

STARS SHINE BRIGHTLY IN THE DARK

*Journeys of hope by relatives
of mentally ill persons*



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editors

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Dedication

To all those relatives of persons with mental health problems
who were generous with their time and readiness
to contribute their poignant experience.

Acknowledgements

This book was produced by volunteers who worked hard and with love to see the project through. We cordially thank the following persons:

For the 14 personal experiences: the relatives of persons who suffer from mental illness who so generously shared their often turbulent and powerful experience with readers. For reasons of confidentiality, they prefer their names to be withheld.

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Types of mental illness featured in the chapters:

Chronic depression (Chapters [1](#), [7](#), [12](#), [14](#))

Post-natal depression ([14](#))

Manic depression ([2](#), [5](#))

Obsessive Compulsive Disorder - OCD ([4](#), [10](#), [13](#))

Paranoia ([4](#), [7](#), [8](#), [13](#))

Personality Disorder ([2](#))

Psychosis ([4](#), [6](#))

Schizophrenia ([3](#), [9](#), [11](#))

Foreword — by Connie Magro

Co-founder of the Mental Health Association (MHA) Malta

This book is dedicated to those who dedicate significant parts of their lives to caring for a family member suffering from mental illness.

Throughout my career as a psychiatric nurse and through the Mental Health Association Malta I have had the honour of working closely with such great unsung heroes. I admire their strength, fortitude and undying love. I have always felt deeply humbled by their humility and by boundless compassion. These family caregivers often plunge into situations which we, as paid professionals, would find hard to imagine and manage.

Very often, the needs of these carers are hardly met in the struggle to meet the needs of the sufferer. Care becomes a constant part of their everyday life

Fourteen chapters of this book are authored by individual relatives who relate their personal stories with utmost sincerity and openness. Follow their narratives as they unfold and empathise with their journeys of anguish, fear, heartache, resilience, hope, compassion and courage.

The book is primarily aimed at new carers. However, it is also useful for professionals who daily deal with families struggling with the reality of mental illness.

I would also recommend this book to students, teachers, clergy and all those who value family experiences.

The book is clearly laid out with an illustration to every chapter. All chapter titles are extracted from the relatives' own words.

It is never easy to find meaning in pain and suffering but we can never see the stars shining unless we look at the darkness.

A wise man once said that salvation can only be achieved through pain.

This book is about this salvation.

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Message — by Kate Gonzi

Co-founder and honorary president of the Mental Health Association (MHA) Malta

Throughout my teenage years, my brother experienced bouts of lack of energy and indifference towards his work and his general well-being. At times, he would sink into a deep depression. These phases brought about a lot of confusion, anxiety and suffering to him as well as to us, his family. We could not understand what was happening to him. We used to think that he was bringing depression upon himself, perhaps because he wanted to escape from his work and studies responsibilities.

When we learnt that his change in behaviour was brought about by a mental illness, the family started treating him differently and for the better. We realised that his change in behaviour was no fault of his and that he needed our care and help as much as possible, as well as professional assistance. Under these circumstances we sought more knowledge and information about his illness.

It gives me much satisfaction and encouragement today to learn that through the Mental Health Association and the St. Jeanne Antide Foundation, families living with someone suffering from a mental illness can be guided through their issues and assisted in the best way possible. I am sure that ‘Stars Shine Brightly in the Night’ will fill a lot of the emptiness existing within carers, and will do a lot of good. I am also sure that had we had such a book, back in those days, our family experience and that of others would have been much more bearable.

The value of this book is in its personal experiences. Mental health and the lack of it is a unique experience for all the family. This is why this book is invaluable. I can just imagine how many readers will come across experiences similar to their own and learn of how other families reacted to their own difficulties. One may also recognise how important it is to show a positive attitude and find solutions to problems in these circumstances. This book should be treasured by anyone who loves a person suffering from poor mental health.

Sufferers of poor mental health need a professional team to be at the centre of decision-making, to decide how the illness should best be treated with regard to medicine and human relationships. The experience families go through can also prove to be a valuable asset to professionals, since it will reveal to them how members of a family handle and overcome difficulties; it shows professionals how essential their intervention and compassion is in order to improve a family situation. This can also result in a two-way communication cycle which results in a faster recovery.

This book is also aimed as a guide for educators, police officers, judges, employers, employees, journalists, civil society groups, and every person in society, for a better understanding of how to treat children, young persons, mothers and fathers, with respect and dignity wherever problems in mental health arise. In this way, every single person in society, including those suffering from poor mental health, will be included within the realm of education, work and recreation on an equal basis.

The publication of this book reveals the recognition and sensitivity towards the needs of families with mental health problems currently being addressed by the Mental Health Association and the St Jeanne Antide Foundation.

This project entailed a lot of commitment by the volunteers that brought it all together, and I am sure it will be used as a main reference for many who work in this sector.

A special thank you goes to the family members who were willing to share their personal

experiences in order to help others face issues related to mental health.

Thanks also to those who helped fill in a missing link in our country, in the sphere of mental health. I hope many readers would make use of this book, which offers hope for a better quality of life for those passing through a vulnerable stage in their life.

With courage and hope.

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1. Love sustained us



Some people recall having had a happy childhood, others mainly remember having lived a turbulent one. Well, mine was neither of these. I think it would be more correct to say that my early years were coloured in shades of grey, depending on whether my mother felt well or unwell.

Without actually knowing that mental illness is a phenomenon, I have realised that it is so from a very tender age. As I take myself back to the early years of my life I re-connect with feelings of confusion I experienced back then as I could find no coherent answer to why my mother spent endless days in bed. In fact, I remember myself being like a scientist, exploring all possible options for a cause, consequence and solution.

Unfortunately, when I was a kid I was not given the right explanations for my mother's depressed moods and days in bed. Rather, I was told that I was a very challenging child and that sometimes my mother needed to withdraw to have a break from me. At other times I was told that I was going to kill my mother with my mischief. This lack of understanding about mental illness and its causes instilled in me feelings of shame and guilt which pervaded my childhood.

Given that I was blamed for my mother's sickness, I did my utmost to be a good girl so my mother would feel better. I recall feeling so frustrated when all my efforts at being 'good' did not pay off! At the age of six I made one big discovery ... excelling at school implied making Mum very happy and proud! That is when I embarked on a journey where the goal was to succeed at doing exceptionally well in my education. As years went by, Mum still got her sick moments but I found meaning in doing well academically and that kept me going despite the adversities and the sadness of seeing my mother lifeless in bed for days and sometimes weeks.

Unfortunately, the comfort and meaning I had found in academic success was cut short when I was transferred to a different school. As I made my first step in class I started being called names. To say that this experience overwhelmed me would be an understatement. I guess I could not get a grip of the sudden

change. I went from being the most admired girl in school to being the black sheep of the class. I lost myself in the experience. I let go of the ambitious person I was and in pursuit of acceptance by my schoolmates my ambition to succeed turned into an ambition to fail. For me it was not just the bullying; it also meant losing the cushion that protected me when my mother felt sick.

However awful this experience might have been, through it I realised how powerful love can be, how it can overcome all the adversities and obstacles mental illness presents. Despite the depression and the lack of energy brought forth by the illness, my mother relentlessly fought to bring me back on track. It was thus thanks to her that I crept out of the vicious circle I had got myself into.

My mum never gave up on me. Rather, at the time she was the only person who believed in me; she believed in my future and for this I shall be eternally grateful to her. I was no easy daughter to handle; I was rebellious to say the least. Yet her love for me made both of us persevere; she through the illness and myself, well she managed to make me believe in myself once again. I will always credit my mother for this. I shall never forget how much she fought to see me growing up and become the adult I am today. Indeed, it is no easy job to bring up a child when healthy but my mother brought me and my brother up, giving us sound values while struggling with her illness.

My relatives, though misinformed about mental illness, played a very important role in my life and have contributed firmly to my being so resilient. Together with my father they gave us (my brother and I) the care and support we needed when my mother was physically and psychologically unavailable. They not only gave us tangible support but also peace of mind as we knew that we were not alone in this and there was always someone we could turn to. Indeed, my aunts have been key helpers in our family to this very day as they give my family a helping hand whenever Mum goes through her bad spells of depression. Through their help my father, my brother and myself could keep going with our lives, whether it was study or work. They also kept at bay the risk of my mother being hospitalised and thus have made the experience of mental illness in our family a bit lighter.

Indeed, the most difficult task I encountered as a child of a mother with mental health problems was coping with the inconsistencies, such as her mood swings and her abrupt change of ideas. Those were the times that pushed me to the limit of endurance. Those were the times when I felt utterly helpless and hopeless and believed that I would never again be happy and at peace in my life. It was the compassion and empathy I felt for my mother and the love towards my brother that fuelled my perseverance to never give up, believing that some day everything would be alright.

This hope I had, though inspiring, for some time coloured my life with love, anger, hate, shame and guilt... a process which went on in one full circle. I recall this bundle of emotions having the power to be experienced all at once as if there was no time and space.

I only managed to get rid of the negative feelings when I started to accept my mother for who she really is; when I gave up the hope that she would ever get better; when I stopped expecting her to be just like other healthy mums. Only then did I feel integrated and fully able to empathise with her. I must admit though that acceptance was no simple breakthrough. I worked hard at it throughout my childhood, teenage and adult years.

One thing that really helped was the fact that I spoke about my experience and asked for help whenever I needed to. With each and every person I opened my heart to, I tried to take something positive with me that could help me cope with my pain. What I also found helpful were the psycho-educational lectures delivered by the Mental Health Association and psychological help provided. Through these I learnt how to take care of myself while at the same time understanding my mother and her illness.

Gradually I started moving away from the parentified child I had become and began respecting and protecting myself by erecting the necessary cognitive and physical boundaries. To this day I am still working on my 'self-acceptance' and while I am able to understand her way of being I pray that my mother can forgive me for the times I failed to accept her illness and as a consequence failed to accept her. Today, I understand that when my mother withdraws it does not mean that she does not love me or care for me; it only means that she is feeling unwell.

As I reflect on my experience I reckon that even though mental illness made my life somewhat difficult it also made it richer. In fact, I capitalised on my experience and through my profession I help other people who like me know the real meaning of mental illness. My experience gave me the ability to really understand the people I work with because it does not take me much to step into their shoes.

Indeed, if I had to choose again I know I would still choose to have the same mother because I know first hand that tender love and care, together with the right support systems, can transcend the troubles caused by mental health problems. Thanks to the support we found, my mother could see her two children grow into two healthy and mature adults who know the true meaning of hitting the ground face down, but also of getting back on their feet. In fact, I wish to conclude my story by saying “Thank you Mum for never giving up on me, on yourself and on our family!” I shall take your example and persevere through the vicissitudes of life.



2. One door closes, many doors open



What happened on April 16, 1999 and on April 23, 2003 changed my life completely.

On April 16, 1999, a doctor at the Emergency Unit of St Luke's Hospital informed me that he had to send my eldest daughter, then aged 21, to a mental hospital because of her mental condition.

I had never felt so confused in my life and I cannot explain what my wife and I felt when we set foot inside the psychiatric hospital. I never thought that one day I will need the services of the mental hospital for the simple reason that I thought that we and our two children would never need such services and help.

I was feeling helpless, as I knew absolutely nothing about what was happening to my daughter.

I was lucky to find two professional nurses who really empowered us and encouraged us to face the situation.

It was there that I first heard of the Mental Health Association. Luckily for us, that same week they were holding a course for relatives of persons with mental health problems. I still vividly remember the first session of this course. A good number of people were attending it and, hearing others talk about their situation, I thought that after all, I was not alone in this kind of situation. I said to myself: "It's reality time and you have to choose between three options: adapt or despair or just walk away." I chose the first option.

It was during this course that we started to learn how to cope with such a situation. I therefore embarked on an information-gathering exercise to be able to understand what was actually happening to my daughter and how to be useful to the medical team caring for her. Not only that, but I started helping the Association fight the stigma surrounding these conditions. I have never stopped learning and sharing since.

It was then that I started to understand my daughter's behaviour during the preceding two years, which involved bouts of either complaints and lies, or of happiness and overspending, which led her to run up debts with various individuals and companies. I had to pay up to keep my child out of trouble. I am still wondering whether I did the right thing in paying off my daughter's debts.

During those two years, I took her to my family doctor several times, a psychologist and also to a neuro-specialist to try and improve her erratic behaviour, which I always attributed to mere adolescent nonsense.

The truth is that I never took her to a psychiatrist since, at the time, as I indicated earlier, I believed that my family was immune to such illnesses and that you have to be mad to go to a psychiatrist; he might tell you that your daughter is mad!

Today, when I reflect back on those early days, I realise how unfortunate it was that I had no information on these conditions through the media or otherwise. I still believe that had such information been available, the stigma surrounding these mental conditions and the fear of going to a psychiatrist will not continue to block family members from seeking help.

Regarding family members and friends, they were either equally at a loss what to say or what to do to help us, or they tried their best to avoid us. Certain individuals had the cheek to tell us not to let our daughter visit them at home, unless I or my wife accompanied her. Such is the fear of mental illness.

Another important point, which I stress is so vital to parents and guardians, is that professionals in this field need to listen to the family and to take note and understand their concerns. This lack of listening and understanding may have led to my daughter getting pregnant and thus set the scene for what was to follow.

The next date – April 23, 2003 – also brought along changes in my life. On that day, my unmarried daughter gave birth to a girl. The baby was later transferred from the hospital to a residential care facility for children.

It was very hard for us. We were at a stage of our lives where we were starting to reap the fruit of our toils after raising and providing for our two daughters. But how could we leave this innocent angel in a residential care home, depriving her of a family environment? So we decided to foster our grandchild after getting her mother's permission, thus enabling our grandchild to be raised properly in a loving family environment, and also ensuring that the child and her mother would keep their natural bond as much as possible.

Even during this period, I think that the professionals should have understood better the needs not only of the mother of the child, but also of us parents and grandparents who were trying hard to get on with our lives, trying to re-organise our lives without neglecting our other daughter, continuing to support our mentally ill daughter and coping as much as possible with a situation which was certainly not of our own making. This was certainly not the way we planned our life, but being responsible persons, we had no other option but to adapt.

I do not want to be misunderstood. I am not all out against the professionals operating in this medical area. Far from it. Rest assured that what I have written so far is not because I am bitter. I do acknowledge that they did and are doing a good job. But I always ask the important question: Is it not absolutely important that parents and family members are actually listened to and treated as partners in the recovery process?

There are other thoughts that I wish to state in this brief story of mine, namely:

The need for information, courses and training on mental health needs to be accessible to schoolchildren, parents and social welfare personnel. If children are enabled from childhood to be aware of mental health issues by experienced persons it erodes the stigma surrounding mental health conditions.

The need to have adequate legislation to protect both the persons suffering from mental ill health and their parents or guardians.

The need to give financial help and free medicines to these persons, since parents/guardians normally suffer financial hardships in trying to cope with such illnesses.

The need for more understanding of the relatives' needs and concerns by the professional persons in order to be able to pre-empt any avoidable situations.

The need to help, especially in the social and financial aspects, those who suffer from mental ill health. It is useless giving a person all the required medical care, if this same person does not have a reasonably good social and economic life coupled with good community care support.

This, I believe, is the way forward in treating these persons and fighting the stigma surrounding these mental conditions.

May I conclude by saying that our life started improving ever since such understanding and co-operation began to be extended to us.

Nowadays, I am not over-protecting my daughter, but just guiding and encouraging her to try to lead an independent life and giving her a mission in life. She gave birth to an angel and I hope this same angel will perhaps some time in future team up with her to form a family unit adequately supported by community care.

I have to do that, because I am sure that I will not be around for as long as I have lived so far.

Until then, my wife and I will try to:

- continue coping as best as we can;
- refresh ourselves again in the art of bringing up and caring for a young grandchild;
- accept the fact that our daughter can experience setbacks and relapses,
- understand that suicide can still be in her book in a moment of weakness and sadness;
- continue to encourage our daughter to live her life as best as she possibly can and to have hope and faith in the future, acknowledging us as her friends and family;
- always be there for her in her time of need.



