

# An Open Conversation About Postpartum Psychosis

## An Interview with Jessie Hunt: Communications Lead, Advocate, and Expert by Experience

Udita Iyengar<sup>a,\*</sup> and Jessie Hunt<sup>b</sup>

<sup>a</sup>Department of Psychosis Studies, King's College London, London, UK; <sup>b</sup>Action on Postpartum Psychosis, London, UK

Postpartum psychosis is a mental illness that is often misunderstood and stigmatized and can have a devastating impact on the women affected and their families, particularly when not identified and treated early on. The first-person perspective of experiencing a mental illness such as postpartum psychosis is remarkably powerful and can shed light on some of the hidden or misunderstood aspects of diagnosis, treatment, recovery, and getting support. With this in mind, we have prepared this interview from both an academic and lived experience perspective of postpartum psychosis, for clinicians, academics, mental health professionals, and members of the public.

### INTRODUCTION

Starting from pregnancy, a mother's brain and body undergo many changes to prepare for the arrival of her new baby [1,2]. Amid the joy and anticipation of new motherhood and bringing new life into the world, a lesser-known chapter can unfold for some women, the bewildering world of postpartum psychosis, an illness that demands our serious attention. Approximately 1 to 2 out of every 1000 women who give birth will experience postpartum psychosis, which may present as having mood changes, manic and depressive symptoms, sleep disturbances, and may also include delusions and hallucinations [3,4]. Postpartum psychosis can occur shortly after birth, requires immediate medical attention [5], and

early detection and intervention are critical. Specialist Mother and Baby Units are methods of best practice and care that can help mothers with postpartum psychosis recover [6], although these are not always available.

The first-person perspective of experiencing a mental illness such as postpartum psychosis is remarkably powerful and can shed light on some of the hidden or misunderstood aspects of diagnosis, treatment, recovery, and getting support. I spoke with Jessie Hunt who has channeled her creative and professional life with her own lived experience of postpartum psychosis, and who advocates for mothers and their babies through her work with the charity Action on Postpartum Psychosis ([www.app-network.org](http://www.app-network.org)). Jessie offers an opportunity to have an open conversation about the experience of postpartum

\*To whom all correspondence should be addressed: Dr. Udita Iyengar, Psychosis Studies, King's College London, London, UK; Email: [udita.iyengar@kcl.ac.uk](mailto:udita.iyengar@kcl.ac.uk); ORCID: 0000-0001-7928-2167.

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psychosis, her journey through recovery, and how it has impacted the work she does today.

**Could you share a bit about yourself and how you came to work in the area of postpartum psychosis?**

My name's Jessie and I am from South East London. From a work perspective, I help charities and museums with marketing, audience development, and digital communications. I have my own business now and I also work part time for the charity, Action on Postpartum Psychosis. I am passionate about the work that I do.

To backtrack, 10 years ago, I became a mother for the first time, and I experienced postpartum psychosis out of the blue after my son was born. I'd never heard of this illness before, and when I recovered from the illness and went back into the working world, I knew that I wanted to use my professional experience to be able to raise awareness of maternal mental illness, especially because it was something that I hadn't heard about before. I wanted to make sure that it was different for other families in the future, so when an opportunity came up to help Action on Postpartum Psychosis, an organization that had supported my recovery journey, I started working with them, initially on their social media and then expanding my role to manage press, communications, and campaigning.

**Would you be willing to share what you went through when you experienced postpartum psychosis?**

My experience of postpartum psychosis began within the first few days after having my baby. I was a very new mum and there are lots of things that go on within those first few hours and days. I had never experienced mental illness before and I had a normal birth but was struggling with breastfeeding when I was in the hospital. That was the first thing that I found challenging and I feel like I didn't get the support that I needed in hospital. I went home but then my baby had jaundice, and we had to go back into hospital which was really stressful because we went back in via A&E. My son was in a children's ward in this blue box getting light treatment at just a few days old. I just didn't sleep and I was still struggling with feeding. I went back home with him and I didn't sleep there either. I was full of energy and I felt like I needed to do things all the time. I was writing lots of lists of all the things that I needed to do. I felt like whenever health professionals asked me questions about things, I was getting more and more confused. I couldn't remember the answers to the things that they were asking, like when did he last feed, when did I last change his nappy? I just couldn't quite remember so I had to write everything down.

