

Chapter 10

I wish I could go back and give myself a hug

In Scotland, Patricia Mullen

Introduction

It is really difficult to decide where to begin; what to include, and therefore what to leave out. In reality, I think it would be difficult to find enough words or the right words to describe the journey that myself, my son and my family have been on for the past 17 years.

However, I will try to give you a sense of the roller coaster ride, our emergence via the process from hopelessness and devastation and our hard-won journey of recovery, healing and hope, so that if you are reading this narrative from a very dark and hopeless place, you might begin to light your own candle of hope and thus begin your own journey through the process of recovery.

Entering the world of mental illness

My name is Patricia and I have two children. My daughter was born in 1974 and my son in 1978. When he was a few months old I left and later divorced his father, who was a violent alcoholic.

I am mentioning this because in later years, when I was going through my tick list of every cause or cumulative cause of schizophrenia (whether factual or not), this fact, and the circumstances surrounding his birth, were relevant factors. I would rage between anger, guilt and grief. I remarried in 1981 and my husband has been their dad ever since.

My son first became unwell in 1994, when it became apparent that something was drastically wrong. At first it looked like the usual teenager going off the rails, trying drink and drugs etc. but I had always seen and sensed a vulnerability in him, and knew his consultant was right when he diagnosed him a year later as having paranoid schizophrenia.

The effect on the whole family was devastating; the bottom literally fell out of my world, and in my mind it was equivalent to a nuclear bomb shattering everything beyond repair.

He was 16 at the time. For a long time I kept thinking and remembering what I'd told him when he was growing up: that he could do anything he wanted to do when he was older, the world would be his oyster... For many years I felt as though I had lied to him.

Instead he was admitted to an acute adult ward in the local psychiatric hospital within just a few months of leaving school. My daughter was at university at the time and later went on to achieve an Honours degree in Economics and Politics.

It is interesting, thinking back, that she was considering a professional career within the NHS at the time. This was not destined to be, however, and she ended up making a completely different career choice. Like myself, all her illusions and beliefs about what should happen in the provision of care, either in hospital or within the community, were completely shattered beyond belief after living through the first five years of her brother's illness and diagnosis.

The constant trauma and stigma of trying to get help and dealing with the services, along with living with the illness, was too much – and although much (but not all) has been forgiven, we have never regained the sense of trust we once had. Nothing in life had prepared us for the world of mental illness at that time.

How we were treated often had a sense of brutality and, more often than not, a basic lack of human compassion. Unfortunately this can still be the case all these years later: I've been working professionally with mental health carers for nearly ten years now, and I often hear carers, families and friends repeating the same experience. It is hard enough trying to cope with the illness, the fall-out for the rest of the family and your own personal feelings of fear, anger, grief and loss without having to deal with the services, no matter how well equipped and informed you may be.

But for every loss of trust or bad experience there are the good experiences; understanding and words of basic kindness that helped to sustain my hope against hope throughout the early years and beyond. My son proved to be

treatment resistant and had little or no response in the first four years. He was extremely impulsive, chaotic and out of control, had made numerous serious suicide attempts and was beginning to self-harm. I had already lost count of his admissions to hospital.

Most of the care assistants on the ward at that time had no training, particularly in mental illness; this is something I still feel very strongly about, and I hope that, in this present environment of cuts to funding, they do not even consider changing back to a system that would have been cheaper in the past but inferior, and costlier to the individual receiving the service. I have worked in the voluntary sector for many years now and still work with individuals who have mental illness, as well as their families, friends and supporters. It's very disheartening that the present funding issues within the community have left many voluntary organisations to bid against each other. Alternatively, the funding situation is so poor that poorly paid, untrained and inexperienced staff are now the way out for many organisations trying to provide support, care and services within the community.

Anyway, to say that the first five years were the worst would be an understatement, and I honestly don't feel it would be exaggerating to describe this period of our lives as a living hell. I did have information, was well informed and also had support from the Glasgow Association for Mental Health and The Charlie Reid Centre⁷, which at that time was part of the national organisation known as NSF Scotland. I later went on to work for these two organisations after completing a series of SVQs⁸ and an HNC⁹ in Social Care, followed by ongoing training courses in anything I could get onto that was relevant to mental health. This was the darkest period for all of us, when the sense of hopelessness came in. I could fill books with examples of the stigma and isolation that come with this illness.

