

Chapter 12

Recovery together

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Recovery for me is a developmental process and some of it is very painful and sad, even today. The story I am going to tell here is about my development as a young Iranian girl coming from a different and war-torn place to live in England and growing up with a brother who was diagnosed with schizophrenia.

30 years ago

30 years ago my brother became unwell and was admitted to hospital. I was with my mother, who did not speak very good English. I asked the doctor what was going on. He just looked at me and said, 'Chronic schizophrenia'.

'What's that?' I asked. He just walked away – that's all the explanation he gave me. Mum and I were bewildered. We had never been to a mental health institution before. It was scary. We didn't know what was going on and we dared not ask any questions. Then they said to us, 'Please don't come in here – please don't visit' because they were going to medicate him. Well, hang on a minute – this is my brother and I want to know what is going on. They said they could not tell us because of confidentiality. My mother was crying. Nobody came to give us any comfort or tell us what was happening. My mum was saying, 'This is my son, I am not going home – this is my son, I want to know what's going on!' The more upset we became and the more we wanted to know what was going on, the more the staff didn't want to deal with us.

Eventually we had to go home anyway. But they didn't ask us what happened in our lives. Nobody asked for our history – it was all so medical model. They called us in the morning and said they would be giving my brother ECT¹⁵. We asked what that was and were told it was electric shock treatment. We were scared by the thought that someone we loved would be receiving this treatment and had no understanding of what it meant.

¹⁵ Electroconvulsive Therapy

Nothing was ever explained properly. My mother didn't understand the language and I was a naïve young girl not educated in mental illness. It was very lonely and we just kept wondering whether we were making the right decision about whether my brother was in the right place.

Days passed and we kept going there. My mum wanted to take food to the hospital because my brother wouldn't eat English food. He liked Iranian food. The staff didn't understand the cultural issues around what food meant for us. It was such a different set-up – so far from my mother's culture. She didn't understand and still doesn't. At that time, over 30 years ago, my country had a revolution and war and my father was stuck there; we didn't know where he was, so we were all very distressed about what was happening in our homeland and our family. We thought that my brother becoming ill might be linked to our cultural background but nobody wanted to hear our story. The difficulty was that we were all depressed as a family and traumatised by the losses at home. Our friends had been killed. We had to live on without anyone understanding what was going on for us.

Eventually they medicated my brother. At first he looked like a zombie, and that was scary too. When we asked, nobody explained why he was like a zombie. They gave him the ECT as well. In a way my mum and I just surrendered to what they were doing. We didn't understand so we put all our faith in the professionals. He was in hospital for three or four weeks. He came home and was a bit better and more settled. But even when he came home there was still no explanation about how we were going to deal with him there. Nobody talked to us as carers about how we could be with him. Our hope was that he would come home and go back to being the person he was before the schizophrenia. We had no idea at all that he might have to go back to hospital again and have more ECT and medication. Carers at that time were not recognised as carers. We were not seen as people at all – most of the time we were just invisible. Even when we were visible, we were just family who were troublemakers. Carers didn't mean anything then.

Two or three years later

Two or three years later my brother was regularly going back and forth to hospital. We were getting angry with him for not getting better and he was getting stressed because we didn't understand what he was going through. At about that time I decided I wanted to learn more and understand.

Someone gave me the number for the National Schizophrenia Fellowship and I rang them up. They were a lot more helpful than the doctors and I became very involved, asking them questions. After that I launched the National Schizophrenia Fellowship in Eastbourne, which is now known as RETHINK Mental Illness. Then I became involved with the Community Health Care Service – which doesn't exist anymore – and became a member of Business Professional Women. We all had to present in the community so I went to the community of mental health and became very active in it.

The more involved I became in the community, the angrier I got about how myself and my mother were being treated. It was really out of order, so I started to organise a carers' group in my own house. A few carers came and, as a result of this, I ended up running a group in a Community Mental Health Team with a psychiatric nurse for 15 years. Meanwhile I went and studied, and gained a diploma in counselling. I then studied psychotherapy for four years, which made me realise how traumatising the system had been for us as a family. I went into my own therapy because of this. I saw how distressed I was as a person and how our family dynamic had been affected by the trauma back in my homeland, the silence in our treatment and the stigma. This and having to justify ourselves all the time left us feeling even more isolated and lonely. Every one of us in the family (I have two sisters as well as my mum) felt lonely in themselves and had their own issues around this. It was very difficult to give a language to all of this and speak to each other about what our brother's illness was doing to us. It caused a lot of conflicts between us, but still there was no help for the family about how we could be there for each other and for my brother.

