

# Chapter 9

## Recovery – or simply acceptance?

*In Scotland, Jennifer Robertson*

### Diary of Despair

When I first started writing about my daughter's – and our family's – experience of schizophrenia, I called my anguished outpourings *Diary of Despair*. This was 1991. Elaine (not her real name), whom a friend remembered as a child always 'wreathed in smiles', was now 20 but had spent the last 18 months in a state of withdrawal, opting out of studies and all her usual activities and spending long hours in bed. Another friend said, 'It will pass. She's too beautiful to be sad.'

But it didn't pass. We didn't understand what was happening. I felt I had to do something, and putting words onto a computer screen seemed the only way.

Don't think I didn't endlessly phone so-called experts, healthcare people, doctors, psychiatrists and consultants. I did. I phoned, was put on hold and waited, with minutes ticking away and phone bills mounting up, only to be told, 'Mrs Robertson, your daughter knows where to come for help' – or, to put this evasive answer more bluntly, 'Back off!'.

Here's an example of a letter I sent to the GP in January 1991.

'On Monday evening I was invited to a support group for a few parents whose children are causing heartache. However, the other children were all 14-16. My daughter is 20. I felt thankful that we haven't experienced the anti-social behaviour of these children but I also felt that Elaine appears more sick than these disturbed kids, in her second year of almost total inactivity. The other families were also receiving a large amount of social work and psychiatric help.

'Last winter (1989-90), when she first shut herself away, I sat with her for hours, brought her meals, listened to her hurts and tried to understand. I initiated things for her to do and tried, when she started to express violence

against me, to absorb this, thinking it would be better to encourage her in every outward-turning activity than to see her turn that anger inwards and hurt herself even more,. But I'm punch-drunk now and simply cannot see the way forward out of this total paralysis of bed, highly negative Bible reading and despair. There are nights when she weeps uncontrollably, howling until 3 am.'

## **The revolving door**

Not long after this letter, a neighbour phoned our GP and said, 'This family is falling apart, you've got to do something'. An appointment was made for Elaine to see a psychiatrist with a view to being admitted for inpatient treatment – we'd already undergone weeks and months of so-called 'family therapy' on an outpatient basis, as the doctors had decided that Elaine was suffering from a maturation problem. Not mental illness, in other words; just a failure to move out of adolescence and a retreat to an earlier, angry childhood. Complete nonsense, as it turned out. So we wasted professional time as well as our own, Elaine got no better and life lurched into a downward spiral with anger, tears and wrist-cutting.

With every other illness we say speedy diagnosis + speedy treatment = better outcome. The same applies to mental illness but, tragically, nobody wanted to know.

So, inpatient treatment seemed the only thing.

I was in another hospital having a hysterectomy. My husband came to see me and told me, 'I'm taking her to the Royal Ed<sup>5</sup> this afternoon. She's to see a psychiatrist. They're going to admit her.'

So I lay there, just a few hours post-op and still strung up with drips and tubes, worrying but feeling thankful that something was being done at last.

Was it heck. At 4.30 that afternoon she appeared beside my bed. 'Hullo Mum!' 'Elaine! What are you doing here? Dad told me you had an appointment at the hospital.'

<sup>5</sup> Royal Edinburgh Psychiatric Hospital.

'Oh, yes,' she smiled. 'I went but they didn't admit me. The doctor said, "This is the loony bin. It's no place for someone like you".'

I stared at her, trying to take this in. Was that really what the doctor had said? Surely not... *She's done a bunk*, I thought. She didn't stay very long and I lay in that hospital bed sick with worry, imagining that she'd run away from the mental hospital and was sleeping rough somewhere.

Ten days later another appointment was made. Her dad took her once again and this time she saw a more experienced psychiatrist who used similar language but persuaded her to stay in. A few weeks later I went with my husband to see this man. We waited for him in a dingy room at the Royal Ed, some sort of classroom by the look of it. He appeared after what seemed a long, nail-biting wait, sat down and said a lot of things, none of which we were able to absorb apart from the terrible words 'Your daughter is very unwell, and may never live a normal life'.