3. Suffering rendered me more compassionate



My brother and I used to be very fond of each other. As his sister, I was six years older and we used to tease each other constantly.

At school he was a model student: quiet and obedient. He was awarded a number of prizes but his classmates bullied him and called him nerd. My brother suffered in silence, though the teasing between us worsened.

At the age of 14, my brother started to suffer from sleepless nights, excessive worrying and anxiety. His speech became confused. The family doctor prescribed medicine which resulted in severe side effects. A consultation with a psychiatrist followed. This time a proper diagnosis was made and proper medication was administered.

My mother and I resigned ourselves to the fact that my brother was suffering from a mental illness. My father however did not accept the diagnosis. Explaining my brother's situation to his teachers was another strain.

On the recommendation of the guidance teacher at school and psychiatrist my brother repeated a scholastic year. This made him very angry, since it worsened his sense of failure. His isolation increased. During this period, my mother and I opened our hearts to each other and strengthened our bond. We used to talk at length about my brother's condition and how to improve it. My father never reconciled himself with the situation and did not participate in my brother's treatment in any way.

Close relatives blamed my mother for my brother's condition, particularly the way she brought him up. They accused her of fussing too much over him and of pushing him hard in his studies. We did not socialise with our neighbours but I am convinced that they noticed the changes. The medicine my brother was taking transformed his lively personality into an expressionless one.

My intimate friends supported me. In those difficult times, I became aware of who were my true friends.

“Why us?” was the question I kept asking myself at the beginning of this painful experience. Though there was no answer to this question, I could not let anger take over and thereby deprive my family of my support. Together we could arrive at a solution. I felt uplifted when I heard friends talking about similar experiences. This made me aware that we were alone.

Sometimes I felt exhausted. My brother’s condition has changed my life considerably. The temptation to stop supporting my brother continued to demoralise and depress me. So I decided to be proactive, by becoming a member of in an association for families of people with mental illness. The members of this association became our second family because of their similar experiences.

This whole experience made me more compassionate towards people who endure similar pain, because now I can empathise with them. This is not always possible because at times I feel disheartened. This happens mostly when my brother has a bad day and turns aggressive. He is aggressive only with us, his family – the people who mostly care about him.

I always accompany my brother on his regular appointments with the psychiatrist and ensure that he takes his medicine, even when my mother isn’t around. I made every effort to get him a job for he finds it very difficult to speak about his condition. Now he has a satisfying job in which he is much respected. At home he continues to act childishly and is at times aggressive too. This behaviour tempts me to leave everything behind and find a new home for myself.

When I evaluate the quality and amount of help my brother requires, I conclude that it is always very difficult to take such a step. The best support my brother received was through my mother and me. As a family, we received support from local and foreign associations. I used the Internet to download useful information.

We made use of public health services and medicines were free of charge. The psychiatrist was always consulted privately. Sometimes professionals portray a darker picture, and leave the sufferer and his relatives struggling alone. The help of the psychologist and social worker was not that significant. Nobody backed my brother in scholastic and career matters. We received support only from NGOs. More importantly, we felt the presence of the Lord in our everyday ordeals.

People living with those with a mental illness encounter many difficulties. My parents cannot go on holiday on their own; their constant worry is about what happens to my brother when they die; how far they can resist my brother’s aggressiveness; and will my brother be able to lead an independent life?

I suggest the following advice for parents living in similar situations:

- Do not pamper your child.
- Nobody will reach out for you, so learn to seek assistance on your own.
- Join an association where you can forward complaints and suggestions.

My narrative may appear pessimistic but it is our experiences of life that define us and make us what we are. My experience of such life taught me to nurture a loving and compassionate attitude while working and living with others.



4. In caring for myself, I was able to cope



We started going out together when we were 19 and after a year he experienced his first psychotic episode. I decided to end the relationship but after four months we met again and resumed our relationship. We continued dating for over four years until we decided to get married. At the time, I was not aware of the gravity of his illness.

After seven years of marriage my husband suffered a relapse and from then on I had to carry the burden of the whole family all by myself. In the meantime, we had two children.

My husband's relapse proved to be a major setback because he never fully recovered from it. He suffered persistently from paranoia from which he never achieved full remission despite the medication he took. Our family experienced increased stress and pain, since instead of supporting us, my husband had to rely on us all for support.

When going out, I had to take out the children on my own because when the time came to leave home, he would feel tired and would want to sleep. On realising the situation, I got used to taking out the children on my own.

I had to learn to meet all the family needs. I experienced my greatest anguish when my husband, on feeling unwell, instead of thanking me, expressed ingratitude. My children were reluctant to invite friends at home. When my husband was in a bad mood, we would not be keen to invite people at home since they would lack awareness of mental illness in general, and because his behaviour would make them feel uncomfortable. At work, he used to fret over the tiniest problem. Due to his paranoia, he used to say that other people are behaving the way they did on purpose.

This experience has affected me badly; there were moments when I felt burnt out and experienced mood swing. For some periods, the illness would temporarily be under control and he would feel fine. But what kept me going was that I always took care of my needs. I never missed an opportunity to go out,

even for a short while such as for a coffee. Moreover, I used to share my problems with a few trustworthy friends understood me and offered their support.

Whenever the pain become unbearable, and I used to feel worn out due to the strain and the difficulties I encountered, I used to feel that I should not have married him. But when I felt better, I used to pluck up courage and do my best so that the children would not suffer so much.

Today I feel empowered because I had to face everything in life on my own. I had to cope with life's challenges.

I had to look after everything – there were times when I visited the psychiatrist on my own. I used to maintain regular contact with him because he gave a lot of weight to what I told him.

There used to be awful days when my husband would experience paranoia in relation to people outside the family and he would ask me to quarrel with them. When I refused, he would tell me that I was their accomplice. There were days when he would have insight and he would realise the suffering he was causing us. In such lucid moments, he used to appreciate and show respect towards everything that we were doing for him.

Relatives were not knowledgeable on mental illness; I used to educate them on my husband's illness from information obtained from the psychiatrist and from the Mental Health Association.

I always sought support and backing from psychiatrists, psychologists, and social workers from Mount Carmel Hospital. However, I always insisted on obtaining the required information and assistance, and I never expected that such help would be forthcoming without first requesting it. I always took the initiative in finding the help I needed.

I always used private mental health services. Professionals assist you by prescribing medicines, but one has to use one's skills to face the problem. Psychiatrists help treat the illness and recommend some brief hints on how to cope, but it is up to the relative to observe the patient's behaviour and determine how best to deal with it.

I always sought professional support. Whenever these services were unavailable at the Government hospital, I would visit the professional privately. You get excellent support and relief when you share your experience with others and know that you are being understood.

What helped me accept the situation – because you either accept the situation or else you succumb to it – was faith in God. This encouraged me not to lose heart.

The greatest difficulties encountered in relating to the mentally ill relative occur when he or she loses touch with reality and because one cannot share one's problems with them as stress is extremely harmful and may trigger a psychotic episode. Partial recovery from mental illness is possible, but not full recovery.

What I would recommend to others is that they ask for help and not lose heart when the information and help they need is not immediately forthcoming. They should not miss the opportunity to obtain information and increase their knowledge on mental health especially by following the course on mental health organised annually by the Mental Health Association. It is a 13-week course delivered by psychiatrists, psychologists, social workers psychiatric nurse and a spiritual counsellor.



5. Mother to my own mother



When I was eight, my mother was diagnosed with manic depression, also known as bipolar disorder. I was very young, so my understanding of what was happening around me was limited. However, there were some things I noticed: my mother had become much slower than usual in her speech and her actions; she had stopped taking care of us and of herself the way she used to; her energy had evidently diminished. No one really discussed these changes with me. No one bothered to explain, possibly because they themselves were also baffled and confused about these changes.

My mother's illness peaked during our move from England to Malta, where my parents hoped for a better life and an improvement in their relationship. They thought that going back to their roots and to my father's homeland would help their situation.

Just before our move to Malta, my two younger brothers, myself and our mum were temporarily staying at our uncle's house, since our home had been put up for sale. Soon after, my uncle accused Mum of being lazy and of neglecting us. My uncle was in denial and refused to acknowledge that Mum needed psychiatric help.

As a result of their frustration and lack of understanding of the change in Mum, my aunt physically attacked my mother in front of us children. My uncle also punched the wall and fractured his wrist. I remember my youngest brother, being just about four years old at the time, jumping towards my mother and clasping her feet so that they would stop hurting her. Immediately after this the family decided to split us up to live with different relatives until the time came for us to leave for Malta.

My brothers soon accompanied my father to Malta so as to get a head start in settling down there. It was about this time that Mum was admitted into a small mental hospital in England, where she did her first set of ECTs. In actual fact, she had admitted herself into the hospital; she had called from a phone box saying that she was experiencing suicidal thoughts and feared she was going to kill herself. Although she had mentioned to her GP, on one of her visits, that she felt she was going 'mad', he never referred her

for appropriate psychiatric care. This was about 20 years ago. Mum's hints fell onto deaf ears. Perhaps it should be no surprise that a number of years later, this same GP committed suicide after stabbing his wife repeatedly. Clearly he could not read the signs of depression or mental illness.

Mum has confided with me the fact that she was very close to suicide several times, but that the thought of us three children kept her back from taking the fatal step; it was the thought of her three children that stopped her from opening the car door and falling out once while driving on the motorway from Wales. This was one of the occasions I vividly remember which she had confessed to me after the journey.

When we moved to Malta, my mother was finally given an accurate diagnosis – bipolar disorder. Knowing what she suffered from helped her, and later us, to better understand what was happening and why. My mum found a lot of comfort and support from professionals in Malta; the psychologists, nurses and psychiatrists whom she still mentions and praises till this very day. Since I was eight, I would often accompany her on visits to the psychiatrist; they would sometimes allow me to be in the same room and occasionally I would also add points to what Mum would have forgotten. Her memory was not very good after she had the ECTs, so I would help her explain stories accurately. It was sometimes frustrating recounting a family event together which she simply could not remember – but this was even more disappointing and frustrating for her, as it's like being somewhere in a body, but not in mind.

We had a very close bond; she shared her thoughts with me in many things and I always had great respect for her. At times I felt like a mother to my own mum. However, she always assumed the role of mother and would get angry at me when she thought I had gone overboard. Fortunately she always remained responsible for her own medication, so we could at least build on a solid foundation.

Going back to our arrival in Malta, we first lived with my father's parents. However, Mum soon needed to be admitted to hospital and this is when my brothers and I were isolated from society as we knew it, and sent into care, living in a home run by nuns. My father did not take on the responsibility of caring for us and neither did my grandparents, although we were taken out to stay with them on weekends. For me this was a massive change since in this home I had to start taking care of my own belongings and of my two younger brothers myself. I went from being a mummy's girl, to being a mummy of two at the tender age of eight. At the time my brothers were aged six and four.

We were made to wake up unusually early, around 6am, in preparation for the day ahead. My morning chores were to help dress my brothers, and do their beds too – I had never even done my own bed before, so this proved to be quite a task. We had the same breakfast every morning before school, which became sickening after a while. After school we would have dinner and do our homework and study for the entire evening, until 8pm when we would have to say the Rosary as a good night prayer before bed.

When it came to entertainment or feeding the imagination, we were only allowed to watch five minutes of the same cartoon video every evening. They chose videos since we weren't allowed to watch TV for fear of being exposed to unsuitable content. Then we would be sent to bed straight away. We spent two years in this monotonous lifestyle. Luckily I became a close friend with a girl two years younger than me; we would try to make our lives more exciting and I would explain to her what lies beyond the walls she had always been living within since the tender age of two. We are still close friends today and a special bond keeps us together forever, I am sure. This life transition for me I would also describe as a partial culture shock.

Unfortunately, as time went by, my brother, who had just turned eight, was taken away from us and

sent to another home for older boys. I was worried about him leaving us because I felt his vulnerability and knew that we needed each other more than ever. My youngest brother and I felt his absence deeply, especially since we were not given the opportunity to contact each him.

During the time we were in care, my mother was going in and out of hospital. Her marriage was on the rocks. She was advised, for her own benefit, to separate from our father, as she could not be stabilised for long, given the souring relationship between them. My mother's ultimate goal was to take us out of care and back home with her. My father did not want this, for some reason I cannot be sure of till today. He did not allow us to leave residential care to reunite with our mum; in those days the father had rights over children admitted into homes; that law has now changed.

After months of fighting for custody rights in the courts – which in reality just made her condition worse – my mother presented a letter from the psychiatrist stating that she was fit enough to take care of her three children. At last, the courts granted my mother custody and we were free to go and live with her again.

For the first few months, the psychiatrists recommended Mum take on just two children, my younger brother and myself, and to then bring the third sibling home once we had settled. Theoretically this made sense. However, when my brother found out that we had been sent home, he ran away from care and caught two buses on his own ... to be reunited with his family. He was only eight at the time, had no money on him and had never caught a bus on his own before. I feel that this event had traumatised my brother. At that age, he could not understand why he was left in care when we were sent home, and I am sure that he felt rejected by this incident.

From a photo that I saw of him when he was in the older boys' home, I saw the fear in his eyes; I know he hated being there, and it should never have happened. The boys he was sent with were not of his kind; most were rough and undisciplined, coming from very troubled backgrounds.

When my brother returned home with Mum, my maternal grandmother came over from England to help us settle and to see how Mum would cope. We were given clothes from family and friends and were all excited on restarting our lives together again. Mum couldn't have been happier, even though she was still recovering from a depressed phase of her illness which could be seen in her slowness of actions and speech. She seemed drained of energy most of the time, but somehow we all pulled through together during the following 10 years.

After these 10 years, my mother experienced a relapse. She needed to be re-admitted to hospital for a 'rest'. I would attribute this relapse to two factors, one being that family relations issues were cropping up due to the onset of adolescence. I need not say that it is not easy to bring up three teenagers, especially if the mother is a single parent, and even more so when the mother suffers from mental illness. Secondly, after years of taking the same medication, the body becomes immune and similar medication needs to be slowly re-introduced.

I was taking my A-levels at the time my mother was re-admitted to the psychiatric hospital in Malta. Doctors were at the trial-and-error stage of the medication. During this time, we were left with the dilemma of what to do without Mum at home. How would we cope together?! Thankfully my grandma came over from England again to help us out. When she left, however, we had to fend for ourselves. I made it clear to my brothers that I had my own life too, and that I could not replace our mum. We were all to pull our own weight around the house and our priority had to be to stick together. They agreed and we planned how to share the house chores and decided who was to do what and when.

A social worker would also visit occasionally to guide us and help keep us move steadily ahead. Along the way, sibling arguments erupted and often our planning arrangements were in vain. I frequently closed my bedroom door, placing my hands over my ears, just trying my best to study amid all the arguing. Objects would get broken in the house, without anyone there to show discipline and set the boundaries. The pressure mounted; I felt it was too much. I remember being at college one time, sitting on the sofa in the corridor during a free lesson, crying my eyes out.

The head of school at the time got to know of my family situation and during prize day she awarded me a prize for effort and achievement. That will remain with me forever, as have other things along the way. I would say that some teachers at school, who really got to know me, provided me with academic guidance and showed they really cared – that also helped me to remain focused. I was always eager to improve the situation I was in. I knew that despite all the odds, even being sent to one of the roughest secondary schools in Malta, I could still gain from what they were offering me – a good education.

I was determined not to end up working in a factory like some of my fellow students expected to do. As I moved up in education, I realised that the school atmosphere just kept getting better. College was a breath of fresh air, even from the pressure felt at home; sports facilities were abundant and I always took part in school plays and singing activities. In fact, from the age of 13 onwards, I was always involved in some sport or other. This helped me to remain positive and not to dwell on my problems at home.

Throughout our childhood, our father paid occasional visits on weekends, but offered no support other than the mandatory maintenance up to the age of 18; this meant that if I was to continue with my schooling, I would need to support myself.

