

# *When your child is diagnosed with schizophrenia:*

## *The skills and knowledges of parents*

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This article documents work with a group of parents in Central Australia who have a son or daughter who has been diagnosed with schizophrenia. The first part of the article collects some of the parents' reflections on the effects of schizophrenia on their lives and their ways of responding to them, while the second part is a collective document produced with the group about their skills and knowledges.

This group work has led to the production of a larger booklet for the wider community, as well as networking and partnering with local community mental health organisations, and advocacy and lobbying of politicians and health services.

Keywords: parents, schizophrenia, collective documents, narrative practice, group work

## INTRODUCTION

The experience of parents who have sons or daughters with schizophrenia can be varied and may range from pain and frustration, to courage, tenderness and love. This paper describes some moving and inspiring experiences that emerged through sharing stories in a parents' group run over four weeks, and also from a series of interviews following this group. Names have been changed to protect the confidentiality of individuals.

The experience of parents whose children have a diagnosis of schizophrenia rarely receives attention. When parents first learn that their child has a diagnosis of schizophrenia, they may experience a range of emotions – from shock, confusion, dismay, sadness, and even anger. Parents often search frantically for answers that may not exist. Due to societal attitudes about mental illness, they may blame themselves or their circumstances for their child's distress.

Up to 75% of people with a diagnosis of schizophrenia are in regular contact with their families (Lehman & Steinwachs, 1998), and more than one third of individuals with a diagnosis of schizophrenia live with family members, often aging parents (Lefley, 1984). Families of people with a diagnosis of schizophrenia face many challenges (Hackman & Dixon, 2008). Families provide emotional and financial support, as well as advocacy and facilitation of treatment to their son/daughter. The stresses of illness exacerbation, coupled with limited social and coping capabilities, can contribute to a substantial sense of burden (Solomon & Draine, 1995).

Whether the parents live with their son/daughter, or live apart, they continue to offer what they can. This article describes some of the parents' journey. This article consists of two parts. The first part describes an exploration of the four different topics that the parents wanted to discuss: shame and sorrow, anger and despair, guilt and self-blame, and ways of coping. The second part is a collective document that was generated through these discussions about what sustains them during tough times. Following these meetings and interviews, all the parents agreed to contribute their stories to a booklet, in the hope of assisting other parents.

## PART ONE: JOURNEY OF SURVIVAL

It's impossible to convey how moved I felt when I first met with these parents. To meet with parents who are witnessing the impact of schizophrenia on their sons and daughters' lives, to witness the courage, the love, and the passion that these parents possess in trying to address the suffering of their loved-ones, is both heartbreaking and inspiring.

When I first started working as a community mental health nurse in central Australia, I met with several parents who had sons and daughters with a diagnosis of schizophrenia. Over the course of several weeks, I heard parents describe various feelings and experiences, many of which were due to prevailing attitudes and beliefs about mental illness in the broader culture:

- Feelings of isolation played a big part in some of their lives.
- Some parents felt plagued by guilt and self-blame.
- Failure was a feeling they described that could sweep over them like a tidal wave. Thoughts like: 'I am inadequate as a parent', 'It is my fault that my child developed schizophrenia', 'I must have some kind of weakness that I have passed on to my child: a faulty gene or some other inadequacy', 'What did I do wrong?'
- Shame and sorrow were common feelings, as were feelings of worthlessness, a sense of powerlessness, and helplessness.
- Depression and anxiety often came, uninvited, to create more of the above feelings.

A colleague and I wondered whether it would be beneficial for these parents to meet and, if so, in what context. We talked this over with the parents and we decided to meet as a group, for two hours every Wednesday, for four weeks. We asked them what felt important to cover in these meetings, and they then prioritised which topics would be discussed. The following are explorations of the topics that the parents chose to cover.

### SHAME AND SORROW AND NOTICING SPECIAL QUALITIES

Some of the mothers and fathers present in our meetings have felt considerable sorrow and shame. Many of the experiences of sorrow reflect their love, hopes and wishes for their children and their

distress at any hardship their children face. Parents' experiences of shame, on the other hand, often reflect the effects of powerful shaming discourses in relation to mental health and also in relation to mother-blaming and parent-blaming beliefs and practices.

