

Chapter 11

Hearing the music and remembering to dance

In Scotland, Elinor Dowson

To introduce this story, I first need to tell you what it is that I am recovering from. Towards the end I will describe what recovery means to me, what has helped and what would help now.

Being a reasonably optimistic, resourceful person with a strong sense of fairness and justice, it came as a shock to enter the world of mental illness as a carer and find myself, at times, completely at a loss as to how to cope with what was happening to my loved one and me. I spent nearly three years realising that all was not well with our relative but was unable to persuade medical staff to listen. If a person is able to present themselves as seemingly OK, even if it is apparent to family and friends that they are acting out of character, they will not necessarily tick the right boxes to be given help. These are that you are considered 'a danger to yourself and/or to other people'. Of course we did not know about these boxes then – we just needed help, and could not understand why it was not forthcoming! We were amazed by how many different professionals told us our loved one was just eccentric or, even worse, that there would be some incident and the police would probably reel them in. This was bewildering and very frightening, as our loved one had never had any connection with the police. What did it all mean?

No one seemed willing or able to put themselves in the shoes of the family, acknowledge our stress or give us any support whatsoever. It was only when I broke down at my own GP's surgery that I was finally listened to and deemed worthy of help. However, I was aware even then that this was probably just because I had a good relationship with the GP and things had been going on for a very long time. The offer of help came as a result of my very great distress, not the wisdom of the professionals. Much later on I came to the realisation that a late intervention can affect the path of the illness; this has given me some feelings of guilt but I try hard to reject them, because I honestly believe I tried every possible avenue to get help. However, I do think appropriate, imaginatively delivered, non-stigmatising early intervention is

something staff must consider much more proactively if they are truly to support recovery, and if it is to be seen as a right.

When professional help finally came it was completely misdirected, as staff did not listen to my advice and all sorts of bad practice occurred as a result. I realised, then, that in order to safeguard the welfare of our loved one I would have to take control of the situation myself. I was completely exhausted at this point but knew I had to protect our family member, so summoned up the courage to tell staff that enough was enough and they needed to do as I said. Our loved one, as a result, received help, but the cost to us all in stress, heartbreak and stigmatisation that day was huge, and its bittersweet legacy will stay with us always. It helped shape my thinking about what a powerful role the family can play if it wishes to support and, if need be, protect the service user. At the time, though, the idea that we should have to protect our relative from professional staff was a disturbing one. Were they not supposed to be there to help us? After all, I had been supporting our loved one, often in very difficult circumstances, for the last three years, without anyone wishing, despite my asking, to become involved. I had taken it for granted that the intervention of mental health staff would give us all a new beginning and that we would work together for the good of our relative. The fact that mental health professionals seemed completely unaware of the stress they caused us all that day was very hurtful and very concerning.

It also made me realise very early on that poor communication from professional mental health staff can be a fundamental hurdle for the family to surmount. It would be so good if they always thought before they acted (or not) about the likely impact of their behaviour, be it emotional or practical, on the service user and their family. It can be a great obstacle to recovery, and we are very likely to have gone backwards on our journey of recovery or stopped altogether as a result. When I spoke of this at a training event for staff, a nurse who had been there when my relative first received professional help came up to me later and said that she'd never given a thought to the idea that staff's behaviour could affect the whole family but, on thinking about it further, she'd realised that of course it would have had an effect. It was good of her to tell me this but very worrying that the training she'd been given had not prepared her to understand our feelings. Our whole family incurred lasting stress that day which, with foresight, could have been prevented.

The diagnosis, when it was finally given, found my loved one and me surrounded by professionals. I tried to hold my head up so that others would

not see the tears coming into my eyes, particularly my relative. It was a label that was incomprehensible to me, and now it had come to our family. What did it mean for us? Then they all swept out of the room, leaving me feeling overwhelmed and so alone. My relative, having realised this, hurried back into the room saying not to worry and that things would be all right. They gave me a quick hug. I was shocked that none of the professionals realised my distress or, if they did, acknowledged it. A kind smile, the offer of a cup of tea and the promise of some help in understanding the diagnosis would have meant so much to me at that moment. It is an experience I have never forgotten. It left me struggling to come to terms with the fact that I would never again be seen as just the relative of that person, entitled to the normal respect and affection that role would bring. My loved one, it seemed, was now in the hands of the professionals, and through them – without anyone giving them permission – the State had taken over my role. The State, it appears, has been imbued with an understanding whereby it does not ‘do’ emotions!