It's very difficult to think back on this time, and although years later we did emerge stronger, some of the scars are still there. There were very few glimmers of the real person, the son he was before this holocaust, and the roller coaster could turn on an hourly basis; the emotional trauma of watching him spiral out of control, suffering, scared and tormented, self-harming or desperately trying to kill himself, hiding and frightened or changing into a monster and smashing up the house, drinking and taking anything he could

⁷ A drop-in support centre operated by the voluntary organisation Support in Mind Scotland.

⁸ Scottish Vocational Qualifications.

⁹ Higher National Certificate.

lay his hands on and threatening to harm himself or us – but all the time so ill and so vulnerable. He did take the medication, he did comply but it just wasn't working. This is the bit I will never understand and for which I will never forgive the services, who then began to talk about his behaviour, that maybe it was just his personality – after all, he was an out of control teenager and possibly the best place for him would be in homeless accommodation. 'Put him out' was their advice to me, mostly at times when I'd just nearly lost him. I just could not get my head around this and still can't. He was already diagnosed and it was obvious that he was treatment resistant. How on earth could they have hoped to improve things by putting a vulnerable and ill young adult out on the streets to make his way to the Hamish Allan Centre?

The police became frequent visitors for a time and were, on the whole, extremely supportive and helpful. They were frustrated at dropping my son off at the hospital only for him to be sent home again, usually within hours. My husband's physical health was deteriorating and my daughter struggled juggling part-time work, full-time university, staying up all night with her brother and supporting me. I very nearly gave in at that point – it seemed so hopeless and we were so desperate. I remember my daughter crying angrily as she told me that the cavalry (meaning help from the mental health services) was never going to come. To me, the thought of putting him in the homeless system was not even an option because he was so great a risk to himself, and I felt that it would be as if I was punishing him for being unwell and treatment resistant. In short, I was terrified for him.

The mental health system did not know my son before he was ill so how did they know what he was like when he was well? I did, but I felt that they were now introducing the scenario of 'mad or bad'. I lost all hope at times and clearly remember thinking that I had no choice but to consider killing myself and my son. This, in my opinion, is one of the biggest unspoken taboos for many carers and I was not sure whether or not to include it, but I think it is too important not to. I did not go down that path but was racked with guilt as to what kind of mother I was that I could even have thought that for a second.

Looking back, I wish I could go back in time and give myself a hug and forgive myself for these disturbing thoughts grown out of love and desperation. I have now worked with carers for many years and occasionally (usually only when the individual is aware I am or have been a carer myself) I am told the same story. A distraught family member will reveal that they have

had the same thoughts and tell me how ashamed they are. It's not rocket science: compassion, kindness and a strong dose of common sense and communication – just treating people as human beings – can stop this sense of hopelessness and desperation. Society still has a long way to go, particularly individuals working in the caring profession, when desperate and vulnerable people who are usually (on paper, at least) surrounded by support workers, CPNs, psychiatric nurses, consultants and GPs are left in situations where they think, even for a moment, that that is their only way out. I did not give up – it wasn't an option. But by this time, and for a number of years afterwards, I myself had been tagged and labelled by many within the mental health system. After all, they'd only seen me when I was overwrought, overtired, overemotional and looking desperately for help and answers.

One of the biggest factors that causes carers, myself included, to become caught up in the process of helplessness is being disempowered by the mental health system, particularly when they are at their most vulnerable. They weren't around the 95% of the time when we just got on with it, and sometimes it was worse and felt even more difficult when I questioned what was or was not happening. It is still very common for carers to be labelled as 'challenging' and it is still unacceptable. In most cases a skilled worker should be able to use communication and listening skills in a compassionate and understanding manner. In my son's case, it would have been easier for them if he'd moved on to live in a homeless unit and most likely fallen into the criminal justice system (although he has committed no crime), especially if there had been no strong family involvement to prevent it. Some CPNs told me bluntly that they thought I was deluding myself and that my son was out of control and spoiled. My self-esteem and confidence were hitting rock bottom but I'm really glad I didn't go down that path. I nearly did but common sense, love and an ability to rationalise the events up to that point left me in no doubt of his diagnosis and continued lack of insight.

