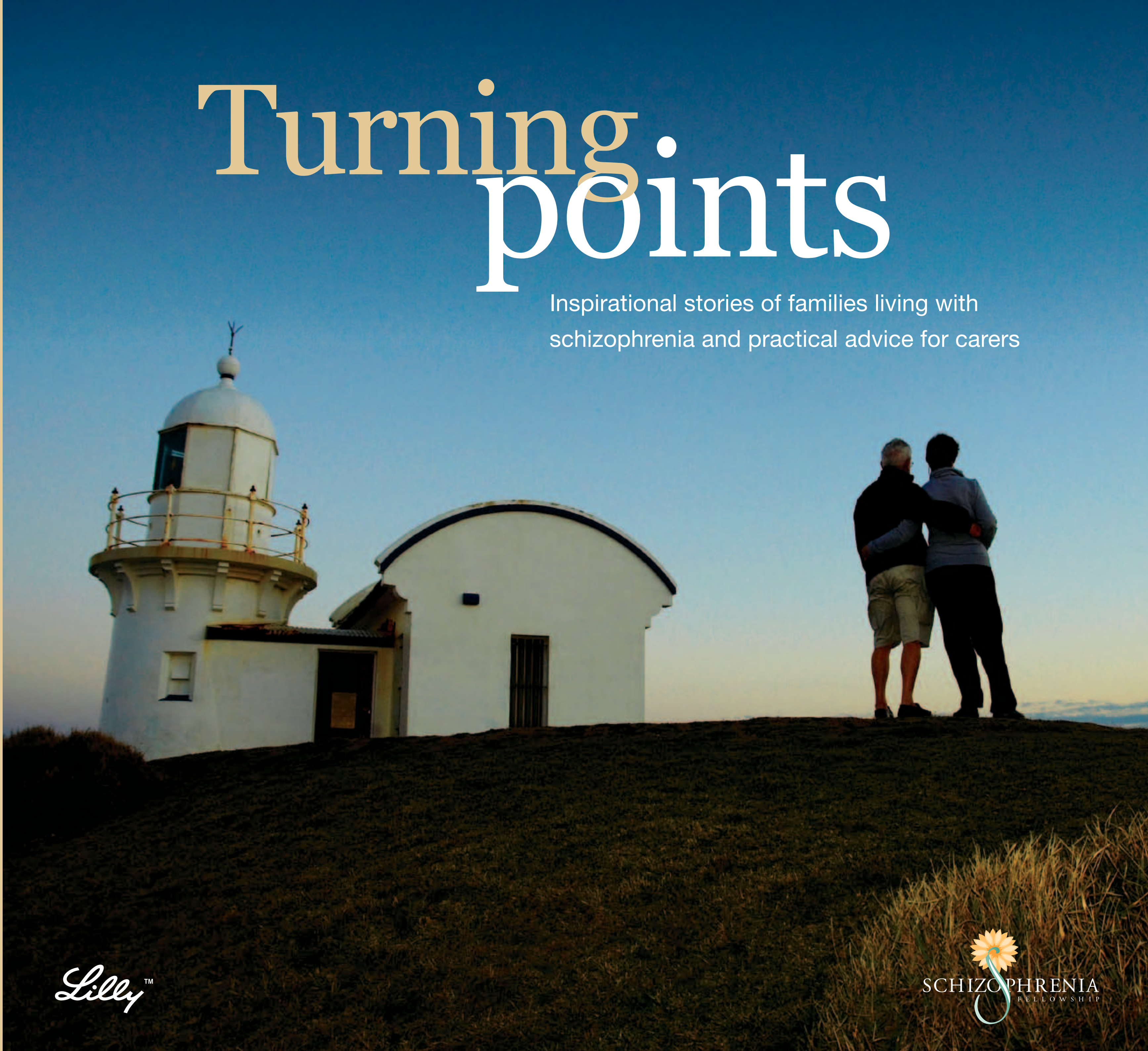
Turning points

Inspirational stories of families living with schizophrenia and practical advice for carers



Lilly™

SCHIZOPHRENIA FELLOWSHIP

Contents

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Foreword

Life is full of turning points and I have experienced a few of them personally and politically.

One of the very special turning points is the birth of a child, a child of your very own to nurture and love. Here is the future so full of promise and possibility.

For some, another turning point comes when you are told that your child has a mental illness. This can be a place of fear, uncertainty and confusion. It can be the beginning of a long and difficult journey for both you as a parent and your child. Yet there is and should be hope. All mental illnesses are treatable.

Although there are no cures, every person with a mental illness can improve and live a life with meaning and purpose. There have been major advances in medical and psychosocial treatments and there is a growing awareness and acceptance of mental illness in our community, which is reducing stigma. Our journeys can be made easier through sharing, mutual support and through an acknowledgement that things have changed but they can still be good.

Within these pages are the stories of folk just like you and a resources section with useful tips and places to get information and support. I commend this book and hope that it is a turning point for you.

The Hon Frank Walker QC

Attorney General NSW 1976–1983

Vice President, Mental Illness Fellowship of Australia

MENTAL ILLNESS
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Amy with her brother Liam

Amy's story

Amy is 20 years old and helps care for her 24 year old brother.

REFLECTIONS

When Liam was younger he was really popular. He was good at sport and was even School Captain in Year 6, but once he started high school he started to go off track.

I remember once he was walking down the road and a dog ran out and apparently bit his foot so he went home, got a knife and went back to the house and started abusing the people inside, and the police had to be called.

I was only nine or 10 at the time so mum and dad tried to shelter me from incidents like this. When the police came to our house they would often tell me to go next door, but when I got a bit older and realised what was happening to my brother it upset me a lot. At the time, I didn't talk to anyone about how I was feeling but bottled everything up inside. I even hurt myself to get rid of the pain.

No one really seemed to understand what we were going through. People just don't understand schizophrenia. I remember someone telling me the illness was like a germ. The neighbours in our street turned against us because of the things that Liam had done. All of Liam's friends' parents stopped them from having anything to do with him and we weren't invited to the street Christmas party anymore.

As Liam got older he got worse. He began fighting with people all the time, got more into drugs and started drinking a lot. He was in and out of rehab, but one of the hardest things for me was that his behaviour was often unpredictable. I could only wake up in the morning and just hope he was going to be in a good mood. You would never know.

There was one time when we were out having a nice day shopping and he just turned to me and told me all these things he wanted to do to mum and dad – hurtful things out of nowhere. He told me to get him in the Pialla Mental Health Unit or he was going to kill himself. I got him home but he locked himself in his room, refusing to come out, but once I called mum, she rushed home to take him and he calmed down.

This was a really challenging period, particularly for mum and dad who also had the pressure of looking after me.

> "Liam and I are closer than we have ever been. While he is not big on talking and sharing his feelings, it is the small things he does for others that reminds me, despite his illness, he really is a kind-hearted soul who would do almost anything for anyone."

TURNING POINTS

Diagnosis

Despite visits to different doctors, it took several years for Liam to be diagnosed with schizophrenia. The doctors just told us he was an upset child but they did not understand what was happening behind our doors. There is no history of schizophrenia in our family but mum has worked in the area of mental illness and was aware of the signs. I remember mum being relieved when Liam, at 14 years old, finally received the correct diagnosis because it meant he could receive the treatment he needed.

