



MENTAL HEALTH COMMISSION RECOVERY SERIES: two

FOUR FAMILIES  
OF PEOPLE WITH  
MENTAL ILLNESS  
TALK ABOUT THEIR  
EXPERIENCES

APRIL 2000

There are many pathways to recovery from a mental illness; this is the second in a series of four publications on recovery.

The first is about the experience of Maori who have experience of mental illness. The other two in the series are on recovery experiences of Pacific people who have a mental illness; and people who have used forensic services.

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# Introduction

*'Recovery is a process and an attitude, not a place. It is about regaining what may have been lost: rights, roles, responsibilities, decisions, potential, and support. It is not about symptom elimination, but about what an individual wants in his/her life, how he/she can get it, and how others can help/support the individual to get there. It is about rekindling hope for a productive present and a rewarding future – and believing that one deserves it! Recovery involves people having a personal vision of the life they want to live, seeing and changing patterns, discovering that symptoms can be managed and doing it, finding new ways and reasons for doing it, and doing more of what works and less of what doesn't. Recovery is about reclaiming the roles of a "healthy" person, rather than living life as a "sick" person. Recovery is about getting there.'*<sup>1</sup>

The paper is about the recovery experiences of four families with a son, daughter or sibling who has been diagnosed with an ongoing mental illness. The four families were interviewed for the Mental Health Commission and their accounts follow.

Each family is dealt with separately, starting with a brief family history, and then a discussion on what helped and what hindered their recovery process. The paper focuses entirely on the families experience and all the quotes are their words. They all describe some very negative

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<sup>1</sup> Copeland ME, Curtis LC, Palmer HP (1996). The Recovery Institute: Knowing and Practising Recovery Skills. A Training Workshop. Burlington VT: Trinity College of Vermont, Centre for Community Change through Housing and Support

experiences, but these are just as helpful in defining what recovery means to them, as their positive experiences. The order of the family stories starts with the person who has lived with a mental illness the longest, through to the person who has lived with a mental illness for the shortest time. The order of the stories also shows that the families who have lived with their relative's mental illness the longest, have had the most negative experiences.

The families are:

- Karen and her daughter Rose
- Ruth and her son Peter
- John, Hinemoana and their son Steven
- Chris and her daughter Liz.

These are not their real names.

The conclusion identifies the general agreements among the families about the factors that have assisted their recovery process. The Appendix quotes the Mental Health Commission's *Blueprint for Mental Health Services in New Zealand: how things need to be* on recovery and the inclusion of families in recovery. It also describes the Commission's anti-discrimination resources.



## KAREN AND HER DAUGHTER ROSE

Karen has three daughters and a son. One of her daughters Rose, has had a mental illness for about 15 years.

Rose was 19 years old when she first became ill. Some of Rose's early symptoms were that she hardly slept or ate, and she turned to religion. She started to wake Karen up at three or four in the morning, wanting her to pray with her. Rose said that she was hearing voices and it was hard to concentrate on anything. Karen and other members of the family had no idea what was happening, or what to do.

Finally, Karen found out that she could take Rose to hospital. Karen talked to Rose about the idea and Rose agreed to get some help. Karen kept thinking to herself as they drove to the hospital, 'Now that we've come this far please don't change your mind Rose.' When they got there Karen felt a sense of relief, although if she had have known what was going to happen she wouldn't have felt relief at all.

Their first stop was the accident and emergency department. They had to sit and wait for someone to look at Rose before she could go up to the psychiatric ward. When they got to the psychiatric ward they had to talk to the doctor for three hours before Rose was finally admitted. Karen remembers them telling her, 'Okay we'll take her now, you can go'.

Karen went back to see Rose the next day. It was awful. Rose was not like the Rose they knew. She was heavily drugged and acted like a zombie. Karen was worried about Rose and started to ask the staff some questions but 'All I was told was that they couldn't tell me anything.' Rose was not capable of saying anything about what was happening to her either. Even when Rose tried to commit suicide in the hospital, the staff told Karen they couldn't talk to her about it.

Rose was in the ward for quite a while but none of the staff said much to Karen. One of the psychiatrists they saw made it sound like it was all Karen's fault. He asked her if she had ever told Rose she couldn't have dessert unless she finished her vegetables. He then told Karen that it was not a good thing to do. Finally, one psychiatrist told her what he thought was happening to Rose and what they might do for her. They wanted to put Rose in to Porirua Hospital but Karen wouldn't let them. She had been there before to visit someone else and didn't like it at all.

