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Remarkable lives: Jen Waring in conversation with Jerome Carson.

Jen Waring and Jerome Carson.

Abstract

Purpose – The purpose of this paper is to provide a profile of Jen Waring.

Design/methodology/approach – Jen provides a short biographical description of her life. She is then interviewed by Jerome.

Findings – Jen talks about her long battle with mental health problems and what has sustained her over this time. She talks about the crucial importance of support from both loved ones and professionals, as well as medication.

Research limitations/implications – Single case studies are of course just one person’s story. Given Jen is an academic biologist, she not only has a unique way of looking at mental illness, she can see the potential of developing approaches in the biological understanding for people experiencing mental distress.

Practical implications – Jen’s account shows the need for long term support for more severe mental health problems. There are no quick fixes! It also highlights the need for interventions at biological, psychological and social levels.

Social implications - People need “somewhere to live, someone to love and something meaningful to do” (Rachel Perkins). Many sufferers do not have all three. Services may only be able to provide two of these.

Originality/value – Accounts of mental illness recovery by academics can often provide us with amazing insights into the world of the mentally distressed (witness Elyn Saks, 2008). They can also service as an inspiration to the many students who experience mental distress.

Keywords Biology, Recovery, Music, Relationships, Diagnosis, Medication, Psychological therapy

Paper type Case study
Introduction

I can’t remember the first time I met Jen, but after getting to know her I realised we had a shared interest in mental health issues. I had the idea of us doing a joint presentation to Cognitive Behaviour Therapy students, as I did a slot on biological aspects of mental illness. Sure enough Jen told us a lot about biological aspects, and she talked of her passion for “glia cells.” However she also shared something of her own personal battles with mental illness. Her decision to speak about her mental health problems in her TedX talk, marks a big step forward in sharing her personal story with a global audience. This story is a further reaching out.

Brief biography by Jen Waring

I was born in Manchester in 1968, the youngest of three daughters. My memories of childhood are happy; as a family, we were very secure. My sisters and I had the usual sibling skirmishes but we generally got on well and I recall afternoons spent in the garden, making up adventures and losing ourselves in these adventures. We moved to the North East coast when I was 6 years old. I loved being by the sea and spent many an hour exploring in my own little world. I was always fascinated by science and my birthday and Christmas presents included chemistry sets and microscopes, rather than the more ‘usual’ toys. Our parents provided us with a loving home and they encouraged us in what we did. Looking back, they made many sacrifices for us to give us the life choices that they didn’t have.

I had one particularly close primary school friend, Sarah. When I first arrived at the school I noticed that some boys were taunting her in the playground because she had a bandage on her head. My terrible temper kicked in and I made it clear, with my fists, that this taunting was not acceptable. Sarah had a brain tumour but I didn’t understand the gravity of this. Sarah and I decided that as soon as we were 18 we were going to buy a boat and sail around the world. We were inseparable and then one day, Sarah didn’t come to school. Mum explained that Sarah was in hospital because her brain tumour had grown. Sarah came home after a few weeks but she
didn’t return to school. I visited her a couple of times and we were allowed to talk on the telephone until she became too ill. Sarah died when we were 9 years old and I felt grief like never before. It took what seemed like an age to recover and I still visit her grave when I return to the North East. Sometimes if I’m travelling by sea, I think of her and wonder what would be different had she lived. I realise that her death left a big hole in my childhood.

I struggled with playground politics throughout school and I felt a sense of not belonging, although I was outwardly happy. At secondary school the biology teacher had a select band of kids who were allowed to stay in the lab at break times. I was also musical and spent lunchtimes in the music room, along with other musicians. These places were refuges and I’m grateful to the teachers who provided them. Sixth Form College brought new challenges, both academic and personal. I played the trumpet semi-professionally and I now realise that this was my lifeline.

I think the first signs of illness manifested themselves during Sixth Form College. I felt a restlessness and an inability to focus on academic work. Sometimes I didn’t sleep at all for days on end. I had lots of energy, but it wasn’t productive, apart from within the bubble of music. My trumpet teacher encouraged me to apply to music school. Although I was principal trumpet in several orchestras, I had an unshakable belief that I wasn’t good enough and that I would be ‘found out’ as having tricked my way through. I spiralled further out of myself and failed my A levels. This gave me a year to decide what to do and I ended up training to be a physiotherapist.