One mother talks about shame being connected and fed by society's lack of understanding about schizophrenia:

*If we had better understanding, and more meaningful, holistic treatment approaches, then shame would reduce, I'm sure of it.*

## EXTERNALISING CONVERSATIONS

In the group initial conversations, I was aware that many parents were using expressions like, 'my son is a schizophrenic'. There was no separation between the illness diagnosis and the person their son/daughter was. Many people in therapy believe that the problems of their lives are a reflection of their own identity, or the identity of others, or a reflection of the identity of their relationship. This sort of understanding shapes their efforts to resolve problems and, unfortunately, these efforts often have the effect of exacerbating the problems. In this context. In our discussions with parents, we engaged with externalising conversations:

*Externalizing conversations can provide an antidote to these internal understandings by objectifying the problem. They employ practices of objectification of the problem against cultural practices of objectification of people. (White, 2007, p.9)*

This seemed to be a turning point for many of the parents. Externalising conversations made it possible for these parents to separate their sense of identity, and the identity of their son/daughter from a deficit-centred account of who they are:

*In the context of externalising conversations, the problem ceases to represent the 'truth' about people's identities, and options for successful problem resolution suddenly become visible and accessible. (White, 2007, p.9).*

## QUESTIONS WE USED TO EXTERNALISE SHAME

- What is shame convincing you of?
- How does shame influence the way you see yourself and your son/daughter?

- What feeds the shame, or makes it possible to have this influence?
- What helps shame to keep going?
- What does shame want from you?

## OTHER QUESTIONS WHICH WOULD HAVE BEEN INTERESTING TO ASK

- What will your life be like if shame continues to play a leading role?
- Do you agree with shame's plan for your life?
- Why do you have this view? Can you share a story that would help me to understand this?
- What would become possible for you if shame was no longer around?

## HOW SHAME HAS BEEN CONTRIBUTING TO PARENTS' THINKING

One mother offered the following account of shame's effects:

*Our sons and daughters don't fit in and contribute to society in a way that is acceptable or normal. They don't meet certain expectations. They have not been able to achieve or fulfil hopes and dreams that we had for them, like marriage, having children, a good career. Because my son doesn't have material success, he is considered a failure, and as a mother, I am therefore a failure. People probably will feel pity, or may laugh and snigger behind our backs. I feel very small, and wish we could be invisible sometimes. Shame can feel all-encompassing at times, it takes me over.*

## WHAT FEEDS SHAME?

We shared views about the various ideas and norms that exist about what people's lives should look like in order to be seen as successful or worthy. Various common expressions were picked out that tend to have an all-pervasive effect on how we rate ourselves and each other:

- If your behaviour is different, then you are crazy and, if you are crazy, then you are on the lowest rank of society.
- If you are not married with children, there is something lacking in you.
- If you don't have a house, and a great job, you are a failure.

- 'If you have a mental illness diagnosis, then you've had it; you're on the bottom of the heap and have nothing to offer.'
- People with a mental illness need to go somewhere to be looked after.

This was an interesting discussion, because many of the parents stated that their sons/daughters actually expressed contentment with their lives. As a loving parent though, this was hard to believe, as their lives were so far removed from the expectations and norms that other people placed on them.

Through the course of this conversation, some interesting developments emerged. I heard one mother comment how she had gone into town one day with her son. On the pavement was a woman in considerable distress; she was confused and agitated. People were walking over to the other side of the street to avoid her, clearly uncomfortable. The son approached her, spoke to her, and the young woman responded to his kindness and attention; she calmed down. They continued to talk for a little while.

The mother stated that while other people did not want to get involved, she feels her son has a special kind of empathy – an empathy that makes him sensitive to other people's distress; empathy that enabled him to have some understanding and some ability to reach out and comfort others when they are in deep distress. This was a sparkling moment, and provided a wonderful opportunity to explore some of the alternative, preferred stories of the other children's lives. Unique outcomes such as these provide a starting point for re-authoring conversations. They provide a point of entry to the alternative storylines of people's lives that, at the onset of these conversations, are barely visible.

