

OUR SUNSHINE PLACE

Written by Marianne Wyder

Based on the contributions, experiences and writings of: Jenny Giang, Birthe Griffith, Deborah Irvine, Sharon Juma, Joan Koenig Hughes, John Maher, Rise Faith Rosello, Helena Roennfeldt, Bridie Stewart, Hoa Ta, Rosslyn Taylor, Marianne Wyder and others who preferred to withhold their names from publication.

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This is the story of Anne. It is also a story of recovery and rediscovery of our 'self' after a time of significant mental health distress.

This first chapter marks the start of this journey. In this chapter we meet Anne and through her eyes get a glimpse of what it is like to be in a psychiatric inpatient unit. We are also introduced to other individuals with similar journeys.

This story is based on the experiences and writings of a group of individuals who have experienced – or supported others experiencing – a time of significant mental health distress. This project started in February 2015, after a workshop held by *A Place to Belong* about the future of inpatient mental health care. Since that time we have met on a monthly basis and shared some of our journeys. During these sessions we also wrote about our challenges and successes.

These writings were then collected by Marianne, who incorporated these into Anne's story. No one character in this story is based on one person's experience and all of our experiences are represented in the different characters in this story.

We are currently writing an academic paper where we reflect on how health care professionals can best support us during these times.

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Chapter 1: In hospital. How did I get here?

Psych ward 2D. That's what I read when I was escorted here. I don't remember much else. I don't know what is real and what isn't. I am so scared. I have these flashes of what happened but they don't make sense. It's all so jumbled; I can't put the pieces together.

What happened to me? I am not too sure. I went too long without my medication; the last couple of years broke down my functioning world. My work and routines were reduced to confusion and alienation from the world. I live inside my head. I just feel out of place, all the time. I don't belong anywhere. My own mind estranged me from people. I want to talk to someone but can't at the same time. I have lost touch with what is real and what is not. I can't connect anymore. I think I lost it.

The night I was admitted the police came with a doctor. My parents looked on helplessly because they couldn't help me understand. I cried while I was being taken to hospital. I was being trapped. As far as I was concerned I was fine. I didn't know why I was taken away. No one even told me, or asked me. It didn't help I shouted at the psychiatrists; shouted that I was Super Woman and that I didn't belong in hospital. I still don't belong here.

My parents came in and they had a meeting with nurses and doctor. I could overhear them talking about me. They were discussing whether I was free to leave. It felt horrible being talked about. I felt so powerless. I wanted them to work with me, not just do things to me without giving me any choice. Why don't they ever ask? Only sometimes I am given choices, but I'm never consulted. Am I not a part of this?

Then I was not allowed to leave. I was told that I would be arrested if I did. Why? Can't I even go to the shops? I realise now how vulnerable mentally ill people are in a society who can determine our freedom. The idea of not having control of my own body, my own mind or anything is terrifying. Did I lose it all?

I have been sitting on this hospital bed for a while now. There is not much in this room to look at apart from the faded paint on the wall. The bed is uncomfortable. I am so tired. My thoughts are racing back to someone banging on the wall. I assume she has been here before. They were trying to calm her with medication. She was screeching; she would shriek, then bawl. I could hear her gasping for air, silence, and then some murmur.

I know I am here to be safe but I am just so scared. This place does not feel safe. Everything is so alien here. I can see some sunlight in the courtyard – that’s comforting. In here everything is just so foreign and confusing. Most of the nurses seem kind and caring. They are always busy and stressed though. Sometimes I feel that in the midst of their tasks they forgot that I am a person. They focus on my symptoms, but forget the *me*. Am I not a human anymore? I have feelings and thoughts. It feels as if my illness has put an invisible wall up between me and the nurses.

When I first came in I did not want to take my medication. I was worried I was already taking too much. I felt drowsy, nauseous and dizzy from the side effects. Nobody asked me why I stopped taking the medication. The nurses were just frustrated and angry with me. Everything just felt threatening and unsafe. I wasn’t even allowed to be scared. Can’t they see how alien this place is? How alien I feel?