When Rose left the ward she went to live at Ashburn Hall in Dunedin. Karen and her mother went down to make sure Rose was okay. They both felt comfortable with the staff and there appeared to be good communication between everyone. Karen was finally finding out what was happening with Rose.

But there was one thing Karen didn't like about Ashburn Hall. They gave Rose electro-convulsive treatment (ECT). When Karen found out she was quite upset. The staff told Karen that Rose had given her permission, but Karen was sure that Rose did not know what she agreed to. Rose stayed at Ashburn Hall for a year before going back to Wellington. One of the doctors, who was going through Wellington, dropped Rose right at Karen's front door.

For awhile things were okay. Then it all started again. Rose lived at home for three months and then tried living with her relatives - the one's who still wanted to know about her. She didn't last long with any of them and she ended up in supported accommodation. Then Rose moved out of the supported accommodation with her partner, who also had a mental illness. They had lots of problems living by themselves. They drank, took drugs, forgot their medication, couldn't budget very well and didn't always eat. Her partner became ill and had to go back to his home. Rose was pregnant and this added more stress.

Rose then went flatting by herself with the supposed support from the local mental health services, but Karen doesn't think that they helped or supported her very much. Rose often called Karen saying she had no food. Rose also started turning up at Karen's work and caused some arguments. At one point Rose tried to electrocute herself. Karen raced over to her place to take her to the GP, who told her to take Rose home, give her some headache tablets and put her to bed. The next day, the psychiatrist told her basically the same thing. 'It was like they thought we were just wasting their time'.

Rose often called Karen to say that she was going to commit suicide. Karen always dropped everything and raced over to Rose's place. But it started getting excessive - about two or three times a week - and Karen was getting exhausted. Finally, a doctor told Karen to tell Rose that it was her choice to commit suicide if she wanted to. So the next time Rose called, Karen told her this and hung up. 'It was horrible, I just wanted to go around there and see if she was okay.' The next day Rose called and spoke as if nothing had happened. She has never said anything about suicide since then.

Rose had her baby and loved her dearly but she couldn't cope, and the baby ended up living with another member of the family.

After that, Rose became quite ill again and was admitted to the lock-up ward in Porirua Hospital. Karen was not allowed to see Rose for some time. Then she had to call before she went to see her, to get permission. Sometimes the staff would tell her not to come because Rose had misbehaved, or because they were trying to get her medication right. Rose got moved to another ward, but if she misbehaved she was sent back to the lock-up ward. Rose told Karen stories of what happened to her while she was in the hospital. Karen believed Rose, but at the same time she didn't want to believe that people could be treated as if they weren't human. The hospital organised some family meetings but Karen feels they were invited just because it was politically correct. 'I don't think they ever really

listened to Rose or me, it just looked good to have us there.' Rose stayed in Porirua Hospital for three years.

At last Rose got her chance to move back into the community. The doctors had changed her medication and there was a noticeable difference in her. Rose moved back into supported accommodation. She has been there for two or three years now and is determined never to go back to hospital.

In that time Rose has been sick twice. Karen had to tell the staff at the house both times, that Rose was unwell. The first time she became unwell, Karen told the staff how Rose was feeling but they thought she was okay. The psychiatrist came to see her at the house and they brought someone in from Community Assessment Team. They increased her medication and arranged a night nurse. Karen stayed with Rose the first day because there weren't enough staff to look after her. The next time Rose got ill, Karen phoned the staff who said they were keeping an eye on her. That was it. 'I just want to be informed about what is happening. Is that too much to ask?'

Karen doesn't feel like she can relax. She doesn't trust the supported accommodation staff, or the mental health services to actually help Rose. It certainly has not been smooth sailing for Karen, Rose and their family.

# What helped Karen and Rose's recovery?

## Information and follow-up from mental health services

The help provided by mental health services has been limited.

The doctor who took the time all those years ago to say 'This is what we think it is and this is what we are going to do about it' made an enormous difference. 'I felt that at least someone thought I was worth something and that maybe I did care after all.'

Recently, when Rose was sick, the psychiatrist came to see her in her house for about six weeks. Rose keeps in contact with the psychiatrist every six weeks now and Karen goes along to these appointments. Rose also has a good nurse now, who she can call on when she needs to. They all keep Karen informed about what is happening. 'Just knowing what is happening makes all the difference, not because I'm nosy, just because I care.'

## Information sharing

Karen and Rose have signed an 'Agreement to Share Information' form that the Schizophrenia Fellowship and a consumer organisation had jointly developed, and this has meant that Karen has been kept informed of most of the things happening for Rose. Now the supported accommodation people sometimes call and let Karen know what is happening.