At the time Mum was readmitted to hospital I was 17 and had met my fiancé who was a godsend, especially at that time. We are married now and he has supported me through all the hard times at home, helping me to achieve the goals I set myself.

During this stretch of hospitalisation, Mum would be sent home on some weekends, but she was too ill to do anything. She would lie on the settee all day, unable to discipline us children. In fact, sometimes she preferred to be in hospital rather than at home, with so much arguing going on.

When Mum was recovering I would notice odd things in her actions; sometimes she would go out and buy unnecessary things for the home. Considering we were on a tight budget, her actions were not appropriate at the time. She would very often give in to my brothers' requests for expensive items, such as game stations, bicycles and PCs. Once she spontaneously thought of buying a car and took it out for a test drive. She hadn't driven a car in 10 years and didn't even have the money to buy one.

Another instance was when she decided to go to Gozo island for a weekend break. She took my youngest brother with her; he was 12 at the time. He got bored, so she allowed him to catch the ferry back on his own and then take two buses home. She turned up a day later dressed in military gear, trousers, and a top and hat that she had bought from the market. I will never forget opening the front door to see her dressed like that. She had a marvellous grin on her face and she couldn't understand why I was so astonished at seeing her in that get up. She explained that she had had an argument with the bus driver on the way home and that he quickly shut up when she shouted at him.

These are funny but poignant memories. However, what was most disturbing for us children was when Mum brought a male friend at home, a stranger to us. Introducing new men did not happen often, however the few times it did I remember feeling very uncomfortable and apprehensive around them and feeling protective of mum as well.

On one occasion, when I knew there was a guest over late in the evening, I stayed awake in bed trying to make sure nothing I disliked or feared would happen. I got out of bed three times to pass the living room where they were. It soon became apparent to mum that I was doing this deliberately, so after being told off, I went back to bed, cried and tried hard to bury my thoughts.

When speaking to her today, now that she's stable, she regrets bringing strangers home and wishes she could turn back the clock. I think it is quite haunting knowing that in the past you lost control of your actions, and that your children suffered because of your illness.

I would definitely say that the ultimate factor which gave me the motivation I needed in my life was the great love and encouragement my mother always gave me. She says that when my brothers and I were born were the best moments of her life. I would say that her love has permeated through to us, providing us with the ability to continue life in a healthy frame of mind.

As her consultant psychiatrist once described mum to me, "her personality shines through her illness." Despite the fact that she sometimes feels guilty that we had to go through many bad times, what she fails to see is that she has – through her love – given us the tools we need to sail through life.

My brothers have both furthered their studies in the UK. The younger one is into financial management, and the other has studied law. We still support each other. My motto at home was "We are family, my mother my two brothers and me," and this I hope will remain so for the rest of our days.

Today, my mother is doing very well. She has been in a stable relationship for some years. It thrills me to know that she is now able to see the beauty in this world, being able to recognise and appreciate scenery and historic and cultural sites she visits; these are often things we take for granted, but try living for one day in the world of a person who is chronically ill, and you will never see things the same again.



6. We never looked back



I wish to share the experience I have gone through and am still going through, though with a difference. I never realised what a mental illness could lead to, since I never ever had any experience of it before.

I found myself in a very bad situation when my daughter was about 17 years old. Things started to go wrong when she began to accuse me that I was touching her inappropriately and on several occasions she told me that I was watching her from behind the door of her room; she also claimed that her school mates were also touching her. We even went to her school to discuss the situation with the guidance teachers. They never realised what was happening.

There were times when she used to call her aunt on the phone to tell her that I was sexually abusing her. At the time I was so devastated that I thought of leaving my family since I realised that my marriage was on the rocks because of my daughter's untrue accusations.

There were moments when I used to call my wife and ask her to watch me all the time as I moved around in the house, and many similar situations. I also had to screen my daughter's bedroom windows because she used to claim that the neighbours were watching her; at the time I thought that this was possible since the windows are close to each other.

There were many other traumatic and embarrassing situations like this which I shall not mention. Things kept escalating until one day, when the situation became intolerable, my family doctor told us to visit a psychotherapist.

We did, and the psychotherapist insisted that we take our daughter to hospital for treatment. We never imagined what we were going to pass through. After consulting the family we were even more afraid that we were doing a great mistake to take her to hospital for treatment but at that time I had made up my mind to follow the psychotherapist's advice.

During our daughter's stay at hospital we realised that we were very tired and confused and to make matters worse, a member of the family insisted with us not to allow the hospital to give her any pills or treatment, since "there was nothing wrong with her and that her behaviour is normal, as she was growing up." This insistence proves that the stigma attached to mental instability is very strong, and that families deny the existence of a mental illness, preferring instead to act as though everything is normal.

One day, we were called from hospital and told that they wanted to speak to us about her situation. My wife and I went to hospital where a group of five medical experts, including the psychotherapist, explained that our daughter was suffering from a mental illness and that she needed looking after. We were shocked and could not imagine what would happen to her and how we were going to cope with the situation.

We were given some contacts and advised to join a small group in sessions organised by the Mental Health Association; we went to all of them. During these sessions we used to describe our suffering and since then we never looked back. These sessions were very useful for us at that time and my wife and I would like to thank all those involved in this group for their help.

I always say that life must go on; although the situation is very difficult we still have to be strong because only in this way can we help our daughter and other members of the family, as well as other people passing through similar situations.

Even though some years have passed now, our relatives still find it very difficult to accept this situation. They simply cannot and will not accept it and keep ignoring the fact that our daughter has a mental illness. Indeed, they say that it is the medication that is causing the illness.

I do not listen to them but I only take the advice of professionals. We have lived through this situation and can say that our daughter now looks better than before. We need to help her more and support her all the time. Our lifestyle has changed considerably and although we accept the situation, we still feel that it is very difficult to live with people with a mental illness.



7. Caring for my mum changed me



Caring for my mum was a transformative experience.

I was not the eldest of six siblings, yet I assumed a caring role within the family that should have, in truth, been taken by a parent or older sibling. Yet, in retrospect, I realise that as an adolescent I never thought there was anything wrong with the way I was allowed to assume a responsibility which was well above my age. I continued to do so without anyone telling me or showing me otherwise.

I loved my mother dearly. As I grew older and ended up being the only member of my family who loved books and learning, my mother and I became friends. I suppose that my openly expressed love for my mother and my deep compassion for her predicament in life led her to be more open with me than with her ever-so-incommunicative husband – my father.

Lacking a supportive family system – her own siblings were almost all abroad and her husband's relatives remotely interested in her – and having no friends her own age, she found a friend in me. I must have relished this role since my most vivid memories of my adolescence and youth seem to be ones where I fought off anyone who abused her loving, kind and caring nature, and being her advocate during her visits to doctors and her psychiatrist.

My father had this phobia of doctors that prevented him from doing his duty to accompany my mother to her medical appointments. Whenever she was hospitalised, he kept away from the doctors and never spoke to them about her state of health. Realising how unjust this attitude was, I did not hesitate to fill the gap in our family relations system.

Half-way through my secondary education, my mother became paranoid and later fell into or depression. She had been taking slimming pills for some time and these made her hyperactive and obsessive. She could not sleep at night and would scrub the floors and disinfect the house while everyone

slept. During the day she slept. In her paranoid state, she became afraid of my father, that he was planning to murder her.

Feeling she had no adult with whom to share her thoughts and feelings, she ended up talking and sharing her fears with me. Seeing her condition deteriorating I swallowed my discomfort in talking about mum's fears with my father and tried to explain to him what her fears were about. I hoped he would try his best to disabuse her of her fears. I don't know what he did since he never gave me any feedback. However, her symptoms became worse. So much so that she once left home in the middle of the night wearing only her petticoat and went to the nearest police station to report that her husband was trying to kill her; he was not.

After this critical incident, our affable family doctor recommended that we take mum to see a psychiatrist. I persuaded my father to come with us; after all, he had just bought a second-hand car and could drive us to the hospital. From that moment on, my mum started battling her mental health problems. I remember us all taking shifts so that there was always someone awake with her all the time.

After completing my secondary education I realised that if I were to continue studying for my A-levels, there would be no one at home during most of the day to be with mum. So I found a solution: I identified experienced teachers in the subjects I was interested in and started going to them for private lessons in the afternoons when my father returned home from work. This worked fine since I had excellent teachers who tutored small groups of three; I helped my mum until mid-afternoon and studied on my own whenever I could.

Not having much of an alternative, my father worked hard to cover the costs which this solution involved. But it worked well for everyone. In fact, I remember this time as a time when my mother and I got closer.

Having chosen Maltese as one of my A-level subjects, I had the idea of inviting mum to read my textbooks and to give me an oral summary after she was through with them. We used to go out for walks together and she would recount in detail the story of textbook she had just read. I would then give her another one. After that it became a kind of book club for us since she went on to read more and more Maltese literature. Not having had the opportunity to complete her primary education to look after her own brothers and sisters, this experiment opened up a whole new world for her. This was our very own special time together.

As I grew to know my mother more deeply, I sensed that she hungered for contact with her brothers and sisters who had emigrated to the USA. We had never realised the depth of her grief when they all suddenly decided to follow each other to the USA. After her own mother's death at 34, she had practically become a second mother to her brothers and sisters while her older sister managed the house. Her silent unexpressed grief must have triggered her depression.

I shared this intuition with my family and we secretly agreed that we would all do our utmost to save money for a special present: we decided we would buy her an airline ticket to visit her brothers and sisters in America. In the meantime, periodic relapses necessitated her having to undergo ECT treatment. This was a traumatic period for us older siblings; the younger ones did not understand what was going on.

In time, we managed to save enough money to buy mum a air ticket. Initially she was ecstatic. However, she told us that she was afraid of travelling on her own since she had never been abroad. My older sister tried to get approval from her employer to take two months off work but her request was denied. As this option disappeared, Mum started to believe in our constant promises to keep the house

clean and to cook hot, healthy meals daily throughout her absence. This reassurance must have helped her decide to go on her own. Seeing her leave us for two whole months was truly painful.

The trip was a real breakthrough for mum. Her significant time with her siblings healed her inner pain and she came back smiling, her soul no longer in torment. We felt blessed to have her back. During the time she was away, I started to do voluntary work in a children's home and used to occasionally invite two boys home for a whole Sunday. My brothers became very excited about this and simply smothered them with affection and gave them clothes which they were growing out of. On her return, mum plunged into this totally new experience and planned elaborate special Sunday lunches for the two boys. Life started to become cheerful and exciting once more.

Today I often find myself imagining a different scenario had mum lived to experience the technological advances that the Internet brought with it. I imagine her being taught to use Skype to communicate as often and as long as possible with her many relatives overseas, seeing her nephews and nieces grow and her own siblings grow older. But hers was to be a short life and I still miss her terribly.

I must admit that we did not have access to any support during mum's long illness. It is true that back then we lacked the support services we are blessed with today. We somehow managed on our own and managed to find a breakthrough intuitively. I would like to think that my relationship with mum and my creative connection with her was an anchor during her illness. Our family pet – a rough Collie who adored mum – kept me in high spirits and hugging and petting him gave me the comfort I needed.

One of the most important lessons I learned during this period was to expect nothing from relatives. This insight was a grace, since I grew up to become a person who did not resent anyone, and who seeks alternative solutions when the expected ones do not materialise. I also learned to care deeply for others who are suffering and to seek ways of supporting them even when my own troubles felt too heavy.



8. Like a thief in the night



Mental illness creeps into one's life like a thief in the night

Our situation did not develop overnight. My wife had been becoming increasingly verbally aggressive for quite a while. Her attitude had been gradually changing for some years. Before she was diagnosed with her illness, she accused me of infidelity. At the time she was 49 and I was 48.

One day, when I was at work, I received a call from my wife's cousin informing me that that my wife had very high blood pressure and needed to be taken to hospital immediately. I left work and took my wife to the general hospital's emergency section. My wife told the doctor who examined her that I was poisoning her. After tests and a two-day stay in a ward, the in-house psychiatrist convinced my wife to stay for a while in the psychiatric ward.

It did not take long before she was admitted to the psychiatric hospital where she was diagnosed with delusional paranoia. In a way I was relieved that our family realised that her accusations against me were unfounded. To me, things started to make sense.

From then on our family faced many difficulties. Foremost among these were the regular intrusions my in-laws made into our home life. I realised that my wife's siblings were in total denial; they refused to believe that their sister was sick. I implored them to tell us anything they knew about my wife's situation that I did not know of, since my children and I needed to know everything to be able to help her.

Slowly, I started to find out that they had been hiding key information from us that was vital to the psychiatrist. Mental illness was not something I easily shied away from since I already had a fair amount of traumatic experiences; both my sister and mother suffered from mental illness.

At one point, our family almost broke up. Five months after my wife was discharged from the psychiatric ward at the general hospital, I began to see that her attitude was changing again. Things started getting worse. Soon she started accusing me of infidelity. After Christmas she accused me of taking another woman to bed with us during the night. The hallucinations were getting worse.

Our children knew exactly what was going on. Moreover, my wife started throwing tantrums during our days off. These lasted for about three to four hours each time. The main ones were about my being a liar, about how I had turned our children against her, and about us blaming her for wanting to leave home and causing a family break-up. My children and I discussed all this with the psychiatrist. At this point, the psychiatrist prescribed my wife different medicines, one of which was an injection. Once I suggested to her that she needed to be hospitalised. She refused, and flew into a rage.

I started to suspect that either my wife was not taking her medication or that it was having no effect on her. Since she was keeping her medicine at her sister mother's place, I was not sure what was happening. I later found out that my wife's relatives suspected that I was substituting her medicine with sleeping pills so as to make sure that she slept at night and thus be free to do what I want.

Months later, my wife threw tantrums every time she saw me. By this time our children and I were so exhausted and overwhelmed that we felt unable to handle her any more. One day, during one of her tantrums, she started accusing me of having installed hidden cameras and microphones in the house so that I could see and hear her any time I wanted. She also accused me of installing a camera in our bathroom so as to upload stills of her and the children on the Internet.

Since my wife is computer-illiterate I realised that someone was feeding her paranoia with lies. I phoned her social worker to seek her support. At this point, with the help of our family doctor, I got all the documents ready to have her involuntarily committed to the psychiatric hospital. We had no choice but to opt for an involuntary admission. We did not tell anybody else about our plan since we had ample evidence that my in-laws had hidden information from us that might have helped her be admitted earlier to the hospital and saved her and us from needless suffering.

On the involuntary admission day, I went to work as usual but I had very mixed feelings about what we were about to do. Was I doing the right thing? I left work at noon. I told a close colleague what I was about to do. I was shaking with mixed emotions. This person agreed that I should go ahead because it was for my wife's own good and well-being. This person could understand because his mother had experienced a similar problem.

I cried and excused myself. I went to the car and left for home. My wife arrived home a bit later than me. Then one of our children arrived. I offered to accompany my wife to the psychiatric hospital but she adamantly refused. She tried to contact her siblings but I had anticipated that and made sure that she would not be able to communicate with anybody. The police had to be involved.

I must say that the police handled the situation very sensitively; I only have gratitude for their support. We finally made it to the hospital. From there, my wife contacted her siblings. All of them, except of one of her younger siblings, were livid with anger. It was this particular sibling who most understood and supported us throughout; my children and I confided in him but did not tell him about the involuntary hospital admittance.

I called all her siblings to tell them what was happening. They began to insult us and tried to convince the family doctor that I was trying to get rid of my wife by locking her up in the mental hospital. The doctor realised they were not accepting the situation and that they were trying every possible trick to

get her out.

At this point, a relative told us that some years before my wife had been taken by her sister to a fortune teller. I could not believe it. My children and I arranged a meeting with this person and confirmed the story. We were told that the fortune teller had told my wife that I had relations with a blonde woman. We were also told that a curse was put on me to harm me. A doll was used to represent me during the curse. Now things started to make sense to us.