From our experiences I realise it is essential that professional mental health staff understand emotions and know how to deal with their own, and other people’s, appropriately. Good emotional intelligence is essential, particularly in the caring professions. For too long professionals have either been taught to keep emotions out of their practice or they were not mentioned at all. I believe that an understanding of their own emotions is an essential skill for their wellbeing and welfare, as well as the wellbeing and recovery of the service user and carer. Staff should be trained to try and put themselves in the shoes of the service user and the family, and should be given this training, I believe, by service users and carers. An appropriately kind or thoughtful word would, at times, have made such a difference to my experiences and helped prevent feelings of isolation and alienation on my part. I sometimes felt I was being addressed by non-empathetic robots unable to understand the human condition, which was very frightening.

As I have said, emotional support has to feel appropriate. I have experienced both the silent handing over of the box of tissues by the psychiatrist and their being tossed across the room to me by a busy nurse who felt it should have been someone else’s responsibility to give me an important piece of information. How I might feel to be suddenly confronted with this startling change of plan did not appear to concern her or, even worse, to have entered her mind. She did not try to put herself in my shoes. She was busy. Her behaviour also added considerably to my shock. It is interesting to wonder why, in the voluntary sector – which is staffed by a high number of social

workers and mental health nurses originally from the statutory sector – services are delivered primarily with kindness and consideration, and even hugs are considered routine. It is the person-centred training which I believe makes all the difference, and their being encouraged to show compassion and realise that emotional support matters, at times, just as much as practical support, in that it makes us feel acknowledged and valued and can stop us feeling overwhelmed by events.

Staff spend a lot of time thinking about and assessing risk. If they are to genuinely support recovery, their decisions must be risk-aware rather than risk-averse and they must assess the risk of their decisions, not only to the service user, but also to the carer and the wider family, and be aware of trying to minimise harm to them all. The fact that this is very rarely done often stems from staff not fully understanding or acknowledging the part the family members play when they wish to be involved as key partners in care, and the importance of everyone working together to achieve the best possible results for the service user. In my experience they often seem not to realise that by not supporting or listening to the family, they are affecting the cared for adversely. They are often totally unaware of the effects of their actions, not just on our family member but also e.g. on Granny, who has been playing a huge part in recovery but is now feeling depressed because no one is listening to her. If staff do hear of it, they often think it is nothing to do with them.

This is because many staff have received no information about working with families in their training, a situation which I believe needs to be remedied as soon as possible if they are to work in a genuinely recovery-oriented way. For staff to suddenly believe that, through their professional role, they know your loved one better than someone who has known them all their life is thoughtless and disorientating to the family in most instances, but also downright arrogant. How would they feel if they were in our position? Just like us, I would imagine – angry and confused at times, especially when we can see the benefits of working together as a team and that information can be passed on quickly to prevent relapse. However, before this can happen meaningfully and be effective, our part in the team has to be acknowledged and valued by the professionals.

For example, my relative, at the very beginning of their care and as the result of a conversation in which they asked me lots of questions, revealed to me, with amazing clarity, the ‘triggers’ for their mental illness. Things not understood by me at the time of their happening now had a ‘reason’ and

I could piece things together in a logical manner. I could understand why they had acted/thought as they had, at the time. I felt thankful for our close relationship and empowered for the future in that I could now recognise these ideas or triggers and would not have to feel confused, fearful or angry about what was happening. That conversation has proved invaluable over the years, but I have never really felt that mental health staff were at all interested in these 'triggers' and my early recognition of them. At best they have just said they were monitoring things or not acted at all, which at times made the situation feel hopeless and hard to cope with and made me feel that staff were on a completely different wavelength to me. I wanted to see change in my loved one. They seemed happy just to see him, which is not the same.

Also, when I have shared knowledge about why I believed my loved one was not wishing to do a particular thing and how my knowledge of these 'triggers'/'ideas' told me it was best presented in another way or even not at all, staff have interrupted me, looked at the ceiling or said that the meeting had to finish at a particular time. This lack of listening left me feeling extremely dispirited and at times despairing – all the more so because my relative had given up attending meetings. At one point my loved one left a full-size, named, cardboard cut-out model of themselves on a chair prior to a meeting at which they were expected. Staff laughed and said, 'Fancy them doing that!'. Sadly they did not focus on the real reason for their not being there, namely that they did not feel necessary to proceedings or listened to, either.