## Support and information from advocacy organisations

About five years ago, Karen found out about the Schizophrenia Fellowship. They have been marvellous to Karen and Rose and the same field worker has been involved all along. Karen has been given

heaps of information and learnt about her rights and Rose's rights. She has also joined one of the carer support groups run by the Fellowship.

'The carer groups are good because there are other people who have been through what you've been through, some of them have a harder time.'

'Having someone take the time to listen to me and give me information has made such a difference. It doesn't take much to be just a friendly ear. Knowing the right questions to ask was also really important.'

'Since I have learnt about my rights and started asserting myself, things are a little better. I wouldn't say they were great but certainly better. I even took a complaint to the Health and Disability Commissioner's office who were really good.'

## Determination and family support

Rose's brother and one of her sisters have been very supportive.

'It's about someone there to talk it over with, someone who sees Rose all the time and has known her from when she was little. Rose's sister also has guardianship over Rose's child and this meant that we could keep her in the family. That was important to us.'

Karen feels that a driving force behind Rose's recovery has been her determination to get out of hospital and not to go back. For Karen has struggled with Rose's illness all by herself, and that meant she became strong – strong enough to stand up and say, 'My daughter has schizophrenia and what does that matter'.

# What hindered Karen and Rose's recovery?

According to Karen, mental health services had a major part in hindering her and Rose's recovery.

'Services have never been quick and easy to get into, so many rules and regulations. Rose is leading a better life but I don't think it's just because of the services. I can't see them helping her do the things she wants to do. I think mostly she is just an illness to them, another person with schizophrenia.'

## Lack of respect from mental health services

If services only treat people as an illness and don't treat them with respect and dignity, it is hard for recovery.

Karen feels that the services they have used have never really treated Rose and herself with the respect that they deserve. Karen and Rose want to be treated like human beings first, but Karen feels like there has been little acknowledgment of this from many of the people working in the services. 'The field worker from the Schizophrenia Fellowship always talks about Rose as a person, not as an illness. It's in the language she uses. No other service we have used really cares about Rose, only her illness.'

In the past, mental health services have not involved either of them in decision making. Although it has been better lately, it is still not a great process.

'Even when we are involved, we do not always feel comfortable. There are times when we just sit in meetings and the staff talk to each other, and don't actually ask us anything. One time, I called a meeting, but before the meeting started the staff person told me they had invited the nurse along to tell me about mental illness. This was only two years ago. I told them I knew about mental illness because I had lived with my daughter for many years.'

Karen feels that if she complains too much, services to Rose will change, though Karen does admit she has never seen that happen.

## Punitive practices in mental health services

Karen feels that mental health services have made it a harder process than it needed to be.

'Locking someone away and not letting them see their family is not great. I don't think punishment like that is right. Not telling family what is happening just makes them worry more and dream up all sorts of things. It doesn't take much to tell us.'

'When Rose was in hospital, they didn't let her do things on the weekend if she had misbehaved, been rude to a nurse or another patient. How does that help? It treats people like they were little kids.'

In Rose's supported accommodation they are working on her aggressiveness. Every time she gets angry, or rude, or speaks in a loud voice, the staff have to write down the time, date and what action was taken.

'We all get angry and lose it from time to time, if I had to have everything written down [about me] I would probably lose it more often too.'

One day Rose had made a scene at her day service. The staff, Rose and the other consumers had sorted it out. But when it got back to the accommodation staff they banned Rose from her day service for a short time.

'What did it have to do with them, if it had already been sorted out at the day service? That would make me mad. Maybe that's when Rose really gets aggressive.'

## Lack of information from mental health services

Karen and Rose were given little information about Rose's illness and certainly no information on their rights. This has been a major hindrance to their recovery.

'I know my rights now and Rose's too, but nobody ever told me about them until the Schizophrenia Fellowship did. The only attempt [the services made] to protect Rose's rights, came when they told me I couldn't find out what was happening because of the Privacy Act. Now I have my signed form that says I can know.'

'When we finally get to talk to someone in the mental health services, they talk at us in jargon or as one psychiatrist said 'I have letters in front of my name, I know what I'm doing!' Well, I wasn't quick enough at the time, but I should have said, 'I have letters in front of my name too, MUM, and I know my daughter.'

## Inflexible, unresponsive services

If services are inflexible and treat everyone in a similar manner it is not good for recovery.