Ten years later

Ten years on from diagnosis, I was going to be married and bring someone new into the family. My partner didn't understand what was going on and didn't want to understand how my brother was. There was also a lot of conflict around this. My father was still stuck in Iran but I wanted him to be here for my wedding. So we paid people to smuggle him out to Yugoslavia. The local MP helped us get him from there to England. The sad part was that my brother is the only son. When my father came back from Iran he was also traumatised from the tortures in our homeland. When he saw my brother it was a distressing meeting. He had come from one awful situation to another awful situation. He was very sad to have lost his only son to schizophrenia.

My father felt like a failure. He had lost his homeland, his security and now his son. All of these issues didn't help my brother. He was always stressed and upset, which caused more conflict in the family. Once again nobody wanted to understand these dynamics – it was always about giving more tablets and more medication. If only they could have listened to our story. It would have been more helpful to him and to us. I did get married and my father did give me away, and that was the nicest part. The difficulty was that my father became depressed with all the torture from Iran, the mental torture of being called every day and receiving death threats. One of my sisters became depressed and one became anorexic. My mother suffered from heart problems and anxiety. All of this was not very good for my brother, causing him more stress and more hospital admissions. Instead of listening to our problems, they changed his drugs – and when things started to deteriorate again, he was put back on the same old drugs. With the new drugs he just became more crazy and mad, and this upset all of us. For weeks and weeks he would stay in hospital to settle down and again we would have the situation of carers not being understood. I feel that my brother's body was very much abused by all these changes in medication. He never got back to how he used to be. Things just got worse and worse. I kept thinking that if only there was some psychological input in all of this instead of just medical input, it would be much more helpful.

Seven or eight years ago

My training in psychotherapy was good training and I learned to understand the family dynamics. Having personal therapy helped me. Still, the more I understood about the hospital situation and the systems, the more upset I became. I thought, 'If only I'd known then what I know now, I could have helped my brother'. This is why I still feel very angry and distressed that nobody ever explained things to me and my mother. At one point, about seven or eight years ago, it was decided that my brother needed some psychological input, so we received family therapy. This was good but late, and not always resourced to work effectively with the language barriers. Because my mother didn't speak good English, we needed to be the interpreter for her. This was difficult because she was speaking from her emotions but didn't want to upset us. They did briefly bring in an interpreter so that we wouldn't have to do the translation but it turned out to be too expensive and was stopped. Being the interpreters between the system and my mother caused a lot of problems, as my mother would think we were not translating things as they should be

and vice versa. This problem of language and interpretation was also missed as a barrier to therapy. In the end, my mother had more rapport with the interpreter than the psychologist!

We have always felt misunderstood and judged because of our differences. Instead of people in the system being able to embrace our difference, lack of understanding made them misinterpret what was going on. But the same was also true of us: my mum was judging of the services as she was not familiar with their culture. It was us as well as them misunderstanding and missing each other. The trauma of cultural difference caused more misunderstandings and stress for my brother too. The other problem was lack of continuity and the way changes kept happening without any explanation to us about them. Nobody looks at the stresses that constant change and making new relationships all the time can cause to a family and the person who's suffering. There was not a good facilitator to bring us and the system together.

Recovery alone

We do have some psychological input now – the family therapy still. But again this feels late because so much was missed and not heard before. We cannot turn the clock back on this loss. Receiving personal therapy in my training gave me a sense of hope and who I am – a sense of self – identifying in me the real difficulty within the difficulties. I mean that, regardless of how angry I was with the system and how angry and hurt I was with the people who didn't listen to me, the training gave me the understanding that the system did not have the knowledge either. This gave me the capacity to forgive the people in the system, as they had no more education around what was happening than I did. But the biggest forgiveness in all this was about forgiving myself, because if I had known what I know now when my brother first became unwell, I could have helped him more. I didn't know at the time and it is okay not to know. The key message here is that if you don't know something it is okay to ask and to challenge and to find out more. Just because someone is a professional doesn't mean they know more than you. Quite often they don't. Hopefully there will soon be more psychological input in the system rather than just the medical model.

We users of services can see the stresses and low morale within the system and the staff. If the staff are not being looked after by the system, how can we be looked after by the staff? Appreciating the difficulties for the staff

themselves when the system changes with every new government helped me to see them as people too. Sometimes we see that they are just running on empty, and sometimes they don't even know if they have a job or not – which causes real problems for the people they are caring for. In particular, we can see mental health issues within the staff as well. This is very scary for carers and for me. When I completed my training and could see the problems, I felt that there was nothing I could do, and this brought a sense of hopelessness. What would happen to my brother if we died? Questions of this sort have been asked many times in our carers' group. It is always difficult as the carers never feel assured about that. This question is still asked and carers can get very anxious about it as many people like my brother are often abandoned by families or outlive them. When I visit my brother in residential care I see many people who have no families to visit them and I can see how difficult it is for them.