I organised a meeting with my wife's siblings at our home to explain how things stood. During the meeting, which was very emotional, my children asked them whether they knew anything about any fortune teller. There was a fairly long pause; everyone was looking at the person who had accompanied my wife to the fortune teller. Then one of them answered that he knew but it had nothing to do with my wife's illness.

My children tried to remind them that they were supposed to tell us everything when their mother was first hospitalised. We tried to explain to them that we needed to know everything so that we could convey all they knew to the psychiatrist. Here they told us more but never admitted knowing about the fortune teller and business about the curse.

I became worried about one of my wife's siblings since he is rather violent. He already had a couple of brushes with the police. We later found out that he was trying to get his sister out of hospital. We became afraid. One of my children phoned him and asked him to stay away from hospital for the time being. He replied by telling her that he might come to our house and do something nasty to us. We became afraid of him.

At this point, I contacted the psychiatrist and informed him about my brother-in-law's threats. I also informed the police. They had a chat with him and I was assured that he would not come near us any more. After this he went to a lawyers' firm to see what he could do. In the meantime, my wife's family stayed away from us.

What was most painful for us was that after weeks of hospitalisation, we saw absolutely no change in my wife. I started losing hope. All she spoke about was that I wanted to get rid of her and that she wanted to see a lawyer to break up the family.

After about five weeks, although her anger had abated, she continued to talk about the same things. In hospital, she was doing nothing except playing cards and smoking. This was not helping her. I expressed my concern. The nurses agreed. They were trying to convince her to do other things.

At about the seventh week in hospital my wife made a remarkable change. I was amazed. Our children could not believe it. At this time we were bringing her home for a day during weekends. We went to a seminar and had a chat with a psychiatric nurse about the change. I was told that my wife had started taking a new medication. After 10 weeks in hospital she was to come home for a week.

This was the week that one of her nephews was getting married. I organised a meeting with her brother and the sergeant at the police station. We met and sort of patched up the situation. I am not going to go into what was said here but he was still adamant about the situation. I tried to fix things for his son's sake and also for the sake of my wife's recovery. My priorities were twofold: doing my utmost for my wife to help her improve and recover and helping to repair relations with her siblings since I believed that if we pulled the same rope together, she would be well again.

At the time of my wife's hospitalisation. I joined a course for relatives of mentally ill persons. I encouraged her siblings to attend but only two did. Her older brother remarked that he knew everything

about these things and did not attend.

Some of my in-laws still think that my children and I should not have committed my wife to hospital. A couple of them, their spouses and their children, barely talk to us now because of their ignorance on the subject.

As regards our neighbours, I always kept things quiet. We did not have any close family friends. Our closest relations were with my wife's siblings. Not any more. As regards work colleagues, I had told my inner circle and my boss about the situation. They have always helped and supported me. I would have broken down without such understanding.

As far as my own family is concerned, they were very supportive and they knew exactly what needed to be done in these situations. They readily supported us; whenever I needed them, they were there for us. They often invited us over to have a meal with them during my wife's hospitalisation. I even nicknamed my brother's house Peprina Restaurant because all we had to do was inform them that we would be eating with them in the evening and my sister-in-law cooked extra for us. No hassle. I often called him to ask jokingly whether Peprina Restaurant would be open that evening and what time the kitchen closes.

Well, they have been through these situations with my sister when I was living abroad. Also their level of education is high, so when they need to do some research, they know where to find it since one of my nieces is a doctor.

It has been almost eight months since my wife's discharge from hospital. She has since made a steady improvement. We now live a normal married life. My wife is an intelligent person. Her condition makes her a bit idle. She procrastinates so she sometimes feels confused and unsure about what needs to be done. For example, she may sit down all afternoon and evening watching TV and then she gets a bit worried because she could have done some household chores instead. I guide her to organise herself to do things. She is getting better and knowing that we support her, she feels comfortable with herself. She is trying to establish a routine.

Looking back, it has been a tough road but worth the effort. My family is now living in peace thanks to the staff at the psychiatric hospital. We are really grateful to the nursing officer, all the nurses of the ward, my wife's psychiatrist and his team, others that were indirectly involved.

I thank the Mental Health Association; I only have praise for all those who voluntarily contribute to this association's mission. I also thank those who, for one reason or another, can no longer contribute to this association since, without the past, we cannot have a present and without a present we cannot have a future. I hope and pray that my wife will not have a relapse.

Those first couple of months before and during hospitalization I became very angry and depressed. I did not sleep properly. I was always thinking about what was happening to us and what would happen to my family if things remained the same or got worse. For the first time in my life, I saw myself in a position where my wife and I would have to separate.

Guilt sometimes took over: had I done all I could to help my wife? Was there something I had ignored? Was there something else I needed to consider? I placed some of the blame on the lies and deceit concocted by my in-laws. I am sorry to say that, even today, I still feel anger towards those who lied and could never bring themselves to say the truth. But I know that anger and resentment are harmful. They hold you back from moving forward.

Today I acknowledge that I have become more mature and decisive. I often reflect on what we have

been through. I admit that I have lost all respect for those who hid the truth from us and put so many spokes in our way, causing unnecessary pain during such a traumatic time. I feel like a part of my family that I was so close to has died.

Although during the worst part of the illness, I used to help with the cooking, cleaning and other tasks, today my wife is well enough to reclaim her share of these tasks of daily living. In fact she is increasingly taking on more responsibilities. Today she supports me in my studies since I have taken up a degree course which is very demanding.

The days I used to consider 'very bad days', when my wife threw tantrums, are almost a thing of the past. It has been a year now since her release from the psychiatric hospital. She is relatively well now compared to the days before her admission.

Apart from my side of the family and one of my wife's siblings, from whom we sought and received support, my wife's social worker, her psychiatrist and our family doctor were very supportive. The mental health system was supportive. I also saw some consultants privately; they were supportive too.

Before my wife's hospitalisation, I too was invited to see a psychiatrist and a social worker. During her hospitalisation I, nurses in her ward and the psychiatric team treating my wife did all they could to help her get better. Looking back, I realise I would have benefited from more help. I could have consulted a lawyer who is very familiar with the mental health system. Such a lawyer could have immediately understood the situation and explained that the machinations and hurdles obstructing my wife's treatment would not have worked. This would have reassured me. As it is, I did consult a helpful lawyer. But finding one who knows the system is different. I also spoke to a police sergeant for advice.

If I were to be asked what I think of the mental health system, I would say it is good. However, specialised legal advice is not readily available within the system itself. Moreover, looking back, I realise that we could have benefited from detailed information about the range of available support services. The way I see it, these practitioners are overworked; this may limit their time to explain services in detail. Another type of support that is essential but missing is a family support group. Group support meetings would be a great help.

What I found most helpful was the initial diagnosis because it gave a name to my wife's critical condition and from then on we simply had to find a way to understand the illness and to enable her to find the right treatment.

There are sacrifices one has to make in such family situations where mental ill health creeps up on you. For example, I wanted to start a business but could not. The most difficult time for us was when my wife refused to go to the general hospital and later to the psychiatric hospital. Therefore, committing my wife to hospital and having to involve our children was extremely difficult for me.

However, I believe there is always hope. My wife takes her daily medication. She also takes a monthly injection. She is doing well at present. As long as she keeps attending the hospital appointments and takes her medications she should keep well. As far as I know, if she misses an appointment I am notified.

Is this recovery? I do not know. However the illness is being managed and controlled.

My main fear and concern for the future is the possibility of a relapse. I am afraid of a relapse and that her condition may be part of a process of a worse condition such as dementia.

I would like to recommend a number of things for people who find themselves in my situation:

- Use professional help. Don't dither, just go for it.
- Try to talk to persons with experience in the situation that you are in. One can get invaluable support from such persons.
- Try to get as much information as possible and make sure that the information is correct.



9. Tough journey



I remember that in our family it was always mother who took all the decisions. She was the hub of our life; we all turned to her for everything. My father used to rely on her completely. She always told my sister and me what to do. Her overriding priority was that we had to study. All this changed completely when she died of breast cancer. I was then 14 years old. I had been brought up pampered and over-protected.

For a time my sister tried to take her place and my father would rely on her. This situation changed two years later when my sister found a steady boyfriend and started to disengage a bit from the responsibilities she had taken over from our mother. From then on, my father had to learn to take decisions alone.

One summer day I was downstairs watching television. I heard my father shouting from the bedroom. I thought he was fighting with someone. I ran upstairs to see what was happening. When my father heard me coming he told me to go away. I became very upset – unable to comprehend what was happening. After some time, my sister came home. She heard my father shout from the end of the street and assumed that he was shouting at me. Together, we decided to call my aunt who lived next door. We decided to do this from the roof so as not to trouble our elderly grandmother.

Our aunt called the family doctor. He immediately decided to call the police. My sister's boyfriend told us to be careful as there were knives inside. Fortunately the police did not face any resistance. In fact I recall them being sorry for my father and saying that he was a good man. Then they took him to Mount Carmel Hospital. We went with father. I almost fainted and was out of breath as I was still unable to understand what was happening.

At the time of this incident, my father was around 51 years old. Before this episode, he had been taking antidepressants since the age of 25. His depression had been sparked off by a major traffic accident in which his father had passed away. I remember that once, when I was younger, Father had been admitted to the psychiatric unit at the general hospital after he became extremely worried about a crack in the roof. In hindsight, I realise that my mother had shielded us daughters from these incidents.

I was very young when all this happened. I was struggling to survive. In hind sight, I realize that I was trying to minimise what was happening so as to live as normally as possible. I wanted to live as my friends were living – a carefree youth. However, I conscientiously made sure that dad complied with treatment. Whenever he had a psychotic episode, I immediately spoke to the psychiatrist so that he would not have to be readmitted to hospital. I often felt bitterness towards my father since I was not convinced he was taking care of us. I also felt bitter that my sister and I were forced into the role of primary caregivers of our father.

After the full blown psychotic episode and his admission to the psychiatric hospital, we became aware that my father had a mental health problem. At the time I did not realise what it was all about. My memory of the events of that summer are quite hazy. It was as if I was living a nightmare. My ignorance did not help. Yet no one bothered to sit down with me and my sister to explain what was happening. We were just expected to contain the situation as dutiful daughters ought to – no questions asked and no answers volunteered.

I remember I was always on the lookout for dad. Whenever his paranoia increased, I learned to administer extra medication. In time I learned to consult the psychiatrist, and accompanied my father to medical appointments. At home I learned to cook, clean and to pick up father's medication.

Emotionally, I felt no one really understood me. I just tried to continue with my life as best I could. I slowly grew to become self-sufficient as no one was there to take care of me. The most stressful time was whenever dad had a psychotic episode. On some days he became paranoid. His behaviour and his facial expressions changed. I checked up on him to anticipate small changes. This caused more stress in me.

What worried me most was that he might drive the car during such an episode. I learned to identify precisely the creeping symptoms without knowing the exact nature of his condition. My sister and I became used to taking him to appointments and administering an extra tablet when he relapsed. The psychiatrist had given us precise instructions about when and how to do this. Fortunately for all of us, my dad was never violent when sick and even during a psychotic episode, he always he did as we told him to.

I must say that my extended family have been a great disappointment. They hardly offered any support and most of the caring responsibilities, including house chores, were left entirely in our hands. Surprisingly for my sister and me, our extended family were only concerned about getting support from us. I recall only a few times that my relatives were actually kind to us. We got the message that they were simply doing their duty by visiting us occasionally.

As regards our neighbours and others in my home town, we never bothered much about them but I must admit, at times I felt ashamed of my father.

Although I functioned relatively well, I never felt safe enough with anyone to show my true self. When, a couple of times, I did try to show my pain to friends, I did not feel understood. To others, I must have looked perfectly functional. On the inside, however, I was a mess due to my trying to contain everything alone, without any guidance from a knowledgeable adult who knew about these things. I simply

muddled on by myself.

I copied my friends' behaviour to gain a measure of normality. But, in truth, I could not be as carefree as them. I still needed to deal with my mother's death. My father's illness pushed my need to grieve aside. I had no adult I could turn to for reassurance and support.

Our family situation negatively affected my studies. I had to repeat one year at Junior College as I did not pass my A-levels the first time round. My sister, though, was affected much more seriously. Her colleagues got to know about our father being an inpatient at the mental hospital. This was such a source of humiliation for her that she gave up her studies. Fortunately, some years later, she picked up where she left off.

Our main source of support was seeing father's psychiatrist at his private clinic. When I later started to work, I started to rely more and more on the mental health system although we still took dad to see the psychiatrist privately once in a while.

I only remember speaking to the psychiatrist. Although he never explained much about the situation, he was quite helpful. Once he was going abroad and we phoned him on his mobile phone as my father was not well. He listened to us and advised us what medication to administer to him.

Although the psychiatrist's help was appreciated, I wish someone could have helped me process what was happening and how the mental health system worked. I became aware of certain rights and services when I started working within the health system. I wish a knowledgeable professional could have explained things to us patiently and clearly. I also wish I received help in processing my feelings towards my father. I feel sad that I spent quite a while being angry at my father for not being like other fathers. Had I understood his illness better, I would have been spared a lot of frustration, pain, confusion and anger. Emotional support was sadly missing. I did somehow manage to deal with life's practicalities but until I found my way, I had to experience unending frustration and worries.

I now acknowledge that this experience turned me into the responsible and caring person I am today. I have learnt to juggle my life's responsibilities. I also know that if I work hard enough I can succeed in whatever it is that I decide to do. I would have suffered less shame and anxiety had there been someone who explained things to me and reassured me. Fortunately, I have worked through these issues. I was lucky that by chance I ended up in a job which taught me much about mental illness and how common it is. I now wish to further my studies and to look for other paths to self-growth and transformation.



10. Through my wife's illness, I met God



It was November 1996 when I met my future wife and mother of my two children. That outing, which seemed to be a normal, relaxing one after a week of hard work, was to change my life forever. She had just turned 17; she was a very attractive girl who seemed to be very outgoing and full of *joie de vivre*. When we talked and started to get to know each other I could notice an element of perfectionism in this person: perfect make-up, clothes matching perfectly. Things you would expect from a girl that age. There is nothing wrong with seeking perfection, as long as it makes you feel better and is not controlling your life.

We used to meet at the weekend until we decided to make our relationship official. We talked to our parents and we started to meet more frequently. We started to get to know each other better. We met every day and this helped us to discover the good and bad side of each other's character. We found this very useful, knowing that our relationship was becoming an important one.

Time passed and after a year or two it was clear that the perfectionism that I noticed when we started our relationship was now controlling my wife's life in a negative way. Obsessions that initially seemed to be under control were intensifying and continuously tormenting my wife's day-to-day life. It seemed as if someone inside her was trying to make her do things she didn't like or want to.

These obsessions included washing herself seven times a day, frequently checking if the cooker knob is turned off, checking if the clock is set to ring in the morning for her to wake up to go to work. One day, I saw her checking this clock continuously. Not knowing exactly what was happening, I really got angry and smashed this clock to bits. Working time was becoming hell for her as she felt really bad when it was time to go to work. My wife was sure that her colleagues at work were continuously talking about her. This intensified her anxiety and the situation was becoming more and more difficult for both of us.

We concluded that we needed professional help. We spoke to a psychiatrist and after listening to our story told us that my wife suffered from obsessive-compulsive disorder (OCD). She started taking medication and still does. With medication, her obsessions became more controllable but were still quite strong and intense.

After six years we decided to buy a new house, since we wanted to have a family. I remember that at the time the situation changed and all those different obsessions that my wife had suffered from had nearly gone. Instead one single obsession was extremely strong and difficult to cope with.

My wife was continuously tormented by the thought that the grooves we had dug in the wall to pass the electrical wiring were not properly done and aligned. So our house became for her, a damaged asset. This thought was so strong that she wanted us to buy another house. Although I started to realise that what was happening to my wife was out of her control, I couldn't allow this to happen. I could not change our house for such an unrealistic reason; it made no sense to me. This was a very hard time.

We talked to the psychiatrist and he suggested that although I should not blame my wife for this difficult way of thinking, I should not allow these thoughts to take over our lives and so I should say no to my wife's suggestion of moving house even if this meant more anxiety and moments of sadness.