I think that when students embark on study away from home there is a sense that they can leave themselves behind, reinvent themselves and find happiness. This is how I felt but reality hit me like a train. During second year, I became very ill and almost dropped out. A period of intense restlessness and lack of sleep was followed by a rapid decline into deep depression. My parents supported me but I didn’t tell them the full extent of my distress. I couldn’t see the future and I spent most days thinking up ways to end my life. My partner, friends and tutors cared for me and even had a system for ensuring I wasn’t alone. I didn’t realise that they were doing
this and in hindsight their care and love enabled me to stay out of hospital and I received outpatient care.

My first experience of psychiatric care is blurry and there was period of time during which I took medication that sedated me heavily. I also received therapy. I don’t think I gained much from this; I wasn’t ready for it and I didn’t understand the process of how therapy ‘worked.’ My ability to function slowly returned, the psychiatrist discharged me and I graduated and started work. I wasn’t fully well though. At the age of 24 my world fell apart again and my partner marched me to the GP. Medication followed, as did 2 years of psychodynamic therapy, which was helpful. I was more mature and the therapist seemed to understand how to unpick my distress.

I left physiotherapy at the age of 27 and went to the University of Liverpool, graduating with a BSc (Hons) First Class in Marine Biology. We moved to Essex where I gained a PhD and then worked in research. Again, I was an ‘imposter’, I’d tricked my way to academic success and would be ‘found out’. I was generally quite well during my 30s. I was able to recognise if things were going wrong and I managed to take steps to prevent full-blown relapses. Paradoxically, I think the need for time off because of a serious physical illness and surgery helped me because it forced me to rest.

I began lecturing in 2008 and I enjoy teaching enormously. Most of the time when I’m in front of a class, it’s like putting on a ‘psychological uniform’. I click into work mode. At times doing this is beneficial but at other times it is exhausting so there is no energy left for other parts of my life. Around December in 2008, over time, the warning bells began to ring for my partner; restlessness, insomnia and mood swings. I didn’t listen or acknowledge the warnings; this would mean facing up to illness again. I spent several awful months feeling exhausted, yet either incapable of being still or incapable of moving. Sometimes I would pace around or walk for miles in an effort to escape from my thoughts. I’m sure I was awful to live with and a lesser person would have left me, but my partner was, and still is, my rock.
I was able to hide my symptoms at work until the sudden crash into despair. Driving to work one morning, I began shaking and sobbing. I went straight to my boss, who was amazing. She listened to me, demonstrating insight and kindness. She ordered me to go home and ring her once I had seen the doctor that day! I saw a GP, Kate, who was new to me. She cared for me with great compassion, skill and patience. I returned to work after a couple of weeks but I remained ill. Thoughts of suicide became all consuming and, without the support of my partner, GP and therapist, I would not be here. Intervention from a kind, democratic psychiatrist was also invaluable. Kate and my psychiatrist eventually convinced me that a longer spell off work was needed and I took almost 4 months off. The instructions were that my days needed to be structured so my partner left me a list of jobs for each day. I have kept these and they serve as reminders of how far I’ve come and of the danger in not looking after myself.

It took a long time to find a balance of medication that worked and didn’t have intolerable side effects. I still take these and I’m told it’s probably forever. For now, I accept an uneasy truce with medication. As Kay Redfield Jamison once wrote: ‘the choice is not between a drug that has side effects or not, life is not ideal. Yes, your drug has side effects and yes, if you don’t take it you’re going to die.’ Kate allowed me to almost take the lead on medication decisions and she was always there to pick up the pieces if things went wrong. Never once did she say ‘I told you so’. Her care went way beyond that which one would normally expect from a doctor and my gratitude seems insufficient.

The apparently incompatible thinking between mental health professionals sometimes frustrates me. I have been treated by doctors who don’t see value in talking therapy because they think that mental illnesses are purely biological disorders. Conversely I once had a therapist who didn’t want to work with me whilst I was taking medication. She thought that mental illnesses were not illnesses as such, but that the symptoms were an outward manifestation of some sort of deep psychological trauma. I am hopeful that advances in science, medicine and psychology will get close to some truth. I have found a degree of understanding of
myself from reading the medical and psychology literature. I do think that many mental illnesses have large biological underpinnings, but that isn’t the same as saying that psychological therapy has no place. It clearly does. I think that there is an urgent need for better diagnostic tools. Of course, it is vital that professionals give time to really hear what patients are telling them, but a symptom-based approach, framed around the DSM, seems inadequate.