Rose's major symptoms have come and gone throughout the years. She lacks concentration and likes to get up and about every 15 minutes or so to have a cigarette break. This makes it hard for Rose to do the work she wants to do in the retail trade, in a supermarket or chemist.

'All of the day services Rose goes to are based around learning work skills but not in an area that Rose wants. I know she won't work in retail but what about her getting to do things that she enjoys? I once asked the head of the mental health service what were they going to do about work for people with major mental illnesses and he just shrugged his shoulders. A lot of good that does.'



## RUTH AND HER SON PETER

It all started after a major trauma in Peter's life. At first he didn't seem to be doing anything really unusual and Ruth thought that he was just having problems coping with the stress of moving into adulthood. But things worsened and after a physical illness, Peter started not eating, or sleeping and became obsessively preoccupied with his health. Ruth wasn't sure what was happening but knew that something was very wrong. She took Peter to see his GP.

The GP didn't tell them what he thought was happening, but prescribed major tranquillisers and sent them home. Ruth had faith in the GP and followed his advice. Peter took the medication and was soon feeling himself again. Because they hadn't been told anything, they thought the problem had been associated with the stresses in Peter's life, and that it wouldn't happen again. Peter went away to university and did very well.

A few years later, Peter's only other sibling was killed. He seemed to cope very well at the time, but after a few months he came home because his symptoms had started to return. This time it was a little bit worse. Peter stopped eating and sleeping, and had delusions about his health, but this time he also went out into the garden naked, was extremely anxious and out of touch with reality. Ruth took Peter back to the GP and again, without any discussion, he put Peter on the tranquillisers. When Ruth tried to get more information, the GP stated that Ruth was manipulating Peter. She felt as if she was being painted as the villain. On top of all this, Ruth was also trying to deal with the death of her other son.

This time Peter had serious side effects from the medication, and ended up in hospital because of this. The doctors at the hospital told

Ruth that Peter should not have been given that medication by a GP, and that he should have been given other medication to stop the side effects.

After Peter came out of hospital his symptoms got worse. Ruth waited a couple of weeks before she took Peter to her own GP, who sent them to the psychiatric ward at the local hospital. A psychiatrist spoke to both Ruth and Peter and then asked them to wait. Ruth had expected a short wait but it turned into a five hour ordeal. There was only one bed available and two doctors were arguing over which of two patients should be admitted. Peter ended up being admitted.

Ruth started asking questions about what was happening to Peter and the staff told her they couldn't tell her anything. She felt that they thought she was a meddling mum. She could see that Peter spent large amounts of time talking to a social worker but there didn't seem to be any clear treatment path. 'It seemed like absolute chaos. Maybe there were things happening behind the scenes but I didn't know about them. It didn't seem like anybody had given Peter any information about what had happened to him either.'

The social worker did tell Ruth that she thought Peter shouldn't live at home because he had an attachment problem, but she made no suggestions about where he should go. 'The social worker had no psychiatric qualifications and it seemed like she was just a nice person to talk to.'

Peter called Ruth from the ward one day to say that he could come home. When Ruth arrived nobody wanted to talk to her. A doctor did finally speak to her but made it clear that he thought she was meddling. But Ruth wanted to know what to do with Peter. He was certainly much better, but obviously not fully recovered, and sleeping was still a major problem for him. Reluctantly, the doctor gave Peter some sleeping tablets and told him when to take them. 'We were given no information and still did not know what was happening to Peter.'

Peter stayed at home for a while because there was nowhere else for him to go. He went to Income Support to get a sickness benefit. Initially they told Peter that he couldn't get a benefit because he was receiving a bursary. Peter told them that he had stopped studying and was no longer receiving the bursary, but they didn't believe him, even when he produced a letter from the university. Peter then called the university and they phoned Income Support to confirm Peter's information, but the person he was dealing with told him the call could have been faked just to get the benefit. Ruth was furious and went in with Peter to see the manager. Finally, Peter got his benefit.

After a few weeks Peter found a job and a flat, and the next year went back to university in Auckland. For the next 10 years things were fine. He completed his degree and started work. At times his friends had noticed he got twitchy, but they didn't notice anything really strange. Nobody thought Peter would become unwell again.

Then Peter was made redundant. He had a year of drifting and living alone on very little money. Then he became obsessed with a new project. It consumed his waking moments but when the project ended, he suddenly became ill again. 'I had seen him not long before and he had seemed fine. But in fact he was becoming unwell and his flat was a mess, he was malnourished and he had some money problems.'