This is when the person suffering from these obsessions becomes depressed. I could feel that my wife had very low self-esteem and she was so depressed that she couldn't even see to her normal everyday needs. We moved into the house I have mentioned. But life was very difficult. My wife felt that she was living in a house she didn't like. It was a daily battle, fighting the same thought but without success. In fact, I knew that we had a beautiful house with everything we needed. It was a house that my wife herself chose before the onset of her obsession. I knew that were it not for that obsession, she really liked the house. We thought that was now going to end but another obsession as intense as the previous one was taking over. What was happening and why did the obsession about our house vanish as if it never existed?

After about two years of marriage we had some wonderful news to share with our family and friends. My wife was pregnant with our first child. I was living a dream because although I am a teacher and spend most of my time working with children, I really wanted to have children of my own. I hoped this pregnancy would help my wife to forget about the obsession with our house and focus more on the pregnancy itself. It really did, but not in the way I hoped it would.

Some weeks before my wife got pregnant we watched a DVD about a young woman having evil powers. Just by watching this film my wife started to believe that our baby was the fruit of Satan. When my wife talked to me about this second obsession that overshadowed the one about our house, I was really shocked. How come that something really beautiful could change so radically? I couldn't understand it, no matter how much I tried to reason it out.

Especially for my wife, it was very difficult to cope with such a thought. We spoke to the psychiatrist and he confirmed that this was how OCD acts. A thought replaced another one; becoming the new obsession. We continued with the medical treatment but this torment was to last for the whole nine months of pregnancy. With every ultrasound image that we took, I could remember me and our families happily noticing our baby growing bigger. However, my wife could identify strange things like a corn on the baby's head, a tail and even Satan's hand on the head.

I really wanted this baby to be born as soon as possible for my wife to see that these were only obsessions and that what she was imagining was not real. Finally the day our child was to be born

arrived; my wife gave birth to a beautiful girl, with no abnormal features that she had imagined. Something interesting is that our girl was born on St Michael's day; St Michael was the archangel who defeated Satan. Was this a sign from God to make my wife aware that He is above all?

I should say that although my wife's obsessions were intense and strong, there were times when she told me that the things she was imagining could not be true. She could reason out that these were only obsessions and cannot be real. However, these were short lucid moments and after some time we would get back to the same unacceptable way of thinking. This second obsession was now replaced with a third one. This third obsession was still focusing on our little girl.

My wife became obsessed that our girl was going to die at three years of age. I was really worried because three years are quite long for us to live through in such a situation. Day after day, the three years finally passed and our child was growing up into a beautiful girl. My wife confirmed that what she was thinking about was nothing but a harmful obsession. My girl's third birthday was very special for all of us. It was a confirmation that we had overcome this third obsession.

By this time my wife had terminated her job to take care of our child. The condition was not helping her to carry out normal housework and to take care of our child adequately. This meant that I had to take over many of these responsibilities. It was a very hard time for the three of us. I had to come from work and do some difficult work at home. Although I really worked hard to keep my family going and I really did my best, my wife was becoming mentally tired by just having these continuous obsessions.

Soon after this third obsession lost its strength, a fourth one was taking over. This fourth obsession is still strong today and it is the one that has lasted longest. We noticed that at home we were finding small insects, furniture mites. After seeking professional advice we got to know that these nearly microscopic insects are very common in Malta and they are caused by lack of air circulation and ventilation.

In Malta we have a high level of humidity and this is why these mites are commonly found in various places. The situation is not so dramatic for me but unfortunately it is for my wife. This was another valid reason for my wife to decide once again to change all of our furniture and if possible sell and buy another house as well. Again, I could not accept this, and I even had full support on this from her family and mine. I knew that it was not my wife reasoning out but the obsession itself. You cannot sell a house just because you found some harmless insects in your furniture.

As time passed, my wife was giving away many things we had at home her relatives because she was afraid that these insects were contaminating everything. I could not see the things I liked most being given to other people. This is not because I do not like to share the things I have, but not in this way!

I couldn't handle the situation of going to my mother or my relatives and seeing our things adorning other people's homes without my consent. I often tried to explain to my wife that what she was doing was wrong, but most of the time the obsession was so strong that it was all in vain. The fear of contamination from these insects was stronger than my suggestion to try and work things out. My wife used to wash her hands even after making a phone call or after handling the television remote control. She washed her hands after touching anything at home.

She is still obsessed with these insects but after taking a second opinion from another psychiatrist and after following a therapy he suggested, the situation is very much under control. Although we sometimes have a very difficult time, things are improving day by day. The birth of our second daughter helped to make this situation better still. This second pregnancy was not as tough as the first and I could

observe that my wife became very determined to do her part as well as possible, as if she wanted to make up for what happened when we had our first baby. As a mother she improved day by day and this fact helped her control her anxiety and disorder.

Obviously, this condition has affected me and my family in a very negative way. I could feel the lack of happiness in our family, lack of serenity and disorganisation at home. Much sadness and anxiety has made it very difficult for us to live the normal and happy life we wished for. At work, my wife could not handle her job any more. Apart from the stress that the condition itself caused, the working hours were very inconvenient for my wife as a married woman with two small children. Nights shifts were an ordeal.

Apart from this, no man feels happy knowing that his wife is not feeling comfortable living in the house that we chose to live in for the rest of our lives. There was a time when my daughters were not allowed to enter certain rooms at home or to touch things. Of course there is nothing really wrong with this, but for this last obsession I mentioned, I couldn't even switch the television on because it would cause my wife anxiety – she would think that the remote control or the television itself would have some of these insects that might contaminate me and my clothes and other things that I would then touch. I couldn't even put my spectacles on the bedside table before sleeping for the same reason.

I felt as if I was under observation for most of the time I spent at home. My children and I could not live a normal life because even when we did something that was quite normal for us to do, it would heighten my wife's level of anxiety. This is when we often felt that our marriage was going through a crisis. My wife stopped taking her medicine twice without me knowing. I could notice a difference in her behaviour, but I did not really understand why until she herself told me some months later.

By this time my wife's odd behaviour intensified. She often told me that it was better for all of us if she died but I always assured her that she had much more to give to our family. I often told her that we all needed her and things without her were not going to be the same. There were times when I phoned my mother or hers to come over so that I could go to work because I felt that it was dangerous for my children to leave them alone with my wife, since she really was unable to take care of them as she should.

Once again we talked to the second psychiatrist and my wife resumed her medical treatment. The situation was becoming much better now although the fourth obsession I mentioned, that of the insects, was still around. I was unsure how to act in such a situation. My big question was whether I should live my life normally or whether I should do what my wife's obsessions demanded of me.

Our psychiatrist suggested that it would help us all if I acted as normally as I could even if this meant more anxiety for my wife. He was sure that after some time she would get used to handling this anxiety much better. It would not help if I accommodated her obsessions because I would make them stronger and they would take over. It was time now for us to fight these obsessions not only in a medical way but also in a practical manner. I hope that, as time goes by, these thoughts will lose much of their strength, thus helping us to live a less stressful life.

Although I now perfectly understand that these obsessions are not under my wife's control, I must admit that there were times when I often felt very angry at her and sometimes I said words I should never expressed; words that do nothing but harm us as a family. Through experience I understood that we should learn to live with this situation as best we could. I wanted to support my wife and family as a whole and not let this situation dominate our lives.

Nowadays I try to think twice before I say anything, even in a moment of anger, although it is better said than done. In a moment of anxiety we try to talk and calm down each other to reason things out. The

relative should be extremely tolerant although there is a limit to such tolerance. If you think that it is better for all the family to say no in a certain situation, you should keep saying no. It should be clear to the patient that although he/she is doing wrong, you are there to take care, to love and to help the person to do better next time. The easiest way out is to abandon ship and move your own way, living your own life, but when you have your family at heart, you will never think of leaving everything behind you.

It should be clear to the person having mental health problems that you are not against them as a person but that you are not happy with their actions, which may be dangerous for all the members of the family. As a family we improved a lot when we spent time talking openly about our difficulties. Obviously practical help is necessary as well. Help in everyday needs at home and outside are very important not to put a lot of pressure on the patient. Responsibility should be given to the patient little by little and it should take as long as necessary to help the person handle one situation at a time. Remember that sometimes even the easiest type of work may be difficult for a person suffering from mental health problems.

Regular exercise and communication with other people helped my wife a lot in her condition. Exercise stimulates the mind and gives new energy to help us carry out activities much better. People suffering from OCD should talk to persons they really love and care about regarding their situation because when you talk you feel much better. It boosts your confidence and self-esteem. Finally, it is extremely important to accept the support that psychiatrists give you, especially from the medical point of view.

Today my wife's condition is still felt in our family but it is under control. We found help from different people and are still finding it today. Although our parents do not understand our situation very well, they are always there to help us in times of difficulty. In their time, mental illness was not considered to be something you should talk about and so it is quite difficult for them to accept and learn about it. However, I feel that by now they are a part of our story as well because we always talked to them about our situation at home.

We found the Mental Health Association course very useful too. We learnt a lot as we talked to people in a similar situation. My wife attends Richmond Foundation sessions once a month and these are also very helpful. However, I feel that the love and respect we have towards each other as a family kept us together because there is nothing stronger than love, and love is never beaten by any mental illnesses.



11. Love and support in large doses



My sister Shirley was born in 1952 in Bristol, in the west of England. She was an energetic child and particularly enjoyed swimming, climbing trees and looking after animals. She was a good swimmer and swam competitively for her school. She was physically very fit.

Shirley had a happy childhood with a sister who was five and half years older than her and a brother who was seven and a half years younger.

Shirley had no health issues of any kind until she became mentally unwell when she was 16. She was at school when her behaviour became erratic and she was finding it very difficult to concentrate. Her thoughts became muddled and her speech disjointed.

At the time our family GP put her erratic behaviour down to her being a ‘troublesome’ teenager. Unfortunately, her symptoms were much more serious than that.

I was 22 when she became ill and I have to say that it was a very complex and confusing time in the life of our family. We felt overwhelmed by an emotional tsunami. Add that to an emotional freight train and it goes some way to explain what threatened to engulf us. Nothing could have prepared us for her illness.

Shirley’s headteacher had recognised from her own experience that Shirley was developing schizophrenia. This didn’t mean much to us at the time as we had no knowledge of any mental illnesses, let alone schizophrenia.

Schizophrenia is a brain disorder that affects the way a person thinks and sees the world. It can be severe and disabling and it has affected people throughout history. The condition can present in different ways. In my sister’s case her thoughts were muddled and disjointed and her behaviour erratic. She would

often be awake at night and sleep well into the day.

We didn't hear that diagnosis again for about two years. During this time my family was seeing a psychiatrist or psychologist on a regular basis. They were helping us to understand Shirley's illness and how best to respond to very new and challenging behaviour.

Shirley had to leave school; there were no opportunities for her to say goodbye, as she was too confused. She did, however, have some awareness and it was enough that she was devastated to have to leave before it was her time to do so.

It is common with schizophrenia that the sufferer has little or no insight into their own illness. This can be very difficult for friends and family members when they realise that professional help is needed and their loved one is not able to recognise that for themselves.

Many people with this condition lose their normal levels of functioning. Shirley's ability to cope on a day-to-day basis became very limited.

For a short time Shirley was admitted to a psychiatric ward in our local general hospital in Bristol. The idea at that time was that with the help of psychiatric medication she would improve and possibly make a full recovery. A quarter of people who are diagnosed with schizophrenia do go on to make a full recovery.

As a family and with professional support we encouraged Shirley to come to Bath, a beautiful Georgian city 15 miles east of Bristol to share a flat with me and a nursing friend. This would be part of her recovery process. The arrangement lasted for three months.

Shirley had to return to Bristol to an acute psychiatric unit where she remained for some time. During this time the medical staff tried to balance her medication, which at that time was the drug Chlorpromazine. The other name for Chlorpromazine is Largactil. This drug was the pharmaceutical success of the 1950s for people with mental illness.

Before these drugs became available for psychiatric patients the mentally ill had to remain in long-term mental health institutions which had been built in the 1800s to protect the mentally ill from society and society from them. They were called asylums, or places of safety. This meant that society had very little idea about people suffering from such illnesses.

Unfortunately, Chlorpromazine has some unpleasant side effects and it is now used less than before. While Shirley's medications were under review she experienced psychotic episodes when she was out of touch with reality. Psychosis is a symptom of schizophrenia. This is a frightening experience for the sufferer and for the family; for friends and for people in the community.

We experienced many years of Shirley running around Britain, walking out of hospital, getting on trains with no ticket, arriving at destinations where station staff were confused and with little knowledge of how to cope. The only plus was that Shirley was always seen as an innocent and not wanting to deceive people. Her lovely basic personality seemed to shine through the muddle of her mind.

One day, Shirley appeared unannounced with no money and no plans. This was difficult at the time as I lived in a nurses' home and was unable to put up a mentally ill sister. A very good friend and colleague helped us out for a few days. Then Shirley disappeared.

Later, when I was working in London, she appeared at the hospital's Accident and Emergency Department around midnight and announced that she needed to see me and stay overnight.

I learned very early on in my sister's illness that I had to know how to look after myself as if

I were to be a long-term carer; I had to be fit and able for the job. I also realised that if I was to be up to the task I had to have good friends and colleagues around me.

In 1974 I went to work in a Central London hospital and I found that my colleagues there were very supportive of my position. I had to prepare them for my sister's unplanned visits.

In Britain it was not until the 1980s that it was decided that most people with a severe mental illness would benefit from 'living in the community'. It was thought that patients became too institutionalised living within a closed community where they became too dependent on being 'cared for' and had to live alongside other people who were also mentally ill. So in 1986 people with a severe and chronic mental illness were gradually "moved into the community."

For our family this meant that Shirley was moved from a long-term psychiatric institution where she had lived for about 15 years and shared a bedroom with 12 other 'patients' to the first community home of its kind in north Bristol. At this home she would have her own room and all the care would be client-centred. The people living along with her in the Home were referred to as 'residents'.

The idea at the time was that residents would stay for about two years and then they would be rehabilitated enough to move on to a house or flat where they would require less support but still have some supervision.

For a short time professionals thought that Shirley was ready to go to a smaller unit where she would have support during the day if she needed it. At night there would be a carer in the house but she would be doing what they call 'sleeping nights'. The carer had her night room under Shirley's bedroom. Shirley was very unhappy in the house and she expressed this by moving her bedroom furniture around the room, which of course prevented the night carer from sleeping.

Shirley was physically very able and a keen walker and would be up and about before other residents were out of their beds. However, despite her physical strength and determination to get on with her life, she was stuck at every turn. Her mental functioning was diminished. If she was not living in a mental health nursing home she would not take her medication, feed herself or manage to work in any capacity.

In the early years of this new arrangement I put in an enormous amount of time at her house as there were only two members of staff on any shift. I attempted to keep Shirley up to date with her physical health checks. The government and health professionals in the UK were gradually realising that people with a mental illness were not receiving the same physical care as other members of the adult population and that this was to their detriment.

Fortunately, now the physical health care of people with a severe mental illness is gaining recognition not only on a national level but also on a European level.

While most people with physical and mental health problems live in the community, it is important not to ignore the needs of those who may be in hospitals and other long-term facilities, including rehabilitation centres, long-stay psychiatric wards and nursing homes.

Research has shown that mentally ill people tend to die 10 to 30 years earlier than their mentally fit counterparts.

At the time, non-mental health professionals did not make allowances for the erratic behaviour of mental health patients and it could be extremely demanding on a carer to try and keep their sick loved one at the required place at the required time.

In recent years our government has legislated that allowances must be made. It is called “making an appropriate adjustment.” Primary Care Trusts and other health disciplines have to incorporate this into their day-to-day practice.

When her home opened, the idea was that every resident would be able to keep his/her room clean and tidy. This plan may have worked for some residents but not for all and certainly not for my sister!