This has put a far greater burden on my immediate family and me, whereby we have had to rally round to solve problems. I believe that staff may, at times, have used our family member's non-appearance, whether knowingly or otherwise, to do what they felt to be right, rather than what I believe was best for them and their recovery. Sadly, because they did not feel worthy, they gave staff the power – and staff have not sought to give it back to them! This lack of partnership working and listening by staff has, I think, very seriously affected the recovery of my loved one and impinged on my own recovery and that of my family.

My wellbeing as a carer has come close to being overwhelmed by the fact that the world of mental illness does not routinely see the 'whole' person. In my experience, if you have a mental illness your physical health needs are not always readily understood by staff and your care can become seriously jeopardised. It is very stressful for me to realise that in the world of their

physical health needs my loved one is seen as a 'survivor' and equipped to cope on their own, but in the mental health world they are seen as 'frail' because of their physical health needs. This has led, in my opinion, to their care being seriously compromised at times. Of course the physical health world is not perfect either, and here the mental illness is often seen as a barrier to receiving physical health support because it is not understood by physical health staff, which has been very degrading for my loved one. This type of action is not recovery-oriented and can result in their being socially excluded, which affects the wellbeing of the whole family and is certainly not conducive to their recovery.

I must tell you this as it is so important: I have been caused worry, concern and a great deal of stress by the problem of staff previously employed in hospitals who are now working in the community. It is to be hoped that they will receive more training, so as to realise that people can receive help in the community and do not always need to be hospitalised at the first sign of anxiety or even issues to do with physical health. This happens even more frequently when there are long-term staff absences or staff holidays – people appear to panic because they feel they do not know the service user and do not always listen to the family. Again, this is a situation where, knowingly or otherwise, staff can wield power unhelpfully and one that training could resolve, otherwise it could be seen as an abuse of the rights of our loved one not to be hospitalised unnecessarily – which is certainly not in line with their recovery, or mine! What would help here, I believe, is more places in the community where people can receive early intervention, as the present number is woefully inadequate. This change of policy and new opportunity would hopefully encourage the doubters and 'fearties' to have the courage to support people in the community when appropriate, and to learn to risk assess this positively.

It would have made such a difference to me to have been able to go to care plan meetings and have my opinion valued, and to feel hopeful and positive that we were all working together for the benefit and recovery of my loved one, rather than feeling that I was in a debating chamber where I have had to resort, on occasion, to being adversarial to get my point across, or just feeling completely alienated or invisible because I am always asked for my opinion last, by which time staff have usually decided everything between them. It is much harder to change viewpoints from this position but carers have a passion when it comes to what they believe is best for their loved ones and they go on, despite the effect on their health. It has saddened and exasperated me

that staff have so little ambition for my loved one and that their talk always appears to be about maintenance of my relative rather than the adventures they might have that could make life worth living. Staff need to focus on and work with the creativity of people, rather than just their shopping lists, if recovery is to be inspired. On the very few occasions when there has been partnership working between us all it has felt wonderful – much more creative and productive.

My relative and I had to come to terms with the fact that not all our relatives or friends understand mental illness. Some, like my youngest son, know instinctively what is required. He knew right away what to take the first time he visited: juggling balls and a joke book. This was just right for us because we all had a turn and could not stop laughing, which was healing for us all. Later on I always took the dog because the dog is not judgemental and does not ask any questions; he was just pleased to see my relative, and they had some great romps together. Other family members and friends have given us unswerving support. They understand that the illness affects not just the service user but the whole family.

There are, however, some family members and friends who have never visited or even asked how we were getting on, which is hurtful. Others have sent gifts of toasters, kettles and even two very nice settees, but have never visited. This is sad and frustrating for us all – our loved one is in need of friendship and support but appears to have been quietly forgotten. In a moment of reflection when thinking about this problem, they asked me whether our family is dysfunctional. I think these family members, with their lack of knowledge about mental illness, would have been a bit surprised to hear themselves described this way. I have a feeling that it might have been how they were regarding our loved one!

