

Chapter 6

Love is the first ingredient (transcript)

In Scotland, Anon

Could you start by telling me what recovery means to you?

It's quite a funny word, recovery, because it is an ongoing process of getting better – that is what is really the thing. Recovery as a carer, or recovery looking at the person in my family? At first I did not think I needed any recovery of any sort. My perspective has changed a little bit on that. Some kind of help is needed on the way for the carer, you know. I notice, I mean I needed recovery as a carer. But recovery for the person who is ill is not totally finished, ever – at least to me, because always as a carer you or the person are always on guard and thinking is there going to be another illness, you know, a relapse. So it's not finished but it is good to see the person recover slowly with help – with my help, for example, and with the help of doctors and nurses. It's an ongoing, long process and you have to learn a lot on the way to help that person recover.

Is recovery a helpful word to use?

Recovery is a helpful word to use – it's not as if there is another word you could replace it with. It's a good word. It is a positive. But in the beginning I wasn't thinking about myself in terms of recovery. As a parent, you know, it's automatic that you help your family, you know, your child. It comes automatically – but there is something to learn about it too, you know. If I did not come across services and things like that I would not have known what other way to approach it and to help. It's my daughter I am talking about, my daughter.

So do you consider yourself to be on a journey of recovery as well?

Yes, myself, yes I do. Because when I first found out that my daughter was ill it was like a bereavement – it's like totally, totally, I mean, it's like somebody died. So you don't know what, you are like a headless chicken running around and, you know... I mean all your emotions and everything is all over the place, so... and you don't understand mental illness – at that point I did not know

much about it. When I saw somebody ill, for example, in the buses or acting funny or talking away, I never thought, 'That's an illness' like, you know, it's *medical* – you never think about it. I wasn't aware and I thought I would change place and be scared of that person. But once you found out it was not like that, you have compassion as a result of that and better understanding.

You said you felt like it was a bereavement – that you had lost the daughter you had?

No, no, the shock of it was like a bereavement. It's the shock you get, such a shock finding out because at that stage – you know, the psychosis stage – it's not like I could see any sign because I did not know. But I see now that if I see somebody else with even a little sign or that combination of signs I am able to recognise it and to catch it. I don't have another daughter, but if somebody I know is in that situation I would know to take them to the doctor. In my daughter's case, I did not know what to do. I did not understand, I did not think about it before we had it – you know, it hit home as we did not know anything.

So you had a steep learning curve?

Totally, yes. But I was very lucky that it happened in 2002 and straight away from the intensive care where I took her in emergencies, they took us to Stobhill² where we met the ESTEEM Group³, and that was a lifesaver because the way they approached it was new – that was the very first year. When I heard later that this was very new, I realised we were lucky to have something that included me in the process a little bit. Not as much as I would have liked but, you know, it was really helpful so I was lucky that we stayed. Unfortunately, it was only for three years because of first episode and the age and everything. But we were very lucky to have ESTEEM because that was the first and it was a very, very good system that includes the family. They gave us an explanation and we had a few seminars for the parents. The parents met, so it was really, really good to know that there were other people there. If not I don't know what the situation would have been today.

So your first experience of working with mental health services was quite positive?

Very positive. Even in the hospital later on I had a very positive experience.

² A psychiatric hospital in Glasgow.

³ An early 'intervention in psychosis' service run by NHS Greater Glasgow & Clyde.

When we met at ESTEEM, other parents had their children – not their first episode but they were there as well. But they said, ‘This happened to us in the hospital’ and this and that. I did not have any bad experiences in hospital. I mean, the nurse in the hospital, the head nurse, sat with me, talked to me, the doctors came, talked to me. That was very, very important to me and people did not experience that before. I mean they had worse experiences. I didn’t, and when I say that to people they say, ‘We really had this problem and that problem’, but I never had that problem.

Did meeting with other carers in ESTEEM and being informed help further down the line?