Gaining insight

I would like to add a little context to this experience by telling you that I now have over 13 years' experience working with individuals who have mental illness at The Charlie Reid Centre in Glasgow, and many of our members have been through the homeless system. The centre was the first drop-in centre specific to mental illness to open in the Greater Glasgow area, and at present we are lucky enough to have a manager who at that time worked with the

homeless team managed by GAMH¹⁰. The work done by this particular team ten years ago made a huge difference in reducing the number of people caught up in the homeless system while diagnosed with and/or experiencing mental illness. This did not happen to my son, but it was very common at that time for young men to fall through the cracks in the system and end up homeless, on the streets or in prison.

Things eventually came to a head for my family and my son, but only after we'd all suffered irreparable emotional damage. My son was admitted to an IPCU¹¹ ward, which is known as a 'locked ward'. At that point I had to take a chance and refuse to take him home; it was one of the hardest things I have ever done. I knew I had not given up on him but I had to do something to stop the endless cycle of revolving door admissions and leave him in hospital long enough to be properly assessed. We were exhausted by trying to keep him safe and by services implying that we were exaggerating, or bringing up the behaviour scenario again. That this was considered necessary four and a half years after diagnosis I still find totally unacceptable, but I can only put it down to the short-sighted and judgemental attitudes of the staff in his usual admissions ward. We were terrified by the thought of him being held in a locked facility but it turned out to be the best thing that could have happened.

I remember myself and my daughter being pleasantly shocked because the staff at the IPCU were kind, communicative, civil, non-judgemental and, for the first time, hopeful. He was started on Clozapine, and that was the beginning of my son's and my own fight in the journey of recovery. One thing I firmly believe from experience in all my different 'hats' is that it's difficult enough to manage and support anyone through an acute phase of illness but even more difficult to manage a young teenager through such a phase. Clozapine was not a miracle but it was enough of a miracle for me, and it gave my son insight into the fact that he was ill. Without insight I had felt that there was nothing to work with, but now there was hope and I was determined to fight this illness with every fibre of my being. I made every mistake possible before I learned that my son had to learn to want to recover to the best of his ability and start his own fight. Although he was still very unwell and on huge amounts of Clozapine, part of him was back – that's the only way I can describe it. Also, after Clozapine gave him his insight it was as if all the other rubbish behaviours fell away. It was very much easier to diagnose and clearly identify symptoms.

¹⁰ Glasgow Association for Mental Health (a voluntary sector social care provider).

¹¹ Intensive Psychiatric Care Unit.

Over the years he had many more admissions but was never put back in an ICU ward. A few years later, while visiting on the ward, I remember the nurses saying to me what a nice lad he was and I thought, 'That's what I tried to tell you before he was finally tried on Clozapine!'. One day we were talking about some of his 'stunts' in a light-hearted way; he laughed but then said, 'Well, I didn't know what I was doing – but wasn't the hospital worried about me, didn't they try to do something about me or for me?'. He was no longer a teenager, and although very immature he had insight and a perspective. Over the next ten or so years came the hard work, when sometimes it felt like one step forward and twenty back. It was extremely difficult, and hopelessness and isolation would still come in waves along with the grief. At that time everyone was speaking about the benefits of creating a stress-free environment for my son.

So there I was, armed with the manual and determined that there would be no stress, but I soon learned that the high levels of medication he was on meant that we'd have to write our own manual of what was going to work and allow part of this to function between good days and bad days. I was creating more stress by trying to create a completely stress-free environment and nobody (especially not families) can live like that, walking on eggshells 24/7. I did realise that his best chance of recovery at that stage was to remain within the family, with the support of friends, until he was well enough to have his own place. As for my working life, I was very clear in my head that if I was to go any further in the mental health field it would have to be for a lot more reasons than just having been and still being a carer. Although I now realise that I had the benefit, knowledge and experience of working both with individuals who experience mental illness and with their carers, families and supporters, along with my own personal experience, having different hats has not always been easy. But at times this has given me a better perspective on the stigma that often comes from the mental health field itself. After many years, I now feel experienced and comfortable enough to use these skills to (hopefully) benefit others. I still experience examples of stigma and judgemental thinking but I now try to be more tolerant and understanding when challenging assumptions, stigma and discrimination.