I lost a best friend with whom I'd been working at the time my relative first received help. I was slightly late on the morning described earlier (when I had to take control of my relative obtaining help because staff had lost control of the situation). I had left word but apparently that didn't matter. Arriving in a state of shock after what had just happened to my relative, I was told that I should not have taken the job if my relative was going to become unwell. What did that mean? I was flabbergasted. I finished the contract and we have never spoken again. I have a feeling she is worried about stigma. Full marks to the understanding mature student who insisted on accompanying me to see my relative that day and produced some welcome sustenance (as I had had

no time for breakfast). The behaviour of my friend was very hurtful to me as she was my 'intellectual friend' and I miss those great conversations we had. But you just have to go on. It is only when people in the community lose their fear of mental illness that this kind of attitude will disappear and professional staff will listen to family members. Until that happens it will continue to hit families like ours very hard and impinge seriously on our recovery.

We also had to come to terms with another kind of stigma – one that, surprisingly enough, directly involved mental health professionals. This was a stigma that could result from their actions. Even their turning up at someone's door is noticed by neighbours, and if language and/or body language is patronising, cheeky, overly authoritative or assertive it is registered by those around as something out of the ordinary, causing tongues to wag. I have found this incredibly annoying and frustrating over the years but some staff seem oblivious or do not seem to care. I have been told on a number of occasions that 'Anyway, the people round about will know' our relative has a mental illness. I have had a visit from a senior social worker I had never seen before, who had extremely confidential information about my relative and was quite content to deliver it to me when I was sitting in my car surrounded by people who did not know that my relative has a mental illness. My relative was quite unrepentant when I told them off for doing such a thing and said they thought I would not mind. This was not the case at all.

Family and friends are very discreet and careful to protect the privacy of our loved one, as mental illness and recovery are not yet well understood in the community. We did not want them losing a tenancy because a neighbour has a fear of mental illness. Things can get blown out of all proportion, thanks in many instances to the press. I cannot understand why staff do not always seem to be aware of the person's recovery and what they can do to protect it, but putting people into housing that is known to be for people who have mental health problems and are therefore vulnerable is, in my opinion, even worse. This is not in the spirit of recovery, and it could put the person and their family at serious risk of persecution; worryingly, the person could even become a target just because of their address. This is so very hurtful when you know that that person just wants to feel normal, be allowed to find their independence with dignity and have their privacy valued, but now they have to deal with all these extra pressures. Would staff like this to happen to them, or to their loved ones? Again, they need to be able to put themselves in the shoes of the service user and the whole family, and try to empathise with them a lot more.

Another source of stigma we have had to endure, and try to prevent where possible, is the way some staff can be rather cavalier in their planned use of interventions to get people to do what they feel is right without having any idea of the stigma and alarm they can cause for the service user, the carer and the wider family, or the stress that can follow. And yes, before we go any further I do know about the Mental Health (Care and Treatment) (Scotland) Act 2003. For many carers, knowledge of this is their protection against unscrupulous use and their yardstick for what is acceptable and not acceptable. Do mental health professionals really think the service user is not going to get a shock if they are suddenly told that they are going to hospital, without any prior warning and for a physical health cause? How is this going to impinge on their mental health? Do they really think the service user is not going to be noticed by neighbours if a police car turns up and is sitting waiting? Have they wondered how they would feel if it was them? What is to be the long-term result of this for the service user if embarrassing thoughts prey on their mind whenever they recall the situation, and how does this help their wellbeing?

One thing that has never failed to astonish me is that, despite knowing that stress is something that can help precipitate relapse, staff do not seem to feel they should routinely modify their actions to prevent discomfort as far as possible. One would think that they, of all people, would be acutely aware of this need, but at times I have felt they were the last to understand. It has made me feel extremely stressed just to listen to their ideas when I know the effect they could have on my relative, and I've tried to persuade them to think of a more person-centred response. At almost all times when I have been directly involved, a more sensitive approach has resulted or no action has been taken at all. It is lucky that I have a sixth sense about when something not good is about to happen but there have been times when I've had to drive at great speed – which is a terrible pressure for me – just to make sure unsuitable decisions are not reached.

Let me tell you about another source of confusion and stress for me as a carer, which can happen when someone who's become part of the mental health system enters a new tenancy. Having been actively involved in the viewing of the premises and the decision-making regarding obtaining the tenancy, mental health staff stand back and leave you, the carer, to pick up the pieces. No discussions are had or decisions made as to what needs to be done, who is going to do it, what it is going to cost or who is going to pay for it. The place needed to be plastered, wallpapered, painted, carpeted, furnished and much, much more.