Twenty-one years later I have not recovered from those words, or from that appalling interview (if it can be called that), for we were given no input, no information, no advice and certainly no offer of support. All I can remember is that I was nonplussed. '*Very unwell...*'

What did that mean? Yes, well, we know there's something wrong, but this is a hospital, after all – you're the doctor, you're supposed to be making her better, aren't you? If only! As for 'never live a normal life', that was too awful to even begin to take in – sadly prophetic though it has proved to be.

Although it is well known that bad news takes time to sink in and requires some sort of follow-up, we were offered nothing. Nothing at all. Not even a leaflet, let alone a follow-up appointment to talk through the implications of this illness. It is also well known that families are deeply involved in mental illness and have to learn to keep calm and unemotional, yet we were offered no advice about how to cope with our daughter's illness. And when she came out of hospital the only treatment given was tablets (Stelazine), which she refused to take. She got more and more ill, depressed, angry, isolated and withdrawn. I remember I once crushed these tablets and dissolved them in her drinking chocolate. I felt like some kind of Nazi, giving her medication without her consent, but when I took the half-drunk mug away I found the tablets at the bottom, undissolved and unabsorbed.

So much wasted energy. So much despair!

It took me six months before I could use the word 'schizophrenia' about my daughter. I looked up the phone number of the National Schizophrenia Fellowship and found their address in Shandwick Place (as it was at that time). My courage was evaporating by the time I got there, knowing full well that this visit would not bring a cure for my daughter. To my dismay I found that I had to speak through an intercom system in an alley between two shops., 'You don't know me,' I said to an unknown person upstairs, my voice breaking, 'but my daughter has schizophrenia'. 'Come on up, we're on the third floor.' So with a heavy heart I made my way up to the third floor, met people in an office and was given leaflets and a book called *Living with Schizophrenia*. I read the book from cover to cover, looking for light. Light?

For the next ten or twelve years we all went through the 'revolving door', with Elaine being admitted to hospital, pepped up with medication and then sent home, only to become ill and be sent back in again. For a good couple of years at the outset of this endless nightmare I was aware that there were people called Community Psychiatric Nurses who could administer medication to patients at home, but we were never offered one – and whenever we asked, we were told there were none in our area.

My husband and myself have a long-term commitment to Russia and had already made plans to uproot and go there. Everyone assured us that Elaine would progress better with us out of the way. So we went, but only for six weeks at first. We settled (or so we thought) our daughter in a flat with a very stable, kind female student but things were awful, and on our return I immediately went off to see the consultant – a different person this time. He said, 'We'll go for the jugular'. By which he meant, admit Elaine to hospital under a Section (i.e. compulsorily) for three months.

Elaine came to live with us in our temporary flat while we waited with dread and expectation to hear from the hospital. Christmas came and went. She was so withdrawn she literally didn't speak, just made little noises in her throat. She ate only with one hand, pushing the food around the plate and leaving most of it. If she ran a bath I had to check she'd put the plug in so the expensive hot water wasn't just running away. She would go out for long walks; her boots were worn down. And instead of cigarettes she smoked matches.

I phoned the consultant. 'What has happened? Why has she not been admitted yet?' 'Oh, I've been busy. I forgot.' There's obviously no hurry with this illness because there's no hope. Or so we felt, but we were due to return to Russia in the new year. How could we leave her like this?

On 31<sup>st</sup> December, at my sister's in Aberdeen, we went for a walk along the beach. Elaine is an artist. She is attuned to beauty and loves the sea. There was a dramatic scene: a red sun, round and glowing, shining through gathering mist in the still-frosty air. Elaine appeared not to notice, but years afterwards she referred to that walk and the scene we'd witnessed that December day when it had seemed she was in another world and had noticed nothing around her. 'The mind has mountains', as the poet says.