It meant I became involved in keeping Shirley’s room clean as her habits were not hygienic. For many years Shirley’s nursing home was run by the National Health Service but in 1988 the home was taken over by a private mental health care trust. Since then the quality of care has improved and is now of an excellent standard. All the staff involved in the care of the residents deserve their three-star status.

The turnover of the staff in the house is very low and I believe that this is due to good management. The staff are respected for the very difficult job which they do very well and their needs are respected in the same way that they respect the individual needs of their residents. The residents are treated in a person-centred way as promoted by the psychologist Carl Rogers. His therapeutic style, developed in the 1940s and 1950s, is the most widely used model in mental health. It aims to help patients find their own solutions.

Now that the central illness can mainly be treated with medication it enables sufferers to be cared for in a more holistic way. It is possible to consider their interests and desires, occupation and lifestyle and help facilitate a way of life that is right for them.

For instance, last year there was an opportunity to take part in an art exhibition with residents of other mental health nursing homes. This gave the people who participated the opportunity to define themselves in a new way.

It is now a statutory requirement that all people with a severe mental illness have a twice-yearly review. This is known as a CPA or Care Plan Approach. Carers are also given the opportunity to have their own needs reassessed.

In Shirley’s case she has always expected me to attend her meetings and she does not expect to have to attend herself, although she would always be made most welcome if she wished to come. In reality, the group meeting is more than she can tolerate. Shirley refers to me as her ‘reference’.

It is a desire of the international mental health community that families work in partnership with mental health professionals. It has most certainly been a two-way process between Shirley’s professional carers and our family during the last 40 years. Everyone’s input is important and no-one is more important than anyone else.

I am able to be an advocate for my sister as we have always had a good relationship. She has seen my input into her care as vital to her situation and no-one in the mental health field has ever disputed it.

Before a meeting I always ask her if there is anything she would especially like me to mention. The meeting is usually attended by her consultant, or his representative, the head of the home or her deputy. Her two key workers are likely to attend, one a trained RMN and the other an experienced care worker. Incidentally, one of her key workers remembers her as a young girl in the early 1970s.

Another member of the team meeting is Shirley’s social worker, who attends to make sure that Shirley’s placement at the home is still suitable. Mental health charities in the UK and Europe realise the importance of the carers’ roles. Throughout the EU, there are more than 100 million family members providing care and support to a loved one with a physical or mental health problem. Not only must the

reliance on these carers be acknowledged and the impact recognised, but the role of carers may be pivotal in helping to promote positive health for people with physical problems and mental health issues.

Caring for the carers must be considered. Caring for anyone with a physical or mental health problem can be very onerous and create significant constraints which may be personal, social or financial as carers may have to give up work or reduce time spent at work. I worked part-time for many years to support Shirley and my parents and also to support my own recovery.

In December 2004, Shirley was diagnosed with breast cancer. It came to our attention when she was invited for a routine mammogram when she reached the age of 50. A year of treatment followed – Shirley would never have undertaken a routine breast check herself.

I have not mentioned my parents' input into Shirley's care. Both my parents were actively involved in the care of my sister; my dad died after Shirley had been ill for 13 years and my mother supported her for 24 years.

My younger brother is 12 years my junior and seven years younger than my sister. He was only nine when Shirley became ill and cannot remember a time when she was well. Therefore, he cannot understand the overwhelming sense of loss and trauma her illness caused.

Over the last 40 years an enormous amount of research has taken place into the impact of mental illness on families, parents, spouses, siblings and children of parents with a mental illness. Like many others I have contributed towards this research.

I can never understate the sorrow I experienced when Shirley became ill. It was a long and complicated experience as she was still living and needed enormous amounts of love and support. All these family reactions are now well understood by mental health charities as families have put forward their experiences.

At the time none of my contemporaries had experienced life-changing events and I found it hard to find someone with whom I could freely express my thoughts and feelings. My mother used me as her sounding board but I needed my own person with whom I could do the same. For this reason there are now sibling support groups across the UK.

RETHINK (NSF) is the largest mental health charity in the UK. It has grown from humble beginnings since its inception in the 197's. It is now a large organisation which covers all aspects of severe mental illness and looks to provide support and training for sufferers and their families. Support and training helps to empower families.

It is important for new families experiencing life with a sick family member to know that the more they can learn about the illness the more they will be better prepared to deal with the challenges they face. There are now many organisations worldwide supporting families with a mentally ill member. There are also training programmes to enable families to learn the skills required to support their sick loved one.

Meetings like the one here today help families to learn more about the condition and it will help them to be able to advocate for their loved one. In addition it is important for people in community positions to learn about and be aware that there may be children in schools who have a sick parent or sibling, and that if this is recognised by people in authority they will be better able to support the family. Children understandably would find it very difficult to express their worries.

The incidence of schizophrenia is one every 100 persons worldwide. Not all people will present as my sister did all those years ago. And some will make a full recovery. There is a wide range of ability

and disability under the umbrella term of schizophrenia.

Unfortunately, I believe that Shirley is one of the 10 per cent of sufferers who do not recover sufficiently to be able to live a more independent life.

I have been what is known as an informal carer as opposed to a formal one. A formal carer is a paid professional while an informal carer is unpaid. An informal carer can be a friend or a member of the sufferer's family. Do not get the impression that an informal carer is less important in any way. Both are equally important. People who care for family or friends with an enduring illness often do not see themselves as carers, so it is very important for carers to have support in their caring roles, as long-term illnesses are demanding on both the sufferer and also on people who do the caring.

There are still patients languishing in long-term institutions in Europe but there are also patients languishing in their family homes where the needs of both carers and sufferers are not being met.

It so happens that in my working life I was a nurse. Many people have the ability to care and you do not have to be a professional to do so. There is much more outside the chemistry of the condition that can be addressed by other people.

My husband has been a fantastic support during the years that we have been together and he really understands Shirley as a person as well as understanding how schizophrenia affects her. He is a good listener and he doesn't make judgments. It helps enormously if the sufferer is understood as a person first and secondly that the illness is understood and how it impacts on the sufferer.



12. I learned to be happy



I was about seven when my youngest sister was born. I was the eldest of four children, a boy and three girls.

This was the time that my mother's moods started to change. She always looked sad, lost her appetite and she stayed in bed most of the time.

My father was in the Navy, so he was abroad for long periods.

My life changed overnight. My mother couldn't cope with all of us. My sister and brother had to be entrusted to the care of nuns.

With the help of my aunt, I took care of my mother and baby sister. With medication and the help of psychiatrists, she was feeling better for a while. Although I knew there was something wrong with my mother, nobody explained that she was suffering from depression. I had to keep my mother's illness secret. How could I explain to my friends and teachers about something I knew nothing about?

In fact, most of the time, when she was so depressed that she did not have the strength to eat or drink, I thought she would die. This was when she was then admitted to Mount Carmel Hospital. I was 10 years old by then and the first time I went to visit her with my father, I remember thinking "Why did they lock my mother up in this place?" When I went inside, I could see normal persons, they always stopped to say kind words to me and encourage me, and they even used to give me sweets and biscuits.

The nurses always reassured me that my mother would soon get better; it was very comforting to hear this and I soon realised that Mount Carmel Hospital was like any other hospital. I had nothing to be ashamed of that my mother was among the patients. In fact, I then realised that she needed those few

weeks to rest and to be taken care. She was much better when she returned home.

From that time onwards, she was admitted around six times to Mount Carmel. I am very grateful that she could find real care there.

I'm 53 now, my mum is 73. She's still on medication and still being seen by a psychiatrist, yet she lives quite a normal life with the help and love of my father. It has been quite some time since she needed hospitalisation.

Life is not easy when a parent suffers from depression but one should know that one can still live a normal life. You have to enjoy "the good days" and learn to cope with the others.

Having to fend for ourselves and being independent gave us a strong character. Although my mother suffers from depression, she is still capable of showing love for those around her, she always took good care of us in her own way and she is also dearly loved by all her grandchildren and great-grandchildren.



13. Everything I needed



Despite the illness, my parents gave me everything I needed.

I have very pleasant childhood memories of my father. He used to read me stories and play with me. He already had schizophrenia during my childhood but it was controlled by medication. In his youth, he had already experienced a set of ECTs. When I grew up, I came to know that because of my father's condition, my mother had to assume all the family responsibilities.

A joyful episode, namely the birth of my younger brother, occurred in the family when I was seven and a half years old. Now I had a new playmate just like several other children. At the time, my father ran a retail outlet and my mother helped him run it. Naturally, after the birth of my brother, she had less time to help my father in the shop. This additional responsibility had a negative effect on the family. My father returned late from work every evening yet despite the long hours he was not managing to be very productive. In time, he began to stay in bed for long periods of time. Very often, my father and I would plan to go and watch a film at the cinema together but at the last moment, he would tell me that he would be feeling tired and that we would not be going. He lacked problem-solving skills. My mother's burdens and responsibilities grew and grew across time, and this had an effect on the whole family. Moreover, my father's behaviour was causing me to feel disappointment and embarrassment.

It also happened that my father's behaviour was becoming aggressive towards us all. Up to then I did not realise that he suffered from a mental illness. However, my mother was aware that her husband was on the verge of a relapse. In fact, he experienced another psychotic episode and had to spend some time recovering in the mental hospital. He again underwent a set of ECTs and was taking stronger medication. This therapy managed to control the psychosis, however it also limited his mental faculties and he never overcame the paranoia he experienced. He used to believe that everyone was his enemy. When we used to insist that this was part of the illness, he would retort that we were their accomplices.

This experience stirred up within me feelings of intense grief. I wanted to sustain my family by refraining from my previously demanding behaviour, and to support my mother and brother. My mother used to encourage me to join religious organisations so that I would receive other people's support and at the same time become involved in activities. I used to enjoy studying and with the help of my teachers, I began to make progress in my education. However, it was very distressing for me when my parents were invited to attend school activities because it was very difficult for me to introduce my father to others.

In the meantime, we closed the shop and took over the business of a relative of ours. My mother was running the firm, among many other duties. To remain strong and effectively supportive, she always sought the help of professionals who offered advice on how best to support my father in his difficulties. When he was discharged from hospital, my mother used to take him out and accompany him to Mount Carmel Hospital for outpatient therapy. She used to find time for relaxation mostly through meeting friends or by travelling on holiday abroad. It is worth noting that although my mother had various contacts with professionals, the latter never requested to meet me and my brother to discuss how my father's illness was affecting us.

Perhaps the effect this was having on me did not seem so serious. However, on completing my secondary education and moving on to Sixth Form, the new environment brought with it a number of challenges; I discovered certain problems in my character as well. I found it difficult to integrate with other young people and started suffering from an inferiority complex. I used to consider the others as being more confident. To some extent this problem has persisted to this day.

However, all this never disheartened me completely and I continued to take an active part in youth organisations despite the internal conflicts I was experiencing. I used to play the piano and this proved to be very relaxing. I was part of a band for some time and accompanied a parish choir on the organ for some time. I also made progress in my academic studies, although in class, especially at University, I was very shy and reserved and at times used to take longer than my peers to understand a new concept.

In the meantime, my father's psychosis was brought under control, although the paranoia was still evident. My mother considered reopening the shop so that he would be active once more. She discussed this idea with the psychiatrist, who agreed. This proved to be a very effective therapy for my father. He continued running this shop until we closed it. After that, father never worked again.

When I graduated from University, I began to work as an accountant and eventually my brother began to work in the family business. I felt the need to help him run the business. I left my job to be able to do this. After some time, due to the fact that my brother took the business very seriously and worked long hours without taking any rest, he also experienced a psychotic episode. During this time, I had to run the business myself with my mother's help and that of my brother whenever he felt well. This experience helped me immensely. Eventually my brother recovered and he and my mother again began to run the business themselves.

During this time, a social worker, who was familiar with our family history, visited us at home. I believed that the support this social worker gave us was very important and I began to perceive my life story from a different perspective.

I had resumed my former work. It was at this point that I decided to read for a postgraduate degree, a Master's in Business Administration, after work. This was a very positive experience and helped me share my talents and my time with other students. Moreover, my job helped my self-development.

Unfortunately, my father developed a terminal illness and as a result had to receive care and

treatment in an old people's home. We visited him regularly and he was very happy there because he used to find suitable company. However, three years ago he passed away.

When I look back, I feel grateful to my parents who notwithstanding all the difficulties they encountered, dedicated themselves wholeheartedly to me and my brother. I would have preferred it had professionals been closer to us when we were younger. However, the support we received from the Mental Health Association compensated for this failing. The families of those who are mentally ill need a lot of support, and people who understand them. Therefore they should be well equipped with the necessary information on how to look for the right help and be of support to their relative.



14. God gives me inner strength to face life's challenges



I am in my early thirties. I have been taking care of my parents for 15 years. My three older siblings have married and left home. My mother had been suffering from mental illness years before I was born. At first it was my father who was taking care of her with much love and dedication. At my birth my mother went through a difficult time as unfortunately I was not the healthy baby she was expecting.

I was born with cerebral palsy and my mother sought the advice of various specialists. During this time she had another bout of depression and my aunt looked after me. When I turned seven my mother had another severe crisis and she had to be treated in a psychiatric hospital.

I finished school at 16 and started working a year later. However, after three months I had to resign as my mother was diagnosed with cancer. This was another blow for us. To make matters worse my mother's depression got worse and she did not recover from it. In the meantime she had two major surgeries for her cancer.

The household chores became my responsibility and this exhausted me. When I returned home from work I had to bathe my mother, clean the house and cook for all the family. During this time my mother was being treated with chemotherapy and later on with radiotherapy. Needless to say this made matters worse. I never thought I would have to manage a household at such a young age! I felt like a married woman juggling my life to accommodate all around me. I was so drained that I had to give up my job and became recluse at home.

I became detached and isolated from friends and colleagues. I remember that when I was 19 I used to peep out of the window to have a glimpse of my friends on their way to entertainment hot spots; I always ended up crying in my bedroom. My only outings were the monthly visits to the oncology and

psychiatric departments and to collect my mother's medication from the pharmacy.

It is said that every cloud has a silver lining. At that time I enrolled to participate in courses organised by the Local Council. This gave me the opportunity to learn several crafts, including Maltese lace-making and *ganutell* (embroidery with silver and gold thread). I started gaining the self-confidence I had lost because of the burden of caring for someone who was chronically ill.

When I was 22, while I was attending a lace-making lesson, my sister came to break the news that our father had suffered a stroke. An ambulance had already taken him to hospital while I stayed at home with my mother. My sister later informed us that his prognosis was very poor. This was a great shock for me. My siblings looked after my father whilst he was in hospital for two and a half months and I took care of my mother.

In the meantime my father's condition improved, but he was unable to walk. This was a big setback for me as he used to give me a helping hand. It was very difficult for me to accept the fact that my active and helpful father was now wheelchair-bound. This took its toll on me and I felt exhausted as now I had to take care of my father's daily needs. I still do that, but the fact that 11 years have now passed has enabled me to balance my needs with my father's.

Although I had much support from my siblings and neighbours, I still felt alone and many times despair at the situation. About four years after my father's stroke, the family received a devastating telephone call informing us that my brother, who lived abroad with his wife and two children, had been killed in a car accident close to his home. The collision happened when the young man driving the car from the opposite direction, lost control while having an epileptic fit. He was not supposed to be driving because of his condition.

This news devastated us, especially my mother; however, I did my utmost to care for my parents in this time of further decision. This mission became more difficult when I was 23. I twisted my leg and although I consulted specialists I did not recover properly at all. For the next three years my mother started believing she was worthless and we started to notice symptoms of dementia. She would on occasions wet herself without realising or forget the cooking on the hob. Her behaviour posed some danger, so I was obliged to seek the help of a nurse.

The nurse began to come three times a week to take care of my mother's personal needs but in time her condition deteriorated and once she even fell and became unconscious. I had to call an ambulance and from then we all decided that she should be taken to a residential home. Although it was a hard decision to make and it was difficult to accept the fact that my mother was not going to be home with us any more, I believe it was the right decision.