To be able to talk about all of these traumas is a very important part of my recovery, as is having learned the skills to help other people. I am who I am, and if my brother had not been ill I would not have taken this path. One of the biggest obstacles to my recovery has been the feeling of loneliness I've talked about here. I don't mean just being alone – I mean not feeling listened to or able to share different points of view, and the destructive feelings that can come from this anxiety conflict. I see this dynamic at work often, particularly in the way the system still finds it really hard to listen to carers or recognise that we are there. The system needs to understand the need to have someone to facilitate listening and shared understandings between these dynamics. When you feel lonely it influences your thoughts, feelings and behaviours, and has consequences for health and wellbeing. Loneliness happens a lot within families looking after someone who is ill. Often the carer gets angry or upset with staff, who then treat them as a nuisance or ignore them, which results in the carer feeling even more angry or upset. This cycle goes round and round, becoming a more and more negative snowball.

Recovery together

Running the carers group' was also an important part of my recovery, contributing to a more positive snowball effect. The people there often told me that they felt listened to and understood, which felt very satisfying for me. Knowing that you can help just by listening and hearing someone's perspective has the power to dispel the destructive effects of loneliness. It

helps me to reach people and empower them to look after themselves; to understand that their loved one is not the only person in the world and that they exist too. If they don't look after themselves the mental health of the loved one can suffer. I learned to nurture myself by doing things I liked, e.g. giving myself massages. I wanted to help carers learn that they have lives too.

This often gets missed because people focus on the person who is ill and not on themselves, but recovery is for both people. For a long time, the focus of my life was my brother and everyone else was forgotten. This gave my brother the sense that he was important because he was ill. Making the person who is ill more important makes them more self-centred and puts them in the victim position of becoming their label (the schizophrenic), so their recovery gets missed too. Not looking at our own recovery can actively harm the recovery of the person loved and cared for. We have discussed the importance of carers making time for themselves a lot in the carers' group, as it is one of the best ways for a carer to find their own importance. I used to find my importance in going to meetings and fighting for my brother and never fighting for my own self because I didn't see myself as important then. It was only later on that I realised I am important too.

Looking back, I realise that I started my journey like a child who expects their parents to be perfect and then gets angry with them for failing to live up to expectations. As I have grown, I have come to understand that nobody is perfect and that recovery might be about accepting this in myself and others and learning to forgive. This does not mean acceptance of bad things but rather of the fact that the people in the system did not intend to hurt us. They intended to make my brother well in the best way they knew how but this was limited, and they didn't try to hear or understand us. There is a difference between loving and caring for someone. I love my brother unconditionally for who he is, and sometimes my anger at his poor care is not understood by the people who provide that care but don't love him like I do. Sometimes, though, my anger has been caused by unrealistic expectations that the services should love my brother as much as I do. Recovery is not just about me learning all of this – it's also about sharing it with services and carers so that we can all work together to help my brother and people like him. I have trained many mental health nurses about carers and cultural differences, and some of my ex-students are now involved in my brother's care. We have started to reach a place where recovery for me, my brother and the people providing services is now looking more realistic, but I know that this is still not commonplace.

Practical tips to support recovery together

1. Realise that good intentions are not enough – actions or the lack of action have an impact.
2. Engage with carers instead of isolating us as troublemakers.
3. See us as people who can help, not as people who makes things worse. This makes us defensive and breaks the relationship before it starts.
4. Communicate problems without breaking confidentiality.
5. Recognise carers as individuals and the impact mental illness can have on a family.
6. We all need to develop and grow, so don't exclude carers from this.
7. Provide a reliable human face for carers to relate to – the absence of this can be emotionally destructive, leading to loneliness and anxiety.
8. Don't dismiss carers when they are angry or upset. It may have taken them a long time to get to that place. Contain and respond rather than controlling and reacting. That means listening and helping to defuse destructive feelings instead of fuelling them with more negative energy. This would help the person-hood of all parties to be listened to and recognised.
9. See everyone as a human being. See the person in the carer and the persons in the system. When there is conflict we see the other person as the enemy, an object with no feelings; when we see them as a human being we want to communicate and talk.
10. Share opportunities for education and facilitate learning from different perspectives.