I also remember saying to my friend that I felt like



Jessie Hunt, Marketing and Digital Communications Coordinator, Action on Postpartum Psychosis, London, UK

I was drunk on love. It was very strange fuzzy, buzzing feelings. I just couldn't relax or sleep, and at the point at which I was able to breastfeed I remember that I had this moment when I felt like I cracked the code of being a mum and that I was super mum and I had worked everything out. I could do all these things. I couldn't understand why new mums felt like they were in pain after birth or why they had to stay in bed. Because I wasn't in any pain and I didn't need to sleep.

It was not normal behavior for me, and it was not normal behavior for a new mum.

With health professionals, I became paranoid if they asked me questions. Were they thinking that I wasn't a good enough mum? I started to become more emotional and with the help of a concerned friend who came with me to see my midwife, I was sent back to the postnatal ward at the hospital with suspected postnatal depression. It was there that I became quickly very unwell, with bizarre thoughts and behavior. They decided to section me and take me to a general psychiatric ward. I was there for two weeks without my baby and I was diagnosed with postpartum psychosis. They then found me a bed at a Mother and Baby Unit – a specialist ward for mums. It was there that I was reunited with my baby.

**What was it that was helping you get through the next stages? Was it family or was it just having the medical support or was there something within you?**

I actually don't remember a lot from that time, and I occasionally have flashbacks to things that happened. I think for my family around me, that must have been so scary. Postpartum psychosis was something none of us had heard of. And it's a really severe, life-threatening

illness.

I know that at the beginning they were helping me with medication so that I could sleep. Sleep is a really important part of recovery. I know that it would have been that combination of medication and support from health professionals in the early days.

For 2 weeks I was in a general psychiatric ward with people who had had all kinds of different experiences, and I was not with my baby. It wasn't an appropriate place for me as a new mum. When I was in the general psychiatric ward, I was asking about how I could pump breast milk for my baby and they had to go and find a pump from another ward and then bring it to me – they threw away the milk without me understanding what was happening. I had postpartum bleeding and was experiencing things that they were not set up to support me with. There was also no way for the baby to be brought in for me to be with, so he had to be cared for and bottle fed at home by my partner and family.

It was really when I got to the Mother and Baby Unit that I started to get better. I was under a specialist team who had supported many mums through postpartum psychosis and I think it was so important to be with my baby again. I was able to sleep and the wonderful staff supported me with caring for my baby. They helped me to feed him, change him, to bathe him, and do bonding activities like baby massage and play. We would go to the local library and do a rhyme time session and go for walks around the grounds. Having that support to be able to do those things along with the therapy I received, was invaluable for my recovery, especially with the kind staff and in the beautiful setting that the Mother and Baby Unit was in, with a garden and surrounded by wildflower meadows and ancient woodland.

***What was your experience and interaction with professionals at that time?***

I think initially when I was unwell with the illness, I felt very confused by the professionals. I didn't know who anyone was, I didn't understand what was going on or what was wrong with me. I was initially in a triage psychiatric ward and I had a week where I was in another women-only ward for 2 weeks without my newborn baby. I was then found a bed at a Mother and Baby Unit. It really wasn't until I was in the Mother and Baby Unit when I started to build relationships with the professionals. There are so many different types of roles that you come across: you can find perinatal psychiatrists, psychologists, mental health nurses, occupational therapists, and nursery nurses that help with your baby. There are many different types of roles where you don't really understand what they do. And then you also interact with social workers and people with roles that are stigmatized and had scary associations

for me.

I really got to know these staff when I was in the Mother and Baby Unit for 3 months. The staff were so passionate and caring and I can't thank them enough for the work that they do. They really, really helped me to find my way as a new mum.

***What was it like coming back to your home life and community after you left the Mother and Baby Unit?***

When I started to recover, I was trying to process what had happened to me. When I eventually went back home and reconnected with some of the mums that I'd met when I was pregnant, they were asking me, "Why did you just disappear for months and months?" and I remember not being sure how to answer. I felt a lot of the stigma about having had psychosis and being in a psychiatric ward. I felt so lonely in my experience, having never encountered anyone with or even heard of postpartum psychosis.