Yes it did but, you know, we did not have ESTEEM on the first night we entered the hospital. I only had one little bad experience but then it was rectified – I was not allowed to accompany my daughter, just at her bed. The nurse was a bit abrupt with me – only that. Apart from that, the rest were good because I asked them questions – I asked what medications, what time, what was she fed and all these things because she wasn’t eating and everything. So in that experience they were really, really helpful and they were really good people. Absolutely, they were doing their best and they informed me every time – they said you can call any time and I did call and they were really good. Every time I came I asked for a lot to be explained and they told me, and when they could not they even asked the doctor we met and everything.

So how long ago did your daughter first become unwell?

Ten years, I think – 2002.

What was helpful during that time?

The first thing that helped was for me to get the information, obviously. Second, I think, because I have been through the process and I have been with the carer group at GAMH (Glasgow Association for Mental Health). Not that it really was any different – I went to GAMH in the carer group because a friend I have known for a long time asked me to come. But at that point it was not a major need for me because I already had the information I needed, really, for helping my daughter at that time. But even before having any information I was sure I was part of my daughter’s recovery – you know, obviously my responsibility, absolutely it was my responsibility to make her better. I was thinking I knew the doctor could help give her medication but the rest of it, in all steps, is my responsibility. So I had to be there for her. Do everything – not the physical, like helping her dress or anything and shoes, but all the things

she went through with the mood like making sure I made jokes and we went out and did other things.

The only bad experience I had as a carer was when you don't have financial help. I had to stop working because we are only two of us so I wanted to be there all the time, and if she was on her own she was not in that state to be on her own. Nobody else offered to be there with her or when she was at home. Anyway, it's not in the system that you can be there twenty-four hours with that person, and if that person doesn't have anybody else you have to be there. So I stopped my business. I was a beautician and then I looked after her. I have given up quite a lot because you have to – because it's important. To take back, I worked between relapses but it wasn't that easy. I changed career many times. In those ten years I have done a lot myself. But in the beginning, when she really was ill and getting better, I was there twenty-four hours at that time. All the time, with her.

So you play a very active role in your daughter's recovery?

Totally, yes. I think everybody has to do that because that person needs somebody. I know people have to work but being a couple of hours on your own when you're anxious in the house must be terrible for that person. It's impossible – even if it is not your child, when you think about other people they should have somebody, in mental illness. In other illness, your mind is okay so you know what you are doing, you can wait, you can do, but this is different. So you really, really, really need somebody there. I played a role in that sense, in that I distracted her a lot from her thoughts and things like that, you know, making sure that she didn't think too much about the illness. All this, I knew how serious it was.

I had to learn quickly. She had nobody else, and I had nobody else here because my family is in France. And the thing is – maybe it is one of your questions, about the stigma and things – that there is a lot of stigma attached to the way Asian families think about mental health. Although we are very modern and we were not brought up in Pakistan or India, we are still Indian and my family still has this difference. Maybe other people have stigma with mental health in this country, but when I was talking about when my daughter had depression, I started like that. I never talked about psychosis as she wasn't even there. So she got mental health – the family said, 'Depression! Take her this and do this'... They do not understand, and maybe I was the same before I knew what happened with my daughter. To this day, even now,

when I say 'mental illness' nobody likes the term. They say, 'No, she's not – she's not mad! Why are you talking about mental illness? She's not mad'. I say she still takes medication, she needs care. 'Oh, you are cocooning her – I'm sure if you let her do what she wants...'. She does whatever she wants, my daughter, she does – and I'm aware that I should not be doing too much for her. When she is well she does a lot and she knows very well, she is very intelligent and everything. When she is well she is fine but she's had a couple of relapses.

So, you mentioned earlier about being aware of the need to not do everything for your daughter and to let her do her own thing. We've done some work before and a lot of people have talked about how difficult it can be to get that balancing act right – when to hold someone and when to give them a gentle push. And particularly difficult for a parent – it must be quite hard?

