

# Chapter 3

## The silver lining

*In Sussex, Mr & Mrs P*

It was summer 2005. Life was buoyant and fun. The weather was fine and sunny, but storm clouds were gathering. Not in a meteorological sense – these storm clouds were of a different genre. They carried an obnoxious potion of fear, uncertainty and panic, all brought about by the onset of mental illness.

### Prelude

Up to this point in my life I'd been blessed with a relatively trouble-free existence. I was happily married for a second time, incorporating my son, who was born in 1983 from my first marriage. The three of us lived a comfortable life. I held a position as a company director and my husband worked as an accountant. In conjunction with my first husband, we were able to provide my son with a private education. We continued sponsoring him into tertiary studies after he was awarded a scholarship to attend a top university, where he followed a degree course related to environmental sciences. He flourished in this setting, being dedicated to 'saving the planet' on the one hand and pursuing an energetic social life on the other. He was a bright, capable, academic young man with excellent prospects for the future. Once out of university in 2003 he quickly acquired employment as an environmental technician. He was still living at home with us and all was going well.

During the early part of 2005, coexistence with my son became a little more difficult. We had upsets over his dogmatic views on life values. There were opinions being foisted upon us relating to religion and criticisms of our apparent disregard for the environment, and we fell out over his sudden acquisition of some rather strange tattoos that were very much out of character. In short it seemed he was intent on continuing a student-type lifestyle with the associated rebel factor very prevalent. As a result, my son decided to leave our house and live at his father's house with his father's partner and her family.

His father prepared for his son's arrival by providing him with accommodation and bespoke furnishings. Despite these efforts the liaison was troubled and my son soon left to take up lodgings nearer his work south of London.

In an instant, my son was introduced to some people in his new home town by an old school friend and duly invited to a party by them. We know now that he encountered the dubious world of illicit drug-taking through these people and it is almost certain that these events caused my son to become psychotic.

Our first brush with psychosis came a few days later, when we received a call from my son's workplace at the close of a working day informing us that he was behaving strangely and that they would be bringing him home to his father's house.

*Lesson 1 taking drugs should be avoided at all times by people predisposed to psychotic tendencies*

That evening, we all wrestled with his deteriorating condition as he lurched from one nonsensical notion to another. His behaviour was so alien to us that we were in a position of not knowing exactly what to do. We did manage to see a locum GP late in the evening who advised us that he was showing psychotic symptoms. He prescribed sedatives for my son and advised us to take him to our own GP in the morning. My son was up early the next morning and very agitated but we did manage to get him to our GP.

## **Episode 1 of 5**

Our GP diagnosed psychosis, and in the middle of the discussion my son stood up, thanked everybody, announced that he was fine and quickly left the surgery. He started running through the streets, calling into pubs on the way; he was advising them to stop selling alcohol and grow organic food produce instead. He ignored our pleas for him to return home. I was extremely worried that some harm might come to him, as he had no notion of how irregular his behaviour was becoming. His fitness level being very high made him difficult to keep up with – he was flying on the wind, and the only way to catch him was to involve the police. He was caught and taken to a mental health hospital. After a few days he was detained in the hospital under a section 2 but within a month he had been stabilised with medication and was released. My son came to live at my home but, being heavily medicated, he was a shell of his former self, although the psychosis had abated and he was able to return to work.

After six months the psychiatrist stopped my son's medication, implying that he had had a one-off drug-induced psychotic event and would probably not encounter the condition again.

*Lesson 2 ensure a carer's assessment is completed by hospital staff during your first encounter with hospitalisation (this will get you into the 'system')*

Two devastating elements had been introduced into my life: my son had experienced a psychotic episode without any insight into his condition and I had been into a mental hospital for the first time and entered an alien world. Little did I know at the time that this first involvement with mental health would be just the start of a long, stressful, and dark journey that at one stage seemed totally hopeless with no resolution in view.

*Lesson 3 seek solace and understanding from carers who have had very similar experiences to your own*

## **Episode 2 of 5**

It had been so saddening to see my only child in such turmoil after a lifetime of normality. All the same, I began to convince myself that this was just a glitch and we would all get back to normal, and for a while that was exactly what happened. My son had gone back to work but decided to change career and move to the West Country to work on 'nature' projects. I can remember feeling so relieved that all was normal again, but I was soon to be devastated as I watched the onset of psychosis take over my son once more.

In total my son was in the West Country for about 18 months, and during that time his condition got steadily worse as I and my family and friends increasingly received strange letters and bizarre telephone messages from him. I visited him on numerous occasions during this period and tried to persuade him to come home but he was set on staying where he was. Eventually, with no work and finding it increasingly difficult to manage (at one point he was living in a log cabin in an open field on a farm), he finally came home. His condition was now causing me great concern and I had to take steps to get him medical attention. This proved once again easier said than done as we attempted to line up the required key personnel to address the problem of a poor soul unaware of his own condition and requiring medical attention. The trauma and anxiety levels were sky high during May 2008.