I wanted the best for my relative's recovery, so I felt aggrieved when another move was planned by the mental health professionals and another large sum of money incurred as more or less the whole process was repeated. This was even more concerning because my relative had not, to my knowledge, even expressed a wish to go to this new place. To me this is certainly not person-centred planning, and nor can it be seen as recovery-oriented when things are done to people because mental health staff think they know best, rather than because the service user is actively involved in decision-making with their views respected. It also leads to difficulty for me with our family member because they believe that it's my job to stop that kind of thing happening when they feel unable to stand up to staff, but this is not always possible for me because things are not always discussed openly, in my opinion.

I have not learned solely from my own experiences of mental illness; I've also formed friendships with other service users and their families that have lasted years. I realise the importance of good communication, discretion, a sense of humour and never being judgemental. We have had lots of fun with games of tennis, swims, walks, music sessions, shared art ideas, parties, telephone calls and lots of laughter. Another thing that gave me a lot of joy was being persuaded to become a volunteer at the local mental health association, which was mostly a very therapeutic experience and helped to heal me. I met so many wonderful people who empowered me so much in my understanding of mental illness and helped form my early views about 'recovery'. I had some great conversations too, and was puzzled when professional mental health staff asked me how I had been able to speak to 'these people' and expressed surprise at how involved in a conversation the service users could get. I do think that they could have known them better too if they had taken the trouble. This kind of conversation with staff left me feeling dismayed and concerned about how much change needs to take place in attitudes and skills, and when this is going to be addressed.

I later volunteered with a friend at the Salvation Army, in a city centre drop-in. This was challenging in that we had to cook all the packets of food that Marks and Spencer had donated and get them all ready at the same time, as well as welcoming the clients and assisting them in what they required. I was, amazingly, the unbeaten table tennis champion there (a skill I perfected when my relative was first diagnosed), and we spent a lot of time practising – they were determined to beat me. Anywhere was better at that time than the world of mental health, and we seized on every opportunity. My relative could beat me at badminton and we were about the same at tennis so we

had lots of good matches and got lots of other people playing too. This was a good way to get to know people without too many words having to be said by them at first. I had been a youth leader in the past but it was the knowledge and experience gained from my many friends who had mental health issues, and the experience I'd gained at the local mental health association, that empowered me to do as good a job as I possibly could there. Having a relative with a mental illness made me much more aware of the needs of those with mental health issues.

I remembered all the times when I'd not known where my relative was and hoped that someone was seeing they were OK. This helped me to know more about mental illness and I felt more capable and empowered in my caring role. I was becoming more aware through this volunteering that mental illness was certainly not just about medication. Through knowledge and experience I have realised that given the right tools – art, music, creative writing, sport, a dog, whatever – people can be empowered to support their own recovery. This helped my own wellbeing as I felt much more optimistic for the future, and once again it helped to form my early views about recovery for my relative.

After my long struggle to get help I was exhausted. The psychiatrist said that she marvelled at how I'd managed to go on for so long, but when I asked what else she thought I could have done she said she did not know. That was the problem! Very luckily, I saw an advert for a local mental health carers' support group run by NSF (Scotland), now Support in Mind Scotland. As soon as I walked through the door I knew I was home. These were people who understood me. I did not have to hide anything. I cannot speak too highly of them and what they have done for me, or of the dedication of the staff. Over the years we have laughed a lot, cried a bit, been empowered to understand more about ourselves, mental illness and medication, investigated psychological therapies, found out about our rights as carers, touched on legislation and policy, got in touch with our creative side and made many friends. They have been my lifeline, supporting me to care for my relative better and protect my own wellbeing.

If Support in Mind Scotland has been my lifeline, the Scottish Recovery Network has been my passion and joy and one of the really positive things in my life. I have been involved from the very beginning because I believe everyone in Scotland has the right to live well in the presence or absence of symptoms and be given the chance to have hope for the future, whether they're a service user or a carer.

At first, my focus when receiving help was very much on the recovery of my loved one with my being supported to assist them. Any therapies I received were, I believed, to help me keep well in order to support the person with the mental illness. You can feel almost guilty if you think about yourself without thinking of a benefit to the person for whom you are caring. I did not know anyone who had had a carer's assessment done, so that probably influenced my thinking too: I did not feel that carers were seen as high priority.