Foundations of hope

In the late 90s I was lucky enough to get on a course run over eight residential weekends. The course was called 'Allies In Change', and for the first time it

brought together a variety of professionals, service users and carers (both the latter are terms I dislike). The people involved in all aspects of the course were all very highly motivated, and at that time it was a revelation to me to listen to and meet with professionals, many at the top of their field, who were caring, highly dedicated and determined to achieve positive change. I felt that I was now seeing the best and hearing what could be possible. The whole 'Allies' experience – the course itself and all the people I met – really came at the right time for me, and although I was not yet aware of the ethos around recovery, this course and the benefits of the whole experience definitely laid the foundation blocks of hope and the potential for positive change, together with good practice for me as both a worker and a mother. The benefits for me at that time (and to this day) were huge. We were told that it was not a 'movement' but, in retrospect, in some ways it was. Out of 'Allies' came Person-Centred Planning and Map and Path Route Planning, and in many areas across Scotland new and innovative projects came to life. For me there was no going back – the motivations, learning, debating and pulling together left me in no doubt that positive change was possible, and I was eager to do my bit and learn from the mix of expertise and experience offered by the individuals involved in the 'Allies' course. The building blocks were laid for many new projects such as Stepping Stones, Lanarkshire Links and the Glasgow Mental Health Network, to name but a few. It was also in the early days of this course that I had my first experience of the divisions between what was known as the 'user movement' and the carer and family organisations.

Historically this was nothing new but it was new to me, and I felt it was critical for me in all my 'hats' to understand it more fully.

Although we now know this is wrong, many families were blamed in the past for mental illness and caught in a cycle of stigma, fear and guilt. Some, like my own family, were encouraged to 'forget' or be less supportive of their ill relatives and concentrate on the rest of their family; more often than not they simply couldn't cope and were given little or no support. Personally, I believe that there's only a very small minority of families and circumstances in which it is not in the person's best interests to remain within that environment but historically, and in general terms, families were and can still be torn apart by stigma, ignorance and fear, losing essential and often critical support skills and the networks available for most other illnesses. I always tried to tell my son that he had an illness the same as any other illness, and I needed him to believe that. Much of the fear, ignorance and stigma that still exist lead on to

isolation and despair and can create one of the biggest barriers to recovery, leaving people to struggle alone and feel unable to seek help. When my son first became ill we were told that mental illness was very common, but for a long time I remember wondering where all the other people were. I had yet to learn that many families had become experts at concealing their situation, cutting themselves off from each other in what they think is a survival strategy. I wasn't for telling all and sundry but I was adamant that my son's illness was nothing to be ashamed of and determined he should believe that he had an illness the same as any other illness, which could improve with medication therapies, and that there would be good and bad times. That was part of my way of coping with the stigma, the services and the illness. We all need people we can turn to for support, talk to or have a cry with, and I was aware that my son had to learn in some way to cope with life, illness or not. We did have periods of isolation but at other times had continued support from friends, family and colleagues. Without this I think we would not have coped in the long term and the isolation and loneliness would have been too much.

A recovery pathway

My son enjoyed playing his guitar and joined various music groups, which I think also helped him to form and keep his own identity. I still worked (my husband was now medically retired), and although that was hard I think it helped me to cope and kept me sane, particularly through some of the most difficult times, as I was able to talk to others. It still felt like I was on call 24/7 and I probably was, but I am sure that we would not have been able to cope or move on with a positive outlook if I had been in the house all of the time.

Even after starting Clozapine he was still very unwell and on large doses of medication for many years. There were good times and bad, but the good times were crucial to the start of the recovery process for us both. Mental illness is a very lonely illness and it's easy for individuals or whole families to get caught up in the isolation and paranoia, sometimes doing the wrong things but for the right reasons. Many have had a bad or judgemental response from family, friends or the services and I was no different. Unfortunately, I have past experience of questioning service providers and making a complaint. I had the benefit of being supported through that process but it was still extremely difficult and stressful. In fact, although I would still do the same again, the experience left me feeling less confident as well as

more isolated and labelled. It really isn't something any carer would consider lightly, because unfortunately there is also the additional fear that if you complain it will have an effect on the services and support available to your relative.

