness of people who were about to be released and had no housing. I listened to people talk about how every day merged seamlessly into one. I heard people talk about how they were trapped in their cells with the monsters and devils they saw, heard and felt, and that there was no escaping them now. I found it hard to find hope in these stories.

I have also started to do some work in Immigration Removal Centres (IRCs), where Mind in Camden is working to set up Hearing Voices groups. The first one was launched in June at Heathrow IRC, the largest in Europe, where people are held, some for days, some for months, whilst their status is processed by the immigration authorities. A third are released back into the community, a third will be transferred to another IRC, and a third are deported back to their country of departure: to me, this huge disparity in outcomes feels deeply unsettling. Much like prisons, I find these environments a mix of sensory deprivation and overload: there is a lot of noise on the wings and in the courtyard, but the buildings are drab. There seems to be very little to do, other than wait, smoke and chase your paperwork.

Here, the men I meet are angry. Many feel punished, although they are not in a custodial environment like a prison. Some speak to me of their lives being in the hands of others. Hopelessness is mingled with hope, but the hope, to me, seems somehow almost cruel, as it rests on something which feels, from the outside, so arbitrary. I find it hard to leave IRCs, and yet I also want to get out. There is a deep irony in that I need my British passport to get in, this passport which so many of them require to leave.

I find the hopelessness I’ve witnessed in IRCs different to and sometimes more challenging than the hopelessness in prisons. In prison, unless the person is on an Imprisonment for Public Protection (IPP) sentence, there is an end in sight however far off. In prison, some people can make sense of their time there in relation to their offence. But in IRCs, I’ve met people who hold a deep sense of injustice about being there, and who feel that their lives are no longer in their hands. I not only feel hopelessness at their individual situation, but also at the wider political one which I feel powerless to change.

Again, these different shades and depths of hopelessness can feel too much. I struggle to find an appropriate response. Hope feels inadequate. Who am I to offer hope? What do I understand about

their lives and their possible futures? In these environments, hope can sometimes feel to me shallow, easy, inauthentic.

But in Hearing Voices groups in these settings, sometimes something transformative would happen. At times, when someone would express their hopelessness, I would feel that we, as a group, were bearing witness. There would often be a silence after the disclosure: no consoling words, no murmurs about how things were going to get better. And with this collective acknowledgement of despair, with this bearing witness, came a sense of connection. For a brief moment, it felt like a small part of the hopelessness was held by the group. I can't say if it was mine or theirs. It felt important to sit with it, and not negate it or somehow make it better, as that would have been dishonouring the depth of the feeling expressed. It has made me wonder if the adequate response to hopelessness is not hope, but connection.

I was privileged to be with my father when he died. He had been sick for some years, and he was no longer able to do anything he enjoyed. He loved eating, but he could only eat small amounts of bland food. He used to swim and walk every day, but his lungs were so damaged he could barely leave the house. He was in near constant pain. At his last hospital admission, he was told there was one possible treatment – but that it would reduce his quality of life even further. He refused it. Before he slipped into unconsciousness, he knew he would die and there was no hope for him. He didn't believe in life after death: for him, this was the end.

Before he died, he talked to us about us – his wife, daughter, son-in-law and grandson. He told me he knew he must have done something right because I named my son after him. He may have lost hope that he would live, but he hadn't lost hope that his life had meaning. He hadn't lost hope in the future – no longer his own future, but his family's future, which was forever connected to him.

I too need to believe that my life has meaning. I need to believe I have agency. I need to believe that I can help change things for the better, that my life has impact on those around me, that I can connect and love – that, in a small way, I matter. I need to have hope, because otherwise I cannot live.

What I have learnt from Hearing Voices groups is that whilst they rest on hope, hopelessness must also be given space. We need to hear it and honour it. I have learnt that for me, hopelessness brings up deep, uncomfortable feelings of helplessness. That has made me reflect on how much I can, or do, or should help people. I have learnt that holding hope doesn't need to be articulated with words, that it is about something that happens within us and between us.

I have learnt that mental health practitioners can feel hopelessness too. Again, it feels important to me that we find a way of hearing this and honouring this – and reflect on what it is about our roles, our working environments and the structures of our system which can exacerbate this hopelessness.

I have learnt that it's OK to feel helpless because I am. Who am I to help anyone? How can I change anyone's life, when I have so little control over my own? Maybe we are all helpless, a little, a lot, sometimes, most often. Maybe feeling helpless can make us better practitioners and friends. We don't have all the answers – in fact we probably have none. Maybe we can just be there, together – sometimes figuring it out, and sometimes getting lost side by side.

I am also learning that the hope I carry is mine. It is my choice. I need it to survive. I cannot impose it on anyone else. It is OK to lose hope. It is OK to hold it. And it's also possible to do both, just like my father did, before he died.

Disclosure statement

No potential conflict of interest was reported by the author.