Medication

It was only when Liam reached his twenties that he realised he did have a problem, because he knew when he stopped taking his medication he didn't feel right and became sick.

When Liam does take his medication regularly, he is much more calm and realistic. While he does still keep to himself and is often paranoid, he has started coming out with me and my boyfriend. He often comes go karting and will even come to parties.

He feels good when he spends time with us because a lot of our friends are people who have known him for a long time and can comment on how far he has come.

The challenge for us is keeping Liam on his medication. Mum usually monitors this pretty well but when she and dad are away for work or the weekend, I stay home and make sure he is ok. While it is hard missing out on things with my friends, Liam really does come first.

Drugs and alcohol

Liam has stopped doing drugs now that he is on medication and while he still drinks, he has cut down a lot. He used to be able to drink an entire case of beer in a day if he wanted to and would drink a bottle of beer like water.

He is now much more controlled and will often sit out the back of our house with my boyfriend and they will have a beer together. He seems to like talking to guys more than girls because he will also spend a lot of time with my dad and speak to him about most things. He doesn't speak to mum much anymore.

Community

There are people in our local area who have known Liam for years and realise that, despite his illness, he is actually one of the nicest people around and will do almost anything for anyone. He has a friend who lives nearby and every fortnight he insists on being dropped off at 8am so he can help him with the shopping and then carry his bags home to save him a taxi trip.

Liam has also started working casually and has a goal to work five days a week. He does do a few days work tree lopping every few months but because it is only for a small company there is not a lot of work. When he doesn't get work, he gets down on himself and thinks they don't like him and he is not a good worker. Mum has to then try and convince him otherwise.

> "He never wanted to be this way and while it is upsetting, I don't see it as a curse or anything like that. Seeing my friends who have great relationships with their older brothers is hard, but I do share a special bond with Liam."
>
> Amy

THE ROAD AHEAD

It has been hard growing up without my older brother and missing out on things other girls my age often take for granted, but Liam comes first and it makes me happy to know that I have made a difference in his life.

He never wanted to be this way and while it is upsetting, I don't see it as a curse or anything like that. Seeing my friends who have great relationships with their older brothers is hard, but I do share a special bond with Liam.

My boyfriend and I have decided that in two or three years we are going to move into our own place and get a granny flat for Liam so he can live with us. My boyfriend is also really supportive because his mother has schizophrenia, so he knows what Liam is going through.

Mum and dad are going to retire in the next few years and need their time together. He can't be by himself so we are happy to help out.

Mum thanks me all the time for my help but they have also found it hard. It was upsetting and challenging for them when I was younger because often I had to be put to one side when things weren't going well with Liam.

Sometimes it does all get a bit much but my best friend is always there for me, and I can just go around and sit on her couch and cry anytime I need a release. Mum and my boyfriend are also really supportive when I need to talk. I think it is important not to bottle everything up inside. I used to do that when I was younger and just ended up taking everything out on myself.

I have also found it helpful to take time out and go away for a holiday. My boyfriend and I have already been to Fiji and New Zealand, and he is going to take me to America for my 21st birthday.

Sometimes when people worry about small things, I think to myself, "You should try and think about what I am going through," but it is just my role in life. It is the way God created us and the way it was meant to be.

Sheila with her husband Alan

Sheila's story

Sheila is a mother whose journey caring for her son began more than 20 years ago.

REFLECTIONS

There were times over the years when I didn't know how I was going to cope. I remember driving David to hospital at all hours of the night, waiting for hours in emergency departments.

There were numerous attempts at suicide, and while my son never wanted to die, he did want all the pain and mental torture to go away. I will never forget the fear I felt as I sat at his bedside in the emergency ward just stroking his leg. I asked the nurse, "Will he be ok? Do you think he will live?" The nurse replied, "I'm sorry, I don't know."

I remember driving home from hospital with tears streaming down my face, hoping and praying that it would be the last time, and one day I would wake up and my youngest son would be cured. I lived in hope and thought, "I am his mother. I should be able to fix this."

My journey as a carer began more than 20 years ago. David was just 13 when his dad and I parted company. My two sons were shattered – the family unit was breaking up – but I was determined to support them.

The three of us got through this difficult time and I met my now husband and best friend, Alan. Looking back, it was during this time that we really noticed David withdrawing. He was upset that I had found a new love. The days and weeks which followed became more difficult, and David's attitude towards me became quite hostile. When I arrived home from work he would find any reason to begin an argument and upset me. There were many nights when Alan and I were in bed and David would appear at our bedroom door, wake us up and ask us if we were talking about him. In hindsight, it's obvious that he was hearing voices.

David's condition deteriorated over the years. He couldn't hold down a job, his thoughts were becoming more irrational and paranoia had set in. After much discussion, we took David to see a psychiatrist, he was given medication and we were told he would be ok in a couple of weeks. I believed this, as I did not know any better.

On New Year's Eve in 1993 David came to me in quite an anxious state, said he needed to see a psychiatrist and wanted to go to the hospital. He was having his first psychotic episode and he was frightened.

"The biggest challenge for me as a mother has been to watch my youngest son miss out on some of the most important years of his young life, but David has come a long way and I feel very proud of him. In my eyes, David is not only an angel but a true hero."

This was the start of many hospitalisations and consultations with doctors until finally we received a diagnosis – David was living with paranoid schizophrenia.

After numerous suicide attempts, frantic searches for David after he would run away from hospital, and a string of other incidents involving the police, a decision was finally made to move him to a long-term rehabilitation hospital at Morisset.

He spent more than eight years there, and it was heartbreaking to watch my son miss out on some of the most important years of his young life. For me it was a very dark and depressing time. I felt a tremendous amount of guilt every time we said our goodbyes and returned to Port Macquarie. I felt like I was leaving a part of me behind.

While this period was one of the most challenging for us as a family, Morisset was where David received the treatment he needed, and plans were eventually put in place for him to return home to Port Macquarie, marking a new chapter in our lives.

TURNING POINTS

Meeting my soul mate

My husband and best friend Alan, has been there for me and my boys since day one. He always tells me that as long as I am ok, he is ok. If I am having a bad day and things are getting on top of me, it is him I turn to for strength and support.

We talk a lot about the concerns we have for David, his future and our plans as a family. We also take time out to spend together and have a lovely group of friends who are very supportive of us.

Independence

The day we drove out of Morisset for the last time was a very happy day indeed. I felt like I was getting my boy back. He initially lived in a group home before eventually moving into his own apartment. He is now a fabulous cook, does all his own shopping, manages his own finances, and has recently taken the important step of being granted permission to manage his own medication.

David also does some voluntary work in the community and is a member of Men's Sheds, a not-for-profit organisation that helps deal with mental health issues by connecting men with their communities. He has also recently started looking for some paid work.

Relationships

David still has his battles but I can now call in to his place and sit with him for hours, just listening and talking with him about his illness and the troubles he is experiencing.