I am always pushing her – it is hard but I am always pushing her to do her own things and participate in the house, and she does, she does a bit of shopping and when she is well she does a little bit. But like everybody else living with their mum or their family when they are children, I think they just get lazy – it's mum's duty to do the dishes. This and that is my duty, to cook and everything. I do ask her, I'm a little bit bossy as well so I like things done properly and maybe she does not care too much. I mean, she does not feel it. We discuss it with the CPN (Community Psychiatric Nurse) and people and I've said she is free to move but, in an Asian context, all my family, even now... Nobody thinks of moving out until they are married. Staying on their own – that's ridiculous. We think, 'What will you do on your own? That's sad!'. So it's not – I will be on my own, she will be on her own, two expenses, she can't work at the moment, we don't see that way. Our way of seeing things, Asian people, is we don't leave the home unless we are married – even boys. Even if they are forty and not married, fifty, they will be staying with their parents and that's normal and that's home. There's no problem really, it's not like we're not independent – nobody's keeping you back or anything but it is just a way of being.

My daughter takes medication really on time, she set up an alarm and everything that way – she manages her illness herself. At the moment, I don't even know what dosage of medication she is on because it has been so long. When she goes to see the doctor, I mean her psychiatric doctor, he says, 'Oh, your mum is not with you because you are better now, you know'. He knows only when she is not and she can't go out on her own and I am with her – if she is anxious, I am with her.

So he uses you almost as a barometer?

Yes, absolutely.

So in terms of your own wellbeing during those ten years, what's been good about that experience and what have been some of the challenges that have come out of it?

I'll start with the challenges: first, when my daughter became ill and I had to leave my job – because that's the very first day I said no and closed the shop. It was a hairdressers but I just stopped. I could not deal with all this and I could not deal with all the paperwork I had to do and I could not deal with my rent and they were sending me red letters and 'Yes, I will pay my electricity'. It's not like I could not manage – I talked to them a couple of times but she was so unwell and I, because I had the shop, did not realise. I could not function, actually – I was doing things for her a lot in the house and then I did not have time to do other things. That wasn't important to me – the important thing was just what I was doing, and I was functioning that way. I did not know that I was in, sort of, a shock state. And I was, I knew I was, for a long time, but I did not know I was, you know – everything went that way. Until everybody was after me and I asked the social for help.

They should tell you because I never asked for any social help before, because I don't know the system in this country and in France I never asked. So I worked and I never knew how to ask for housing benefit or anything, although I knew they were there. In the process they said, 'Why don't you do this and that'. I think, at that time, somebody needs to sit down with you and make sure your financial things are okay. I was struggling. Although I got the financial help like I was unemployed, I had to still finish the business part and show them this and show them that. I did not have time for all this. That's where I needed somebody, some kind of help. I did not know what kind but that's when I needed somebody there to do that bit. You know, the social bit, social worker bit.

So looking back, it would have been good to have someone right at the beginning to say, 'This is what you are entitled to, this is the information you need'.

Yes, now I think they do, they do. Like, 'You're okay?'. They didn't ask me, 'What are you going to do? Did you stop working?' – I just stopped working. Actually, I did not even apply for benefit until maybe two or three months later. I don't

know if I got any backdated or anything – some problem there as well – and sometimes I got something and sometimes I had to pay. I ended up paying a whole year's rent because I neglected to answer the question and nobody could take it out for me. So that was three thousand or six thousand housing benefit, for all the years I had to pay it – it's not a good experience that way. I think having someone explain at the beginning is what we should experience.

The positive things I have learned with recovery is there is always hope, obviously, to see in the person. But knowledge is also very, very important. From the beginning you learn about the illness, about the medication, about how to handle the person, and along the way I met people who helped me. Which is good, you know. That was my positive experience – that you need to learn about it with others. Sometimes this is not there – for example, I went out to a carers' group which I did not like, in a church in Partick or something. I found the crowd was too old and had no interest for me. Although they had sometimes... some speakers sometimes, it was a bit, kind of, very slow. I left it after a few months and was looking for something else, and my Asian friend came and she wanted me to do some more sessions. Although it was not really for me, I think being there supported her and the group. I stayed because the group did not really gel together. It's not a huge group so I felt like, okay, I'll just be here, but I learned plenty because we had the recovery, you know, the WRAP (Wellness Recovery Action Planning) training, and we did a lot over the time. Sometimes I felt like I was wasting my time but I still learned plenty.

