

Gathering and publishing personal stories about mental illness

From Julie Leibrich

Preface

Julie Leibrich set the standard and pointed the way for many of us when, in 1999, she led publication of, 'A Gift of Stories: discovering how to deal with mental illness.'ⁱ You will read in what follows that Julie has many roles and responsibilities but at the time of this publication she was a Commissioner with the New Zealand Mental Health Commission when it was leading the world in contemplating what being focused on promoting personal recovery was all about.

There have been personal accounts of mental illness and the struggle for recovery before but this was new and special in representing a collaborative endeavour between the people offering their stories and the compilers and publishers, with the overall intent that the book would be a source of hope and guidance to others – and it was.

More than 10 years later it remains the model and sets the standard for others to follow not only because of its attractive format and engaging contents but also because of the guiding values and respect it embodies for all its contributors and those who offer their stories as a gift to others. Much has followed. 'A Gift' was the inspiration for, 'Beyond the Storms: reflections on personal recovery in Devon'ⁱⁱ and the touchstone for development of Recovery South Westⁱⁱⁱ as a Regional response to the emphasis on Recovery in the Royal College of Psychiatrists FAIR DEAL Campaign^{iv}. It has also served as an inspirational guide for the succession of anthologies produced by Jerome Carson and others^v and much else.

But if we value personal stories and are inclined to follow Julie's example how do we ensure we take appropriate care for both the stories and the tellers? Within the book Julie not only includes her own personal story but also describes in some detail how she went about gathering stories and working with story tellers to be sensitive to their needs and wishes and enable them to create a personal story that was authentic to their experience and which they were comfortable with offering to others. Both the Devon and SW Regional stories projects have leaned heavily on that guidance and in wanting to promote the value of personal stories of mental health recovery as a source of hope to others they also want to promote a clear and responsible ethical framework for those involved. We could think of no better option than to ask Julie herself for permission to reproduce her guidance and she has responded with typical generosity by both reviewing it and making some small amendments and granting us permission to publish what follows on both the Recovery Devon and Recovery South West websites.

Glenn Roberts 28.11.11

Why gather stories?

The gift of a story

When I was a little girl, my grandmother Gertrude used to tell me stories. On winter evenings we would snuggle up beside the fire and she would stare into the flames and gather up stories from the shapes of the burning coals. She'd look for dragons and fairies and strange faces, and listen to the hiss of the coal to find the words. As the heat of the fire grew, so the story grew, and if she lost its thread she would just poke at the fire a bit to get another chapter.

Sometimes the stories made me laugh, sometimes they made me cry, and sometimes they were scary. But always they fired my imagination and let me see new things, or old things in new ways. Sometimes she asked me to tell a story, too. At bedtime, as the flames subsided and the coals began to cool, the stories came to an end.

In this way, from my grandmother Gertrude, I learned a love of story, and decided to be a storyteller myself.

The power of stories

Stories have been told over the fire for centuries. Before written language was born, myths and legends were handed down by word of mouth in almost every culture. They were told in carvings and etched in pictures on the walls of caves, where they were added to and revised and kept safe in what were perhaps the earliest libraries of all.

Stories are one of the world's oldest and surest method of teaching ideas. They help us *realise* ideas: they make ideas real because they ask us to use our intellect and feelings at the same time, and sometimes they also speak to our spirit.

Personal stories, which tell us about individual experience, go one step further. They not only make ideas real, but they fill ideas with meaning. They show how a person tries to make sense of their world and they give 'the truth' as the storyteller sees it. They offer us people's wisdom.

Every story is unique - even if two people have shared an experience, they will tell different stories. This is not 'make-believe'. It is 'make-sense'.

Stories change and grow all the time. We continually revise our stories, not simply by adding new things that happen to us, but reinterpreting the past in light of those things. It is as if we need to make sense of our lives in an ongoing way. Stories even change as they are being told - at that moment when they meet the listener, for as listeners, we add new meaning to them in light of our own experience.

This is why stories give us far more than information or knowledge. They give us an opportunity to understand something - to stand *under* knowledge - and the chance to gain insight - to see from *within*.