## RE-AUTHORING CONVERSATIONS

The practice of re-authoring is based on the assumption that no one story can possibly encapsulate the totality of a person's experience; there will be inconsistencies and contradictions. There will be other storylines that can be created from the events of our lives. As such, our identities are not single-storied – no one story can sum us up. We are multi-storied (Russell & Carey, 2004). The sparkling moments, or unique outcomes, above were painting a different picture of the parents' sons and daughters. These stories were not about 'failure' or

'having nothing to offer'. I was acutely aware, however, that these stories could again become buried beneath the dominant, problematic storylines, so I was keen to ask further questions, to take them into an alternative storyline of their son's or daughter's life. As Michael White comments:

*The status of such steps can be tenuous if they are not taken into a storyline of their life. Steps like this can be judged as a 'one off' initiative, or the outcome of unusual circumstances. This tenuous status renders such steps vulnerable and unlikely to provide foundation for change.* (White, 2007, p.110)

For example, by asking questions that encouraged these steps to be taken into a storyline, we learnt that the son's skills of knowing when someone is upset and knowing how to respond to them also came into play on other occasions. During a stay in the mental health unit, a young woman was admitted one day. She was frightened and very shy. The mother saw her son take the young woman under his wing, show her around, point out where the tea and coffee was, and welcome her. His mother had witnessed her son offering a hand of kindness. Other parents shared similar stories where their sons and daughters had displayed acts of empathy to others.

As we explored what seemed to be important to their sons and daughters, what they gave value to, and how they demonstrated these values, the parents were able to recognise and recall further stories of their children reaching out to others in a way that showed great empathy. One mother wondered if the level of her son's own suffering enabled him to see and understand the depth of other people's suffering – enabled him to reach out in a way that was also able to be received by people in deep distress. Another mother described how, as a small child, her son would often reassure and comfort his two older brothers when they were distressed. Acts of thoughtfulness and consideration were steps he often took.

The parents recognised that they held these same values very precious, and this acknowledgement really contributed to a feeling of lightness and optimism. This was very moving, and caused one parent to really review her relationship with her son. By listening out for sparkling moments such as these, we heard about many special skills

and qualities that their sons and daughters possessed. The use of externalising conversations had provided a base for these parents to richly-describe alternative accounts of their children's lives, their relationships, and their identities.

## **ANGER, DESPAIR, AND A SENSE OF JUSTICE**

Parents expressed anger that there were so little resources for people with mental illness diagnoses. Quentin, especially, felt a lot of anger: so much so, he stated, that he despaired at times. Quentin had made numerous phone calls to the local mental health services, expressing concern about his son. He had also complained of the inadequate care that he felt his son received. He had written letters of complaint, but he felt it was all to no avail. He expressed doubt in himself, adding that he felt like giving up sometimes, wondering what the point is. Some days, this despair was quite immobilising, making it hard for him to get out of bed. He felt like a failure, a 'father failure'. With this thought, feelings of depression would engulf him, and at times he felt he was 'drowning in the waves of depression'.

I was interested in what Quentin's despair spoke of, what was 'absent but implicit' (White, 2000) within this despair. The following questions generated interesting discussion: 'Quentin, you mentioned there that you feel like giving up sometimes; can I ask you what it is that you would be giving up on?' 'Despite this despair that you have felt, I'm wondering how you've been able to hold onto this hope, this hope that things could get better for your son?' 'How have you managed to keep this hope alive?'

Quentin was really taken aback by these questions. He stated that when he believes in something, he has excellent focus, and he is really able to stand his ground. I was curious as to how Quentin had been able to continue to do this despite the presence of despair in his life, and asked him questions that encouraged an exploration of the skills and knowledge that helped him to keep going along this 'path of hope'. Quentin spoke more about the love that he felt for his son, and his commitment to 'stick by him through thick and thin'. He stated that this commitment is what helps him to keep going. And even though some days he felt like curling up into a ball, this commitment to

his son helps him maintain his focus. Quentin said he also held onto his hope that society will find a way of working together to help improve the lives of those who are struggling. He takes his role in trying to bring this about seriously.

Other parents who witnessed Quentin's commitment spoke about what this inspired in them. The group spoke about actions they had taken, how they had been able to do this, what assisted them, and what this told them about their hopes and dreams. Different skills and knowledges quickly became apparent and, as a group, they decided to take further steps. They decided to continue meeting outside the group to pool their energy and skills, and take further action. They decided to undertake some research into what resources in other states and countries were proving to be helpful, and to write letters to parliament, forwarding recommendations based on this research.