Peter's father brought him back to Wellington to stay with him, but when he insisted on going to see Ruth he wandered off from Ruth's home and nobody knew where he was for an hour or two. Ruth was distraught. They finally found out about the Psychiatric Emergency Response Team, phoned, and got an immediate and very helpful response. Peter was admitted to hospital that night. This time his delusions were about his recent project, rather than about his health.

While Peter was in hospital, the psychiatric nurse in charge of him saw Ruth and gave her a boost by actually talking to her about Peter's condition and treatment. He told Ruth that he thought Peter did not

have a bipolar disorder, as previously thought. 'At last someone recognised my need to know what was happening, so that I could understand and help Peter better.'

When Peter was discharged there appeared to be no discharge plan and once again nobody wanted to talk to Ruth about what was happening. Peter was still up at all hours of the night and insisted that he go back to Auckland. 'I knew he still wasn't well but he was an adult and could do what he wanted.'

Peter had in fact been given a referral to an Auckland community mental health team and he started seeing a psychiatrist on a regular basis. But Ruth had to go up to Auckland when he became suicidal.

Peter was then diagnosed as bipolar and put on a low dose of lithium, and started to see a counsellor regularly. He found a job and was doing okay. However, he missed a blood test and was admitted to hospital with lithium toxicity. He almost died. Peter had made an appointment with his mental health social worker who found him unconscious and called an ambulance. He had a good relationship with his social worker and this had saved his life.

After the lithium poisoning Peter made his mind up to try something different. He stopped going to the mental health team because he thought they were running on a trigger-happy medical model, and he went to a drug rehabilitation service instead. They were extremely helpful and talked to him about his whole situation. They analysed his sleep and decided that his problem had a lot to do with anxiety. They put him on a low dose of valium to calm him down. Peter trusted them. He is now completely off medication, has learnt to manage his sleep and his eating, and doing really well.

'Peter has started organising some new work. He spent three weeks with us recently, and all I can say is that he is spectacularly better now. He says he feels better than he has ever felt before, and he certainly seemed so to us.'

# What helped Ruth and Peter's recovery?

## Information and responsiveness from health services

The mental health system has been a mixed bag for Ruth and Peter. Ruth explained that the Psychiatric Emergency Response Team was very responsive to their needs in a crisis, and this made their lives so much better. They knew where to go and what to do. 'We called them at a very distressing time when we really needed help and that is what they gave us.'

A psychiatric nurse at the hospital who provided information to Ruth helped her feel better informed and confident that Peter was getting the immediate help he needed. One of Peter's psychiatrists was also very helpful.

'His psychiatrist was perfectly willing to keep me informed. I wanted to know what I could do and I was reassured that I was doing the right thing and that he was being well looked after. This was the first time I had felt that.'

The medical people at the Auckland Hospital where Peter was admitted for his lithium toxicity were wonderful. 'The doctor who revived him phoned me personally to explain what had happened. Our need for information and reassurance was recognised.'

The drug rehabilitation people were also very helpful. They looked at Peter as more than an illness, and didn't focus entirely on a medical model.

## Information from Schizophrenia Fellowship

Ruth contacted the Schizophrenia Fellowship a couple of years ago when there was concern that the local mental health services were going to dismantle the Psychiatric Emergency Response Team. Ruth who has a journalist background, did some research for an article about the proposed changes. But she had to stop work on this in midstream, when Peter got ill again.

'I spoke to the Schizophrenia Fellowship after Peter got sick. They were marvellous and gave me lots of information. I didn't go to the groups because when I had time I wanted to do other things besides think about Peter's illness. Also, we are lucky, he is so much better now. But I know that they are there.'

## Counselling for Ruth

Ruth also went to counselling when Peter became ill after her other child had died. 'I didn't know why I felt so flat and low! She told me I was seriously depressed and it was no wonder, when one child had died and the other had a mental illness.'

The counsellor asked to see Peter too, and got him to promise to eat and take care of himself so Ruth could safely go away. She also suggested that Ruth needed to express her own anger and distress. 'Once when Peter was out I jumped up and down on his mattress and felt better!' A year later I found another counsellor whose own child had died. She understood what I was still going through. Just talking about it together really helped.

## Peter and Ruth's strengths

'I think my strength was that I felt I could not spread the grief and distress of my other child's death by going under myself, we all had to recover somehow'.

'Peter's strength was going to the drug rehabilitation people himself. He trusted them about drugs because their job is rehabilitation.'