David and I like a good cup of tea together and we still manage to have a lot of laughs. In fact, I purposely like to make David laugh as he has a really infectious laugh and a great sense of humour. I really cherish these times we get to spend together.

Helping others

My experiences with David have made me determined to fight for my son's rights and for others who are living with mental illness.

I have always considered myself to be a kind and caring person but this journey has helped me to become a more confident, compassionate and understanding person. It has given me the strength to help as many other people in the community as I possibly can.

"It has given me the strength to help as many other people in the community as I possibly can."

Sheila

THE ROAD AHEAD

I feel very proud of David because I know how much he has suffered over the years, and understand that unless science finds a way to cure schizophrenia, he will continue to have his good days and bad days.

David deserves to have the best in life and we will continue to strive to do all we can to support him. Since day one of learning about David's illness, I have thrown myself into learning more about mental illness and helping others.

If I have a bad day and things start to get on top of me I say to myself, "Well this is today and tomorrow is another day. Get a good night's sleep and hopefully things will be better in the morning."

While Alan is always there for me, I do have moments where I feel alone – times when I wish mum and dad were still here and I could talk things over with them – but that wasn't meant to be. I never once dreamed that in my retirement I would be doing what I am now as leader of Hastings Mental Health Support Group, but as it turns out, there has never been a moment where I have wished I was doing anything different. I have had other people say to me, "Your life would have been so different if David had not become unwell" but now I just don't give it a thought.

If I had my time over, knowing what I do now, I think I would have pursued a career as a social worker. But for now, my husband says, "You are too busy being a mum."

David is such a kind, sensitive soul and it's these attributes that I enjoy most about our relationship. Our personalities really are quite similar and I can often relate to how he is feeling. We both have the same love of camping and fishing, and one day my dream is to buy a campervan and take David on some trips around Australia to show him this wonderful country of ours.

We carers do a lot of grieving, for the grandchildren we will never have, for the loss of the life that my son could have had. However, with the support of my husband and friends, I know I can overcome any challenge that mental illness throws at me.

I am grateful for all those members of my family who want to support me, but not everyone is interested in being educated about schizophrenia or mental illness. For those who don't, I just see it as their loss and move forward.

I feel positive that when it is my time to leave this world I can confidently say without fear or contradiction, "I have done my very best".

Lou with his brother Joe

Joe's story

Joe has cared for his older brother Lou since both their parents passed away.

REFLECTIONS

I have grown up with Lou and lived with the effects of his illness since I can remember. Deep down he is a gentle guy, but it is never rosy looking after someone who does crazy things to you – sometimes you feel like you are going to go crazy yourself.

The hardest time for me was when he first got sick. We didn't know what to do or where to get help. Even the doctors didn't seem to know how to help us. I will also never forget the day I forced him into rehab. It took me three months to recover from the sense of guilt I felt.

Lou was wild when we were young and growing up in Sicily in Italy, and it is now clear to me that his symptoms were apparent from a very young age. He was aggressive, unpredictable and fearless. I remember he would climb up the ledge of a terrace more than 12 metres high and walk along the sides of the building. If he fell he would have died but he didn't care. He had no fear.

When we moved to Australia just a few years later, his behaviour seemed to change, as if he had been cured. It wasn't until years later when he was in his mid-20s and began dating that he showed signs of his illness again. He was extremely irrational towards his girlfriends and very jealous.

We all lived together under one roof but our family was quite dysfunctional. My father had an affair and this upset Lou greatly. They used to fight all the time, both verbally and physically.

When dad died Lou had not forgiven him, they had not made peace. I cried but he did not show any signs of emotion. He often escaped to his room and turned his music up really loud.

It all came to a head when the police picked him up from the middle of a main road trying to direct the traffic. It was then he was taken to hospital and diagnosed with schizophrenia. We had known Lou was sick but seeing him like this was a big shock. Unfortunately it was the start of many hospitalisations.

> "My brother's transformation from wanting to be isolated to wanting to share his life with friends is extremely positive, and while it doesn't erase his illness, it does allow him to have a much better quality of life."

Lou went through many ups and downs, and even improved to the point where he decided to go overseas to Indonesia to get married. My mum and I tried to stop him but we couldn't. Six weeks later, he came back, married, and things seemed to be working out perfectly.

Lou's wife was beautiful and moved in with us, and Lou found himself a job. But then things took a turn for the worse. She started getting very jealous and even violent. It soon became clear she was also battling a mental illness.

It got to the stage where her jealous thoughts affected her so much that she committed suicide in our house. The worst part was we didn't know where she was but mum found her downstairs in our garage. We were all completely destroyed, and Lou deteriorated very quickly and ended up in hospital.

He spent six months recovering in hospital, and the shock was very difficult for all of us to live with. However, despite what he had been through, Lou was eventually discharged from hospital and even managed to hold down a part-time job.

During the next few years, he went through good periods and bad periods in which he was in and out of hospital.

When mum died Lou refused to go to her funeral because he wanted to remember her alive. He did well for a while but once he started to deteriorate again, I stepped in. My mum was a softy and so let Lou get away with a lot.

When I became his main carer, things changed. I was putting my foot down.

TURNING POINTS

Rehabilitation

I moved in with Lou but it quickly became clear to me that he was getting worse and worse. He had completely withdrawn, was talking to the TV, smoking all the time and wasn't taking his medication properly.

It got to the point where I knew intervention was necessary. A police officer and psychiatrist came to the house and forced Lou into rehabilitation, where he would spend the next four years. I felt a tremendous amount of guilt and questioned my decision, but deep down I knew it was the right thing for Lou.

I used to see him practically every day at the hospital, and he would constantly ask to come home. I would argue with him that he must first learn to do things for himself so he could be independent.

The first step was the shopping, which he now does on his own, and while he made a number of improvements including starting washing, cleaning is still really not his thing.

Community involvement

I also encouraged Lou to start catching the bus on his own and, once I was comfortable with his progress, he began taking new steps including enrolling in a course at the same TAFE I was attending. He is now considering applying for another course. He really enjoys being in the class and meeting new people.

He also now goes out practically every day to meet with friends for a drink or a coffee, which is really encouraging.

> "I have learnt that if you think you are struggling to cope with a situation, you need to take a step back. You need to think about the impact on you both emotionally and physically."
>
> Joe

Independence

Since receiving effective rehabilitation Lou can now live on his own. While he still struggles to keep the place clean, he does have more insight into his illness and when he starts not to feel well, he knows he needs to get out of the house.

He receives regular visits every night from a community mental health worker to ensure that his medication is taken, and I also live close by and stop in most nights during the week. We also generally catch up on the weekend.

THE ROAD AHEAD

I always hoped that my brother would get better as he got older, but despite the glimmers of hope I think it is going to be an ongoing struggle.

While his delusions and paranoia continue to plague him to the point where, for example, he believes he can control the outcome of soccer games through the television, there are noticeable improvements.

His transformation from wanting to be isolated to wanting to share his life with friends is extremely positive and, while it doesn't erase his illness, it does allow him to have a much better quality of life.

I often take him out on weekends and we go for a drive to my sister's or aunty's place. Otherwise, we might go to a cafe and just spend some time together.