## **TAKING ACTION**

Four of the parents sent a letter to the senior managers and politicians who influence mental health services in their region. In this letter, they proposed that certain treatment approaches and facilities that have proved to be helpful in other countries and states be considered for Alice Springs. Their research demonstrated that these ideas had shown a good measure of success in other places. The group received a letter in reply, but they felt that this letter was a dismissal of their proposal. They were not deterred, and sent a further letter in response providing more evidence as to why current treatment approaches were failing, and the potential success that could come from their proposals. They finished their letter stating that: 'We need to act now with knowledge, understanding, compassion, wisdom, and long-term vision'.

I asked how they had been able to do this, what it said about what is important to them, and what hopes and dreams this was speaking to. One mother stated:

'I know now that I have worthwhile knowledge; this really is based on a lot of experience. I realise that we do all need to work together, and by working together and listening to each other, we can come up with some good ideas. I feel I have a purpose now: to share my knowledge, to get the right people talking with

each other. By doing this, I really hope we can influence the development of services here and I won't stop, because I love my son. What helps me to sustain this is meeting with the other parents; we continue to talk, to share our ideas, to express ourselves. I really feel that I have something to offer now'.

One father commented: 'By continuing with this action, I am giving value to the life of my son, and all people with a mental illness diagnosis. I am giving value to my belief that all people deserve a chance. I am giving value to the importance of people working together to improve the lives of others that are struggling. This feeds my desire to be an advocate on their behalf.'

When I asked what sustains him, he said his belief in what he is doing, and knowing that he is making a worthwhile contribution to the lives of people affected by schizophrenia. The fact that he is meeting with like-minded people in a group that acknowledge each others' contribution and skill really helped to keep up his energy levels. Having this recognition gave him strength. In the past he had tended to be a loner, and struggled by on his own. Now he was valuing his meetings with other parents, and really recognising his skills in taking action. He was aware that his enthusiasm and drive was really appreciated by the parent group, and this really gave him hope that they could influence positive changes in treatment approaches and facilities for people affected by schizophrenia.

## A SHIFT IN SELF-PERCEPTION

I was interested in this shift in how the group were seeing themselves. When we first met, these parents described feeling a low sense of worth; a wish that they were invisible, or a feeling that they already were invisible; and a feeling that they were failed parents, with nothing to offer. I was interested in this change. It was apparent that, by continuing to meet in groups, these parents had been providing themselves with opportunities for being seen in their own terms: they were garnering witnesses to their worth, vitality, and being (see Myerhoff, 1986). Through the process of these gatherings, the way these parents are seeing themselves had radically changed. Now they were specialists and advocates for people affected by schizophrenia, with

an important role to play in influencing the direction of care and treatment facilities.

This makes me think of Michael White's words when he described identity as a *public and social achievement, not a private and individual one; identity is shaped by historical and cultural forces, and is the outcome of deriving a sense of authenticity through social processes that acknowledge one's preferred claims about one's identity and history.* (White, 2007, p.182). For example, as I reflect on the changes now, I remember that Quentin was 'an angry father': this is how others perceived him, and this is how he perceived himself. Through the process of meeting with other parents, Quentin now perceives himself as having skills, enthusiasm, and drive, and these are seen as precious qualities in the group. They are acknowledged to be a strong driving force in creating positive change.

The ideas and the actions they are presently taking is really valued by some organisations/people in Alice Springs. A focus group has been funded to look at the accommodation needs of people with a mental illness diagnosis in Alice Springs. A report will be put together by early next year. This move is giving further validation to the work of these parents, and contributing further to their sense of identity.

## GUILT, SELF-BLAME, AND NURTURING SPACE

Guilt is a common feature in many parents' lives. It's a challenge for parents to take time out, go on holidays, or have a dinner party, instead of spending time helping their son or daughter. Guilt can disrupt such plans. Guilt can also follow parents around, convincing them that they are never good enough. Externalising conversations were used to create some space to explore 'guilt': what were the effects of the guilt on their lives, their relationship with themselves, their sons/daughters? What sustained the guilt and what factors contributed to guilt coming in the first place?