About six years ago I realised that, overall, I had seen, experienced and received some of the very best care and support from many professional and caring individuals. I was also very aware that at times we had also experienced the worst, and although in balance this was not always the case, I think that it felt worse because the bad experiences always seemed to happen at the times when we were most vulnerable, or had reached crisis point. Writing this has brought back many memories, good and bad, but I think it is important to try to give you something of what I was and still am recovering from. We were already on a path of recovery at that stage but I did not realise this at the time or understand that it can be a long haul, not down to any one thing but rather to a cumulative process often hard-won.

When I first heard about 'recovery' I really didn't understand the concept. I remember being angry and thinking that some people might be tempted to come off their medication. I also worried that it was some new term or process more suited to individuals with mild to moderate mental health problems, and that service provision might be monopolised around this new buzz word to become a tick box exercise around the positive outcomes required for funding. In itself this would not have been bad but I was extremely worried about how it would work for individuals with severe and enduring mental illness – a much more difficult and challenging thing to measure or address. The seed was sown, however, and I was soon thinking about how this would or could work for my son and the members of the centre where I worked. At that stage I was not thinking about recovery for myself; I was barely even ready to admit or consider my own need for recovery. But I was soon to realise, and see more clearly, that we were already on the recovery path, and that although our recovery paths were at times linked, we were both moving on towards our own individual experience of this process. This in itself was another link in the way forward.

My prospects

In 2003 I travelled to Holland with a small group of carers representing

Support In Mind Scotland¹² and took part in the first ‘Prospect’ self-development training programme organised for family and friends by EUFAMI¹³, which was attended by carers and supporters from ten of the member countries. It was through my initial and continued involvement with this programme over the next eight years that my overall and personal understanding of recovery grew, enabling me to clearly see my own journey as well as the brave and limitless possibilities for everyone involved in the process. Back in 2003 I was overwhelmed by the fact that although I was with other carers from various countries, languages and cultures it was very apparent that we shared a common bond in terms of our understanding and experience of mental illness. In 2004 I returned to Holland and completed training to become a facilitator with the ability to deliver Prospect training; this was when I really got my teeth into Prospect, and when the words – Real, Worthwhile, Coping, Hope, Change and Recovery – really began to mean something real and achievable.

Prospect is based on a global philosophy that breaks the cycle of isolation, limitation and discrimination and enables participants to embark on their own journeys towards recovery. Initially made up of ten specific modules, it is a training initiative aimed at opening up fresh perspectives for carers, family and friends of individuals with mental illness. It stems from a need to provide a family education course that not only addresses the needs of carers in their own right but has also been developed in conjunction with them. At the heart of Prospect is a fundamental belief that, in the right setting and with the right support, carers CAN and WILL set about regaining control of their lives, allowing them to discover and recover skills and strengths within themselves. I have now seen this process work and begin to enable positive change in the lives of many carers over the past five years. All Prospect facilitators are required to be or have been a carer or supporter, and to have completed the course themselves. As a facilitator I feel that I gained an added perspective and overall understanding of this process, which was definitely more than just a course.

In 2006, Support In Mind Scotland successfully piloted the programme for a little over a four-year period. My involvement and my own personal experience as a carer over that period confirmed to me that ‘recovery’ is not a one-off event or course but an ongoing process which I now describe as my ‘bag of

¹² A voluntary sector social care and campaigning organisation.

¹³ European Federation of Families of People with Mental Illness.

tools', ready and available for me to use or add to in the future. The Prospect course itself is usually delivered over a residential weekend with a follow-up weekend three to six months later. The specific modules are designed to touch upon areas often excluded from formal education programmes and therefore not openly discussed. Although a group setting is used to deliver new and up-to-date information, the course itself is not based on information-giving but is experiential and based on group participation that allows for the exchange of experiences, problem-solving and the defusing of misconceptions and, perhaps more importantly, enables carers to offer each other solutions, hope and the support essential to improving their own quality of life.