For me, the journey hasn't been easy. I don't believe that any family member who cares for someone with a mental illness can get through the challenges without suffering from some form of depression. I have, but I was lucky – I had friends to support me so the impact was quite mild.

I have learnt that if you think you are struggling to cope with a situation, you need to take a step back. You need to think about the impact on you both emotionally and physically.

I make sure I take holidays and I am heading overseas soon for a few months. I will make sure I have a mobile phone so Lou can contact me and my sister will be there to help out. Lou does get upset about me leaving and he does panic about the fact I am not going to be there, but I explain to him that he needs to deal with it, otherwise I basically get no time off.

It has been harder for me to get away since my mother died because I am now Lou's main carer, but I don't feel like I have missed out on anything. I am comfortable with the way I am. I have a good job and I feel like I do a lot of the things I enjoy.

Bev with her partner Paul

Bev's story

Bev cares for her son Lincoln with the support of her partner.

REFLECTIONS

I have never stopped fighting for Lincoln from the moment he was born. I have exhausted every possible avenue to support him and left no door unopened.

I remember when he was just eight years old pinning a name tag to my little boy every Monday morning and putting him on a plane to go to Sydney where he could get the help he needed. It would break my heart. He would sob uncontrollably, grab hold of my leg and plead with me not to make him go, but I had no choice.

The nuns from the hospital would tell me, "Call at lunchtime after the plane lands. Everything will be fine." I would drive home alone and wait for hours by the phone until I could make that call. I never realised how much it affected me until now.

I used to pretend to the world that everything was fine but that was a lie. I was desperate for someone to understand what I was going through and what was happening to Lincoln. I always believed my boy was different – he was obsessive and would often isolate himself from others. I remember he would spend hours just staring out the window without emotion.

I will never forget the relief I felt when discussions with a psychiatrist eventually confirmed my suspicions. Lincoln was living with schizophrenia. We could finally get him the help he needed.

Lincoln was offered a place in a special school in Sydney for emotionally disturbed children so we packed our bags and moved to the city with Lincoln, my daughter and my new partner Paul by my side.

I remember the day Paul and I committed to spend our lives together. Ironically, it was almost like a business meeting. We resolved from the outset to be brutally honest with each other. We both realised trust and a united front was the only way we could support Lincoln and each other.

"Lincoln is a lovely young man who touches the lives of people who take the time to get to know him. His illness is just one part of him."

One of the struggles we faced moving to the city was the increased cost. Rent was much more expensive and I had to juggle my job as a cleaner while also trying to be there for Lincoln. Paul helped out financially but he was travelling for work so I was often on my own. There were days when I did not sleep but I managed to push through – I had to, for Lincoln.

There have been many psychotic episodes over the years, both during our time in the city and back at home. As a teenager, Lincoln would spend his spare time digging in a drain – when asked why, he explained he wanted to be like Poppy, his grandfather who had passed away. It wasn't unusual for him to run away in the evening and sleep in a churchyard. His thoughts were dominated by his fear of going to hell, which he described as "the bad place".

We were never shocked by what we would discover on our return home after leaving Lincoln in the house on his own. Sometimes he would try to clean but would get confused and use detergent to try to clean the inside of our DVD player or he would wet the floor and try and mop it up with an electric vacuum cleaner. It also wasn't unusual for him to put a knife into a toaster. He had no fear.

During his darkest hours he would walk in circles, worried about things he could not put into words. He was oblivious to his surroundings. I'll never forget the day we had to call the police – he ended up in hospital, crouched in a foetal position, refusing to acknowledge the outside world. He seemed to have become a mute. I was frantic.

Over the years we all learnt how complete and real Lincoln's delusions and hallucinations were. It was a frightening and confronting time for all of us.

TURNING POINTS

Medication

While the ride was still bumpy, when Lincoln was taking the right medication, the bumps were smaller and the ride was smoother. Most importantly of all, effective treatment helped him begin to talk again.

It also helped reduce his delusional thoughts and allowed him to live a more normal life. I used to encourage him to take his medication by warning him that if he didn't, those scary images he saw and dreaded on his walls would reappear.

Moving on

A few years ago we were notified the House With No Steps was establishing a group home in our area. I knew we couldn't care for Lincoln forever and that he needed to know a life outside of me.

He moved into the newly built home and while he is still an obsessive young man, he is talking more and has started to express his opinions. He even sits down at the table to eat on occasions.

He does call and nag us to let him come home. I try to explain that it is not that I don't want to look after him but I need to work and he needs to learn to get by without me because I won't always be here.

Community college

Lincoln now attends day programs at the community college. Among his interests is spending time on the computer searching for information on a range of areas but he particularly enjoys focusing on religion.

He also has an arrangement with the staff that he can attend one church service every Sunday.

> "When you go through something like this, you really find out who your friends are and who will stick by you through thick and thin."
>
> Bev

THE ROAD AHEAD

The decision to put Lincoln in a group home wasn't about us but about Lincoln and what was best for him. We are getting older and when we die, he will need others who can help support him and help him to improve.

He is such a lovely man who touches the lives of people who take the time to get to know him. His illness is just one part of him. While it has presented a lot of challenges for Paul and me, it has not diminished our relationship with Lincoln.

Over the years I have also learnt a lot about my self-esteem and new things about others. When you go through something like this you really find out who your friends are and who will stick by you through thick and thin.

In some ways, I feel when you are a carer, it is a bit of a curse because you can't stop caring. Lincoln may be moving on, but I find myself now also wanting to support others in our community. Our home has become a bit like a drop-in centre where people know they can just come for a chat.

While there are still many in our community who don't accept those with a mental illness, I have come to the conclusion that the problem is actually with them, not with me or Lincoln.

Paul and I still have our ongoing struggles. Since Lincoln has gone into the group home we no longer receive the Carer Payment so I have gone back to work in the aged care sector, which is tough but you do your best to make ends meet. I just try to take my life day-by-day.

We love the time we get to spend together listening to music and renovating the house but our latest pride and joy is our little grandson, our daughter's baby. We are determined to give him the best life possible.

I think the biggest lesson I have taken from my experience is while just being a carer for a child with a mental illness seems simple enough, it can be the biggest challenge a person can face.

The sense of loss is one of the hardest things to bear but I will never stop fighting for my beautiful son.

Pat with her husband Col

Pat's story

Pat and Col are married, they care for each other.

REFLECTIONS

I was very involved in the cause for social justice and wanted to learn more about it so I enrolled in a course and that's where I met Col. His name rang a bell, so I asked him if he was the same Col who had written an article I had read for a social justice newsletter about how hard it is to be put into a psych hospital and the feeling of powerlessness in that situation. It turned out it was the same Col and I was very excited to meet the man who was brave enough to write that article but as Col explained, mental illness is both a human rights and a social justice issue.

I was a nun before I met Col and was contemplating leaving the convent; I felt it was time to move on. I found it very difficult but meeting Col made it easier somehow. Col was also dealing with his own battle to move on, he was separating from his wife at the time and it was largely the trauma of separating from his family and the inevitable divorce that triggered his psychosis. So we started being there for each other, meeting up, having lunch and getting involved in all sorts of social justice causes. Two years later, we married.