Through this exploration, an interesting discussion arose about the various discourses that suck people into blaming parents. Parent-blaming is so widely prevalent. We discussed what these discourses convince us about ourselves, and other parents, what impact this has on us as individuals,

and on our relationships. Through this discussion, it became apparent that guilt had made it hard for some parents to really care for themselves, to take time out, and to have a gentle attitude towards themselves. Having this awareness alone seemed to create some breathing space and, in this breathing space, parents were able to start asking some questions of guilt, and its value in their lives.

Some parents spoke about times when they had defied 'guilt', when they stood up to it, weren't prepared to listen or entertain guilt, and instead had been able to focus on what they needed to do for themselves, to nurture themselves. One mother spoke of how she had learnt to do this by listening to other parents who were part of the Schizophrenia Fellowship. She stated that these parents had lived through so many worrying times, and had really learnt the importance of looking after themselves, thus defying guilt and the discourses that say you should always put others before yourself. She stated that her ability to make tough decisions helped her to make good choices – choices to look after herself, even when the 'going was really tough'. A rich discussion then took place as parents explored alternative stories of not giving in to guilt, and providing nurturing space for themselves. We asked the following questions:

- Can anyone share other stories of when they have been able to defy guilt? How did you do this? What steps did you take? How did you prepare yourself?
- I'm interested in where/when you learnt how to do that kind of self-nurturing ... is it okay to ask you this?

By asking these questions, I was interested in creating a context in which the steps that these parents had taken, and the knowledges and skills that these represented, could become known, and profoundly acknowledged. Michael White has often spoke about how:

*In times of stress – when we find ourselves under significant duress when facing situations of adversity – we are all vulnerable to being separated from our knowledgeableness.* (White, 1995, p.142)

As these parents responded to questions and shared stories about how to defy guilt and create nurturing space, a wealth of knowledge and skills became available that were not only acknowledging, but also very sustaining.

## **HARD TIMES AND COPING THROUGH HARD TIMES**

Stories about hard times were shared. At times, parents expressed that it all felt too hard. They felt like rolling up into a ball, giving up. I was curious as to what helped them to keep going despite all this distress. We explored the skills, knowledges and values that they felt had helped them to get through the hard times, where they had learnt these from, and to whom/where these skills and knowledges were connected. In this conversation, some really special skills and knowledges were rendered visible. However, the group was taken aback at my amazement, not considering them to be anything special. I wondered aloud, 'I wonder what it would be like for other parents who were finding themselves in this kind of situation, with a son or daughter diagnosed with schizophrenia?' When I outlined the skills and knowledges that they had shared with me, some parents realised that this could be very helpful for other parents. In this way, the idea of a booklet for other parents was born. I was encouraged by this as I had seen the significant ways in which collective narrative documents can be developed and used (Denborough, 2008). Other parents outside the group came in on the booklet project, and the document that was generated through these discussions follows.

## **PART TWO: THE COLLECTIVE DOCUMENT**

I prepared the following document from the parents' words during the group meetings, and in the interviews which followed. This document was prepared both for the parents and their families, as well as a way to reach out to other parents. However, the group later decided to prepare a longer document and publish it as a booklet for a wider audience.

## **WHAT SUSTAINS US THROUGH HARD TIMES: SPECIAL SKILLS AND KNOWLEDGES**

In Alice Springs, between November 2007 and March 2008, a group of us spoke about our experience of having sons and daughters with a diagnosis of schizophrenia. We shared many stories, happy experiences, and sad ones. We also spoke about what sustains us during the tough times.

This document has been put together in the hope of reaching other parents, with the wish that it may be of assistance to them. These are the ways that we journey through tough times.

### **NOT STEPPING AWAY**

Sometimes people say to us, 'Why don't you step away?'

What stops us from stepping away?

One member of the group, when talking about his son, stated: 'I couldn't do that; he needs me so I am there for him. I never knew my father and never met my mother until I was 23 years of age, so family is very important to me. I have a very strong commitment to my children. I love my boys very much – just to be around them.'

Another commented on why stepping away wasn't an option: 'I know they're mine, my responsibility; they didn't ask to be here. I just could not walk away, couldn't do it. I get this from my Mam. She saw the good in everybody. Even if you were really nasty, Mam would forgive you – she'd let it ride. My sister and I are very much like Mam, more loving, more forgiving, more caring and more nurturing. That's a thing we learnt from Mam.'