I receive, therapy from June, a close colleague of my GP. She has an open mind and is accepting of my need for medication. In fact, she has helped me to make my peace with it. I refused to entertain the prospect of trying one particular mood stabiliser. I was afraid of it and June helped me to understand why and to rationalise my thinking. It turns out that this particular drug is probably the one that has the most benefit. June isn’t afraid to explore the darkest recesses of my thinking with me. She is very astute, homing in on important, but subtle nuances in my language with laser-like precision. We work using a variety of approaches- Gestalt, person-centred therapy, TA and CBT. I’m sure there are other approaches that we use, but I don’t know the names of them. On occasion we’ve just sat together and she’s provided a safe space for me to just talk or to cry. She seems to get me. Sometimes she does challenge my thinking quite firmly and we have had major disagreements, but progress often follows these. June encourages me to draw and write for my ‘homework’. I’ve been able to depict or write things that I’ve struggled to find words for and the most productive therapy sessions have often followed on from my pictures and writing. Therapy has enabled me to face illness head on and work through some of the most difficult years of my life. It has also enabled me to think about recovery in a different way. I’ve always assumed that recovery is a complete absence of symptoms. I now understand that this isn’t the case and recovery for me is about learning to live alongside my symptoms, pay attention to them and do what I need to do to manage them. Medication is important; as are the therapeutic relationships I formed with doctors and with June. I still encounter very difficult periods of time but I have the ‘toolkit’ to deal with these
My long-suffering partner remains my rock and a lesser person would have walked years ago. Professionally, I don’t think I’ve been ‘found out’, yet!

Jen in conversation with Jerome

Jerome: Some people have argued that music can be a tool that can lead to recovery (for instance the recent Gareth Malone programme with veterans suffering with PTSD). You used to play the trumpet. Has music helped you?

Jen: Yes, enormously. Dad’s a musician so I grew up surrounded by music. I don’t play the trumpet anymore but I’m an avid collector of music and listen to a range of genres. At times when I’ve not been able to focus my mind and I’ve been very distressed, I’ve found some solace in music. I often play music quietly throughout the night when I can’t sleep. Music helps to distract me. I find the music of Max Richter, Philip Glass, Arvo Pärt and Dobrinka Tabakova particularly therapeutic. There is an intensity to their music that seems to mirror some of my feelings. Some of their works are also very calming. Max Richter has recently composed an eight-hour piece called ‘Sleep’. It’s his lullaby for a frenetic world. He encourages people to play the piece as they sleep. I have done this but I also play it during the day; it slows me down, in a good way. I also enjoy the poetry of song lyrics. Laurie Anderson, Jane Sibbery and Natalie Merchant are wonderful wordsmiths. Icelandic folk music is a recent discovery- not a clue what they’re singing about but it’s very beautiful.

Jerome: Clearly your partner is a very important person in your life, yet mental health problems can sometimes cause problems in relationships. How have you both managed?

Jen: We met when we were 20 and 21, so we have grown up together in many ways. I think it’s difficult for partners to be there for someone who is mentally unwell because so much is unpredictable. I imagine the feeling of being ‘responsible’ for someone who is ill is a very heavy burden. I think it’s also a very lonely place to be.
As a couple, the hardest times have come during recovery. I’m not always the best judge of when I’m ready to resume responsibilities or make seemingly simple decisions. On more than one occasion, I’ve slipped into ‘adapted child mode’ and snapped ‘You’re not the boss of me!’ There have been times when I have been very distant and detached but I’ve tried to be present in the ways that I can, no matter how simple they seem. I’m the cook in the house and feeding someone well says ‘I love you and I’m here’ even when there’s been that distance. I’ve tried to do this whenever possible. I understand why relationships do falter but I am very lucky and very grateful for what we have.

Jerome: You recently gave a TedX talk on “The search for light and hope in the absence of both?” (see https://www.youtube.com/watch?v=U_aTx73luho). In a sense you went “global” on your mental health problems. What made you decide to do this?

Jen: I was invited to speak about anything I wanted to and initially planned to talk about the challenges facing marine ecosystems! The more I thought about it, the more convinced I became that talking about my own experiences would be more ‘authentic’. I see more and more students who struggle with their mental health and this worries me. I’m not sure if it’s because people are more open now, or if the pressures on people mean that more are becoming unwell. My fear is that there is never ‘down time’. People are expected to stay connected via the Web or their mobile devices. People need to be able to slow down and just ‘be’ rather than have to ‘do’ all the time, be that email, social media, online gaming, online study etc. Students also have increased financial pressures. I think you could almost think of it as being like blowing a fuse if you overload it. We need mechanisms to escape that are safe. Max Richter’s ‘Sleep’ should be available on prescription.