I shared my experience with two of the mums. One of them was a child psychologist and had worked on a Mother and Baby Unit previously and then another had experienced psychosis as a teenager. I felt so lucky that I had two mums that I could talk to and feel like I could be quite open about it.

When I would meet up with other mums, everyone was breastfeeding and I was the only one in the group that would have bottles. I felt so sad because I wanted to breastfeed too and I felt that this was taken away.

I remember the first time that someone asked me if I would have any more children. That was such a jolt, such a difficult question. I hadn't even thought about it myself and having to come up with an answer on the spot was really challenging.

***Can you tell me more about the charity you work with Action for Postpartum Psychosis and how you came to work with them?***

Action on Postpartum Psychosis is the world leading charity supporting and advocating for mums and families affected by postpartum psychosis. It works through awareness raising, training for health professionals, facilitating research, and offering peer support, where you can talk with staff and trained volunteers who have had similar experiences.

When I was recovering from the illness and during my time in hospital I hadn't met anybody else who'd experienced postpartum psychosis. I had been told "don't Google the illness" because there was a lot of stigmatized media at the time, so it took a while for me to start researching. I was actually watching an episode of the TV program *Call The Midwife* and the storyline was about

someone who experienced postpartum psychosis. I just started searching on Twitter and I found someone else who was talking about their lived experience. I reached out to them and they were the first person that I talked to that had postpartum psychosis. We decided to meet, as we both lived in London. She told me about the charity Action on Postpartum Psychosis, so I got in contact with them and signed up for their newsletter and database of people with lived experience.

**What was it like reading about other women's lived experience?**

It was so powerful to read other people's stories. I vividly remember the first time reading other people's stories on the Action on Postpartum Psychosis website, and them putting into words all of the things that had happened to me that I'd never been able to express myself. Their experiences were so much like mine, and it helped me to understand that it was an illness and it wasn't "me." Well, it was me, but also they were symptoms of the illness and other people had it too.

A newsletter from Action on Postpartum Psychosis had a call out for an art workshop retreat for a few days. I went on this and met other mothers who had been through the same thing. It was just so inspiring and healing to have the experience of meeting other people, who were just normal mums.

**Based on the work that you've done with Action on Postpartum Psychosis and your lived experience, what are a few things that you think are helpful for other mums and the public to know about postpartum psychosis?**

For people who are concerned that a new mum seems strange, it's really important to encourage them to help her to get help and to treat it as a medical emergency – she needs to be urgently seen by a specialist. It may be that she doesn't think that she needs help and it was the same for me – it was the people around me who helped me to get the help that I needed.

Mums like me can seem really well because they're really trying to hold it together on the outside, so I think you have to watch them carefully and know that you need to get help for that person. If they do show signs of postpartum psychosis, they need an urgent appointment with their GP. If you're not able to do that then midwives and health visitors can refer to perinatal mental health teams too. Each area of the country has a mental health crisis line too. Or if you feel anyone is in danger, go to A&E or call an ambulance.

It's also really important to know that recovery is possible. We know from Action on Postpartum Psychosis research that mothers who go to Mother and Baby Units

get better quicker and feel less traumatized by their experience. Peer support is also really important for processing what's happened. That's not just for the mum, but for the people around them. For the dads and co-parents, for family members or friends who have been part of that journey... you have to know that it's possible to get better from it. I was on medication for a year and I have for the last nine years been back to "me."

**How do you think arts and creativity has helped you with the recovery process?**

When I was in hospital there were lots of creative activities to get involved in. I really enjoyed the art sessions in the hospital.

There's one session I did, which was dance therapy, where my baby was on a yoga mat in front of me. I've since heard the person who runs those dance classes do a talk at a conference, and it was fascinating because she was saying that for mums who are not able to talk or maybe not able to process things and are still really unwell, being able to have dance and movement therapy is something that's incredibly powerful for recovery.

I remember doing lots of drawing and art activities in hospital, like baby footprints with paint and things like that. During my recovery process, I've written about my story, my experience, and I even tried a bit of poetry. I had never done poetry before but I was inspired to find words to help process and explain the experience. I never shared them. It's always just been for me. To creatively express my emotions through making art in the Action on Postpartum Psychosis art workshop was another way I was able to try to make meaning of what happened to me. Hearing the other mums at the workshop talk about their own artworks was also therapeutic and helped me to feel less alone in my experience.