The courage of telling personal stories

We all have stories we could tell, but some of them we keep secret, locked inside ourselves for a very long time. Sometimes we are afraid to tell them in case people won't understand. Sometimes we have tried but nobody listened and the words got lost. Sometimes we are simply silenced.

Yet these are the kind of stories which can say the most significant things about life – even unlock the doors to life – but they take courage to tell. This is a book of such stories.

The stories here are by people who have, at some point in their lives, been diagnosed with a mental illness. In their stories, they talk about how they learned to deal with the illness and what they discovered about themselves in the process.

The act of telling stories can restore people ('re-store'). The telling of our story to someone who is genuinely interested and who relates to the telling through their own experiences is a very precious thing. But if a story is told and not understood, then a part of oneself has reached out into nothingness:

they died because words they had spoken
returned always homeless to them.

*Janet Frame*¹

Some people even say when you lose your story, you lose yourself.²

It takes great courage to publish a personal story, for you have no idea who the reader will be, and cannot know if they are really listening. All these people have told their story before, but most have told it only to a few close friends. Very few have seen their story written down and put in a public place. The contributors here have found the additional courage to speak out about their experience in a world which is profoundly prejudiced against people with mental illness. This is one of the reasons why the stories told here are so precious.

Gathering and presenting personal stories

A personal story belongs to the person who lives it, to nobody else, unless that person makes a gift of it. But it is often *other* people who tell stories about someone's

¹ *The Pocket Mirror* by Janet Frame. Vintage. 1992. From the poem 'The Suicides' page 72.

² Laurens van der Post makes this argument in several of his books, for instance, *The Heart of the Hunter*, Penguin, 1965.

experience of mental illness. These *other* stories are sometimes called 'case histories', novels, newspaper articles.

The people in this book speak for themselves. Their stories were recorded on tape and written down in the teller's own words. I took great care to make sure that these stories are authentic, and that they belong to the people who told them to me. At the end of the book, I have given a detailed description of how I gathered and presented these stories. I hope you will take time to read it as it is very important to understand how context determines content in this kind of work.

The stories also speak for themselves. It was never my intention to comment on the stories or try to interpret them as I believe that this would be an intrusion on each person's integrity. This position led to my facing a dilemma as I came to end of preparing the book for publication. Several people with whom I discussed my ideas about the book felt that I should summarise the stories. My training as a social scientist, and my background as a psychologist, almost tempted me to do this, for the material here is so rich. But I am glad to say that my instincts as a story-teller were finally stronger. All I am prepared to do is mention what *I* learnt as a result of doing this work, what insights *I* gained. And I have included these in my *own* story - for that is where they now belong.

The much more important question is: What do the stories tell *you*? What insights will you get from reading them? Will you be able to open your minds and hearts and really listen? For this is a book of extraordinary gifts, to you, from people who want you to hear their story.

Understanding mental illness

In our society there is a vicious circle of fear and ignorance about mental illness: We fear what we do not know; and we do not want to know more about what we fear. There are so many obvious and overt unfair acts - the insulting images and language used about people with mental illness, the denial of their rights to good housing and employment, the fact that the mental health sector has had to fight tooth and nail for adequate funding.

Such things are not easy to deal with, but they are mostly visible and tangible, and can usually be pinned down and dealt with in the end. Much harder is the invisible, intangible prejudice, such as seeing mental illness as a person's primary characteristic, or even as their entire identity. This is what happens when we limit someone by a label. There is a danger we will limit them forever.

Some might say, for instance, this is a book by 'people who are mentally ill'. But I would say this is a book by people who have a lot of different talents and skills and achievements, *one of which* has been dealing with a mental illness that has significantly affected their lives.

Mental illness is not choosy; it affects people of all ages, backgrounds, abilities, and experiences. Some might say, this is a book by 'schizophrenics, manic-depressives' and so on'. But I say it is a book by people who are artists, mothers, fathers, typists, poets, lovers, researchers, analysts, doctors, sons, daughters, university teachers, sculptors, cousins, students, school teachers, reporters, gardeners, friends, health workers, factory workers, singers, voluntary community workers, cat lovers, grandmothers, uncles, aunties, sailors.