Then they took me to the isolation room. I couldn’t understand. How am I a threat? Why? It felt like a prison cell. There were bars on the windows. The doors are always locked. They called three security guards to hold me down. Two nurses then administered the intra muscular injections. This happened every time I refused to take medication. This happened twice a day. After a few days I agreed to take the medication. I was forced; if not by their hands, by my own. I had no choice. I felt so violated. I was already confused, and they responded with violence and calling security. There is no choice. I felt I had no other options than to become angry myself; to yell and scream. They would just inject more medication. It feels like medication is the only intervention we get. It just feels so wrong. When you are ill, you are violent and then they deal with you in a violent way. Then they lock you up.

Even after being injected, nobody spoke to me about this. Why aren’t we given some choices about the drugs we take? Why don’t they ask me? Talk to me? I want to know why I am on the drugs! That’s all. The doctors’ attitude and compassion are so important. They need to work with me and not just my symptoms; I want them to work with *me* to find the right medication for *me*. The doctor is technically competent but just so impersonal. He never asked me what is truly bothering me. I want more, I want to talk, I want counselling. I want to feel valued and encouraged. I want staff to be supportive and aware of *me*. I want feel hopeful about my future and that I can recover from the mess – the mess my mental illness left in my life.

All I do here is to wait. I am not sure what I’m waiting for, or who. I just sit here and listen to the noises of the ward. I am still wondering why I am really here. I just want to go home where the healing can start. I am not even sure how long I have been here now. One week? Maybe two, or is it

three? Every day is just the same. Nothing happens. Confusion reigns supreme. It was enough time to become fearful of everyone, everything. Their reality is skewed but in a different way to mine. No wonder some people treat you differently when your world is distorted.

I like listening to the nurse's conversations about their lives and work. It is comforting to know that there is a life outside these walls; a world where things are still normal. These ordinary conversations make me feel safe. The extra-ordinary of the ordinary. Everything on this ward and in my head is just so strange. I wish I was at home, where people know me. Nobody here knows who I am. They see my symptoms but don't know me. How could they? I have said and done some pretty weird stuff. It is too painful to think about what I said and did. But they never ask about me, about the *me* before all this.

There have been beautiful moments in the hospital; moments where I felt connected. Moments like when Nurse George made time to come and see me every day. Sometimes we just sit. Yesterday we talked about taking pleasure in the simple things. It is easy to forget this in here. Things like sitting outside and enjoying the sun on my face, or drinking a cup of coffee. I miss the simple ordinary things in my life. George is so kind. He took me out for a walk afterwards.

I am not here to make friends, but it helps to have people to talk to. Having people that are non-judgmental, a space to talk and connect – a space where the trauma can be healed. John has been one of those people. He was brought in an ambulance. He feels safe in hospital. It is a refuge from his thoughts and life. I watch him from my room. I hear him joke with the nurses "it is good to back at the motel for a rest". I wish I felt like I was a guest who was here to have a rest. He has been here a few times, the ward is familiar to him. He told me he feels cared for. People on the ward know him, know what he is like when he is psychotic but also when he is well. They know about his life. Maybe it is those connections that help him get through the difficult first days when everything is alien and confusing.

John values the camaraderie and friendship with the other patients. I sometimes come close to experiencing that feeling. Art therapy is one of those spaces where this happens, where I can express myself and feel connected. To like how we sit around a table and paint, make cards, sculpt, bead, journal or make a vision board. I look at our art and just see so much sadness but also glimmers of hope. It is in these moments that my social isolation cracks and I form friendships and connections with the other patients; moment where we share problems and experiences. He described this as "moments where the mundane and stark world of being on the ward becomes filled with colours, textures, ideas and goals to achieve'. he is so right! Art allows us to rise above

our illnesses and to express ourselves. I always feel different after these groups. During the day I am my illness, but in the group I am just me. The invisible wall between me and the world disappears. Art and music made my stay in hospital more bearable. It contributed most to my recovery. I wish I had more of those moments, moments where the environment is less hostile, where we are cared for differently.