**How do you think postpartum psychosis is portrayed in books and media and has that helped you with your understanding and recovery?**

I think it's been really powerful to see experiences of postpartum psychosis on dramas or TV, like I was saying about the TV show *Call the Midwife*. Action on Postpartum Psychosis has also worked with *EastEnders* on a storyline and we were really lucky to work on a storyline with *Hollyoaks*, where I consulted on the script to make sure the story that came to life was authentic. When there are documentaries about the illness, they have sometimes been really hard to watch because what I experienced on the inside is quite different to what it looks like on the outside.

**What are some of the barriers that women still**



**face for accessing treatment?**

There are unfair disparities in terms of the help and support women and families from different backgrounds and experiences are able to access. I think that for some mums and families, there's even more stigma and it's even more difficult to share experiences and that is going to be a barrier to people getting help.

Where you live is also linked to what help and support that you get. In Northern Ireland and the whole island of Ireland for example, there is no Mother and Baby Unit. I'm really passionate that women and families have access to those specialist services, no matter where in the world they live.

**What other areas are you devoting your time to in the field of mental health?**

I joined the Bethlem Gallery (Bethlem Royal Hospital, London, UK) as a Trustee. It's a really, really special place that is close to my heart. It was quite challenging at first because it meant going back to the Mother and Baby Unit that I had been treated at – the Gallery is at the same hospital. But the moment I re-visited for the first time, I felt comfortable again. I feel so passionate about the arts supporting me in my recovery and being able to help raise awareness of the Gallery and support artists who have experienced mental health services. I also recently joined a panel which is for a Wellcome Trust (London, UK)-funded project in partnership with the Bethlem Gallery. It is exploring art and maternal mental health, and it's a research study that is going to use art. I thought that was quite interesting thinking about art as a way to explore research.

**How do you think the perception of postpartum psychosis has changed since your experience, and how do you approach it now?**

The perception of postpartum psychosis has really changed in terms of stigma and awareness for this illness. I think a lot of that is due to the work that the charity Action on Postpartum Psychosis has done. There is still a huge stigma around psychosis. I still always think about who I share my experience with and what I say. I was really worried that if I talked about my experience that it might be a barrier to me being successful when applying for jobs, for example, but actually that hasn't been the case.

**Do you think that science and research about postpartum psychosis filters down to different audiences or do you think that there needs to be more translation of research that can help other mothers, the public, or other professionals in the field?**

I've been a participant in lots of research studies and I think it's so important to take part, but postpartum psychosis is still an under-researched area, and there are so many gaps in knowledge; it's important that more research takes place. I also think that there's so much more that we can do in terms of storytelling and sharing findings. I think there are opportunities to share these things within the media, and I think that journalists want to hear these stories about new findings and the impact of that.

I know that when I've shared my experience, it's the lived experience with the research and data together that has an impact and creates lasting memories for people. There is so much effort that goes into developing a research study and as much effort needs to go into communicating the outcomes of it.

I still don't know why I had postpartum psychosis or what the cause was, and I would love to know that.

**CONCLUSION**

Thank you, Jessie, for sharing your story so openly and honestly and with a sense of resilience and optimism. I think you are doing incredible work to advocate for women with postpartum psychosis while supporting the research behind it. Indeed, more research studies are needed to understand the etiological factors associated with the occurrence of postpartum psychosis [7]. There has also been a burgeoning interest and emphasis on incorporating user-led (or lived expert) experience and perspective in the development of mental health research, evidence-based policy and practice, as well as education curriculum [8-11]. From our conversation with Jessie, it is evident that there are tremendous benefits when women with lived experience of postpartum psychosis can work together with researchers and academics to conduct meaningful and insightful research and help shape policy for a future generation. As a researcher who has studied about the brain and biology of parenthood, and a mother of two young children myself, I often think that the transformative period of motherhood is not nearly addressed or understood well enough, and it truly is a collective effort to heal the women and mothers who may be struggling or suffering, no matter how big or small.

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