There is no one thing called 'mental illness'. Just like physical illnesses, there are many kinds, each of which differs in its effect on people's lives. Some illnesses are relatively mild, some extremely serious. Some people have a single episode of illness, some have episodes throughout their lives, and for others the illness is ongoing.

The diagnosis of mental illness is a complex matter. Even though there are standard criteria for diagnosis not everyone would agree with the validity of this system, which tends to be categorical. Some people prefer to describe mental illness in terms of the dimensions of human experience.

This book is about human experience rather than medical categories. That is why it does not give a glossary about specific diagnoses. Several of the people in this book were given more than one diagnosis over the course of time. Some accepted the diagnosis, some did not. Some found the diagnosis helpful, some did not. But most importantly, several explain how that diagnosis became a label which became a problem in itself.

A diagnosis of mental illness does not say anything about a person's capabilities, personality, or future. The *vast* majority of people who have some kind of mental illness: get better, can hold down jobs, make good partners, lovers, parents, and are not dangerous, and have a great deal to give to the world. In fact, the very act of dealing with a mental illness often gives people extraordinary strength of character.

Getting the right kind of help early on can make a great difference to the outcome. It can reduce the symptoms and speed up the process of getting well. Yet many people never seek help *at all*. Partly that is because the right kind of services are not always available, but it is also because in a society prejudiced against people with a mental illness, it is very hard to 'admit' to having one.

Real stories challenge discrimination

The Mental Health Commission is committed to getting rid of the prejudice and discrimination in society against people with experience of mental illness. It exists in communities, organisations, government, individuals, and in the health sector itself. One of the ways we can do this is to educate people about the reality of mental illness.

It is my hope that A Gift of Stories will be a powerful resource - a source of inspiration for people with mental illness and those who are close to them, a special teaching tool

for people who work in the mental health area, and a way of opening doors on mental illness and letting some light in, for *all* of us.

How to gather stories?

Context defines content

My friend Betty Munnoch taught me, years ago, that context defines content. We were both students at Edinburgh and used to study together. Before we began a discussion, Betty would always ask me, 'Now when was it written? What was going in the country at that time? What about the politics? What was the economy like? And what about the author, what do we know about the author?' That was one of the most valuable lessons I ever had.

Since then, I have never wanted to separate process from content. That is why I believe it's important to know the process of producing these stories.

The first aim of this work was to produce a book of stories about how people deal successfully with mental illness. The underlying purpose was to produce a document which would help to counter discrimination against people with experience of mental illness.

For me, inevitably, a secondary aim was to understand what it really means to deal successfully with mental illness. What is involved? What lessons can be learned from what people say? Is there something *I* can learn from this which will make my work as a Commissioner better? What will it teach me personally as well?

In a sense, this was also research. This very special kind of writing and research has a fascinating methodology. It's a process of continuous evolution. Because it moves through stages of interview and discussion, transcript, draft story and discussion, final story and discussion, there are opportunities for insights to emerge all the time. Meaning develops as the work progresses.

There was no 'grand' design to this book. I just decided it had to be written and then it just seemed to happen. However, I had written a similar book some years ago and for that I developed a methodology which served me well again³.

The people who told me their stories came from all around the country and were not chosen in any systematic way. Some people had heard I was planning this book and asked to be in it. Others were approached directly or by other people. Everyone had the choice of being identified or being anonymous, and I also made it clear that they could drop out at any part of the process, prior to publication.

³ *Straight to the Point: angles on giving up crime* by Julie Leibrich Otago University Press: Dunedin, 1993.

The initial interviews (which were recorded) were carried out over a period of two years, so the understandings I got about how people deal with mental illness filtered in slowly. And of course they became integrated with and informed by other parts of my experience – both in the present and historically.

In trying to really *hear* people's stories, I had many more advantages than anyone reading this book. For a start, I spent quite a lot of time with most of the people. Some of them I already knew, others I came to know during the past two years. I also heard much fuller versions of their stories – some of the transcripts were over 40 pages long. I also heard things which people did not want to be recorded and the things that were recorded which they didn't want to go into the written story. I also heard parts of the story told again in more expansive ways during the second interviews. All of these versions of their stories contributed to my understanding.