After my brother's death I realised that my life was hardly a pleasant one. I did not blame it on the fact that I had to dedicate so much time to my parents, because it was not their fault for getting ill early in life. It was because life itself is short and should be enjoyed. I opened up to my friend about these feelings and she helped me a lot. I also spoke to a social worker who told me I should go out and enjoy myself with my friends. This advice helped me greatly because I was getting obsessed with the thought that I would be neglecting my parents if I did go out and enjoy myself.

It felt odd at first but I began to go out a few times. I have learned much from my experiences and I have no regrets as regards the past. I try to focus on the positive aspects of what our family went through and appreciate them in order to raise my morale. I believe I've matured through self-discipline, support from my sister especially, my married brother, friends, family, neighbours, the Hospice Movement and

above all, the Lord.

Today I am working part-time and broadening my knowledge on things that interest me while still taking care of my father and visiting my mother often. I am proud of myself in a good way because I have progressed through this mission that has taught me how to deal with life and its difficult circumstances with the strength that only comes from God. These days I feel that serving others is important in my life and in fact when I see an elderly person in need, I automatically try to find ways to help them.

One has to face life with faith in order to move ahead.



15. Towards a strong voice for relatives



by Connie Magro

Family members who shoulder the responsibility of caring for a mentally ill relative need to make their voice heard. They need to summon up the confidence to ask more questions of professionals, to unite and to take well-planned action together. For relatives, this means that while they fulfil their duty as caregiving relatives and as citizens, they need affirmation as citizens who are contributing in a meaningful and invaluable way to community care.

- Caregiving relatives face a number of overwhelming challenges:
- Limited availability of hospital beds, especially in the general hospital;
- Limited spaces in residential facilities, especially when the sick person is under 60;
- Fulfilment of day-to-day caregiving without any support or little respite;
- Having to solve problems that professionals often fail to recognise;
- Bearing crippling financial burdens;
- Lack of a key person who acts as a reference point;
- They are able to identify service gaps but do not know how to make their recommendations known to policy makers;
- Having to improvise in a crisis situation;
- Feeling isolated;
- Failure to acknowledge the need to care for themselves physically and psychologically so as not to break down under stress;
- Fear of developing mental illness themselves;

- Learning how to keep calm in crisis situations;
- Reluctance to ask for help from their extended family members and friends;
- Juggling job, family, caregiving and social life responsibilities;
- Fear of losing their job – an all too frequent occurrence, since caregiving is very demanding;
- Living with stigma and discriminatory situations;
- Fear of losing one's temper when insulted or threatened in a crisis situation;
- Accessing effective and dependable mental health services.

Main concerns regarding carers' sick relative

Apart from these day-to-day challenges, family caregivers feel highly concerned about their mentally ill relative. Some of these concerns include:

- Fear of being harmed by their relative, fear of self-harm or harm to others;
- The secondary effects of medication;
- Difficulties faced by the relative in taking medication or stopping medication;
- The effects of non-compliance and relapsing;
- Concerns about what would happen to the sick relative when the caregiver is unable to provide care or dies; the effects of being unable to continue providing care;
- Difficulty in accepting the limitations and constraints of mental illness;
- Erratic contact with professionals or frequent change of professionals.

What action do families of mentally ill persons take to make their voices heard?

The following are some examples:

- Families and caregivers across Europe have set up organisations to combat stigma and discrimination;
- They are organising self-help and support groups;
- They organise psycho-social educational talks, seminars and conferences;
- They engage in activities that raise public awareness of the needs of families of mentally ill persons;
- They are promoting the concept of triadology – dialogue between three concerned parties;
- They are uniting especially at European level; EUFAMI is a prime example, having a membership from 28 countries.

EUFAMI (European Federation of Association of Families of People with Mental Illness) contributes to family empowerment across Europe through the following initiatives:

- Promoting best practice;
- Helping to reduce discrepancies in the provision of care between Eastern and Western Europe;
- Identifying bad practice so that lessons can be learned and more robust practices promoted;
- Campaigning for positive change and challenging certain concepts that are creating obstacles to change;
- Spearheading new research on the causes and treatment of mental illness;
- Campaigning against stigma;
- Advocating and promoting partnerships and collaboration with health professionals;
- Identifying barriers to partnerships so as to be in a stronger position to tackle them;
- Through its PROSPECT programme, sensitising social and health professionals;
- Suggesting new approaches;
- Helping to improve communication between all interested parties.

Suggestions for other stakeholders

Professionals should:

- Recognise and affirm family caregivers' invaluable contribution;
- Facilitate communication with relatives;
- Become a reference point for families;

- Encourage relatives to express their views on their subjective experience;
- Identify the carer's needs, concerns and worries;
- Involve families in a care partnership;
- Inform families about the illness, the medication and any side effects;
- Provide much needed information while using understandable language;
- Ensuring family perspectives in research studies;
- Be humble enough to acknowledge that professionals can learn from the experience of family caregivers.

Employers should:

- Create flexi-time opportunities for family caregivers who constantly struggle to juggle family and work responsibilities, making them risk losing their job;
- Consider offering such workers the possibility of reduced hours, especially during crisis periods;
- Consider approving emergency leave-taking especially when under heavy stress;
- Be informed about mental illness and the overwhelming pressure and pain of mentally ill workers and their families, including caregiving workers;
- Seek creative supportive measures so that workers do not risk losing their jobs because of caregiving responsibilities at home;
- Acknowledge the diversity of individual situations.

Policymakers should:

- Policymakers need to acknowledge that family caregivers are saving the state millions annually in social and health care services. Policymakers should therefore:
- Develop specific support services for family caregivers;
- Finance helplines that provide emotional support to carers;
- Involve relatives in planning and providing support services for other carers;
- Provide well-planned and dependable mental health services that can be accessed by carers;
- Establish a legal framework on the rights of family members and caregivers;
- Set up standards and guidelines to be followed by mental health practitioners with respect to supporting family caregivers;
- All mental health services should be monitored to ensure quality while at the same involving experienced caregivers in the process.

The current reality of family caregivers

- Families become more altruistic when a member develops a mental illness;
- They are breaking barriers to partnerships with professionals;
- They are becoming more aware of their own personal needs as carers;
- They are seeking opportunities through which they learn to communicate better with their ill relatives and with professionals;
- They are calling for a greater equality of mental health legislation across Europe.

The future

The European Declaration on Mental Health and the Mental Health Action Plan for Europe identified the empowerment of people with mental health problems and their families as a key objective for the next decade. The Action Plan will be focusing on holistic care that embraces the crucial role of the family and its support. Families are putting pressure on policymakers to change the content of academic training of professionals; they stress that relatives should be included as resource persons in the curriculum implementation and that professionals should be trained to move away from the medical model of practice to a bio-psycho-social one.

Conclusion

“As a person who provides support to a family member with mental health problems, do not allow anxious thoughts about the negativity around you to erode your balance and well-being; you are in control of whether to allow troubling situations to disempower you or not. Rather, focus on ways that give you a handle on how you can manage difficult situations so that you do not give up.” (Les Brown)

An empowered person is able to turn any situation into a blessing and advantage. An empowered person is able to embrace challenges and turn them into opportunities. The most effective way of overcoming stigma is for the family to speak out. For carers to know another carer's trials and successes is knowledge and knowledge is empowering. By voicing their commonly felt concerns, suggestions and needs, family caregivers turn the tables on stigma – making it a catalyst for empowerment and positive change. Empowerment restores hope, reinforces courage and bolsters resilience.

Source: Author's presentation at an international conference on Empowering Families and Patients organised by the World Health Organisation (WHO) at the University of Leuven, Belgium, November 2010. Visit the website of EUFAMI (European Federation of Associations of Families of People with Mental Illness): www.eufami.org



16. Frequently asked questions from teachers

on the impact on children of parents' mental illness

QUESTION 1: Can having a parent with a mental illness affect a student's full participation in school?

Firstly, it is important to stress that parental mental illness may not affect a student's school participation. For example,

Parental mental illness may be well managed through medication or other treatments and may have little impact on the student.

Many parents will have mild or short-lived mental illnesses, and their children may not be unduly affected if the illness is of short duration

Students may see school as a place where they can 'take time out' from their family difficulties and simply focus on participation and learning.

Many students will be able to effectively put into practice the excellent skills and abilities they've developed in progressing through adversities in their life.

Secondly, if a student with a parent with a mental illness is having difficulty at school, it's wise to remain open to other explanations for those difficulties. They may have little or no link to the student's family circumstances.

Any marked changes in manner or behaviour, or any persisting difficulties are triggers for school staff to explore the need for additional support for a student. There is a range of indicators that may alert you to the student having difficulties relating to their family situation including:

- absences from school,
- incomplete homework or difficulty meeting work deadlines,
- periods of poor concentration or extreme tiredness,
- difficulties relating with peers and others,
- disturbed or self-destructive behaviour, or
- the student being a victim of teasing.

However, many young people will not be so obviously affected.

It is important to note that the indicators listed above may also be observed in students with a range of other individual or family changes or problems (e.g. a student or parent with a learning difficulty, a student or parent with an alcohol, gambling, or substance abuse problem, changing family structures and circumstances, personal physical or psychological health issues) so it may be difficult to identify the cause of the student's difficulties.

School staff may also never learn that the causes of a student's difficulties are related to parental mental illness because:

- Many parents and children choose not to reveal parental mental illness to others (often due to the current stigma attached to mental illness in society).
- The parent or child may not wish to reveal that they have a mental illness because they are concerned about the confidentiality of information disclosed.
- Some younger children simply do not realise that their parent is unwell.
- The parent or child may not believe the parent has a mental illness.
- The illness may not be diagnosed.

- Some parents (and their children) try to keep their illness a secret, fearing that the children will be taken into care.

However, schools do not always need to know the cause of a student's difficulties at school, as long as they have systems to offer support to enhance the student's successful participation in schooling.

QUESTION 2: How can I deal with the student's problems if I'm not sure of the cause?

You're probably doing a great job already if you can acknowledge that a student is having difficulty accessing the curriculum, no matter what the cause. All children and families are different and it is important that you address the individual issues as they present themselves to you. Utilise the procedures/practices within your school to assist with the most common difficulties students encounter, whatever the reason. For example:

- Is there a school policy that covers negotiation of work timelines in the face of individual or family difficulties? (If so, are students fully aware of it?)
- Do students have access to a 'homework' location outside their home?
- Is there a clear policy about student support and confidentiality so that students know who can be approached for support and what is likely to happen if they do this?
- Are there strategies to support hungry children or students with other care needs?
- Can students access counselling services if necessary?

QUESTION 3: What can I do if a student or parent reveals information about a parental mental illness?

- Listen in a non-judgmental way and value the person's experience.
- Assure the student/parent that they are not alone and that many parents – and other community members – have mental health problems at some time in their life.
- Ensure confidentiality and respect privacy – for both the student and the parent – except in situations where you have concerns for the parent, student or other person's safety. If there is a potential threat to others you should alert your Head of School so that the situation is reported to the child protection service or the police.
- Ask the student/parent if they can foresee or are aware of any barriers to the student's participation in school as a result of the parental mental illness. Remember, parental mental illness does not automatically mean that the student will have difficulties accessing the curriculum or interacting with peers.
- Encourage the student or parent to speak to an appropriate support service if major difficulties are identified. This may be the Head of School, a school counsellor or psychologist.
- Encourage the student/parent to realise that all families are different and that there is a lot to be celebrated about difference and the unique skills and experiences that students living with illness in their family bring to their school life.

Source: Materials developed for teachers by the Children of Parents With a Mental Illness (COPMI); an initiative undertaken by AICAFMHA (Australian Infant Child Adolescent and Family Mental Health Association) for the Commonwealth Department of Health and Ageing, 2003. Information about the initiative and links to relevant resource information can be found at: <http://www.aicafmha.net.au/copmi/>



17. Declaration on the Rights of Family Caregivers

Organisations of carers in Europe have come to the conclusion that since family caregivers are the primary providers of community-based care:

1. They should be openly acknowledged as equal partners in the provision of care;
2. Their views should be heard and their contribution recognised;
3. They have a right to information on how to swiftly and effectively access help in a crisis situation;
4. They have a right to learn from expert practitioners about the nature of both the illness of the family member they care for and the prescribed treatment regimen and how to deal with particular situations;
5. They need access to learning about key preventive measures to protect their own health and safeguard their well-being;
6. They need effective support services for themselves in order to be able to continue providing effective care as well as to sustain their care provision;
7. They need up-to-date information on relevant support services and how to access them;
8. They have a right to life beyond their caring milieu in line with the Universal Declaration of Human Rights;
9. They need to be fully consulted and involved in the development, implementation and evaluation of policies which are affecting them or which can potentially affect them.

Source: Adapted from a document issued by the World Health Organisation (WHO) in conjunction with Schizophrenia Fellowship Scotland.



18. How...? 14 principles for relatives

How to relate to mental illness: 14 principles for relatives.

REALISE that the illness is not rare. It may seem to be, but that's because it is 'not talked about'.

LEARN as much as possible about the illness: its cause, its course, its outcome.

NEVER blame yourself: it can destroy your chance of coping. Mental illness is not caused by relatives.

SEEK professional helpers who are **EFFECTIVE**.

CONTACT a self-help group for families with mental illness.

ACCEPT that with such a complex illness, we relatives **DO** need training.

GET TO KNOW the ever-increasing pressures to which we relatives are subject.

PAY GREAT ATTENTION to the needs of the other members of the family.

TAKE HEED that unlimited conditional self-sacrifice is fatal to effective caring and coping.

BE AWARE that spending massive amounts of time with a sufferer can make matters worse.

MAINTAIN AND ESTABLISH friendships, activities and hobbies.

SET YOUR SIGHTS on appropriate independence for your relative **AND** for yourself.

DON 'T BE SURPRISED that in the end **IT IS THE ABILITY** to change and look at things differently, that will distinguish relatives who will cope from those who will not.

TAKE very great **CARE** of yourself.

Source: – Ken Alexander, Victoria Organisation for Relatives, Australia. Adapted with permission



Afterword — by Nora Macelli

This book is the result of a lively and continuing collaboration between the Mental Health Association and the St Jeanne Antide Foundation, two organisations that strongly believe in the significant silent contribution of family caregivers of those afflicted by mental illness.

After reading the experiences of 14 persons who have been, and are still, bearing considerable responsibilities, one will see that there are several points of similarity across the narratives. None of the contributors had any meetings with the others to discuss their own experiences. Nevertheless, their testimonies point towards a number of common lessons that we should keep in mind whenever we are in a position to manage any support given to such family members. What are these common lessons?

1. When one of the parents chooses to ignore what is crystal clear to everybody else, then the family suffers and fragments. When both parents acknowledge that there is a problem; together seek professional help; look up information about the mental illness at the time it is being identified; summon up courage to discuss, learn and seek help as a family; then the chances are that the family will grow in unity and strength.

2. When the professionals involved in treating the mentally ill person refrain from making the effort – because of pressure of work, or maybe from a belief that the treatment is being given to the patient and not to the family members, or for other reasons – then the family suffers needlessly. The voice of the family caregivers is very clear: help us by listening to us, dialogue with us, teach us and guide us; it is we, the family members, who have to live 24 hours a day with your patient, not you. We shoulder the lion's share of the responsibility for care and treatment.

3. All the contributors to this book emphasise the need for information. All agree that clear and timely information about the disease and its treatment would remove the dizzy disorientation that they feel, would help them to focus, and would restore to them a measure of control over their own lives.

4. Young children also contribute their share. Several of the chapters were written by adults who have, since childhood, been taking care of their mother, father, brother or sister. You will see how much we need to reach out to find such unacknowledged, unknown children, who are giving their best, in most cases without any support. Please read Chapters 1, 3, 5, 7 and 9 and you will see what difficult circumstances must be suddenly faced by some children; you will also see how they discovered inner resources, coped, and even developed a strong personality. All of them will tell you how deeply they felt the need for someone to be with them for a while, to explain to them what is happening and what may still take place, so that they may understand, and may know what they can do.

