

### Rachel Waddingham grew up in Leicestershire ...



#### 1. What did your mother and father do for a living?

My mum looks after my niece and nephew and my father is the manager of a voluntary sector organisation.

- 2. Do you have any siblings?
  I have two older sisters
- 3. What is the earliest memory you can remember?

My parents coming back home with what seemed like a giant monster (a relatively small dog that to a 4 year old seemed huge and scary). I was

expecting a puppy, but when this giant thing bounded through the door and ran around the house I screamed and jumped up on to the sofa. This dog, Dylan, became my best friend whilst I was growing up.

At age 20 Rachel ended up in hospital after a mental breakdown, it was due to trauma she had experienced in her life leading up to this point, but most importantly, it was due to the inhibited 'silence' of dealing with the trauma. "By that point I was trapped inside a confusing world of alien conspiracies, paranoia, voices and traumatic flashbacks..."

### 4. What was your most effective 'coping strategy' for when the voices were at their worst?

Early on in my journey I struggled to cope and relied solely on medication and hospital to contain things. When I started to attend a Hearing Voices Group, and learn from the wisdom and courage of other members, I learnt the importance of not taking what they say at face value (speaking with others to try and make sense of what they were saying and why).

Currently, my most useful coping strategies are grounding - finding ways of staying connected to the world. This includes '5 things' (saying 5 things I can see, 5 things I can hear and 5 things I can touch ... then saying 4 things ... 3 things ... 2 things ... 1 thing), tai chi and having things around me that stimulate a different sense (e.g. my sense of touch, smell or taste) and focusing on that sense instead of the voices to give myself some space.

As I still hear some angry and/or distressed voices, I now speak with them and try to help them find ways of expressing their anger or pain safely. I have a punch bag, art equipment and plenty of writing paper. I hear these voices for a reason – they reflect the bad things that have happened to me. It's my job to try to make sense of this and help the whole of me find ways to feel safe.

#### 5. And for dealing with your unusual experiences?

I have all kinds of experiences – tactile experiences, smells, visions and paranoia. I've had to develop different ways of dealing with each of them. When I feel things crawl on my skin, or feel as if my skin is burning, I often use body lotion and self massage to help me focus on another sensation. When I smell gas on the tube, I do a quick check to see if others are reacting to the smell (to see if it's a shared experience that I need to worry about). If it's just me, I try to calm myself and repeat a mantra to help myself feel safer or do a grounding exercise. No matter what the experience is, once I feel calm, my best strategy is to try and make sense of it. For me, it's a sign that something in my internal or external world is affecting me – triggering memories of feeling unsafe. Recognising this has helped me to deal with the real cause of my experiences, rather than follow my

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beliefs 'down the rabbit hole' into a world of alien conspiracies and experiments.

### 6. What was your most effective coping mechanism for dealing with 'self-harm'?

I started self harming from the age of about 14, but by the time I was at university it got of control. Whilst it was, for a time, an effective coping strategy – it had serious limitations. I felt guilty, powerless and like I was a freak. Whilst I wanted to stop self-harming on many levels, I struggled with is because it was the only way I knew of dealing with my feelings. My recovery, paradoxically, came when I started to value self harm as a coping strategy. This allowed me to explore what it helped with, and what it made worse. I read Tracy Alderman's book ('The Scarred Soul'), which helped gain a greater understanding of myself. The more I understood about my reasons for self-harming, the more I was able to start to find other ways of managing my feelings. Tailoring the strategy to the issue was key. I had to learn ways of expressing anger, comforting myself, bringing myself back into my body, dealing with guilt and bearing intense overwhelm and anxiety.

I haven't self-harmed for years now and am finally comfortable with my scars. I see them as part of my history and signs of my survival.

### 7. How did you ultimately 'break the silence'?

Whilst at university, a friend of mine realised that things weren't great for me. She had experience of self-harm, herself, and recognised the signs. She encouraged me to see my GP (and helped me go back and see another one when the first merely gave me a leaflet on depression and asked me to read it). I was referred to a psychiatrist eventually, but even then I never told them about the voices, the aliens and the conspiracy. Things spiralled out of control and I stopped taking care of

myself – it became obvious to the people around me that something was badly wrong. My parents moved me back home and took me to see a psychiatrist there. This doctor finally asked whether I had any unusual experiences and I was so desperate I poured it all out. I was glad someone had finally asked the right question.