When people told me their story, I also watched their faces as they talked to me. I heard the silences in their stories, the inflections in their voices, and the things they repeated in different ways – saying, in effect, “now this bit is *really* important”. I heard the pauses and the emphases and the tone in which they said things - the moments of wry irony, the sadness, the anger, the relief. Most important of all, I had the opportunity to *relate* to the people. This is the most central gift in understanding. Relating our story is a way we can relate - make a relationship - with someone else.

I try to find *relation points* in an interview. The relation points are what make or break an interview. The best interviews are those in which there are several relation points, because that's where insights begin. It's through the relation points that I understand what somebody is saying, and gain wisdom rather than just information. In this kind of research, I'm not just trying to get facts and information, I'm trying to understand, and so the whole point is that I learn **through** - learn through absorption, learn through my own experience of their experience - learn through insight.

Such interviews are often intimate, and this is one of the reasons why they are so demanding. There's no such thing as going in and being bland and unaffected. Of course some of the relation points are quite painful for me, quite difficult at times. In every case, I was touched by the interview.

In most cases about a year went by before I began to draft the stories. Partly this was because of other work commitments, but in this kind of work, it is important to let time do its job as well. The time lag served two really important purposes. Firstly, it gave people longer to consider whether they really wanted to go ahead with the book. Secondly, it gave me time to think.

I said earlier that a secondary aim of this work was to understand what it really means to deal successfully with mental illness. The greatest challenge in this kind of work is to tolerate ambiguity and wait for understanding to emerge rather than to try to impose it. Patterns have to be allowed to emerge rather than be 'extracted from data'. It is uncomfortable not to understand things, and tempting to impose clarification, but in this kind of work, solutions cannot be forced.

This analysis is about *being* not *doing*, so that I can absorb the stories I hear and make sense of the worlds of the people I meet. Waiting is part of this analysis. It allows ideas to mature. It is important to take the time to make *connections* between what different people say. It calls for times of stillness. The more I gnaw away at some things, the less I see, and the more I might change them from what they actually are. I have to find a balance between absorption and distance, going in closely, trying to hear and use the language, then standing away, holding onto ambiguity until resolution comes through insight. I called this 'the intuitive analysis'.

The stories were produced during a very intensive 12 week period when I travelled round the country and met people again. These interviews were usually much longer than the first interview as we now worked together to discuss and finalise their story. During this time, I asked my friend and colleague, Tessa Thompson, whose story is also in the book, to interview me. The interview was transcribed, and then I wrote my own story, adding some reflections about the work on the book.

Before each meeting, I cast a draft story by editing the person's transcript. (Every interview had been typed up into a verbatim transcript and checked for accuracy.) The rule I used was that I could delete and move, but not add any words. I chose the most crucial/eloquent/expressive/lucid/articulate parts of the person's story. This was a very subjective process and I saw the results as very much a *first* draft.

I sent the draft story and a full copy of the transcript to the person to make sure I hadn't left out things they really wanted in, and to let them remove or change anything. Then, about a week later, I visited them and we worked on the draft together (directly on the computer) until we arrived at a final version. I aim for 'close-to-spoken language', and at this stage we also tightened the language slightly. After this meeting, I posted two copies of the 'final story' a few days later and asked them to check it and discuss it again with me if necessary, and then give me written approval for publication.

Content determines presentation

'A Gift of Stories' challenges some traditional ideas. People who have experienced mental illness themselves say what *they* think about mental illness and how to deal with it. For some readers, who are only used to considering what health professionals think, some of the ideas here might be quite a shock. Even more challenging, the information is not given as principles or 'best practice notes', it is given in stories.

So we needed to find a form of presentation which would signal that something different is being said here. That is why the appearance of this document is different from usual government reports, because its *content* is different, and is intimately related to the innovation this project demanded.

One of the purposes of this book is to show that not only does mental illness affect all kinds of people but that people with mental illness have all kinds of facets to their life.

That is why there are pictures throughout the book. I took photographs of each person and of things that are important to them, for example their pictures, poems, artwork, photos of them as a child, certificates about seamanship or social work, marathon achievements, and others. These images are there to remind you that these are real people speaking, who have everyday lives. The word stories are about the person's experience of mental illness, but the picture stories are simply about the person. Finally, we want it to be known that mental illness can also be a gift. Moreover, many of the contributors are artists of various kinds. This is why we wanted the book to be beautiful.