5. Family caregivers are very creative. In one way or another, even when all doors have been closed in their faces and they feel without any support, they find new ways of helping their sick family members. Please read Chapter 7 and you will see a living examples of such creativity, drawn by deep love and an intuition that remained alive.

6. Another common thread is the strong message that "the more we work together, the more we will be able to find a solution." This message emerges clearly from the experiences of family caregivers who became members of the Mental Health Association after taking part in a course designed for relatives, and found totally unexpected fellowship of cooperation with other families. Our experience teaches us that when you organise a course for family members, door after door opens up for them; new friendships with other similarly afflicted families; access to more information and knowledge; capacity building on self-

care; and the potential of giving voluntary service to serve other families that may be still disoriented and distraught.

The same things happen in a support group. Support groups are a boon to relatives, especially those who find no support from their own families. As the book's contributors tell us: when your own family members show you no understanding, you will find, in a support group, persons who become your second family.

7. Relatives of mentally ill persons are at high risk of succumbing to depression. Some become depressed and recover with some assistance. Others have learnt early that if they don't take care of themselves they will collapse, yield to chronic depression, and for them all is lost. Persons who worked hard to avoid falling into a depression and succeeded, remained healthy and continued to shoulder the responsibility they undertook, thanks to the solutions they found and the assistance they got.

The solutions mentioned are diverse, but all of them have the same motivation: I need to be positive and to remain open to whatever it is that I can do. Among the solutions mentioned we find sports, drama, singing, studying, taking a holiday, and finding friends who know how to listen and be compassionate rather than judgmental. As one young woman tells us, "since I turned 13, I have always been active in some sport, so that I remain positive and don't brood over the problems I had at home."

8. A collective effort is important for the mentally ill person to learn to take responsibility for their own medication. Family caregivers tell us that where this happened, some equilibrium was reached in the family. "Fortunately she remained responsible for taking her own medicine, so we could build on strong foundations. If she had not continued to take her medicine consistently, there is no way we could have kept some order at home."

9. Throughout these pages, the voice of all the family members and relatives is hoarse with the grief and sorrow of agonising circumstances. But the radiance of the star of hope enlightens all experience, as whoever cares for a close relative at all costs does this because he or she knows how to love.

10. Most importantly, we see strength and humanity germinating from the suffering. "This experience made me more human, more able to be compassionate where there is suffering, I learnt to stand in the shoes of whoever is suffering, and walk a mile in them." "Taking care of my mother brought about a transformation in me." "I found God in my wife's illness."



Appendix 1: Tool for writing a personal experience

by relatives of mentally ill persons

The Mental Health Association and the St Jeanne Antide Foundation have jointly planned a book containing personal experiences of relatives of persons with mental health problems. Some of the aims of the book are:

- To provide encouragement and hope to close relatives of newly diagnosed mentally ill persons;
- To sensitise professionals to relatives' experiences;
- To show relatives the range of helping roles that relatives may have so that they become self-empowered;
- To reassure relatives and carers by showing them that there are others who share their experience and that they need not be alone;
- To provide direct guidance to carers and close relatives on how to accept and manage their reality;
- To provide a tool for sensitising and informing teachers who may have students of mentally ill parents in their classes;
- To sensitise the media about mental illness.

In order to facilitate the writing of one's personal experience, we are providing relatives with a list of questions as a focus and guide for their writing.

GUIDE FOR THE PERSONAL EXPERIENCE CHAPTER

A. Before onset and just after:

- Describe your own life and family life and the way it changed with the onset of your family member's illness.
- How old was your family member when diagnosed? How old were you?
- What were the signs and symptoms that led the family to suspect that there was a problem?
- How long did it take you to realise that it was a mental health problem?
- Once you realised that the relative had a mental health problem, what were the difficulties all of you faced?

B. Effects on the family:

- What effects did the mental illness have on relationships within the family; extended family; neighbours; friends; colleagues at work?

C. Effects on yourself:

- What kind of distress did you have: distress, pain, fear, loss, lost hopes, guilt, burden, anxiety, stress, burnout, anger, shame, felt excluded or not accepted by society? Explain.
- What changes did you observe in yourself?
- Did you look at yourself in a different way? If so, how?
- Have you ever blamed yourself in any way? Explain.
- Did anyone blame anyone else in the family?
- Do you still have some of these? Explain.
- In what way did the experience enrich you and in what way did it diminish you?

D. Your support role:

- Give examples of tasks you had to do in connection with caring for your relative. (Examples: administering drugs; being his/her advocate; liaising with professionals; accompanying to appointments; cooking, etc.)
- Describe a bad day and a good day for you after the onset of the relative's illness.
- How far were your relatives helpful?

E. Support services tapped:

- What did you do to seek support? What difficulties did you encounter when you sought support?
- How difficult was it to decide to approach a professional? Did you go privately or through the mental health system?
- Tell us about your experience of professionals.
 - What kinds of professional help were you offered?
 - Which of these did you need or not need?
 - What were the difficulties, if any, in getting this help?

- How do you judge the professional help that your relative received?
- How do you judge the professional help that you and your family received?
- Did you have sufficient information about support services (government and non-government)?
- What do you have to say about the quality of the professional services given?
- What did you find most difficult in relating to professionals?
-
- Looking back, can you think of any form of professional support that should have been given? Explain.
- Looking back, can you think of any form of support (non-financial) that was missing? Explain.
- What were the things that helped you accept the situation?
- Was there anything that you had to give up because of the illness?

F. Your overall opinions:

- Looking back, which part of the experience did you find most difficult?
- Do you believe that there can be a recovery from the mental illness for your relative? What did you find most difficult in relating to the person with the mental health problem.
- What are your concerns for the future?
- What would you like to recommend to other people in your position?



Appendix 2. Caregivers: How are you?

Caregivers self-assessment questionnaire

Caregivers are often so concerned with caring for their relative's needs that they lose sight of their own well-being. Please take just a moment to answer the following questions. Once you have answered the questions, turn the page to do a self-evaluation.

During the past week or so, I have:

1. Had trouble keeping my mind on what I was doing. () Yes () No
2. I felt that I couldn't leave my relative alone.() Yes () No
3. I had difficulty making decisions.() Yes () No
4. Felt completely overwhelmed.() Yes () No
5. Felt useful and needed.() Yes () No
6. Felt lonely.() Yes () No
7. Been upset that my relative has changed so much from his/her former self. () Yes () No
8. Felt a loss of privacy and/orpersonal time.() Yes () No
9. Been edgy or irritable.() Yes () No
10. Had sleep disturbed because of caring for my relative.() Yes () No
11. Had a crying spell(s) () Yes () No
12. Felt strained between work and family responsibilities() Yes () No
13. Had back pain.() Yes () No
14. Felt ill (headaches, stomach problems or common cold).() Yes () No
15. Been satisfied with the support my family has given me. Yes () No
16. Found my relative's living situation to be inconvenient or a barrier to care.
17. On a scale of 1 to 10, with 1 being "not stressful" to 10 being "extremely stressful," please rate your current level of stress.
18. On a scale of 1 to 10, with 1 being "very healthy" to 10 being "very ill," please rate your current health compared to what it was this time last year.

Comments: (Please feel free to comment or provide feedback.)

Self-evaluation

To determine the score:

- Reverse score questions 5 and 15. (For example, a "No" response should be counted as "Yes" and a "Yes" response should be counted as "No.")
- Total the number of "yes" responses.

To interpret the score

Chances are that you are experiencing a high degree of distress...

- ... if you answered "Yes" to either or both questions 4 and 11; or
- ... if your total "Yes" score = 10 or more; or
- ... if your score on question 17 is 6 or higher; or
- ... if your score on question 18 is 6 or higher.

Next steps:

- Consider seeing a doctor for a check-up for yourself.
- Consider having some relief from caregiving.
- Discuss with the doctor or a social worker the resources available in your community.
- Consider joining a support group.

Source: American Medical Association



Appendix 3: The Mental Health Association (MHA) Malta

The Mental Health Association is a non-government organisation that supports families and relatives of persons who suffer from mental health problems. The aim of MHA is to eliminate social stigma about mental illness through:

- educating the general public, school students and relatives of sufferers;
- disseminating information and propagating knowledge about mental health;
- liaising with community-based services in support of relatives;
- publishing books for relatives;
- encouraging sufferers and their relatives to help each other and themselves.

History of the Association

Originally launched in 1982 as *Schizophrenia Association* by then Consultant Psychiatrist Dr Abraham Galea and others, the aim was to provide group support to schizophrenia sufferers and their relatives.

In time, the group felt it should also begin to help other persons who suffer from other types of mental illnesses and their relatives. In 1998, the *Schizophrenia Association* was renamed the *Mental Health Association*.

EUFAMI (European Federation of Associations of Families of People with Mental Illness)

There were times when members of the Association felt they were alone and wished for support from international associations. In 2000, MHA was invited for the first time to the annual EUFAMI Congress which was held in Berlin. MHA gained an associate membership of EUFAMI in 2001 and full membership in October 2005.

EUFAMI is the European Federation of Associations of Families of Persons with Mental Illness. The non-profit international organisation strives very hard to support caregivers to be in a better position to improve the care and well being of patients who suffer from mental health problems and to raise the standards of care. EUFAMI encourages its members organisations to work together at both national as well as on a European level through the sharing of best practices and anti-stigma campaigns. EUFAMI assists member organisations with their efforts to improve conditions within their respective countries, whilst respecting each country's autonomy.

The development of the Association

In 2002, the Prime Minister's wife, Mrs Kate Gonzi, was chosen Honorary Chairperson of MHA. In May 2004, representatives of MHA attended a course on how to promote an anti-stigma campaign. This course was a great opportunity for MHA to speak more in favour of the rights of persons with mental health problems. On 10th October 2004 the campaign Zero Stigma was initiated as part of a wider EUFAMI strategy.

In May 2006, MHA participated in the PROSPECT course which was held at Amersfoort, Holland. The purpose of PROSPECT was to provide information to persons with mental health problems, their families and friends, as well as professionals who work in the mental health field. In September 2007, MHA members attended the fourth EUFAMI Congress in Turin, Poland, explored topics related to best mental health care practices, community services and policy making within Europe and other countries.

MHA Activities

MHA organises support groups for relatives to share their experiences and provide assistance and mutual encouragement. The Association also organises lectures by professionals within the mental health sector who provide valuable information to relatives.

MHA has published three children's books on mental health problems within families. These books have been distributed to primary schools whose students range from 6 to 9 years through the Personal and Social Development (PSD) secondary school Teachers during the 2005-6 scholastic year. MHA implemented an educational programme in primary schools who's students range from 6 to 9 years (from the fourth year to the sixth year of primary). The purpose of this educational programme was:

- to significantly reduce the stigma that is linked with mental illness which affects children and their families;
- to promote mental health amongst school communities.

Conclusion

The process to establish the MHA was long and entailed significant commitment from members. It is with satisfaction that a number of initiatives, such as the annual course on mental health, have become synonymous with MHA. Membership of EUFAMI has enabled MHA to be a member of a wider and richer family through which it can continue to work to empower relatives of mentally ill persons.



Appendix 4: The St Jeanne Antide Foundation (SJAF)

The St Jeanne Antide Foundation (SJAF) is a family- and community-focused not-for-profit organisation committed to identifying and supporting very vulnerable and poor families in a holistic manner. It was set up by the Malta Province of the Sisters of Charity of St Jeanne Antide in collaboration with lay persons and is administered by a governing board with a chief executive officer. It is registered as an NGO with the Office of the Commissioner for Voluntary Organisations (VO/0005).

SJAF is based in the community of Tarxien and works in partnership with community-based organisations and state agencies and NGOs that are national in scope. It engages in outreach work as a means of identifying and supporting hard-to-reach vulnerable and poor families, assisting them as closely as possible to where they live. Since its establishment, the Foundation has set up a number of core services. Being based in a local community, SJAF has naturally evolved into an organisation that is at the service of the local parish communities and its neighbouring ones. Its scope is local, national and international.

The objectives of the Foundation are:-

- to identify, understand and raise awareness about under-served and un-served categories of excluded or vulnerable persons;
- to develop and implement programmes in support of identified under-served and un-served categories of vulnerable persons, families, and minority groups;
- to support and train a number of persons to make their own contributions to society and to persons in need;
- to provide the opportunity and training to service users so that they themselves can provide services to others in need;
- to be open to voluntary service of young people who would like to offer time and energy at the service of others in order to gain experience and insight;
- to create links with overseas agencies that work in line with our mission, to share experiences, give and get support, and widen our vision.

Services

The Antide Centre

A drop-in centre welcoming individuals and families facing a number of life challenges. Families are offered access to psycho-social and learning support and information about existing public and NGO services. The Centre is open daily between 7.30am and 5.30/7.30pm in winter time and from 7.30am to 1.30pm in summer. It is based at 51, Tarxien Road, Tarxien. The Centre issues a monthly e-magazine for its volunteers, staff and collaborators (all downloadable from: www.antidemalta.com). The Centre is a hub for educational activities and service provision. Volunteers provide a range of services at the Centre. Service users are encouraged to become volunteers.

Social Work and Counselling Service

Social work and counselling services are offered to vulnerable individuals and families at the Antide Centre, the Żabbar office and through home visits. Emotional freedom therapy is offered to service users. A volunteer nurse and volunteer befrienders regularly undertake home visits in support of lonely, home-bound, frail persons. Non-formal education courses are organised around interests expressed by service users themselves. Service users are encouraged to volunteer as part of their support and growth process. Referrals are encouraged from neighbouring parishes. The majority of referred families have a member suffering from mental health problems. Community outreach in neighbourhoods with a

concentration of social problems ensures that hard-to-reach vulnerable individuals and families are identified and a relationship built with them. Assistance is extended to parish Diaconia commissions who request guidance on the development of support services. Volunteer handymen undertake home improvement work in poor people's houses.

LWIEN – support to family caregivers of mentally ill persons

The LWIEN Service acknowledges the key role of family members in caring for a mentally ill family member. Aware of the overwhelming burden of care of such family caregivers, including the need for specialised support for them, LWIEN offers them:

- family consultations with a senior psychiatric nurse, including home visiting;
- support groups – Depression Support Groups and Caregivers Support Groups;
- social work support, counselling and emotional freedom therapy;
- provision of self-help materials aimed at family caregivers.

Learning Support Service

Through this service, vulnerable and poor persons of all ages are encouraged to access a range of learning support opportunities so as to continue their lifelong learning journey. Opportunities include:

- A learning support service for children: A group of volunteer tutors offer learning and homework support to children of families being supported by the Foundation's social workers. The service is provided on two weekday afternoons: Wednesdays (Arts, crafts, music, reading, cooking) and Fridays (homework support).
- Non-formal education courses for adults: A range of courses are designed and offered to service users and volunteers depending on their interests, suggestions and volunteering roles. Basic Maltese literacy and self-esteem courses are offered on a regular basis. A Family Club focuses on parenting, managing the family budget, cooking nutritious meals on a budget. Cultural outings are organised on a monthly basis.
- Live-ins: for socially excluded youths and children.

The Homework Support Service

A group of volunteer tutors offer learning and homework support to children of families being supported by the Foundation's social workers. The service is provided on two weekday afternoons: Wednesdays (Arts, crafts, music, reading, cooking) and Fridays (homework support).

Non-formal education courses:

A range of courses are designed and offered to service users and volunteers depending on their interests, suggestions and volunteering roles. Basic Maltese literacy and self-esteem courses are offered on a regular basis. A Family Club focuses on parenting, managing the family budget, cooking nutritious meals on a budget. Cultural outings are organised on a monthly basis.

Live-ins: for socially excluded youths and children.

Overseas Development Assistance

The Foundation develops projects in support of poor communities in developing countries in association with other organisations. Partial funding from the Overseas Development Aid of the Ministry of Foreign Affairs, Malta is sought for these projects. These include the building of a rural clinic in Pakistan (2010), resourcing a vocational education centre for poor women in the Central African Republic (2011), a women's development project in South Sudan (2012) and the construction of a rural clinic in Malawi (2013).