For the next 10 years she ensued on a road to recovery, dealing with 'the system', medication and ultimately the 'label' of being diagnosed with 'Schizo-affective Disorder'.

#### 8. What has been the most important to you on the road to recovery?

Inspiration and hope. This was in short supply in the early days (when I was diagnosed with schizophrenia I initially gave up on life and my future — everyone did). Going to a Hearing Voices Group was my turning point — it helped me form a social network and hear about others who had recovered. People like Ron Coleman, Peter Bullimore and Jacqui Dillon helped me get my spark back. Voluntary sector organisations (like Network for Change) backed that up with the practical support I needed to regain my independence.

#### 9. What has been the hardest part on the road to recovery for you?

Giving up the label of schizophrenia, schizoaffective disorder or mental illness. I had spent over a decade in a system that understood my difficulties as the result of a chemical imbalance, so I'd learnt to see myself as ill. Whilst people were aware of some of my childhood trauma, it was seen as a tragic coincidence rather than an explanation. Schizophrenia/Schizoaffective disorder acted as a 'trump card', making everything else seem irrelevant.

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Learning to see myself as a survivor – a human being that has had an understandable reaction to extraordinary circumstances – meant revaluating who I am and how I got here. Confronting this reality is probably the hardest thing I have ever done.

#### 10. Was there any easy part?

Recovery is a journey, and every journey needs pit stops. I've had some wonderful times that have allowed me to catch my breath before moving forwards. These often involved connections with others — a conversation, a gig or a beautiful gesture. Learning to see the wonderfulness of other people, and how generous they can be, has been really awesome. As part of the Hearing Voices Network, I know I'm not alone — I'm part of a worldwide community of fantastic people.

Three years ago you decided to come off your medication, you say that you "now hear voices more than ever..."

#### 11. What was the driving force behind your decision to come off your medication?

Once I came to see myself as a survivor, rather than a victim of a biological illness, I started to question the role of medication. It helped me cope by dulling my experiences, but it didn't fix anything deeper than that. To me, medication is simply a tool — a tool that had some quite debilitating negative effects. I had developed lots of other tools in my journey, so wanted to test whether these were enough to keep me balanced. It was a difficult road, but one I took with my eyes wide open. I thought it through, did it gradually and learnt from others who had travelled similar paths.

### 12. What has been your most effective 'coping strategy' for now dealing with this increased intensity of your psychosis?

I don't really equate hearing voices or having more unusual experiences as psychosis — it's just part of who I am. The medication suppressed a lot of my emotions and traumatic memories, so coming off medication has allowed them to resurface. The increased voices come from this. At first, this was incredibly difficult — but it's also empowering. I'm finally in a position to deal with my past and resolve things that have been bubbling away under the surface for a long, long time. As with all my other experiences, grounding is my first port of call. Then, for me, it has been about trying to change my mindset from one that avoids and fears the voices to one that is interested about where they come from. This is a work in progress, but I'm lucky to have support to help keep me on track.

With a wide range of articles and ideas on her website blog, in one Rachel explores the coping strategy of boxing, after realising through her psychosis that she was dealing with pent up anger, and seeking advice from her therapist, who recommended this coping mechanism for her as a means of self-expression. 'Boxing – Trauma, Anger & Self Expression' [link]

#### 13. Can you now throw a pretty good left hook? ©

It's getting better ;-)

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### 14. Did the boxing help? In what way?

Yes, massively. The things that happened to me in my childhood were wrong — I can say that in a rational way, but actually 'feeling' it is another matter. Connecting with my anger from all this has been a challenge, which is why some of my voices carry that anger for me. Reclaiming my anger and finding ways of expressing it safely is definitely a good thing. Boxing is also helping me to change my 'freeze' reflex. When people are traumatised and can't escape, they sometimes escape inside and 'freeze' on the outside. When I'm stressed now, I still sometimes freeze. Back in hospital it was seen as catatonia, but I see it as a survival strategy left over from my youth. Boxing helps me connect with my body and realise that I am strong. I am not a child and now, as an adult, I can defend myself if I have to. This means I'm starting to spend less time 'frozen'.