Anne came to see me. It is comforting to just sit and play board games. She is this friendly face in an otherwise bland and scary environment. She told me she is a peer worker. Anne talks while I manage my silence. Since I slumped into my depression I don't seem to talk much anymore. I panic when I don't have anything to say. I can't believe she was once where I am now. She seems so strong, so whole. It gives me hope. I wish I could absorb her wisdom, her experiences and make them mine. I ask her 'What was your hospital admission like?' Her answer surprises me. She told me, 'even though it has been traumatic staying in the mental health wards, I will be eternally grateful for all the help I received while I was sick. It was a blessing in disguise. It was free health care, which meant I didn't have to get into debt. It was a nurturing cocoon out of a messy situation, the start of a process of transformation from a scraggly, prickly ugly caterpillar into a beautiful, colourful butterfly. My mental illness has been a spiritual awakening, a process I had to go through to attain enlightenment. I truly have a wonderful life.'" For her, all those that crossed her path are like angels, saviours and beacons of light in an otherwise treacherous and dark journey. I can't believe she talks about her journey as fulfilling. Having talks like this give me hope and glimmers of faith that things may change. Our experiences are so similar. I feel heard and understood.

Nurses don't have the time to listen. Everything here is fast paced. They are always busy and need to do so many things. They try and find snippets of stolen time from their task to listen. They are under a lot of stress, which is why bad things happen. They have limited options. There are so many people on this ward that are very ill and distressed. When they leave, their place is taken by others. The pain and suffering in the world seems endless. It must be hard to work here.

I now know it was Elizabeth who was banging on the walls the other night. We sat together at dinner. She was mumbling to herself. Suddenly she turned to me and said "I feel like I have been missing for a thousand years". I don't know what to say. I wonder if she just wants us to understand what her voices say to her. Wants us to listen to them and what she hears them. It is hard to make sense of what she says but it is clear that she cares about others, the world; maybe too much. Sometimes I think we force people to comply with society's norms even though the values are totally skewed. Maybe it is us who are sane. Maybe our problem is that we can't handle the cruel and terrible things that are happening in this world. We just don't know how to communicate this.

I am scared I will become like Elizabeth. Scared no one will take the time to listen to what I say. Maybe if society would value our experiences and not see us as a waste of time it would be different. We just seem to be expected to 'just' get over it. There is just no time and patience to hear our inner crying voice. I wish I could see a counsellor. I just need to talk.

I also keep on thinking about Lucy, who was discharged yesterday. This was her second time in hospital. Six months ago she came to hospital. All she can remember is that one day she eating Oranges before ECT and then, like it was the next day, she was discharged. She was told 4 weeks had passed but she remembers none of these. She does not remember anything she had said, done or experienced during those weeks. Friends, family, and her psychiatrist try to remind her of some these. She just has no memory as if she lost that time. Her words still echo in my mind. "I totally lost weeks of my life. I know it was only temporarily but I am terrified and cannot comprehend how I reached that state". She was readmitted to hospital because she could not sleep. She was hearing voices. That terrified her. Like if she had PTSD. I wonder if the nurses, that first time she was discharged, had explained her delusions and hallucinations to her, this would have prepared her to absorb what happened to her. Sometimes I wish I could forget those awful things I did; forget about my shame. Maybe having no memory is worse, I don't know.

The doctor came to see me today and told me I was going to be discharged tomorrow. He is always in such a hurry. He asked me the same questions he always asked. How is your sleep? How is your appetite? Are you taking your medication? Sometimes I wonder if he really listens to my answers. I don't talk about weird nightmares I have been having and how the world still feels weird and terrifying. If I would tell him that he may keep me here longer. I just want to go home where I can start my healing. I sometimes I feel that they only care about my medication but the medication is only part of what I need if I want to recover. I don't feel I am ready to go, but I won't stay here any longer.