A year before we got married, Col had another psychotic episode. Some of my friends said, "...Oh that's a bit dicey, marrying someone who has psychotic episodes..." But he was just Col to me.

I can still remember the episode I experienced with Col, he wandered off in the middle of the night, it was terrible. I spent the whole night crying and looking for him – eventually he just came home. We put him into hospital and he was put onto antipsychotic medication straight away. It never occurred to me to break off our relationship, Col was worth it. He is such a lovely man. I saw him every day in hospital. It took a long time for Col to feel himself again. I suggested that he write about what had happened. Writing became part of Col's recovery – it stopped him dwelling on the experience and helped him move past it.

Col was initially diagnosed with paranoid schizophrenia, a label that has stayed with him despite being re-diagnosed with schizophreniform psychosis and later, with a form of trauma-induced psychosis. Once you've been diagnosed with paranoid schizophrenia, it's a label that stays with you – many of Col's past friends and family will probably always see him that way.

> "You care for each other every day, in small but important ways. You take a couple of steps forward and then a couple of steps back on your own personal journey but if you are on that journey with someone who loves you or cares about you, it makes all the difference."

Eventually we got married and Col didn't really have another episode so when we reached the 10-year milestone, we had a big celebration with friends and family. Of course, you still have your ups and downs like most people.

When Col was sick, I never really thought of myself as a carer, it was just a part of life. When Col's children came to visit him when he was unwell, I used to tell him how much they loved him and reminded him how much they needed him. If you have a reason to recover, you do.

Schizophrenia is still misunderstood by a lot of adults, so it was no surprise that Col's children struggled at times to understand what he was going through. When the children were playing hide-and-seek with him one day, they suddenly stopped and said they didn't want to play anymore in case he got *sick* again.

TURNING POINTS

Breaking down the barriers

The word "schizophrenia" is such a terrible word – people are scared of it. It was while I was teaching at high school, surrounded by so much misinformation and fear around "schizophrenia" that I decided to run an education program about mental illness. I didn't broadcast the fact that my husband had been diagnosed with schizophrenia but the school counsellor let the kids know that if anyone wanted to talk about schizophrenia they could come to me.

So, Col and I developed a training program involving mental health professionals, carers and people living with schizophrenia coming to talk to students about the illness. The feedback from the students and school counsellors was extremely positive. It was so effective that some students said it was the best thing they had ever done. The ripple effect of this program was wonderful. A mother of one of my students told me that when she sat down with her daughter one day to tell her that her father had a mental illness, her daughter replied, "That's ok mum, I know all about schizophrenia, we learnt about it at school."

Express yourself

Col and I both love reading, writing, music and painting. Col feels that part of his recovery is due to his creative expression. We are both pretty convinced through our work with Blue Fringe Arts and the One in Five Creative Arts Association, that what gives people hope and the desire and the ability to move on, is being able to create things and express themselves through artistic endeavours.

It really helps people to focus on the simple beauty of what they've created as a way of coming through the other side and being able to live a meaningful life.

I think it's about finding beauty and happiness in the simplest things. Since we began working with people in the Blue Fringe and the Creative Arts Association, we have made many friends. We see them firstly as friends – as artists, poets, musicians, photographers and as equals – not just people with a mental illness. Isolation can be a killer, literally. The worst thing you can do to a person living with a mental illness is to avoid them or leave them alone, unconnected to the rest of society.

I like to express my creativity too. I worked with Col on oil paintings then I moved on to acrylics and I even had some of my work selected for exhibition. Painting helps relieve any stress or anxiety I may be feeling. I suppose I never really saw myself as a carer, so I never saw it as a burden – just a partnership – it's life and life can be hard!

> "One of the things I've learnt from living with Col is the importance of validating and respecting people for themselves, not their illness. We need to validate people for who they are, not by the label they have been given."
>
> Pat

Mutual trust and respect

In the psychotic episode I experienced with Col, he wasn't taking his meds and he was going into psychosis – I didn't recognise it. By the time I did the situation had become worse and Col wouldn't take his tablets. I had to call the doctor. Once Col spoke to his psychiatrist, he became compliant and took his meds. After that episode, we came to an understanding based on trust that if it happened again, Col gave me the permission I needed to ring his psychiatrist. Giving me the ok to do that was a big step for Col. This arrangement works in our case because of our deep level of mutual respect and trust.

THE ROAD AHEAD

I think we both feel quite exhausted at the moment and for the first time ever we have decided to go away for three months to write and paint. We haven't always been good at setting boundaries with other people. We say "we can't" – but we do. We say "we won't do it again" – but we do. It's hard to say no to people who need you but we've realised we need time to ourselves.

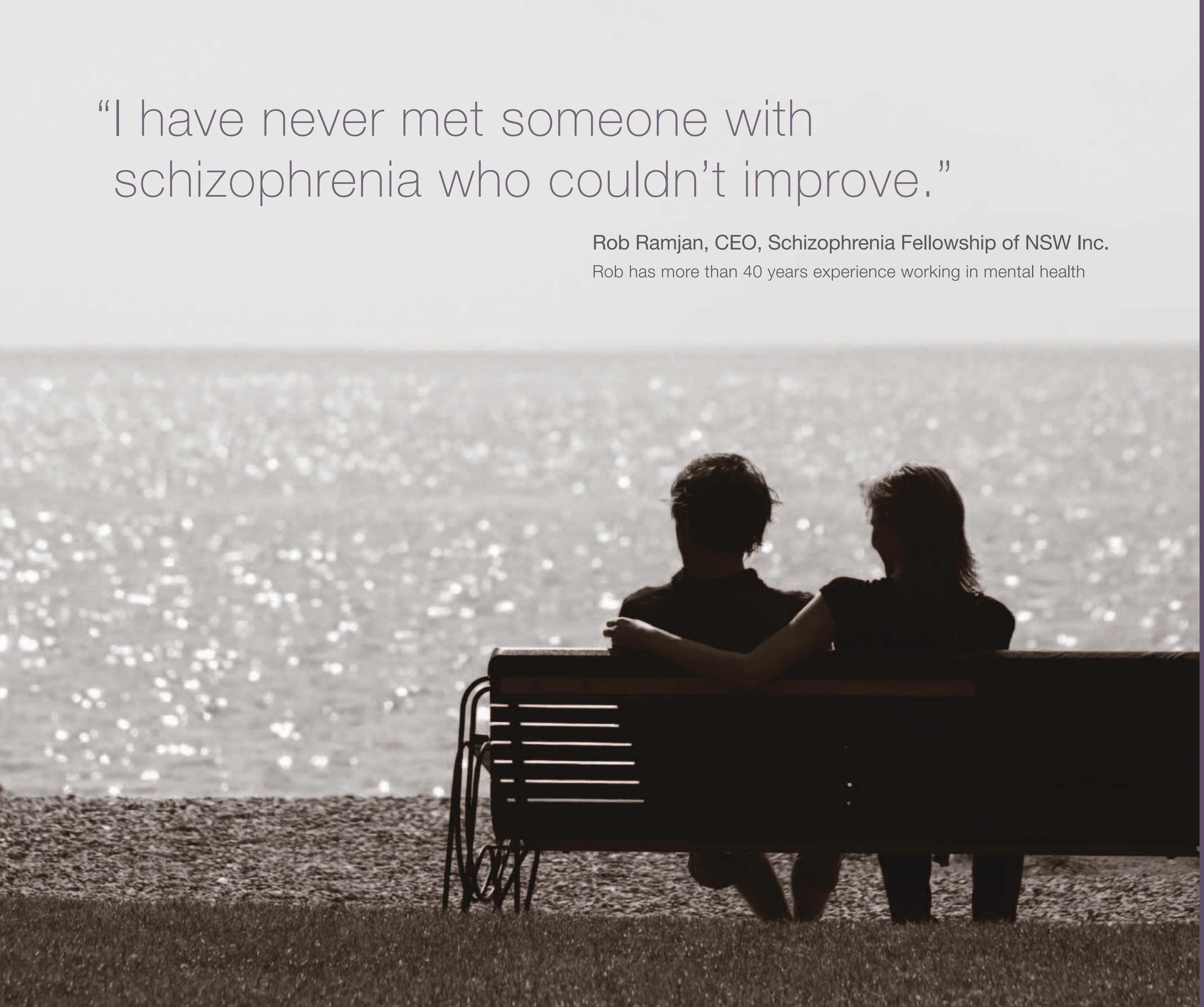
Sometimes Col can see I'm not in a good "headspace" as he puts it and he knows that I can suffer from depression. When he pulls me up on that, it's a good reminder to check-in with myself, to stop saying "I'm fine" and to look at how I'm feeling and what I might need to do to reduce any anxiety.