## 15. What has been the most effective approach to recovery for you? Physically, mentally (psychologically) and spiritually?

For me, recovery is not about managing or recovering from an illness as such. It's a journey that involves reclaiming my sense of self, my healing, my life, my future and my potential to contribute to the world. Childhood trauma, labelling, stigma and being stuck in the mental health system robbed me of these things – I'm now starting to take them back, one step at a time. This is a hard journey, though, so I find it very important to travel it with a curious and appreciative mind (both towards my inner experiences and the world around me). I feel really lucky to be alive, to be working in a



job that I love and to be married to a man that I love. These were the things I was told I would never have, so I wake up in the morning with a little smile feeling like I've got a fresh chance at this thing we call life.

#### **Favourite Quote:**

"...I choose to be me. A survivor. A musician. A wife. A supporter. An artist. A trainer. A daughter. A geek.

Psychotic. Creative. Introspective. Caring. Flawed. Strong. My identity remains fluid. I am not limited because I

am a survivor – I am spurred on by it. Life is opening up for me..."

You can catch all this and more of Rachel Waddingham at www.behindthelabel.co.uk

#### More Info:

I manage the London Hearing Voices Project at Mind in Camden - that includes Voice Collective, the Hearing Voices Groups in Prisons Project and the London Paranoia Groups Project. We also co-ordinate the London Hearing Voices Network - running training so that people can set up and/or facilitate hearing voices groups for adults.

Great to hear you're interested in coming to the VC training. I'm guessing Yan, one of our development workers, was hesitant because we have almost 'sold out' and have little space left. We always leave spaces for people outside London - as you say, it's important to spread the approach out. Still, we have to prioritise helping groups get started in London as this is what helps us keep our funding. I'm guessing our out of London places are booked up already.

Still, let me have a look at space and see what I can do. As you're very interested in getting something going I'd love to be able to support you with that. Is there anyone else you know from your local area (someone with lived exp or not) who might be interested in working towards this with you - and maybe booking on the course

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with you. In my experience, it works so much better if there's a core team trained up - to keep momentum going and help make things happen. I know that's probably a strange question given that we only have one place left on the course ... but if we can have you on the course I want to give your group the best chance of happening.



When did you start your work with Voice Collective? (http://www.voicecollective.co.uk/

I was lucky enough to get the job of London Hearing Voices Project Manager at Mind in Camden in 2007. At that time, the role was focused on helping people set up and sustain Hearing Voices Groups for adults. Inspired by the work of Sandra Escher, and my own childhood experiences, we developed Voice Collective in 2009. The London Hearing

Voices Project also includes a project developing Hearing Voices Groups in prisons, and establishing a network of peer support groups for people who struggle with Paranoia or overwhelming beliefs.

### In your own words what exactly is voice collective?

Voice Collective is a London-wide project to support children and young people who hear, see or sense things that other people don't. We have three main strands – direct work (where we support young people and their families through face to face meetings, email, peer support groups and creative workshops); capacity building (where we train and coach other youth workers so that they can support young people in this way); awareness-raising (where we produce information, outreach to mainstream organisations and go into schools). Our ultimate aim is that young people won't need a specialist service like ours in the years to come, but that they will be able to get the support they need from mainstream youth services. Until then, we are doing what we can to make that happen.

#### What does the future hold?

Some of the young people who come to Voice Collective have created a fantastic animation about their experiences. Our next task is to work with them to get it in to schools so we can get young people thinking about voice-hearing as a human experience. We have also developed a special training course for teachers and people who work in education on voice-hearing ('Removing the Barriers'). We're also working with SLAM (a mental health trust in London) to launch two new Voice Collective Groups. Things are pretty busy on the project, but this is a good thing. There's lots of do:)

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