Through EUFAMI in Holland, I watched and listened as carers throughout Europe began the process of positive change and recovery through Prospect. For me, the missing piece of the puzzle came when I was working in Scotland as a facilitator. I was witnessing and recording evidence that showed that when some carers began this process for themselves, it often led to the beginning of the same process for the cared for; it's as if it had a knock-on effect. Carers – myself definitely included – did not see this as a quick fix. We understood that we were at the beginning of the process of recovery and that, by trusting and adjusting the process, specific tools and skills to our individual needs, we could begin to make changes (no matter how small), reclaim our lives and have dreams and hope for the future of our relatives' journey on the path of recovery.

Taking my own advice

Many of you reading this will be aware that not everyone fits neatly into the box of service user or carer all of the time; we all have varied and different labels throughout our lives and, like everything in life, nothing is ever that simple. People's circumstances change over time and many, many carers develop physical and/or mental health problems. Many people with a serious mental illness also have a partner or friend with a similar illness, and usually the person who is well at the time becomes the carer. My own physical health had been greatly affected at times over the many years of stress. Part of my recovery was to allow myself to come to terms with the overall trauma and serious long-term stress that had taken its toll on my mental health. I suffered and was affected by stress and serious anxiety, and although I now knew the reasons why this had happened and that it was often common in carers, I still found it difficult at times to take this on board and seriously consider

my own needs. My son was always my first thought in the morning and my last at night. I advised carers that to go on the long haul they had to be good and look after themselves, but I didn't always take my own advice. Looking back, I realise that my son had become very dependent on me and had grown to expect me to manage his illness in many ways. This was really difficult at times because some of the resentment he usually felt towards his illness would be focused on or towards me.

Much had improved but we still struggled and did the wrong things, sometimes for the right reasons but sometimes just because it was all we could do to manage through yet another crisis. I was handling things an awful lot better but emotions can take over and I often forgot the knowledge and skills I'd gained and developed, particularly when it came to myself. I distinctly remember that on two separate occasions when I arrived to facilitate at a Prospect residential weekend, I was desperately trying to keep my own emotions in check.

Like many carers, I was busy trying to juggle various responsibilities, dashing around trying to fix things and looking after everyone else. I was going down the slippery slope of not looking after or making time for myself again, and forgetting that it was okay for me to have a bad day; I needed to allow myself to grieve as part of the healing process. Sitting through some of the modules as an observer, I thought, 'I know all this, so why am I not doing it?'. So for me the timing couldn't have been better, because there I was again bringing out my bag of tools. It was more than just the modules – it was being in an environment with others who had or were having the same experience but were, as a group, full of hope and determination. This was really helpful as it allowed me to feel supported and to stand back and get things in proportion. I picked myself up and became more determined than ever to really start to make the hard decisions and changes that would be instrumental in my own journey of recovery.

Drawing back

Many carers became friends through Prospect and have since set up their own support network so they can stay in touch and support each other whenever they wish. Prospect also allowed me to explore and work through the acute distress, shock and trauma that mental illness had caused in my life, and I began to rebuild my confidence and self-esteem. Mutual understanding

and peer support enabled me to reactivate, identify and go on to use coping strategies and plans. I began to plan routes forward with a strong and determined sense of hope and a desire for positive change. My new thinking was about 'what's possible', i.e. what could realistically change. Even if I started small or failed in my first attempts, I was determined to try and to move forward. I also felt braver about this now because I'd witnessed the benefits and changes in the lives of many of the carers who'd engaged in the process of recovery through Prospect. They were all given the opportunity to tell their personal stories while attending the Prospect weekends and it was inspirational for me to hear what they had to say, particularly on the follow-up weekends.

Like many other carers, my biggest worries were about what would happen to my son if I wasn't around – how would he manage on his own? In some respects the time might never have been right for him to leave home and get his own place, but I wanted to try this out while I was still able to offer support and a safety net of sorts. I had learned that given time, hope and the right support, so much can be achieved. He has now had his own flat for nearly five years. It hasn't always been plain sailing, particularly in the beginning – I had to learn to draw back in stages – but the rewards have been great for us all. He slowly learned new skills and his independence grew, which initiated a new life with new choices over which he had control. He still receives support to maintain this quality of life and independence but, looking back, I am sure that no matter how scary or risky it seemed at the time, it was definitely the right decision. He loves having his own space and now I have mine. It was nobody's fault but we'd got to a point where we were stifling each other. Now we are able to spend quality time together, and our relationship is better on a more equal basis.