## What hindered Ruth and Peter's recovery?

### Unpredictable and disruptive illness episodes

'Peter isn't chronically unwell and it has only really been three acute episodes, followed by various periods of recovery. What is so devastating is the sudden eruption and not knowing if or when it might happen again.'

Ruth is divorced and cannot share the experience of Peter's illness with his father, and while her new partner is very supportive of her, he does not relate to Peter in the same way as a parent does.

'Graham once said " It's the disruption to our lives that I can't handle" . But it's the disruption to Peter's life that I find most distressing, rather than the disruption to ours.'

### Unresponsive services

Ruth and Peter had an unhappy time with their first GP. He seemed to blame Ruth for Peter's sickness. Ruth feels that Peter was not properly assessed at the start. Until recently she was only very rarely involved, or included in decision making.

'If he had been properly assessed and helped originally, maybe things would have been different. It would have saved everyone a great

deal of anxiety, effort, and money. The first two times the immediate crisis was dealt with in some way, but nothing else was done to restore him to health and help him stay well. I got the impression that he was just not considered seriously ill enough, compared to others, to warrant more help. If they had have been more proactive it might have been better. I know it's difficult, but they didn't make time.'

The experience with Income Support left Ruth and Peter in shock. Peter needed help, after a major loss, but they were treated like criminals trying to rip-off the system. This placed undue pressure on both of them.

## Lack of information from health services

The GP and the people in the hospital ward prescribed very heavy tranquillisers without giving any information. The first time Peter was sent home from hospital it took Ruth some time to convince the doctor to give him some sleeping tablets. No information was provided and Ruth felt completely in the dark.

'Families have to know what is going on. It's not that we want to pry or cause trouble. We are the front line, we are the ones living with the person, we are the people who make sure they take their medication and that they don't kill themselves. And we support them as they recover. We have to know what to do, we are the people who actually care the most.'



## JOHN, HINEMOANA AND THEIR SON STEVEN

John and Hinemoana have four children. Steven is their eldest, at 21 years old. Steven left home at 17 and moved in with his grandmother. He started hanging out with a group of people who were into drugs. John and Hinemoana were worried about him but had no idea what was to happen over the next few years.

Steven first became ill when he was 18. He started hearing voices, biting himself, scratching himself and destroying anything he could. Steven moved back home to his parents but nobody knew what was wrong with him. His girlfriend's aunt worked in the mental health area and she suggested contacting the local mental health service.

John called Psychiatric Emergency Response Team and he thought they were great. They checked whether Steven and the family needed help that night, or whether they could wait until the morning. The family brought Steven in to see a psychiatrist the following day, and he told them that Steven was quite ill and should be put into hospital. Steven and his family didn't want that and so they got some medication and took Steven home.

Over the next year Steven continued to take drugs and the family struggled with his behaviour. Steven's so-called friends got him to buy their drugs for them even though he was on a benefit. At one point he was admitted to hospital for two weeks. He did go voluntarily but his family had arranged to send him even if he decided he didn't want to go.

At last Steven decided that he couldn't continue to take drugs and he gave them up. His friends didn't really understand and weren't

very supportive. He did get a little better and started work again. Steven saw a caseworker regularly at this time which appeared to be helping.

At one point, the family discovered that Steven was using drugs again and that his caseworker had known about it all along. Steven's parents gave him an ultimatum - to stop taking drugs, or move out. It wasn't that they didn't want to help Steven, but they had three other children who had taken a back seat for a while.

Steven has given up drugs again and is working hard at staying well. He has a full-time job, is the father of a 10-month-old baby and continues to live at home. He is into a routine now and continues to grow stronger day by day.

## What helped Steven and his family's recovery?

### Responsiveness and respect from health and welfare services

The mental health services that Steven and his family used have been very responsive to their needs and have treated Steven with respect at all times. They were also offered the option of going to the Maori mental health unit but chose to stay in the service they had started with.

'We have always been involved in making decisions for Steven and this has been helpful because we are the people who live with him all the time. It is so good that his caseworker listens to us as well. We feel valued.'

Income Support has been helpful too. They made it easy for Steven to go on the benefit and always treated everyone with respect.

## Steven and his family's determination

'I think our greatest strength has been the fact that we are determined that Steven will get better. Steven has determination too. Determination not to end up in hospital again. He said he was frightened in there and it was not very nice.'

'We spend time chatting with Steven about what's happening and try to work out with him whether it's the illness or just growing up stuff.'

## Extended family support

Steven's extended family has been very supportive and has been a big help in the recovery process.