I have counselling every now and then but I probably need more of a debriefing session occasionally and then I just get on with it.

I feel you should use your experiences, the good and the bad, to understand yourself and to help others. It's a bit like the schizophrenia program we ran at the school. It has allowed us to say, "Look it's not that horrible, we have survived it. It doesn't have to be a life sentence."

I've thought about the role of the carer and in our case, sometimes I'm the carer and sometimes Col's the carer. You care for each other every day, in small but important ways. You take a couple of steps forward and then a couple of steps back on your own personal journey but if you are on that journey with someone who loves you or cares about you, it makes all the difference.

One of the things I've learnt from living with Col is the importance of validating and respecting people for themselves, not their illness. We need to validate people for who they are, not by the label they have been given. The other lesson I've learnt, and I know it sounds like a cliché but it's true – is that you have to keep your sense of humour, you have to be able to laugh – at yourself and with each other. Laughter is one of the most important emotions but at the other end of the spectrum, you have to be able to cry too.



> "I have never met someone with schizophrenia who couldn't improve."

Rob Ramjan, CEO, Schizophrenia Fellowship of NSW Inc.
Rob has more than 40 years experience working in mental health

So what now?

Support for family and friends of those recently diagnosed with schizophrenia

Schizophrenia: The basics

What is schizophrenia?[1,2]

Schizophrenia is a major mental illness affecting the normal functioning of the brain. It is characterised by a disturbance in a person's thoughts, perceptions, emotions, thinking skills and behaviours.

What are the symptoms?[3]

A person with schizophrenia may show a range of symptoms. Some of these are listed below.

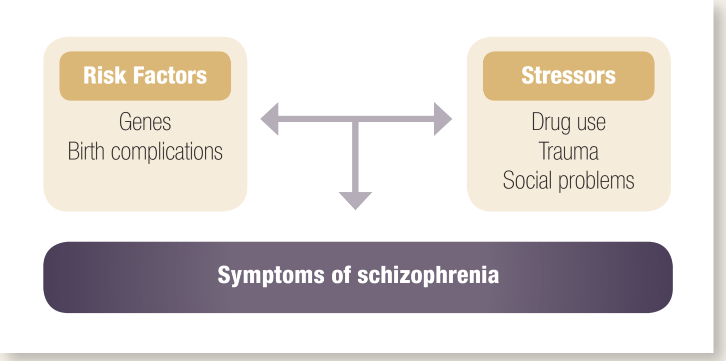
- **Withdrawal** – isolating themselves from others.
- **Delusion** – fixed and false beliefs e.g. someone outside of them is controlling their thoughts.
- **Hallucinations** – perceiving something in the absence of a sensation. These perceptions are very real to the person e.g. hearing voices, food tasting strange, seeing things that aren't real and distortion to the sense of smell.
- **Disturbance of thinking** – a change in the process of thinking which can make conversations with them difficult to follow e.g. jumping from one idea to an unrelated thought or being unable to concentrate on a particular issue.
- **Change in mood** – appearing distant, unresponsive or uninterested due to a diminished expression e.g. lack of facial expressions.
- **Low motivation** – a loss of concentration, willpower and drive to reach goals e.g. no longer pursuing their interests at work or home.
- **Loss of insight** – inability to understand the reality of a situation.
- **Anxiety** – the person can be very frightened of situations or going out.
- **Cognitive** – changes in attention, concentration, memory or planning skills.

What causes schizophrenia?[4,5]

While no single cause of schizophrenia has been identified, there are several factors often associated with schizophrenia. Some of these are listed below.

- **Hereditary factors** – a family history of schizophrenia, with a relative previously diagnosed with the illness, increases the risk of other family members developing the disorder.
- **Biological factors** – these include a wide range of factors that may have affected the person before their birth e.g. maternal illness, or the use of certain drugs such as cannabis. These factors are thought to alter the structure and the function of the brain.
- **Environmental factors** – stressful life events.

The diagram below shows that an accumulation of stressful events in vulnerable people can lead to symptoms of schizophrenia.[6]



Schizophrenia is **not** caused by:[4]

- Domineering mothers;
- Passive fathers;
- Bad parenting;
- Poverty; or
- Weakness.

How common is schizophrenia?[1,7]

Around one in 100 people will develop schizophrenia. This represents around 224,000 Australians.

Schizophrenia affects both males and females alike however, onset often occurs earlier in men than in women and slightly more men than women are affected.

What can I expect after diagnosis?[8,9]

A diagnosis of schizophrenia does not necessarily mean that a lifelong illness is inevitable. While there is no cure, people do improve and recover with effective medication and rehabilitation.

It is estimated for people with schizophrenia:

- 25 percent experience full recovery;
- 40 percent experience recurrent episodes with some degree of social disability and (for some) periods of being unemployed; and
- 35 percent experience long-term (chronic) schizophrenia.

How is schizophrenia treated?[1,10,11]

A combination of medication, psychological and community support are essential to help people living with schizophrenia live full and active lives.