### **DOING OUR BEST**

We do what we can. We try to do our best. Some of us have done this with the love and support of a good family behind us. Others of us have battled through alone. One member reflected: 'I've always battled through on my own; when something needs to be done, I just do it'. Another commented: 'I had a really good family behind me. That's what it took. If they didn't want to know, I don't know how I would have done it.'

### **DOING THE RIGHT THING**

Knowing that we are doing the right thing can really give us strength through hard times:

'We had to get the police to come and help us take my son to the hospital. That was the worst thing I've ever had to do, but I knew I was doing the right thing for him. I just knew this was the right thing. I knew there was something wrong; I knew he wasn't well. As much as he complained, and fought and argued and threatened, he needed help, and I couldn't give it to him. He needed more than what I could do. I couldn't talk him out of it, I couldn't reason with him. My parental love, that's what helped, because I knew I had to do something. As much as I didn't want to, I was scared he would hate me afterwards, and a lot of the time, he did. But then it all stops when he gets well again.'

### **HOLDING ONTO HOPE**

Feeling a sense of hope can help us break through the darkest of days. We each have different ways of holding onto hope. After a bad day, when things have especially been tough, one of us ends the day with the thought, 'tomorrow is another day':

'I learnt this from my mother. "Tomorrow is another day; things always seem worse at night, wait until the sun comes up" – she would say this to me. The first time I had to call the police to take my son to hospital, I was absolutely devastated. Reminding myself that tomorrow is another day helped me to get through this. With this thought comes the letting go of the day's struggles, and the possibility of a brighter day to follow.'

## **FAITH AND SPIRITUALITY**

For some of us, it's faith and spirituality that gets us through. There are many ways in which spirituality can bring a sense of peace to people, knowing that we are not alone. This can be a huge source of comfort to us, especially when things get too hard, when we might feel like giving up:

'Somebody asked me how I cope and I said to her, "When it gets too much and I just can't do anything anymore, I just shove it off to God". I say, "Too much, I can't do that – now you do it". Because there comes a time you just can't do it. You don't have to carry everything yourself because you can't.'

'My faith kept me going. I knew I had to be strong and not give up because my daughter took it very badly – she suffered a lot and still does, so I knew I had to be strong for her as well. I think having that strong belief has helped her as well. I regard it as a gift to me to cope. My mother was always a strong person, managed, and was supportive; maybe I had a bit inherited from her.'

'My faith kept me going. I know this is not all there is to life. You just have to do your best and if you can't change something, you can't change it. I just try something, and I know that there will be an end to it someday and hopefully something better will come along. I have a very strong belief that our life here is impermanent, so I try to do my best, nothing is perfect.'

Others of us find comfort from the words in the Bible: 'Today is Wednesday. Pastor will be here 6 or 7 o'clock; he takes me and my husband for Bible studies, every Wednesday ... this helps to keep us strong'.

Having something to look forward to, having this time to feel our spiritual connection, helps some of us to keep going, gives us strength to get through the hard times.

## **FINDING THE HUMOUR IN CRAZY SITUATIONS**

'You've got to have a laugh sometimes and laugh at some of the crazy stuff, even if it wasn't a funny thing at the time. If you don't laugh, the pressure and the tension can make you sick. It's important to know that we are allowed to laugh about horrible things. It doesn't lower you. Finding the humour in situations has really helped me to cope through difficult times. Sure, I choose the time and place to do this; that's really important. This ability to laugh was in my family even when I was a young child. It feels like an instinct of survival to me now.'

## **FOOD AND HEALTHY TUCKER**

Sharing and eating good tucker can be a way of nurturing ourselves. Two members of our group spoke about how they keep themselves strong with good tucker, fruits, and veggies:

'We really like to go out for bush tucker, good tucker from out bush, honey ants. Sometimes we take our tucker from the shop here and make damper. Sometimes on a weekend, when we had a car, we used to go out to hunt for kangaroo. We learnt the importance of sharing good tucker when we were kids. Sometimes our parents had time away, and we would stay with our aunties and uncles. I remember how we would all sit together and share good tucker.'

## **KEEPING GOING/DOING SOMETHING**

Some of us have found different ways of keeping ourselves encouraged, to keep going.