I had been given that poem to critique when I was eighteen. I had no idea that it was by Gerald Manley Hopkins but the words stayed with me:

*O the mind, mind has mountains; cliffs of fall  
Frightful, sheer, no-man-fathomed. Hold them cheap  
May who ne'er hung there.*

We were hanging by our fingernails on a sheer precipice of the mountains of the mind. Then, in the new year, it happened. We had sheriff's men at the door with official documents stating that Elaine was to be admitted compulsorily to hospital. An ambulance came for her. She wouldn't go. In the end I called a taxi – but it sat outside for thirty minutes before she agreed to get in it with me.

So, she was admitted for three months and given injections at once. Guess what? They let her out for the weekend. And now, having become more aware of her surroundings and her fate, and realising that we were going away to Russia for good – although actually only for five months in my case, as I would return in May to be around for her – she cried and begged not to go back to hospital. I took her back by taxi once again and she immediately ran away. Her friend called to say that Elaine was at her house and she didn't know what to do. Our son picked her up on his motorbike and took her back to us, her long coat trailing in the spokes of the back wheel. She could have had a serious accident at the very time when she should have been safely inside the hospital. I phoned the ward. 'Don't you know that one of your patients is

missing?' They had no idea! 'Can you bring her back?' they asked.

This time the taxi stood for 45 minutes outside our flat before I could get her back to hospital. So what's the point of having sheriff's officers and all the paraphernalia of court procedure if the ward can't look after its own forcibly admitted patients?

Home the following summer, I struggled in vain to find the inner peace to deal with all this. Our flat faced north and my heart too seemed full of winter in spite of the summer outside. A poem written then reflects this bleak feeling:

*'Woman, be free!'*

Choosing the sunshine, I try to forget  
she's in the shadows, sleeping at noon-time.  
Try to find comfort in birdsong, waken each morning  
to cadences carolled from branches and bushes  
while she is shuttered in her summer of stupor,  
a full-blown June rose, beautiful, blighted,  
living with me in this house facing winter.  
The sun doesn't brighten our windows, visit our garden.

I am still waiting for the sun to break through in our lives.

Once I went for a few days to a Christian fellowship where I truly tried to find inner sustenance. I turned to the Gospels and found the story of how Jesus healed a woman whose back had been bent for 18 years. 'Woman, be free!' he commanded. In a spasm of anguish I realised – and wrote – that I cannot be free because she is not free.

And that remains my situation. The years have gone by. Our daughter married and is still in the relationship, although she lives in a care home where she receives excellent support from Carr Gomm<sup>6</sup>. This has certainly taken the pressure off us as parents. She overnights with us once a week, her husband visits her once or twice a week in the home (though he has to leave by 9 pm each time), and she spends one night a week with him in his flat. Each bus journey, ten miles across the city, is a major achievement as she believes that passing cars can read her mind, the bus driver is out to get her and people on the bus know she is a mental health person and feel critical of her – or even

<sup>6</sup> A voluntary sector social care organisation.

think evil, harmful thoughts about her.

She is well monitored on oral medication that MUST be taken daily and receives support in all the 'activities of daily living'.

## **North Wing**

Elaine has lived in all kinds of accommodation. She once lived in a care place where another 'inmate' committed suicide, jumping from an upper landing in this new town building with its high spiral staircase. She has also been homeless.

When she was 27 she was kept in the acute ward of a mental hospital for two years, awaiting a bed in a long stay ward because she had nowhere else to go (her husband having failed to pay the rent). Is that not traumatic enough for a well person, let alone one whose inner self is under constant assault? He owed the council £1,000. It cost them far more to house our daughter in hostels and places for the homeless, to say nothing of the stress this added to her already overloaded inner life.

I wrote to our MP and the heads of this, that and the next healthcare organisation to try to get things moving for her. After nine months they gave her a single room opening on to the ward. The door didn't fit and she could hear all the screams and swearing and abusive language as desperately ill patients were admitted from the street and medicated. There was no toothpaste on her washbasin, no soap, and when I complained to staff I was told, 'She knows she can ask us for toiletries'.