'Our family has been amazing. They don't all understand but they have tried to be there when it mattered. I have a brother and mother in the same street and that is wonderful. We often get together as a large family group. Steven doesn't always join in but he does poke his head in and say hi. It's good knowing that I can call on them at any time of day or night.'

## Steven's work

'Steven is employed and this helps to keep him focused. Working has been very useful in his recovery.'

# What hindered Steven and his family's recovery?

## Steven's involvement with drugs

Steven continued to take drugs from time to time which made it harder for him to start getting better. 'We suspected that Steven was on drugs again because he was doing stupid things.' Steven's friends were not very supportive and they kept trying to get him back on drugs. This was not useful and he had to learn that they weren't really friends. A hard lesson to learn.

## Lack of information from mental health services

'We just want to know what is happening so that we can help Steven. John puts his medication out in the mornings so we need to know what [the medication] is.'

When we found out that Steven's caseworker didn't tell us he was taking drugs he said it was Steven's right not to tell us. 'What about our rights? We have other children and we have to think about them as well. If Steven wasn't prepared to help himself, what could we do for him? It just disappointed us. Also, if we had have known sooner we may have been able to do something more to help him.'

## Steven seen as just an illness by mental health services

'The only other thing that could be seen as a criticism of the mental health services is that they treat Steven's illness but don't necessarily see his life as bigger than his illness. He's a young father, with work commitments and an illness, that's a lot of stress and it's not just his illness.'



## CHRIS AND HER DAUGHTER LIZ

Chris is the mother of three girls and a boy. Chris and her daughters all live in the same city and her son lives in Australia. Liz, the youngest, is 19 years old and has just had her first psychotic episode.

Liz lives with her older sister, Michelle, and her husband. Things started to go wrong when she started a new job. Liz started to act a little strangely. She didn't eat or sleep, and had grandiose ideas about her life and what everyone else should be doing. Her family started to worry and talked to each other on the phone about Liz.

Liz's odd behaviour became much worse in the second week. The rest of the family decided they needed to do something for Liz. Her other sister Rebecca, suggested calling the Schizophrenia Fellowship.

Chris found the Schizophrenia Fellowship very good because they listened to her and arranged for one of the field workers to phone and the family. The next day Liz, her mother and the field worker went to see the family GP who said that she didn't have much experience in this area, but was very positive.

The next day the family went to an appointment at the local community mental health service. Everything went as smoothly as could be expected. The psychiatrist told the family that Liz was having a psychotic episode and gave her some sleeping tablets. Liz stayed at her mother's place for a few nights to get her sleeping back in order. The rest of her symptoms disappeared as well.

Liz only took the sleeping tablets for about four days and initially saw her psychiatrist once a week. Now, a couple of months later, she only sees someone once a month. Liz still lives with Michelle and her husband. She has been offered her old job back but feels it

would be a backward step. She wants to feel totally better before going back to work.

Liz was not unwell for long but she is having some difficulties getting back to full strength again.

## What helped Liz and her family's recovery?

### Responsiveness and respect from mental health services

The experience itself wasn't good because of what happened to Liz, but her family are very positive about their success at wading through the system. The mental health service that was used was quick in responding to the crisis, they always treated everyone with respect and always included the family and Liz in all decisions.

'The psychiatrist has been great. She has always included us and kept us informed. It's better knowing than not knowing what is happening. This was made easier by the fact that Liz said it was okay to tell us all what was happening. I think everyone concerned has treated Liz like she was a person first and focused on her, rather than her illness.'

### Family solidarity and support

Liz's family feels that one of the most helpful things in their recovery was their determination to get through it as a family.

'We spent and still spend a lot of time talking to each other and supporting each other. This has meant that we have never given up hope. The family has stayed together as a family unit and we are strong because of it.'

One of the things that helped Liz through the process was that her boyfriend was really good. He has always been there for her and supported her throughout.

## Support from the Schizophrenia Fellowship

"The Schizophrenia Fellowship were very supportive and gave us exactly what we needed at the time."

## What hindered Liz and her family's recovery?

### Liz's loss of friends

One of the hardest things for Liz to come to terms with was the fact that although she had heaps of friends before, they were not visiting very often any more. She did explain to them what had happened but they don't really understand why she can't go out drinking with them.

### Slow service and rudeness from Work and Income New Zealand

One of the other things that made the experience more unpleasant was Work and Income New Zealand. Originally they were quite supportive, but when things weren't happening when they said they would, Liz started to question them. Liz was given the wrong forms originally and had to keep filling in more forms and was then being asked to see different doctors. It became a bit like jumping through many hoops. They started to get very rude and were quite nasty sometimes. But Liz just needed to have money to pay rent and for food.