- **Early intervention** – over recent years greater attention has been given to early intervention and the positive outcomes that can be achieved. Early intervention means getting assistance as soon as the symptoms of the disorder are recognised and treating them accordingly.
- **Hospitalisation** – a stay in hospital is sometimes needed to treat an acute episode of schizophrenia due to the severity of the symptoms or because of safety issues both for the loved one and their family. This may be involuntary as the person with the disorder may not realise they are unwell.
- **Medication** – medication is used to treat schizophrenia, to alleviate or ease symptoms, to help decrease distress or agitation, to improve sleep patterns and to help commence the recovery journey. The ongoing use of medications can also assist in stabilising symptoms and preventing relapse. Medications have both desired effects and undesired effects, commonly called side effects. The aim for each person is to find a medication that effectively reduces symptoms, is tolerable and has the least number of side effects.
- **Psychological treatments** – these therapies can be useful once your loved one has been stabilised on medication. Cognitive Behavioural Therapy in particular has been proven to be beneficial in reducing the effects of delusions and hallucinations.
- **Community support** – while medications are the cornerstone of treatment for most mental illnesses, they are not sufficient in themselves to lead people to recovery. The psychological aspect of rehabilitation and recovery is encouraged and includes counselling, support groups and participation in employment and education programs.

What can I do to help?

Whether it is your child, partner, relative or friend who develops schizophrenia, it can have an impact on your entire family, and require substantial time, energy and money to help your loved one.[12]

Of any illness, this is probably one of the most puzzling, misunderstood and difficult to handle.[13]

Below are some tips that may help you along the way.

What can relatives do?[14]

- Go slow – recovery takes time and remember things will get better eventually
- Stay calm and remember it's nobody's fault
- Give them space – time out is important for everyone
- Set limits – everyone needs to know what the rules are
- Keep it simple – say what you need to say clearly and simply
- Follow doctors' orders and help your loved one along the way
- No illegal drugs or alcohol – they may make symptoms worse
- Pick up on the early warning signs
- Solve problems step-by-step
- Don't forget the rest of your family or yourself

Help minimise relapses[15]

Identifying the early warning signs is essential when helping your loved one minimise the chance of relapse.

If you answer "yes" to some of the questions below about your loved one, it may indicate they are facing an impending relapse.

Sleep has been restless or unsettled	YES	NO
Isolating themselves more than usual	YES	NO
Rapid mood swings	YES	NO
Feeling tense, afraid or unsettled	YES	NO
Having difficulty concentrating	YES	NO
Feeling irritable or quick tempered	YES	NO
Feeling unable to cope and having difficulty in managing everyday tasks	YES	NO
Feeling tired or lacking energy	YES	NO
Feeling depressed or low	YES	NO
Feeling confused or puzzled	YES	NO

Your loved one's psychiatrist or case manager may also be able to help you recognise the early warning signs of relapse. This will help you organise treatment as quickly as possible.

Support during an acute episode[15]

If a loved one does relapse and experiences an acute episode, it is important to stay calm and put the plans that were developed while the person was well, into place.

The following tips may be useful for communicating with a loved one, in this situation.

- Show understanding and compassion
- Be non-judgemental and remember the person lacks control over what they are doing and saying
- Try not to take things personally
- Ask how you can help e.g. sit with them in the room or give them space
- Be clear about the limits of what is and isn't acceptable
- Sit beside them but avoid direct, continuous eye contact or touching
- Try to find common themes for discussion
- Be positive and helpful
- Limit external stimuli such as radio, television and other people
- Stay calm and keep voices low
- Acknowledge and discuss any threat of suicide

Helping your loved one stay on their medication[16]

Having a simple conversation about the importance of medication can make a difference. Below are some ideas that may help.

- **Highlight the benefits** – helping your loved one to understand the benefits of medication can encourage them to take it. Listing the pros and cons of the medication can also often help.
- **Address the side effects** – encourage your loved one to discuss the side effects with their doctor and develop coping strategies.
- **Build a routine** – try to establish your loved one's daily routine and make medication a part of it.
- **Get organised** – using pill boxes can make life easier.
- **Make them accountable** – introduce consequences for not taking medication, such as not receiving their allowance or not going on a trip or outing.

Five steps to tackling addictions[17]

Excessive drug use and alcohol consumption are among the most common challenges experienced by people living with schizophrenia. Cigarette smoking is also common.

Here are some ideas to help your loved one beat their addiction.

- Talk about drugs, alcohol and smoking with your loved one but remember not to blame or be judgemental.
- Try to understand why they use substances.
- Help their motivation by exploring how quitting will help them to achieve their personal goals.
- Encourage them to consider new ways of getting their needs met, such as coping with symptoms, socialising or having a meaningful daily structure.
- Explore possible avenues for help such as a community mental health centre or Alcoholics Anonymous, which may help your loved one along the way.

How do I stay strong?

If you become stressed and run down, you won't have the inner strength you need to take care of yourself or your loved one.

Think about how you feel[18]

Caring for someone with schizophrenia is a complex and demanding role and it is normal to experience a range of emotions. It is important to know that your feelings aren't right or wrong. Some typical emotions are listed below.

- **Guilt** – you may feel responsible for the illness but no one is to blame.
- **Shame** – the stigma around mental illness can cause embarrassment but try not to focus on what others think.
- **Fear** – it is normal to fear for your loved one's future and worry about what will happen to them if you are not around.
- **Anger/frustration** – you may feel frustrated about being a carer or angry others don't pitch in.
- **Sadness** – you may grieve for the loss of the relationship you used to have with your loved one and the life you had together.
- **Love** – your feelings for your loved one may deepen and you may feel more motivated to help.
- **Isolation** – you may find that your usual support networks aren't sure how to help you and may withdraw due to a lack of understanding or simply feeling overwhelmed. It is important to seek out people who can empathise, listen and assist you during difficult times.

Equip yourself for the journey[11,18,19]

Below are some ideas to help ensure you and your family are ready to meet the challenges ahead.

- **Get informed** – find as much information as you can about schizophrenia, which will enable you to better understand the issues your loved one is facing and the impact it will have on you.
- **Build your own support structure** – having a friend or someone you can talk to without judgement is important. Community support groups or counselling should also be considered.
- **Stay healthy** – staying healthy will help you withstand stress, so try to eat well-balanced meals and exercise regularly.
- **Make time for yourself** – set aside some time for relaxation, respite or enjoyable activities like catching up with your friends or playing sport.
- **Plan ahead** – a day-to-day routine can make things more manageable.
- **Keep track of your finances** – seek support through practical financial schemes available, such as Centrelink.
- **Take a break** – access your local carer respite program and take advantage of the respite available.

Self-care check list[18]

- Do I have someone I trust to talk to?
- Do I get enough breaks from caring for others?
- Have I got regular times for relaxation?
- Am I getting regular exercise?
- Am I eating regular, nutritious meals?
- Do I get enough sleep?
- Do I need to ask for help?

Remember, what you are going through is hard[20]

Sometimes it's hard to accept how much your loved one's journey with schizophrenia impacts on your relationship with them. It may help to remind yourself of the following.

- "Despite having a mental illness, my loved one is still capable of having relationships and experiencing enjoyment in life."
- "My loved one's symptoms are the cause of their upsetting behaviours."
- "My efforts to help my loved one are important, no matter how big or small."
- "Underneath the illness, they are still my loved one."

How and where do I get help?

Finding help for your loved one[21]

Many families and friends caring for someone living with schizophrenia feel very isolated and rely entirely on their own strength and ability to cope.