Learning to trust again

Over recent years I have learned the importance of not getting stuck in the past. I did not want to be caught up in bitterness as it could have damaged my own mental health and affected me moving forward. I am now also in a position to realise that trusting my son's care team was another part of my recovery – I was learning to trust again. He has a very good consultant and CPN whom I trust implicitly, and it is reassuring for me to know that I can speak to them if necessary. On a lighter note, the last CPA¹⁴ meeting I

¹⁴ Care Programme Approach.

attended – where I joked that hopefully they wouldn't be seeing me again for a very long time – was nearly two years ago. This was a huge step for me, and if someone had told me even three years ago that I'd one day get to this stage, I probably would not have believed them.

I'm still on call but very much on the back burner. I learned the hard way that to survive the long haul you have to take care of yourself. We can all give advice but it can be hard to take it – and even harder to do something about it – if we're not given the right information and support. It has definitely been a 17-year journey, and although it's probably not one I would like to repeat I have met so many inspirational and courageous people along the road. I've gained a wealth of knowledge and experience and, just as importantly, regained my sense of self, my own identity. I now have a greater understanding of how my life was affected in many ways, particularly emotionally. For many years it felt like I was fire fighting; I'd got used to being on a high state of alert, ready for any crisis. My own health needs didn't really come into it as long as I was in what I thought of as 'survival mode'.

I was lucky enough to be in the right environment and to have the right support, which enabled me to stand back from crisis mode and clearly see the benefits of positive change while repairing some of the damage, trauma and effects of long-term stress. Whenever I felt like I was drowning in a sea of hopelessness I clung desperately to the good times (some of which were *great* times) when we never lost our sense of humour or hope for the future. In life you can easily become such an expert at hiding your own true feelings, keeping secrets and trying to convince the world you are coping that sometimes you can even fool yourself. I have learned to give myself days when it's okay for me not to cope and, over time, the bad days have become fewer. I still have periods when I am affected by anxiety, and I know I have more work to do on my own recovery path, but both myself and my son are now in a place that previously would have seemed unreachable. This was achieved in small steps with a lot of hard work, heartache, determination, support and – most importantly – hope for the future.

For my ongoing recovery I need to learn to be good to myself, to make time for my own needs and to be confident in my ability to make use of the experience, knowledge and understanding I have gained over the years. By using, sharing and adding to my bag of tools, I'll be ready for whatever life throws at me.

Key learning points

- If you want to be there for the long haul, you have to look after yourself and acknowledge your own needs.
- Given time in the right setting and with the right support, individuals CAN and WILL regain control of their lives, recovering strengths and skills from within themselves.
- Recovery can be a cumulative process, often hard-won. Remember the importance of hope and build on small achievements.
- Sometimes you have to write your own manual to survive and to make progress. This can be very hard as it means taking risks and chances with the person you care for, but it can improve the longer-term outcome for your relative and yourself.
- We often learn the hard way, with no training and little or no support. Finding your own path involves making mistakes; remember that you're only human, and that bitterness and guilt can be destructive emotions. Seek help and forgive yourself for things you could have done differently.
- Services often confuse behaviours and personality, and they may use this as an excuse for not offering support or intervention – particularly when things are at their most complex and difficult.
- It is hard enough trying to cope and come to terms with mental illness but this is often made even more traumatic when you try to get help and support from the services, no matter how well-informed you may be.
- Being supported by people who are non-judgemental is key; even if service relationships have been bad in the past, there's no reason to think that that will always be the case. Try to move forward and in time you will relearn trust.
- Professionals need to listen and instil a sense of hope, balancing real communication with understanding and compassion using a holistic approach and an understanding of the unique circumstances of the people they support.
- Don't isolate yourself or your relative, and try to keep your own identity. Meet and learn from others. Hang on to the good times and keep your sense of humour and hope.