To make a difference, we need to act differently - but not simply for the sake of being different. There has to be a fundamental logic as to why and how we need to be different. It is only by being at the edge of change that we can make a difference - which is what we committed ourselves to doing by producing *A Gift of Stories*.

A reflection after gathering stories

When I began this book, about two years ago, it was because I wanted to contribute something positive to the images we have of people with a mental illness. I also wanted more insight into how to deal successfully with mental illness.

I started simply by thinking about recovery, asking myself what does it involve? What will people say about it? What does it mean to 'recover'? However as I listened to people, I began to struggle with the word 'recovery'. Some people in the book were quite comfortable with the word, and talked about stages of recovery. Others didn't want to use the word, because it can imply a simple and finite solution. Yet very few of us had a story which said "This happened and I got over it and I'm a box of birds now." In fact, I don't think *any* of us said that.

Most of the stories I heard were about serious and life-changing illness, and perhaps that is why I am so struck by the complexity of the process of getting well. As people talked about dealing with illness, their stories were about the progressive discovery of solutions.

At the same time, something else emerged, something more expansive than discovering how to deal with illness. People talked about the discoveries they had made about themselves. I have often felt that dealing with my own illness has given me something beyond recovery, something more than recovery. And now I heard others say the same. This was a precious insight.

So, at this point in my understanding (when I have to overcome my fear of the permanence of publication), if there were one word I would choose to describe what I heard throughout this work, it would be **DISCOVERY**. The stories told to me were full of discovery - not just *about* dealing with mental illness but *through* dealing with it.

Right now, the best way I can describe dealing with mental illness is **making our way along an ever-widening spiral of discovery** in which we uncover problems, discover the best ways to deal with them, recover ground that has been lost, discover new things about ourselves, then uncover deeper problems, discover the best ways...and so on in an intricate process of growth.

I think that most people, at least in the world I know, attempt to make sense of their lives, and when a profound experience (such as a mental illness) strikes us, we struggle to make sense of that too. Why did it happen? What caused it? We may even impose an explanation. But sometimes there *is* no meaning - at least not one we understand. Then we have to put up with the pain of not understanding and eventually we have to *put aside the need to know*.

What I began to understand through listening to the others' stories and thinking about my own was that getting well and staying well depend on coming to terms with meaning. Ultimately, we are able *either* to make sense of things *or* to accept that we cannot. I think this is a very important point because it is to do with getting peace of mind. It means we can stop asking "Why did this happen?" and start asking "How can I best deal with this experience?"

I also saw that, at some point, people began to take control of the things that were in their power to control, and through this, they began to get well. What is so poignant for me about this realisation is that I think we still have a mental health system which is built on a model of controlling people. Perhaps this is why the decision to take charge so often rises up from an experience of bad treatment - as if a person is finally forced to say "I'm going to find my own way through this."

People told me about some disgraceful things which happened to them while they were in mental health services. And I once experienced them myself. Some of them do not even appear in this book because of the shame some of us feel about having 'allowed' ourselves to be treated in this way. At times, as a Mental Health Commissioner, I felt ashamed to be connected with the system. Even though these accounts were about historical events, I am aware that some of the things people talked about still happen and that the treatment can be far worse than the condition.

It is also so clear to me what a wonderful difference it makes when you meet a really good health professional, whether it is a nurse, psychiatrist, counsellor, GP, social worker, key-worker, or whatever. But what is the essence of 'really good'? It's not just having knowledge and skills, it's using them with *respect* for the person you are treating. The therapist might be the expert on the illness, but the person is the expert on themselves. A partnership of *real* power!

I think it is about the nature of *relationship*. It is to do with giving someone the chance to say what is going on for them and actually listening. Seeing, if you like, 'their side of the story'. This came across to me, for instance, as I listened to what people said about their experiences with medication. It can take a long time to accept that you

need and are willing to take drugs, especially when you have had some dreadful experiences with medication. It's only when you find someone who actually listens to those experiences, and helps you sort out the best drug and right dosage, that drugs can do their job.