An assessment was arranged that involved two psychiatrists and a social worker. They deemed he was to be admitted to hospital as a section 2 patient – detained for up to 28 days. If he went voluntarily that was good, but if he didn't then the police would be called. In the event he went voluntarily but the entire process was incredibly intense and emotional as he struggled to understand what all the fuss was about and I struggled with his abject irrationality. I was beside myself with grief, in mourning for a lost son and at the same time buffeted by a brutal hospital induction ritual.

*Lesson 4 have an action plan in place that can be executed should hospitalisation be required*

Visiting my son in hospital already had a mild familiarity about it. He was heavily medicated yet still managed to maintain some fairly paranoid opinions that he would suddenly lay on me. The combination of confused thought processes and the stress of hospitalisation resulted in him making some strange decisions. At this stage in his illness he decided that I would no longer be his next of kin and that it should be his birth father – my first husband – instead; this despite the fact that I had brought him up without his father for the last seventeen years. Paranoia had replaced normality, causing my son to give away his possessions, adopt rigid eating patterns and hold religious views to a delusional level. Driving such attitudes was a belief that he had been wronged by his immediate family and that it was their fault he had been 'swallowed up' by a mental health system he was unable to rid himself of. He was then released from hospital but this time on prescribed medication that had hefty side effects, again for a condition he did not believe he had.

*Lesson 5 poor insight may have a psychiatric cause but will probably require a psychological solution*

By now my personal life was so ravaged by the necessity to constantly focus on mental health issues that it had become unrecognisable from just two years ago. Strains were put upon previously unassailable relationships and an underlying feeling of oppression prevailed, not helped by the dismissive attitude adopted by my son's father, who became a very noticeable absentee from the entire scenario. From a family perspective I felt very isolated, and I was always mindful that my husband was not directly related to my son and conscious of the burden being placed upon him.

*Lesson 6 demonstrate a strong parental relationship providing strong, unwavering support*

There followed a period of ‘splendid tranquillity’ during which my son became ‘normal’ for many months. Initially he was lethargic and suffered weight gain from the medication, but after a while he became fit, lithe and energetic. His strong intellect appeared unblemished by psychosis either during or outside episodes, and nine months out of hospital he successfully applied for a course on the teaching of chemistry, physics and biology that was to start in September 2009. This direction was fully sanctioned by his consultant. Things were looking positive for a change.

### **Episode 3 of 5**

Then, in October 2009, the world came crashing down around our ears. Unbeknown to us, my son had stopped taking his medication back in March.

*Lesson 7 constantly check that medication is being taken regularly*

This tied in with the renewal of vitality and energy we had been witnessing since March and made him vulnerable to relapse. There had been a problem with the university’s medical form processing that led to significant delays. By the time they made the decision that he was medically unsuitable – despite achieving best student status and being elected student representative for the course – my son was already well into the course. After raising his expectations and involving him in a solid life skill he was suddenly dumped and abandoned. The stress created by this action buckled my son and he became very psychotic again almost immediately.

*Lesson 8 stress is a major factor with regard to triggering psychotic episodes*

Once again we were confronted with the daunting prospect of hospitalisation; the level of emotional trauma now rose exponentially with every occurrence.

*Lesson 9 social services and associated organisations (except the police) are very poor when it comes to the act of hospitalising mental health patients*

The pattern was now beginning to follow a very predictable cycle: 1) no medication; 2) psychotic episode; 3) stressful journey to hospitalisation; 4) erratic hospital treatment towards stabilisation; 5) hospital discharge on medication; and 6) the wait for it to start all over again. My husband and I were beginning to tire of this roller coaster process.

Recovery in hospital this time involved my son spending time on the acute ward as there were no beds available elsewhere. This was not helpful. He seemed to take much longer to respond to the medication and remained in a confused state for what seemed forever. But a recovery did take place and he was able to leave within a month.

His overall condition had worsened since the first episode, although the psychotic symptoms had not changed. He was still in denial over his condition and keeping him on medication was not going to be easy.

## **Episode 4 of 5**

Once again my son stopped his medication and was hospitalised with the assistance of the police. This time it had only been 196 days since he'd last left hospital and he was back in again during April 2009. We had been subjected to the hospital entry façade once more and felt wiped out by it.