Eventually she was given a bed in a long stay ward called North Wing, a separate house within the precincts of the hospital. It's now the physiotherapy department and is no longer used for hands-on patient care. Here's an extract from another poem:

### *North Wing*

North Wing is a hostel within a hospital, set among trees with its own front door like other old stone houses she has homed in.  
Once-spacious dwellings for the well-to-do  
now house those who can no longer do,  
whose bodies function but whose minds are broken.

Paid carers point me to an open door,  
a room chokingly smokeful, an uncarpeted floor.

I find my daughter there, among four dulled males.  
Her eyes are closed, booted feet rest on a chair – she'll always break the rules.  
'I'll be thirty soon.'

Half her life she has been:

in and out of hospital,  
in and out of hostels,  
in and out of council housing.

Evicted five times, made homeless twice;  
eight addresses in as many years,  
the hated hospital the only constant factor.  
Brought in by car, taxi, ambulance, police car,  
held down and forcibly injected.

She has had an army  
of key workers, support workers, community workers, social workers,  
consultants, lawyers.

She has lost most of her friends.

She has lost the right to care for her child.

*And she has no idea why all this has happened to her.*

'I should never have come in here. That was the biggest mistake they ever made, putting me in here. It was the start of all my troubles. Why did they put me in here, Mum?'

She sucks her thumb, alone in a big, bad, adult world. Lost and stuck, reduced and overcome.

## **Losing a child to adoption**

Yes, she has lost the right to care for her daughter. In January 1995, Elaine and I sat together in the absolutely horrible waiting room where Children's Panels were held. I was going through radiotherapy at the time for breast cancer, and struggled through the snow with her to the hearing. Our surroundings reminded me of remand homes I'd visited when I was a social worker in Glasgow, and I remember saying to her, 'You should never be in a place like this'.

Her baby was adopted, causing her immense pain. It is an open adoption so we all remain in contact, although for Elaine this ongoing contact is, as

a support worker said, 'a poisoned chalice'. Because she can never hear her daughter call her 'Mummy', never experience snuggling her on her knee, tucking her up in bed – and now that our granddaughter is a teenager, Elaine unwittingly makes it heavy by often treating her as the little curly-haired child she lost.

Do we not all recognise that losing a child is the most devastating thing that can happen to a parent? Yet my daughter and her husband, through no fault of their own, have to endure this heart-wrenching loss.

Our granddaughter is now living with my husband and myself, which is a huge joy for all of us and probably the thing that has brought me personally the most healing. It does mean, though, that I can't do quite as much with and for my daughter, who is so very needy. Elaine is like a sweet, charming, chain-smoking child who believes she is nine months' pregnant. There is little self-care and, sadly, she has recently had two teeth extracted near the front of her mouth. Anyone else would be fitted with a denture, but she would not be able to cope with it so is left with gaps.

Yet she remains the most generous-hearted and noble person I know, immensely intelligent, full of a lovely gentle humour and able to take a laugh against herself (a rare gift). A health visitor once asked me what was left of her from before her illness and I said, 'Her sense of humour'. Her ability at art, too, is with her still, impaired but flourishing. She goes to an art class weekly and derives a lot of satisfaction from this. She is also a good swimmer and I now take her swimming with me. She never stays long in the water, but looks so relaxed and contented. She loves the Jacuzzi too. It's lovely to see her doing normal things with normal people. She attends church faithfully and derives great comfort and help from that. Sadly she has lost almost all her friends, so depends on her family and support workers for social interaction.

## **Recovery, no! Acceptance, perhaps**

Schizophrenia affects families. Our son has chosen not to have children because he knows that this cruel illness is genetic. Our granddaughter – who has already done some major fundraising for Support in Mind (previously the National Schizophrenia Fellowship) – is exposed in a big way to an illness that, as one friend put it, most adults find challenging if not downright impossible to deal with.

Recovery? No. A sort of acceptance, perhaps: this is the way things are and we have to work along with them. But the heartache never goes away. We just wish for a better life for her, that she should be freed from the dark delusions that persist and truly haunt her in spite of the medication, that she should be able to become more independent. 'Woman, be free!'