On a deeper level, the 'therapeutic relationship' also depends on making it possible actually to relate. When I gathered these stories, I did not set out on a path of healing. Yet a lot of people said that the *process* of telling their story to me was healing for them. There were times of laughter and fun in almost every interview, but there were lots of tears as well. Almost every person in the book cried at some point when they were telling their story - and it was not just the pain of the memories, it was also a kind of relief in sharing them.

The experience was healing for me too. I was always touched in some way by a person's story. This morning, as I write, I still feel very moved by the whole process. I am deeply aware of the pain that we have suffered because of mental illness. Yet through that pain, and often anger, came the determination to survive. But we have to survive not only the illness, but also the consequences of it - the lost things that we may never recover. And finally, we have to survive the memories. That is why it is so terribly important that we can also see what we have gained from the experience. And that others recognise that, too.

I believe that people heal themselves. I say this because I see treatment as something that happens from outside, whereas healing happens from within. This is why I believe that the voice inside, which tells a person what they need, should be listened to. I heard about many different kinds of treatment, from traditional to new age, from sophisticated to simple, but what I heard most of all was that we got well when we found the treatment which was *right for us* (and rejected the ones which were not). That is to say, we make wise choices, based on our expert knowledge of ourselves. And that is why we need a range of choices in health care.

I also saw people make wise choices about 'expert' opinion on them. The people in these stories *questioned* things - we didn't just accept what we were told. And I think this is one of the reasons we got well.

Diagnosis is usually determined by someone else, standing outside the person - someone else tells you what's 'wrong' with you. And diagnosis usually comes along with a prognosis attached to it - someone else tells you what the outcome is likely to be. But if all you have is someone else's diagnosis and prognosis, then your recovery might also be prescribed by that. That is to say, someone else will tell you when you are 'right'.

Looking closely at what people said, many of us had to question our diagnosis and prognosis *in order* to get well. I think this is terribly important to understand because our stories all showed that **recovery is self-defined**. It is defined, in fact, through **discovery**.

Diagnosis is a rather subjective science and one which is still evolving. In these stories, we talked about the need to understand our 'diagnosis'. But we weren't talking about text books – we were talking about insight into our own experience.

Insight is one of the most wonderful things we have, as human beings. It is the thing which takes us beyond information and knowledge. It is the key to wisdom. I think information is just about facts - things that are usually told to us. Knowledge comes from integrating those facts. But wisdom comes through understanding - standing *under* knowledge and allowing the insight we gain from our own experience to illuminate knowledge. That's what's in these stories - wisdom. And that's why they are so valuable. That's why you need to hear them.

For instance, I see wisdom in the way many of us interpreted diagnosis in terms of vulnerability. This meant we could see how to protect ourselves better, and begin a kind of practice of natural prevention. I am talking here about the ordinary things people tend to do when they have a good life. I mean the things some of you may take for granted – like being kind to yourself, getting enough rest, some exercise, eating nutritious food, having little treats, having fun. What is extraordinary is that for many of us with a mental illness, seeing the importance of these things is a kind of revelation. They are something we have to *learn* how to do, and then do almost self-consciously, until they become second nature.

Then of course, there are the 'bigger things' to do with finding your place in the world – a home, family, friends, loving relationships, people who know and value you for who you are (not for who you might become), a sense of belonging, a sense of purpose, feeling useful. You might say, well of course! But these are the very things which are so often denied to those of us with a mental illness *because* of the illness. Yet when doors are opened and we are able to take our place in the world it makes all the difference to dealing with mental illness.

People need their place in the world, not just a place in hospital, or on a 'case-load'. For me, this is one of the strongest arguments of all for the closure of large 'warehouse' psychiatric hospitals. The trouble is that *community-based* care came to be understood as being *community* care. And we all know what happens when *that* doesn't work – when the community *doesn't* care, or when it doesn't *want* to care, when it doesn't know *how* to care, or when it isn't funded well enough to be able to care. 'Out in the community' is a very cold abstract term, in these circumstances. But what *is* a community, anyway?

It's easy to see what a community is in traditional terms, in the sense of a small village, or an extended family, or a small local neighbourhood. But is there really such a thing as a community in the centre of a big city? Or a whole country? I think not, at least not in the sense of shared interests and meaningful relationships.