I succumbed to illness on this occasion, the stress of it all being too much to take. I could no longer go on being an ineffective bystander amid this whirlwind of unpredictability. I had to fight back somehow, so I decided to find out if there was anybody else suffering in the same way as myself. All this time we had been isolated and I was truly surprised to find so many people suffering identical crises. A new word became symbolic of our plight: carer! I was a carer for someone with a mental illness. I was not alone any more.

### *Lesson 10 wholeheartedly step into the world of carers*

I met with a local support body and was introduced to some fellow carers, who all seemed to have the same issues as me. Although there were groups established in nearby towns there was not a carer group for our town. So I started one and set up monthly coffee mornings that were immediately well attended and have remained so to this day. It was an excellent forum for sharing, and much advice and learning resulted. I experienced a renewed energy and a sense of purpose and community from this development, and a

newfound strength from feeling I was at last doing something positive to help my son. However, there was to be more upset.

## **Episode 5 of 5**

My son was still in denial over his condition with extremely poor insight, and he stopped his medication yet again. But this episode was to be different in a number of ways where his treatment was concerned.

In January 2011 he became very unwell – the worst, in fact, he had been since the onset of his condition. He was more distracted than ever with confusion, thought blocking, unsolicited laughter, distraction and poor mental processing. We went through the most awful experience to get him into hospital that ended with him being arrested in a public place after a particularly harrowing period where he went missing. The relief when he was taken to hospital was palpable, yet somehow, despite the awfulness of the experience, I was able to gather myself into a pragmatic package that was determined to get a much better result for my son on this occasion.

*Lesson 11 don't be subservient: assume a position of leadership*

Notification that my son was to be held under a section 3 this time signified the seriousness of his condition. He was to spend up to six months in hospital, where, initially, his paranoid behaviours were extreme and his response to medication very poor. So poor, in fact, that at times we doubted he was taking medication at all.

## **Final recovery actions**

This time it was going to be so different. I was determined to have a much better outcome following hospitalisation.

Because the internment period was so protracted this time it gave us more of a chance to analyse the processes used by the hospital. Firstly, there was the ludicrous position that patient confidentiality applies to mental health patients. It is unbelievable that someone with severe mental processing difficulties is given the responsibility to make decisions on their treatment and overall life direction while the 'normal' carer is excluded from these

discussions, particularly as the carer has responsibility for post-hospital welfare. It was a situation we were determined to overcome.

*Lesson 12 establish a very close relationship with your patient's consultant*

We started by developing a close relationship with my son's consultant. Although he had to strongly adhere to the confidentiality nonsense we eventually made an agreement that we could put our thoughts and desires into a letter to him. He would then respond to us by answering the letter verbally, thereby creating the desired communication path. We were only able to discuss my son's treatment at a fairly superficial level but it was better than nothing and did yield some good joined-up actions. We wrote the letter to the consultant every week, timed to reach him the day before he visited my son for his weekly assessment. The letter also had the effect of addressing another issue.

We had noticed that staff input to the consultant prior to the weekly consultant's assessment was not sufficiently comprehensive. Staff continuity was poor due to holidays and frequent training days on top of stretched staffing levels in general. As we visited my son regularly we were able to offer some solid feedback about his thoughts, his mental and physical states and when he was responding and not responding to treatments. All this went into the weekly letter.

At the same time my husband and I went on a crusade to learn about mental illness. I bought numerous books from Amazon, visited libraries and attended lectures by psychiatrists. We even learnt about the causes of and treatments for patients' poor insight into their own mental health conditions. We armed ourselves with the correct information and understanding of what we were dealing with and we had a strong dialogue with key medical personnel. We were no longer on the outside peering into the mental health abyss with bush-baby eyes. We were an integral part of the system and it felt good.

During the research we came across an American doctor who had some interesting views on the psychological approach to use on psychosis sufferers. It is important to understand the most suitable language to use on patients to aid communication and understanding on both sides and we found his book *I Am Not Sick – I Don't Need Help!* most inspirational and helpful. It's by Xavier Amador (with Anna-Lisa Johanson).

*Lesson 13 research the subject of mental health that relates to your patient.  
Doctors do not know everything!*

The result of this ‘involvement’ type of approach has been remarkable. We pinch ourselves regularly to make sure we are not dreaming the life we now have. My son still has the condition but it is much better controlled. We are aware that relapse is possible at any time, but in that event we are much better prepared to deal with it. Life is fun once more!

## **Epilogue**

I am in no doubt that the information we provided to the consultant enabled him to arrive at the best and most suitable medication for my son. He has the medication administered by monthly depot injection and experiences the mildest side effects we have witnessed since the onset of his condition. He has a Community Psychiatric Nurse (CPN) appointed whom he trusts, and we even had a say in the selection of that CPN.