I was completely caught up with the recovery of my loved one right from the beginning. Their progress and welfare at any given time was (and still is) the main barometer for measuring my own wellbeing. When they are doing well I feel better. I was aware, when I was very stressed, that I had to do something to restore the equilibrium of my wellbeing as soon as possible in order to keep well. I have had respite twice through carers' support and this has really helped (I always hope it will be delivered, but it needs to be assessed by specialist mental health carers' support workers. The thought of councils assessing mental health carers' stress is alarming to me as it might lead to carers not getting help when they badly need it). Swimming, walking, working in my garden and massage have helped me relax, as have the support from carers' support workers specialising in mental health and the peer support of other carers. More recently I have benefited from WRAP (Wellness Recovery Action Plan) training delivered by a mental health carers' support worker.

During a particularly traumatic time when I was too numb even to realise how stressed I was, I lay on my settee and read – not the more serious classics I usually enjoy but light modern novels, more and more of them. I then bought even more. I have no idea what I read but the world of the novel was a place to get away from the pain. If I concentrated really hard on the text I could not be thinking about anything else. That was my escape, and I think it probably saved my sanity. I am always careful now to read some light-hearted literature; it is a good place to be when I'm feeling stressed. I also had – and still have – a great need to listen to live classical music and jazz. I once set off for a Tommy Smith concert in a snowstorm without being absolutely certain I could get home! I just knew it was a way of restoring my equilibrium and that it would prevent me from becoming unwell.

However, these actions do not deal with the accumulation of experiences you have to address if you are to truly recover as a carer instead of just restoring your equilibrium. I also think it is harder to deal with recovering, as a carer, if you do not believe that the person you support is at that moment

experiencing recovery; you know how hard they have tried in the past, only to be knocked back and discouraged by the barriers in society, such as access to employment, that can prevent real recovery taking place and the less-than-helpful system of paying benefits, which is not flexible or progress-enabling.

I recently had an interesting conversation with an Italian psychiatrist who felt that in order to fully recover and be free the service user and carer have to be able to examine the baggage they are carrying, acknowledge their losses, discard them and then move on. I think this may also depend on the length of time of the illness. The sooner you get quality help, the less baggage you are likely to have to lose and the smaller your losses will be. Likewise with your experience of caring. It is not enough, he asserts, just to live well in the presence or absence of symptoms, as this could lead to people who are not ambitious for themselves leading a life that is not challenging enough for them. They could end up just existing and not much more, and this is not really recovery.

I think this is where a lot of carers find themselves, because nobody has acknowledged their need to recover their lives or said that they must be actively supported not just to help their loved one but to remember if they wish to recover their own lives. This depends, I believe, on whether the individual feels hopeful enough to engage with the process and how self-motivated they are, but also on the empathy of support workers, the support being person-centred and the quality and relevance of the support offered.

Recovering fully is a challenge because the systems around the individual are not wholly in place. You may have ambitions but the mental health system can stigmatise you and make it hard for you to move on, leading at times to feelings of helplessness and possible self-harm. This is why staff and others must be so careful of their actions. It may not just be in that moment that they are affecting the service user and the carer but in the future also. For this reason, service users and carers who have been in the system for a while may need specialist help to kick-start their recovery and give them hope.

Hampering my own recovery and requiring much thought is the following problem, which is very painful to deal with. I can accept the diagnosis, the vagaries of the mental illness and the lack of understanding about mental illness in the family and the community because it is natural for people who have not had experience or education about something to feel fear and prejudice. What is harder to examine and discard is all the mistakes the

professionals have made through not listening to my loved one and me. We live with the consequences of these mistakes every day. You might think you have examined them and discarded them but, because of their severity, you may only have slammed the lid on them temporarily – in which case they’ll keep coming back to haunt you. The memories make me weep even when I least expect it so I am not free, but I believe I should be able to be as free as possible. I deserve to recover my life and I don’t think it’s arrogant to say I deserve support to help me do so. I did not plan to be a carer, I just have to deal with the issue by hoping that what I’m saying will be taken seriously and that staff will receive training. And because it is service users and carers who are the experts by experience, it is they who should be delivering this training!