Where I learned the most is in the voluntary work I do – that's where I really, really learned. When my daughter was well I looked for something for myself, so to start again I went for some training. I volunteered my skill as a beautician in the Partick Health Centre. We had an annexe open where I used to give the service and learn other things there. I am still with them, still involved with GAMH and all this, and in between I worked with the NHS. Through work in The Annexe⁴ I got training in smoking cessation. I did that and got a job with the NHS for a project – ethnic minorities and smoking. So I did that for about a year. Then it was drug and alcohol, so I did work, and I did work other times as well in those ten years but I've learned all the time.

4 A community enterprise in Glasgow, delivering health and wellbeing initiatives.

We've touched on this earlier, but do you consider yourself to have had a recovery journey, in the same way that your daughter is in recovery? Do you think that's appropriate?

Yes, I think it is totally appropriate because – I think I said in the beginning – it's like a bereavement. It's a shock and it's not only physical. Each relapse, each time you are helping and everything, you're not there – it's not like I have an illness but it's like part, like totally part of that thing, that illness. And you have to manage it and you have to do all this because that person has a mental illness. In other illnesses it's okay, that person can manage their illness, but if that person's mind is not there and it is not working the way it should then you have to be there for that person. When she is better I still have to carry on, even now – jokes, and making her laugh and after, it never stops. And your recovery, my recovery is meeting people outside her and doing my own things. And letting her go and do her own things. She goes out a lot with her friends and they go dancing, eating, going to cinema. My daughter also did a good thing after leaving ESTEEM. She met a couple of people there and they got together one day in our place after she invited them, and from there they all went out together. They were all recovering. We weren't using the word 'recovery' at that time but they were all getting better, and in ten years they are still meeting. They still have that group. When my daughter was well she also studied to be teacher – she is a teacher of English as a second language. So she does voluntary work at the moment but she can teach later on now she has got her certificate. She had a relapse after that due to a bereavement in my family – my dad passed away. I don't know if that triggered it or anything but that's what she thinks triggered it and that's what the doctor and everybody thinks. Her mind did not accept his death. For me, recovery is about recovering from the shock of relapses. We have had at least three relapses in ten years: two major relapses and one minor that was caught in time because we got a bit more expert about it.

That's what I was going to ask: would you say that your expertise and your ability to respond to those circumstances have changed as you have become more knowledgeable and aware?

And the system helped in that – like I said, in GAMH we did the WRAP training. My daughter came as well, because it was there and there were other people who were not well there. I think the whole group had experience of some kind of mental health issue except a couple of parents who were there. I think if somebody is not well and if, yourself, you recover from emotion like we went

through, I think we need that as well. And what also helped was when the CPN comes and they do the relapse programme, although she did that with just my daughter. I also asked her to involve me and she did so we talked about it a lot, and also I have to work with my daughter on some things.

So you had to ask to be involved with that?

In the beginning, yes – but after it was a second relapse it was kind of automatic to be involved. In the beginning, I think in 2002, it wasn't really said, except for ESTEEM. I think they started the movement of including the carer. It's good for the carer. I don't know how much the doctors and the CPN need to know about us because it will work, the treatment will still work, but we are 50% involved and then are necessary for the betterment of that person. I know that for sure.

In the very beginning I just assumed that if I needed something I would ask them to involve me. I just asked the doctor, 'I need time with you, I need to assess, I want to talk to you'. I used to ask one doctor here and we talk quite well. I can talk to the new doctor here, although this one is not as approachable.

Do you have a message for people who work in mental health services about the role of family and carers in recovery?

I think they already know nowadays that it is important to include the family in care, because without the family they cannot achieve the result quickly – you know, accelerating the healing process. Families are a necessary part but maybe there are families that are not so close to each other and they have problems, and maybe that is why. But even those families who have never taken interest in their family should speak with somebody in the health service – they should have a bit of counselling themselves and be given all the information they are looking for, even if they are not looking. I was not looking for information about the brain, about medication, and I got it from ESTEEM in the beginning. And I am very grateful about that – that was really good luck for us to be in that. So, they need all this information and they are very, very important in this and need to be taught how to help if they cannot and they are willing to help their children or their family member who is not well. I have no problem – I have positive kind of experience in the help I got. I cannot say, 'I feel bad about this service' except for that social thing – I needed help and didn't know how it could be. I think, the first time, people should think about

the carer and what they are going to do – are they going to manage? What help do they need themselves to help the person? If you take my worries or guide me to do my social thing, applications and things like that, I am a bit more available and less distressed myself. That understanding from the doctor and health service is very important, because the parents could also be in trouble as all of a sudden they have this and they have other problems.