It was also important for me to convey the message that it’s possible to recover but seeking help is very important. I have worked with students who have discontinued their studies and, for some that was the best thing to do. Others have been able to continue, given the right support. I hope that people see that mental illness need not be a barrier to study or to working. You do need strategies to manage though
and sometimes you do need time out. I have talked with several students who have been considering suicide. Clearly, I’m not qualified to ‘treat’ these people but I am able listen and talk with them and ensure that they get appropriate help quickly and remain safe. I’m also able to be very candid about my own experiences. I hope that this has been of some comfort. If, by being open and honest in my TedX talk and in my interactions with students, I have helped to keep one person safe, then it’s worth it.

Jerome: What has been the reaction to your TedX talk?

I’ve been surprised by the reaction from students, which has been very positive. This term I taught a third year module in sensory physiology, during which we covered topics such as pain perception. The students tried to define ‘pain’ during an in-class discussion. They were very keen to try to define psychological, as well as physical, pain and they asked me some very direct questions. I don’t think they would have asked these before the talk. I was able to answer their questions honestly and the discussions continued on and off for several weeks. We covered a lot of ground. I have also received emails from students and colleagues thanking me for giving the talk and telling me that a lot of what I said resonated with them. My closest colleagues knew of my struggles before. The support from Dr Frankie Kerridge was great when I was ill. She was at the conference, as were my partner and GP, so I felt supported there. It was the hardest conference talk I’ve ever given.

Jerome: What does the concept of hope mean for you?

Jen: That’s a big question! Sometimes you have to rely on the hope of others. Emily Dickinson wrote that ‘Hope is a thing with feathers- that perches in the soul.’ Hope, for me, is being able to imagine that there’s a tomorrow and that tomorrow need not be feared. It’s been impossible at times to imagine a future and plan. I used to get very anxious about doing simple things like planting seeds or booking something too far in advance. I’m going to a concert next week; I booked the tickets six months ago and as I booked them I smiled and felt excited. I planted lots of seeds in spring
and I’m looking forward to watching them grow in summer. That’s huge progress, and hope.

Jerome: What changes would you most like to see in mental health services?

Jen: I’d like to see more research into better diagnostic tools. I think that the current methods aren’t ideal. To rely solely on ‘symptom-based’ diagnostic tools is inadequate and unhelpful but currently that’s really all we have for now. Symptoms are very important to understand though. For example, I see depression as a symptom but there are myriad causes. For some people these may be largely biological and for others psychosocial. Interventions need to be appropriate for the individual. It seems to me that there is still a lot of disagreement within the sector about what causes these symptoms and what is or isn’t ‘illness’. This is unhelpful to the person who is in distress. We are all products of our genes, our physiology and our life events. Diagnosis needs to consider all of these things. I am hopeful that the science is progressing, but we’re a long way off. My hope is that better diagnostic tools will lead to better, more targeted treatments. For this to happen, we need more investment in research at the lab bench and in the clinics.

At the ‘grass roots’ level I think early intervention is important, along with access to therapies, be they medication and/ or talking therapies. What worries me, not just about mental health services, is that the type of treatment that’s offered and funded is increasingly dictated by sets of guidelines, seemingly based on generalist evidence. What alternatives are there when these treatments don’t work? I heard something on the radio recently about people being labelled as ‘non-responders’ to CBT or medication. That language is such that it actually reinforces that person’s negative thoughts; ‘I didn’t respond, therefore it’s my fault!’ It’s not. The treatment didn’t work so alternatives need to be offered.

Jerome: What are your views on the use of medication for mental health problems? In your story you say you have now “made peace” with medication. In what ways?
Jen: I’m in no doubt that medication is very important in helping me to manage my symptoms, in combination with talking therapy. Insomnia is both a symptom of and a trigger for relapse. I have medications that have sedation as a side effect so I take them at night. My sleep is better so I’m not as exhausted. I also take a mood stabiliser. This was suggested a long time ago but I refused to entertain the idea. Actually it turned out to be a ‘game changer’. I was reluctant to take additional medication because I worry about potential long-term effects. My GP, therapist and psychiatrist put it to me that we need to address the problems that are the most dangerous in the here and now. That hit home. It’s either worry about long term effects or potentially not be here to experience those effects, should they happen.

We can deal with problems that may occur in future if needs be. Unfortunately, I do have some adverse effects. My short-term memory isn’t great, although I’m told that’s normal when one’s advancing towards 50. I also struggle sometimes with my coordination, especially when tired and I hate the weight gain. In the past I’ve argued with doctors about medication and I have stopped taking it. There are lots of conflicting views about long-term medication and the evidence from the literature seems confusing. What I do know is that I feel better with the combination I take currently so, for now, I’m not going to make any changes.