Below are some suggestions which may assist you to find the help you need to support your loved one.

- **Write a list** – outline the things your loved one is doing that cause concern and seem to you to indicate deterioration.
- **Take the list to a medical professional** – talk to a doctor or psychiatrist about what your loved one is going through and get some advice.
- **Consider community groups** – there are a variety of organisations you can seek help through including Mental Illness Fellowship of Australia, Schizophrenia Fellowship of NSW Inc., ARAFMI, a Community Health Centre or the Mental Health Association.
- **Refusal to accept help** – if the person is refusing help or presenting themselves so well that doctors cannot see the illness, the situation is more challenging and your list will become more important.

It may become necessary to hospitalise someone who obviously needs treatment but is refusing to accept help voluntarily. If this does occur, it is helpful to understand hospital procedures.

For more information, contact your local Mental Illness Fellowship on 1800 985 944.

Clubhouses[22]

Clubhouses may help give your loved one the structure they need and give them more meaning in their lives.

Run not only for people who have a mental illness but also by them, clubhouses balance the working day by organising daily after work social activities and a recreational program.

For more information, contact Pioneer Clubhouse on 02 9907 9999.

> "The Council of Australian Governments (COAG) has announced a number of new services established across the country including the Day-to-Day Living Program (D2DL), a centre-based program with some similarities to Clubhouses; the Personal Helpers and Mentors Program (PHaMs) for people with a major mental illness who are isolated or without support; the National Respite Development Fund to provide respite for carers of a person with a mental illness; and a number of additional community programs. These are proving very valuable and there should be one near you."
>
> Rob Ramjan, CEO, Schizophrenia Fellowship of NSW Inc.

Finding support for you

There are a range of organisations and services available to help assist you to manage the impact of schizophrenia on your relatives or friends.

A full list of contact details for organisations mentioned is available on page 34 of this booklet.

Support and carer services

- **Family support services** – organisations such as Schizophrenia Fellowship of NSW Inc. and Mental Illness Fellowships offer services such as information, support groups, respite, education and training.
- **Carer Associations** – in each state and territory there is a Carer Association working to bring the needs, views and concerns of carers to the attention of the community.
- **Commonwealth Carer Resource Centres** – these provide referrals to services and practical written information to support carers.
- **Commonwealth Respite and Carelink Centres** – there are over 80 centres around Australia that can support you to take a break. There are also a number of non-government organisations that directly provide respite services.
- **Carers Australia** – the peak body for carers in Australia provides services including counselling, advice, advocacy, education and training and has branches in every state and territory.

Government financial support

- **Carer Payment** – the Carer Payment was introduced to support people who need to use their time caring for a person with an illness and are unable to work more than 25 hours per week.
- **Carer Allowance** – compensates people for some of the costs associated with being a primary carer for someone with a mental illness.
- **Carer Brokerage Funds** – in some regions, area mental health services also have access to funds designed to financially support carers to maintain their caring role.

Support groups[23]

Support groups are a great opportunity for you and your loved one to receive support and share with people who understand the challenges of living with schizophrenia.

There are a diverse range of groups available to specifically meet your needs, whether that be sharing experiences with others, providing an avenue for you to learn more about schizophrenia or taking on an advocacy role to improve mental health services.

For more information about support groups, contact the Mental Illness Fellowship of Australia on 1800 985 944 or visit **www.mifa.org.au**

MENTAL ILLNESS FELLOWSHIP of Australia Inc

the lived experience

The Mental Illness Fellowship of Australia (MIFA) commenced informally in 1986 as an association of the various state and territory Schizophrenia Fellowships then in existence

NEED HELP NOW?

Click here for our Help and Advice page.

40,000 FORGOTTEN AUSTRALIANS

In 2010, why are 40,000 Australians still missing out on basic mental health services? What you can do about it.

KEEP IN TOUCH

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FACT SHEETS

What is mental illness? Learn more about it by reading our fact sheets.

NEWS FEED

mifaoz: Don't miss "Four Corners" on Monday, investigating the hidden voices on mental illness in Australia:

mifaoz: Time magazine links schizophrenia to marijuana usage, but how strong a link are we looking at?

mifaoz: People with #bipolar more susceptible to migraine:

mifaoz: Musician Kristin Hersh talks about the impact #bipolar has had on her work.

FEATURED VIDEO

7 Steps To Better Mental Health. Austin Wellnes...

FIND YOUR MEMBER

The Mental Illness Fellowship of Australia has member organisations in states and territories around Australia, apart from the ACT.

Click on your State above to view its website.

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Alan Openshaw

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Corporate partners

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Ogilvy Healthworld

Writers' note:

The personal stories shared in this booklet have been written following interviews with family members of those living with schizophrenia. Their journeys have been told in their own words, edited directly from transcripts.

We thank the families who invited us into their lives and shared their very personal experiences with us to help others. Many expressed the relief they felt at being able to share their story with us and we hope this booklet has provided them with some comfort.

Each of their journeys is unique, providing insights into what it is like to be a mother, sister, brother or partner trying to support their loved one, their families and themselves. We, and those interviewed, hope that these stories will provide support to others as they face similar challenges and turning points on their own personal journeys.

More information

Schizophrenia Fellowship of NSW Inc.
02 9879 2600
Locked Bag 5014,
Gladesville NSW 1675

The Old Gladesville Hospital,
Building 36,
Digby Road,
Gladesville NSW 2111

www.sfnsw.org.au

Carer Assist
02 9816 5652

Remind Mental Health Training & Education
02 9879 2600

Respite Services
1800 124 121
02 9879 2600

Pioneer Clubhouse
02 9907 9999

Helping Hands
02 4423 4987

Mental Illness Fellowship of Australia
1800 985 944
08 8272 1018
www.mifa.org.au

Mental Illness Fellowship Victoria
03 8486 4200
www.mifellowship.org

Mental Illness Fellowship of Western Australia
08 9228 0200
www.mifwa.org.au

Mental Illness Fellowship of South Australia
08 8378 4100
www.mifsa.org.au

Mental Illness Fellowship of North Queensland
07 4725 3664
www.mifnq.org.au

Mental Illness Fellowship of Queensland
07 3358 4424
www.mifq.org.au

Mental Health Carers Northern Territory
08 8948 1051

ARAFMI Tasmania
03 6331 4486
www.arafmitas.org.au

Other useful resources:

Carers Australia
1800 242 636
www.carersaustralia.com.au

Carer Payments
Centrelink, information and applications
13 27 17
www.centrelink.gov.au

Commonwealth Respite and Carelink Centres
1800 052 222 (business hours)
1800 059 059 (outside business hours)
www.commcarelink.health.gov.au

Lifeline
13 11 14
www.lifeline.org.au

Mental Health Council of Australia
02 6285 3100
www.mhca.org.au

Mindbodylife
Tips to enhance physical wellbeing
www.mindbodylife.com.au

Recipes for Life
Tips for optimising lifestyle
www.mindbodylife.com.au/recipesforlife

SANE Australia
1800 187 263
www.sane.org

Schizophrenia Library – Schizophrenia Research Institute
02 9295 8688
www.schizophreniaresearch.org.au

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