## CONCLUSION

### Families' Recovery Needs

*"Having a family member with a mental illness has a profound effect on the whole family. Parents, siblings, partners, extended family members and the person with the mental illness all take an unplanned, unwanted ride on a "rollercoaster". Their lives become turned upside down. Many families find the journey too turbulent and become fractured.<sup>2</sup>*

Each of these families has a slightly different story to tell, although they have similar views about what has been helpful in their recovery.

Mental health services and government agencies such as Work and Income New Zealand help in the family recovery process when the people who work in them:

- respond quickly in a crisis
- respond effectively to the stated needs of consumers and their families
- treat consumers and their families with respect
- take time to provide information and don't talk jargon that only a few can understand
- believe and value the family's experience – they know about their son or daughter

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<sup>2</sup> Schizophrenia Fellowship, Wellington. *The Sun will Shine Again: Stories of Survival and Optimism in the Face of Mental Illness*. Wellington, 1999

- enable families and consumers to be truly involved in decision making
- treat people with mental illness as people and not just an illness
- provide hope and explain that it is not all gloom and doom.

The families also valued the role of other agencies and services in their recovery, especially the Schizophrenia Fellowship which was consistent in providing much needed information and support for them.

All the families recognised how important their own strengths, determination and solidarity were in their recovery and the recovery of their family member with mental illness. They also considered it helpful to have acceptance and support from extended family and friends.



## APPENDIX

# The Blueprint on Recovery and the Role of Families

## What is recovery?

The Mental Health Commission's *Blueprint for Mental Health Services: how things need to be* makes it explicit that mental health services need to adopt a recovery approach in the work they do.

'Recovery is a journey as much as a destination. It is different for everyone. For some people with mental illness, recovery is a road they travel on once or twice, to a destination that is relatively easy to find. For others, recovery is more like a maze with an elusive destination, a maze that takes a lifetime to navigate.'

Recovery is happening when people can live well in the presence or absence of their mental illness, and the many losses that may come in its wake, such as isolation, poverty, unemployment and discrimination. Recovery does not always mean that people will return to full health or retrieve all their losses, but it does mean that people can live well in spite of them.

Historically, mental health services have failed to use a recovery approach. Recovery could never take place in an environment where people were isolated from their communities and cultures, where power was used to coerce people and deny them choices, and where people with mental illness were expected never to get better.

Some people have experienced recovery without using mental health services. Others have experienced recovery in spite of them.

But most will do much better if services are set up and delivered to facilitate their recovery. Virtually everything the mental health sector does, can either assist or impede recovery.'

## Families and recovery

The Blueprint recognises that families can have a major role in the recovery of people with mental illness.

'People with mental illness are not ill in isolation. Their families, extended whanau, and significant others, whatever they think about the illness, cannot escape being affected by it. The lives of people with serious mental illness are inextricably involved with the lives of those they love and care for, and the lives of those who love and care about them ...

Family inclusive mental health services should:

- pay attention to the emotional, educational, social and clinical needs of the whole family
- assess the strengths, problems and goals of the person with a mental illness and key family members
- formulate a plan that co-ordinates all aspects of a person's treatment and support so that all involved are working toward the same goal in a collaborative and supportive relationship
- provide the family with the skills and strategies required to cope with the illness, to facilitate recovery, and to maintain good relationships within the family
- provide the person with mental illness and key family members with information about the illness and its treatment.'

## Anti-discrimination resources

- *A Gift of Stories: discovering how to deal with mental illness* (1999) is a book in which people who have at some point in their lives been diagnosed with a mental illness tell their stories.

The Mental Health Commission is committed to getting rid of the discrimination towards people who experience mental illness that exists throughout our society. It believes that sometimes stories, rather than facts, figures, and case studies, are the best way to tell "the truth". Stories make ideas real, and personal stories go one step further; they fill ideas with meaning.

The book has been produced as part of the work of the Commission's Anti Discrimination Action Plan Team. The Commission hopes that it will be a powerful resource – a source of inspiration for people with a mental illness and those who are close to them and a special teaching tool for people who work in the mental health area. *Available from book stores or University of Otago Press, P O Box 56 Dunedin.*

- *Map of the Journeys Towards Equality Respect and Rights for People Who Experience Mental Illness* is the plan the Commission developed for countering discrimination, after extensively researching the nature and persuasiveness of discrimination in our society. *Available from the Mental Health Commission.*