I once saw a film about people being given Clozapine, the medication Elaine now receives daily. I'd read about the big improvements this drug can make. One of the people in the film, explaining what a difference the drug had made, summed it up with 'Nothing much, you know. Just ordinary things'.

I once asked one of her nurses why she seems unable to keep herself clean. His reply frightened and depressed me: 'It's to do with the disintegration of the self, the separation of character from body'.

And I recalled the words of a writer, Doris Lessing, and thought, paraphrasing her: *Blessed are they who feel the earth beneath their feet. Who are aware of the experience of cold and heat – or even pain; who know that it is uncomfortable to be unclean...* These are the basic ingredients of normal life, and they have gone.

Just normal things – like feeling your child's breath upon your cheek or the mutual exchange of friends, with no effort made on either side. Gone, quite gone!

'This medication is giving her insight but not ability,' the psychiatric nurse had said. 'We're between a rock and a hard place.' Hope deferred makes the heart sick...

An elderly Anglican monk who fell and broke his hip while visiting us at our flat in Warsaw said quietly, 'It has happened, so we must just accept it'. What wisdom in those simple words! Am I wrong to refuse to accept her schizophrenia? It took me so many months before I could apply that word to her – it's like cancer, I guess, or how cancer used to be. I identified with Terry Pratchett when he said, 'We talk about "battling with cancer", about the "brave fight with cancer", but about mental illness (Alzheimer's in his case) we say only negative things.' I have come to learn that, unfortunately, out of mind most definitely means out of sight.

The good things in life have floated away, unattainable as butterflies, while I sink in clay. I read lines from a Lakota Sioux: 'Sometimes I go about pitying myself. And all the while I am being carried in great winds across the sky'.

But I'm not pitying myself; I am pitying her. It's the same with those wise words about acceptance. Yes, the way of wisdom and growth is to learn to accept the pain that happens to ourselves – but how can we accept the pain a loved one bears?

I have written down a quote from Toni Morrison: 'The function of freedom is to free someone else'. I recall those words from the Gospel – 'Woman, be free!' – and my heart-stopping realisation, 'I cannot be free, because she is not free'.

O come, great winds, and carry us across the sky to freedom, both her – and me!

## **Key learning points**

- The slow, insidious onset of an illness is initially hard to diagnose but this early time, when the inner and outer worlds of the patient and the family are beginning to fall apart, is precisely when help, structures, relief and coping skills need to be given.
- Unhelpful, judgemental or coldly professional responses at this stage cause deep wounds that, added to the grief and horror of the illness, never heal.
- When a young child is involved, the whole thing goes even more awry. Too many professional bodies are involved: psychiatrist, mental health officer, social workers, the family... but there is no unified voice, no meeting together, and decisions that will forever affect the child's life – and the rest of the family's lives – are made in an ad hoc, mismanaged, unplanned way that causes irreparable damage and distress.
- In my case I am a carer of my daughter – even though she is married – and her child – even though she was adopted. My sister, as church elder and a member of a caring group, has recently had to help a 75-year-old grandmother with terminal cancer who is the sole carer of a five-year-old grandson whose mother, aged 40, is a lone parent

with schizophrenia. There are no care plans in this case either, and that grandmother will die grieving.

- Since the whole family is affected – in our case, my husband and myself, our other grown-up child, our daughter (the sufferer), her husband and his family and, above all, my daughter’s child – the whole family needs counselling and help at different levels and different stages. Each member of our family has been torn apart by this illness, and each person’s lifestyle has been radically and negatively affected.
- Tolstoy’s novel *Anna Karenina* famously begins, ‘Happy families are all alike; every unhappy family is unhappy in its own way’. But families with severe mental illness are alike in their suffering, as this book shows – living on a knife-edge of horror and grief, along with the total disruption of ‘normal’ life. For myself, to sum up, I am like another character in that novel who ‘did not want to talk of her sorrow, but with that sorrow in her heart she could not talk of outside matters’. My sorrow, because of my daughter’s tragic plight, has eaten me up, and I find no therapy for that wound.