In the mental health system, we need to clarify our concept of community, if community-based care is really going to work. *Community* needs to be understood as something much smaller, if community-based care is to make real sense. What I heard

people talk about was their warm and intimate worlds - family, whanau, circle of friends, workplace, local neighbourhood, their small town.

Finally, there is spirituality. I think talking about personal spirituality is one of the hardest things to do in our society. And because we are not accustomed to talking about it easily, we are losing the words. It's like the last bastion of silence - after sex, politics and money. Talking about spirituality often seems to cheapen it, and embarrasses some people. In the absence of shared meaning in words, there is sometimes a sense of hollowness or pretentiousness when people talk about 'being spiritual'. But without a doubt, what I heard people talk about was the importance of spiritual ease.

Coming to terms with the knowledge that you *have* a mental illness is almost as difficult a personal task as coming to terms with the illness itself. What does it mean to come to terms with it? I think it means acceptance. Seeing it as being only *a part* of who you are. Learning to live with it, staying real and honest about it, and having an environment which makes this possible.

Just because you *have* an illness does not mean you are always ill. And one of the hardest parts of accepting the illness is accepting that you *might* get ill again - the symptoms might recur. This may be true of learning to deal with any serious illness, but with mental illness I think there is the added barb of 'internalised discrimination'. If we get ill again, we often feel worthless again, even though we have once said to ourselves *This is the score*. The insights of self-acceptance which we have when we are well are hard to hold on to when we are ill. This is why it is crucial to have people who believe in us and give us hope.

Again and again, I heard about the benefits that illness brought: how the very experience made people stronger, and how the courage they found to deal with the illness meant they achieved things they had never thought possible. I think this is why some of us say that mental illness is a gift - because you can discover many wonderful things about yourself *through* dealing with it.

This is not in any way to deny the suffering involved. In fact, I think it's the very process of dealing with that suffering which brings one of its greatest gifts - strength of character. I suppose this is true of overcoming any adversity in life generally, but I think those of us with mental illness are tested in ways which are sometimes unimaginable to others. Partly, this is because mental anguish is often invisible, and partly because we are often forced to conceal it from others. Perhaps that is one of the reasons why there is so little recognition of the heroic journeys of discovery that we have to make. And why prejudice against us is so particularly cruel.

One of the most distressing things about mental illness is that it often involves a disintegration of self. So dealing with it, and surviving it, almost inevitably means that there has to be some kind of reintegration of one's self. This 'putting yourself back together' can lead to valuing things about yourself which you may never have even recognised before.

You can come to see, for instance, that the very same sensitivity which at times is the dark side of the illness, also brings light, and means you can have something very precious to give to the world - a deep capacity for compassion. And the closeness to a sense of dying which some mental illnesses bring, can create a profound appreciation of life. Also, for some people, the dividing line between creativity and 'madness' is very fine and the link between highs and creativity is as clear as day.

You also come to see that, at almost any cost, you have to stay real with yourself. You have to be fundamentally honest with yourself. It is a terrible irony that a world which is prejudiced puts pressure on people who have a mental illness to be dishonest about themselves, to deny it and so to deny their selves. That is why these stories are such a gift.

Many of us in this book have considered or tried killing ourselves at some point. I think you have to take that as a measure of the pain experienced. The simplest measure, really. And of course, Alasdair finally took that way. When I think about him now I wish to God there had been some other way for him, because he was one of the most courageous people I have ever met.

I heard about his death when I was in Dunedin doing interviews and was so very angry with him. I couldn't believe it had happened. It was only a few weeks after I had seen him so strong. But the point for me about Alasdair's death is that I believe that ultimately we all have the right to say "This is enough".

So I'm not angry with him any more. But I am terribly, terribly sad. I miss him. And I will miss him at the book launch. I will miss his face, and his hat and Motley. I will miss his strength.

It was the kind of strength which made me want to do this work and I saw that same strength in all the others in this book. I met some remarkable people during the last two years, people full of hope, determination and creativity.

I finish this work amazed by the ability of human beings to overcome adversity and discover new life.

Julie Leibrich
First written when Commissioner
Mental Health Commission
Wellington, New Zealand
August 1999.

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