Do you have any messages you would like to convey to other carers or family members about your experiences, your recovery?

Yes – I think, for a start, be there 100% for that person because they need you. To understand and learn. Especially learn about what is happening, all about their illness, about their medication... Go out there and look for help. For example, get involved in anything like I got involved in GAMH. In an Asian context it is actually really needed to understand the need to go out. The person who is treated is not allowed to go out, really. I have a friend who is treated and I know her mother, who talks to me. I ask her, 'How is your daughter?' – 'Uh, she is lazy!', 'She is not doing any effort', 'Oh, she is just, now she is better, she does not think she is better, she is not working, I don't know what to do with her', 'She is not married'... I say, 'My daughter is not married', but they have lost that big chunk of their life and they are not able to function so you can't really blame them. For me it was difficult as well to understand that my daughter wasn't lazy, she was recovering. I still think she is a bit lazy – I tell her, 'You are not participating in the house – you can physically do it'. She does now but I think the parent role is, especially Asian people, the parents' role is to do everything – you are always a child. She is 36 and I still sometimes treat her like a child... Not like a child, but sometimes when I am not on guard, I'll talk to her like 'Do this and not do that'. Then I rectify: 'Well, do what you want'. I am just saying that is not very easy. Because you are a parent and you are looking after that person when they are at that stage, when they are ill, they are like a baby for you and for themselves when they need you so much.

So you think that while being conscious of the extra love and care somebody needs when they are at their most ill, you should be careful to change that for a time to help them?

Yes, and that is difficult sometimes, but she is kind of independent so she is making sure she knows her place as well – she has pushed me away, so I remember to do it, so she helps me not to mother her too much either. But you said just there a very important word: love. Without that there is no

recovery. Absolutely not. That's the first ingredient for me. I had some friends and I still have them, but even last week I was at a carers' meeting with a friend from GAMH. I went there because a person from Stobhill came to talk about the triangle of care and the help and things like that, so I went to listen. I don't always go but I will go once in a while, and this lady was talking about her son and in the past I had also a similar problem. They cannot express love and affection to their children and I say you have to – they need to know, they so need to know that and they will recover faster.

My daughter's friend, the one who moved into her place, understood because she saw me all the way. I'm not ashamed of cuddling, kissing and things, and maybe because of my French background I'm a bit more so than here. In Scotland I notice that people don't show affection, not always, but they have to show affection, here and back home. We talk about men sometimes and we say there, if a person passes, going down the street, and men are looking at them and they like them they will turn their head and whistle. Here people will curse you if you do that – it's not done, it is a different culture. And Asian people don't like that, but for me here it is a compliment – for example, if I am in France I feel quite fine about it. 'Oh, yeah, it must be something it looks like – I am this or that, some little bit thing.' So I say you need to show affection to the children – that's what they need the most, you know, especially at that age from twenty-five when they are trying to do their own thing. They feel rejected from the family and wonder, 'What will I do? I have too much responsibility, I am a burden' and all of this. You show them it's not, because you are there for them, that's what I think. That's the way I feel and have always felt, and it's quite natural. It's not a big deal at all. Any other questions?

No, not really; I think you have covered an enormous range of issues and are really inspiring. You're obviously an incredibly supportive, encouraging and empowering person for your daughter.

But I think it is natural. I always think it is very natural or extraordinary, but through all this I have learned a lot. I made so many good friends, I think my life changed in a good way. I don't say if I did not have this I would have been... I would have been a different person but I really met so many beautiful people, nice people. I mean, I have made so many friends – the people I met not only in the hospitals but the parents of people I kept in touch with, four or five of them, all the voluntary sector like The Annexe. By meeting so many people it is so good. I like it and it is good for me.