Jerome: How do you think mental health services can best help promote recovery, which is said to be the goal of many services?

Jen: I worry that, with funding pressures and reduced resources, there will be fewer opportunities for long-term care. Continuity of care is also important. It is very difficult for people to form trusting, therapeutic relationships with doctors and therapists if they don’t see the same person consistently. I have received excellent care in the primary care sector and I’m in the privileged position to have been able to afford to pay for aspects of my care e.g. psychiatry. I think that, for most people, interventions are more effective if they feel as though they have some control over what happens. Trust is crucial for this to happen. Perhaps we also need to work on the language we use. I sometimes wonder if we need to reframe mental illness (yet again)! I’ve recently been thinking that maybe there would be less stigma if we think
about mental illnesses in the same ways that we think about brain injuries. There’s a lot we need to think about.

Jerome: Have you been inspired by any mental health professionals you have come across?

Jen: There are several people who made a big difference. In my early 20’s a Psychiatry SHO, Dr Hughes-Guy, cared me for. She was very down to earth, but compassionate in her approach.

In recent years my GP, Dr Kate McMichael has been brilliant. She looked after me when I was at my lowest ebb. She negotiated treatments with me yet, when necessary, she laid the cards on the table and was always very honest. She’s a very ‘human’, intelligent person who took time to listen and really hear what I was saying. She didn’t give up on me. She worked closely with my therapist, June Holden. June is very open-minded and uses a variety of approaches. We’ve covered a lot of ground, using approaches including Gestalt, TA, CBT and person-centred therapy. June has challenged my thinking and has never been afraid to do this, but it’s always been done with care and with respect. Her continued and careful assessment of my state of mind and my needs has helped with progress. As with my GP, she’s sat beside me when I’ve been in great distress and hasn’t judged me or told me how to think or feel. Compassion is a more powerful medicine than any prescription drug. Had the roles ever been reversed, I’m not sure I’d have the courage and wisdom of these two women. For a time, I saw Dr Amal Beaini, consultant psychiatrist. He was very democratic in his approach and I’m grateful for this.

Jerome: In terms of people with lived experience of mental health problems, have any specific individuals impressed you?

Jen: I’ve learned a lot from reading Kay Redfield Jameson’s work. Her books ‘An Unquiet Mind’ (Jamison, 2015) and ‘Night Falls Fast- Understanding Suicide’ (Jamison, 2000) were particularly valuable. The insight that she brings to her academic work is also very evident. I admire, enormously, people in the public eye
who have been open about their struggles to try to end stigma. People such as
Stephen Fry, Ruby Wax and Alistair Campbell have done a great deal to help start
important conversations within society.
On a more personal note, I have a close friend who walks a very difficult path and
does this with great courage. I admire that and take comfort from the support that
we are able to give to each other.

Jerome: What challenges lie ahead for you? What do you most want to achieve in
the future?

Jen: Professionally, I'm pretty much where I wish to be. I'm not ambitious in terms
of promotions and making more money but I am very ambitious about increasing my
skills as a teacher and the range of teaching strategies I employ. I relish the
challenge of ‘unlocking’ students’ brains and I love working with them as they
navigate through their studies. I also love learning so I’m in the right place.
On a more personal note, I would like to learn to sing properly. I won’t play the
trumpet again I don’t think, but I enjoy singing. Singing or playing a musical
instrument demands full attention. In a way it’s a form of ‘mindfulness’.
A couple of years ago, I couldn’t plan more than a few hours ahead. Now I can see a
future, probably retiring to Cornwall with my partner and having a smallholding.
Getting there will be a challenge but I hope we make it. Sometimes keeping hope
alive is a challenge in itself and I am thankful to all who have walked by my side.

Jerome: What would you most like to be remembered for?

Jen: I think I’d like to be remembered as someone who noticed others, recognised
their distress and sat down beside them. I’d also like to think that students
remember me as someone who loved working with them and wasn’t afraid to fight
their corner when necessary. My family and friends will remember me for my
baking.
Conclusion

Jen’s is a remarkable life. Her comments about recognising the distress in others and sitting beside them, reminded me of Dr Glenn Robert’s comments about his own episodes of depression, “...which has given me confidence to sit in the dark and on the edge with many other since,” (Roberts, 2012, p.217). We are all recovering from something. Jen’s story started right back in her childhood with the loss of her close friend, who died when she was only nine years old. Her mental health problems really started at University. Now as a University lecturer she is able to share her own insights and wisdom of dealing with mental health problems with today’s students. She will be remembered for a lot more than her baking.

References


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