Like service users, carers should be entitled to systems of protection from those professionals who harm or threaten to harm them and the effects of their actions on the wider family and siblings. I believe a lot of the problems stem from a previous system where mental illness was seen as a tragedy about which nothing could be done. Better training must be given so that staff realise that the things we have endured hinder our recovery and that, in Scotland, recovery is a right. I also believe that they must have a better understanding of their role in supporting recovery and what helps, and that this must be continually evidenced and evaluated. Likewise, whether services are really recovery-oriented must be evaluated by service users and carers, with action taken immediately if they are not. It is an ongoing process. The passivity of the past has to be replaced by genuine partnership working between the family, service users and professionals, with good communication becoming the norm and good person-centred planning offering choice and creativity. The importance of the carer and the wider family (when they choose to be involved) to the recovery of the service user must be better understood, with more use made of the service user’s existing relationships.

However, as the years have rolled on I have found myself realising that my own life is passing and things that I might have liked to do have not been done. I also realise now that I am not always capturing the equilibrium like I did in the beginning. I, who tried my hardest not to let it happen and had such high hopes for partnership working with staff, have become worn down by the system at this moment in time. It is my belief that the mental health professionals could have made a much better job of understanding my relative if they had listened to us both a lot better. As for my wellbeing, if things had been done differently I would not have suffered such a lot of pain and stress and I might have had more choice about how I lived my life. I often wake up

finding I am weeping as I remember things; I still have some way to go in my recovery as a carer as I have lost a lot of my hope. For the sake of my loved one, my family and me I shall have to find it again!

One way I have found of dealing with this stress positively is to take part as a carer in selection, teaching, assessment and research at the nearby university, and to have a different social work student shadowing me every year. I introduce them to my life as a carer and it is such a rewarding experience to hear them telling contemporaries in a presentation or essay about my experiences as a carer, and general issues in mental health. It makes me very proud that they are so keen to understand and make a difference, and of course I learn from them too; this is a far superior approach to that of 'book learning only'. I am also involved in the Doctorate of Clinical Psychology programme at another university in a similar role. I am particularly keen to get involved in this way because I feel that cognitive behavioural therapy is a particularly superb way to support recovery. The therapist and the service user/carers are on an equal footing, which is the very basis of person-centred planning and therefore of recovery. It is also an excellent means of putting the service user and carer in control, and may result in less medication being required.

I do hope that the system will respect the knowledge of these students, and that the 'old hands' will be inspired to learn from them. I saw a brilliant student nurse in action recently. His communication skills were quite amazing. He suddenly appeared just before the care plan meeting and offered my relative and me a cup of tea. That thoughtful gesture and his communication had the effect of making my relative feel empowered to attend a meeting for the first time in many years. He was successful because he was a people's person and genuinely interested in them – and, most importantly, he had empathy. He also spoke to us as equals. With staff like this around, it is possible to feel hopeful.

I have also been part of the selection process for a new psychiatrist recently. It was such a joy to hear this young man speaking passionately about recovery, and to hear from other service users and carers that this is what he is genuinely about. I am only sad that my own relative will not be able to benefit from his skills, as he has since moved out of our area.

I also support two other people who receive older people's services. Here the services are about empowering people to stay in their own homes. They seem

much more responsive to the needs and choices of the people concerned, and more in line with the principles of recovery. Adult services need to learn from this model, I believe. They need to give up some of their power, take part in person-centred planning and really listen to the service user and the carer.

At the beginning, before I was weighed down by the trauma of mental illness, I used to laugh and dance a lot. I hear the music now but I do not always remember to dance. Caring has robbed me of a lot of my spontaneity and confidence. A service user asked me today if I am still in love with life; the fact that I had to stop and think for a moment made me realise that I still feel numbed by my experiences. I have to find a way to recapture that joy of life and own it again if I am to truly recover as a carer.

I have only shared a few of my experiences, as many of the others are too painful or personal for me to recount. I am grateful for the support I have received as a carer and for this opportunity to share my thoughts, but I think my recovery will be a little while in coming. I still have too much baggage to lose.

What would immediately help? For carers and their needs to be taken seriously, and for their role in their own and their loved one's recovery to be better understood. It is not just about restoring one's equilibrium but about recapturing a life. Staff should understand the importance of positive risk assessment, good emotional intelligence, good communication and creativity of approach in their dealings with service users and carers, and be aware of and make good use of psychological therapies and respite. They also need to understand that carers and service users are experts through experience and should therefore be the teachers of the future. If we are to be serious about recovery for service users and carers in Scotland, a lot of change has to happen, because our lives are happening now and we want to be able to live them to the full. Is it not our right to have that choice?