Times can feel really hard: we can feel stuck, and not know what to do. One of us spoke about the importance of talking with friends and family:

'When my son was ill, friends of ours starting pushing us to do something. My brothers always said, "You've got to do something about it". The worst bit for me was trying to do something about it, to actually take that step forward. Having that outer circle of friends, giving you that little bit of a push, helped me to be game enough to get the ball rolling.'

For some of us, talking with friends and family, sharing our concerns can be a huge support.

There are many different ways to feel that encouragement to carry on, to move forward. Some of us are spurred on and keep ourselves going by avoiding procrastinating, not letting procrastination steal our energy. One of us commented:

'Procrastination came up for me at AA (Alcoholics Anonymous). That's when procrastination came into my vocabulary. I'd gone along to Al Anon. I'd gone with people in order to support them. In the AA meetings, they used to teach us that procrastination stole time and energy, and in the meantime nothing constructive was being done. So now I know that you can't procrastinate, you've just got to get on with your life. There's no point feeling sorry for yourself, because it isn't going to change anything. Just get on and get what's got to be done done. I have found over the years that attending meetings like this, attending support groups and self-help seminars can be a source of inspiration, a way of supporting ourselves and others through painful times.'

One member reflected: 'Even if you get one little smidgen from it, it hasn't been a waste of time ... and if it helps you, then even better'.

### **GETTING THE BETTER OF ANXIETY**

Another member reflected on what helps her to feel encouragement to keep going: 'It's helpful to not allow anxiety to mess things up for us'.

One of us uses the following line in our own family, to support a son through worrying times: 'Anxiety is interest paid on a debt unearned'. This reminds us that being anxious about something that may not happen is a waste of time.

Another of us likes to remind ourselves that: 'If we can change something, then change it, then you don't need to worry. If we can't change it, then what's the point in worrying anyway. I learnt this quote from a friend when I was feeling really stressed out; it helped me to feel some calmness in a turbulent time. I still use it now, it helps to calm me.'

### **FINDING INSPIRATION**

There are many lines and quotes that can help and support us along our way. One of us finds inspiration in a poem called 'Don't quit': 'I used to have it on my desk at work. It can be applied to any catastrophe in your life. During times of feeling 'down', this poem has given me strength and inspiration to carry on, to get on with it, to not quit!'

There are other ways that help us to keep going through hard times: 'I like to keep very very busy, and I set projects for myself and go and do it, like pulling the shed to pieces. I'm always doing something. I've always been very active. Sometimes it helps me to block off, so that I can keep going.'

These are some of the skills and knowledges that sustain us during tough times. We hope that, by sharing these stories, we will find some comfort in each others' words. We hope these words can find a way of bringing support and assistance to others.

## **REFLECTIONS**

In this paper, I have described some of the discussions that took place with a group of parents who have sons and daughters with a diagnosis of schizophrenia. I had been keen to explore ways of helping parents whose lives seemed to be plagued with shame, sorrow, anger, despair, guilt, and self-blame. Through using narrative conversations, this

group of parents and I all went on an interesting journey. Skills, knowledge, and wisdom that these parents have developed over the years were rendered visible. They were a little taken aback as they slowly began to recognise and acknowledge this in themselves. By far the most exciting part of this project for the parents was the hope that some

of this knowledge could be helpful to other parents. As one parent stated, 'My life has certainly been challenging in places, but it will certainly feel worthwhile if any of my story can act as a comfort or a guide to another parent'.

Besides writing the document, 'What sustains us through hard times', we compiled a booklet about the parents' journey. This booklet discusses some of their experiences: what they have found helpful, what they have learnt along the way; and skills they have acquired over the years. This booklet is a resource for other parents. Other parents in Alice Springs have been made aware of this booklet, and are looking forward to reading it and meeting these parents. Putting together this booklet of insider-knowledge has been an interesting project. As the booklet has grown, so has the confidence and the self-worth of the parents. Their voices are becoming louder. Their contribution to service development is becoming more assertive and more informed. Initially, there was some shyness about putting a booklet together for other parents – thoughts like, 'Oh, what do we know really?' were prevalent. Now the same parents are saying, 'Wow, there is some really good knowledge in there, isn't there? I wish something like this had been around for us. This really will let other parents know that they are not alone. We are so glad that we can offer this support.'

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