We have a better understanding of the entire approach to treating psychosis – including the psychological aspects – and that helps when we communicate with my son. We are also able to assist other carers with our newfound vigour and, in many cases, offer some guidance on the best way to approach the mental health system and its pitfalls.

As for my son, he has the best life that could be hoped for as a sufferer of psychosis diagnosed with paranoid schizophrenia. He has a job and works 20 hours a week. He has a girlfriend he met in hospital at the end of his last treatment and they are planning their wedding day for 2012. This is a position I never even dreamt I would be in and both families are giving total support to this couple.

One thing I am extremely grateful for is that drugs and alcohol do not feature in either of their lives, for if they did it would surely ruin everything. There is, however, a factor other than drugs that should be scrutinised: the genetic trail created by the ‘family tree’. Important clues can be obtained by examining family history and traits, for example evidence of depression, social integration, etc. This history can provide important pointers about treating the condition you now face.

Below is one of the letters we compiled during our information-sharing with the consultant, and I hope it serves well as a model for anyone wishing to follow our approach (in the interests of confidentiality, all personal details have been removed). Writing letters can be a tedious chore but in this case the advantages are numerous. Written matter is a one-way communication. You can put down your views without interruption in the manner you wish. Letters serve as a solid reference for past events. It's too easy to forget undocumented information after verbal communication as data tends to get confused or, even worse, overlooked after a short period. And there is the chronological aspect: in a letter, events are recorded and time stamped so there is no doubt about what happened when. It is an irrefutable record.

This whole experience has been one of trauma, so it may sound strange for me to say that I am pleased in some way to have lived through it. We have found out that my son has a predisposition to this condition and we have to deal with this. Along the way I have met some amazing people; I have a high regard for my son's consultant, who has made this recovery possible along with my husband and I. My husband has been my solid rock throughout, and considering he is not the father of my son I regard him as a very special person to have shared this experience with me. I feel that because he is not the father of my son he's been able to adopt a pragmatic view on the whole thing, with an emotional detachment that is not easy to accomplish as the parent. My son, whom I admire greatly for his positive attitude and the special, thoughtful, caring ways he displays to people, has recently published a book containing his deep thoughts on life and the behaviours he feels one should adopt for it. He has great faith, and this has carried him forward through the struggles of his illness. I am delighted he has met a very loving young lady whom he adores and can share his life with. They are two very special people indeed.

In the future we will continue to monitor the situation by constantly reviewing his wellbeing, looking for signs of regression. We will be ready to put our remedial plans in place the minute we detect a diversion from the norm.

Lastly, I would like to say to all carers, 'Never give up hope'. Be positive and strive for the outcome you want for your loved one. Don't be afraid of the medical profession – work alongside them to achieve the best possible outcome. It can be done, so I hope this story will enlighten others and inspire them to achieve the best possible result for themselves and those they care for.

**MOST PRIVATE AND CONFIDENTIAL**

Your Address

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Consultant's Address

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Monday 7<sup>th</sup> March 2013

Dear Dr \*\*\*\*\*,

**Re: Patient's Name**

I am keeping you informed of my/our observations regarding **Patient's Name** to give you further insight into his/her condition, particularly conversations, visits and letters.

We feel Quitapine works so well for him/her and has the fewest side effects. However, we are convinced from experience and from comments made by **Patient's Name** that he/she is again not taking his/her medication. **Patient's Name** spoke to my mother on the telephone yesterday. He/she appeared confused and unable to string a sentence together. He/she said, 'I am upholding the law'. This is the type of thing he/she says when not taking medication. From experience all the signs are there, and I would suggest that he/she stopped taking medication over a week ago.

His/her current condition points to him/her not actually swallowing the medication. I understand the staff are being so helpful and are trying their best for **Patient's Name**. I don't want for one minute to tell the nurses how to do their job, but would respectfully ask that **Patient's Name** be requested to poke his/her tongue out when he/she has taken medication. **Patient's Name** is a bright, clever young person who will try everything he/she can to deceive them as he/she is so against taking medication. I called the staff nurse yesterday to discuss this point.

**Patient's Name** knows how switched on my husband and I are regarding his/her condition, and this also goes for his/her grandfather. We are the ones he/she does not want to visit him/her in hospital as we are the closest to him/her and can see when he/she is meddling with his/her medication, having been a part of this journey from day one.

**Patient's Name** wrote to me last week saying a dear friend had had a heart attack and this must have been caused by the medication he was on. He said he left a message for him on his telephone wishing him well and 'God bless him'. The letter was dated 28 March. This situation would have worried **Patient's Name**.

Yours sincerely,

.cc Nurse (hospital)

.cc Community Psychiatric Nurse

.cc GP

(COPYING THESE PEOPLE IN KEEPS EVERYONE AT THE SAME  
INFORMATION LEVEL)