Exploring the perspectives of people whose lives have been affected by depression

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> *"Only the sufferers know just how difficult it is, what it is like to be in a black hole with absolutely no emotion … (but) it is common to hear people say: 'You look fine! What's your problem? Do something!' Have those people ever looked into the eyes of the sufferers, dull and lacklustre? Do they see a smile or a tear? No. They save their compassion for the physically afflicted."*
>
> *"…when I feel depressed, I feel like I am at the bottom of a deep well. I try to climb out of that well to get closer to the light, but every time I seem to be making progress I fall back to the bottom of the well."*

ABSTRACT

Objectives: To describe the experiences of people whose lives have been affected by depression.

Design, setting and participants: Thematic review of data collected from 21 community meetings (1529 people, providing 911 evaluation forms) and nine focus groups (69 individuals) held nationally, and written feedback and website-based interactions with *beyondblue: the national depression initiative* between April and December 2001.

Main outcome measures: Barriers to social participation experienced by people whose lives have been affected by depression, and their interactions with the healthcare system.

Results: The key theme was the experience of stigma, which was evident in healthcare settings and in barriers to social participation, particularly regarding employment. Inadequacies of primary care and specialist treatment systems were highlighted. Particular emphasis was placed on limited access to high-quality primary care and non-pharmacological care. The stigmatising attitudes of many healthcare providers were notable. Within society, lack of access to knowledge and self-care or mutual support services was evident. Lack of support both from and for people in caring roles was also emphasised.

Conclusions: People with depression are subject to many of the same attitudes, inadequate healthcare and social barriers reported by people with psychotic disorders. Consumers and carers prioritise certain notions of illness, recovery and quality of healthcare, and expect healthcare providers to respond to these concerns.

MJA 2002; 176: S69–S76

IN AUSTRALIA, the National Mental Health Strategy (1993–2003) recognises the rights of consumers of mental health services and carers of people with mental illness. It seeks to extend their roles in the planning, delivery and evaluation of mental health services and to reduce the stigma associated with mental disorders.[1,2] Mental health providers have become familiar with the benefits to be gained by promoting such roles and incorporating consumer and carer perspectives into ongoing medical education and publications.[3,4] Much of this participation has been by people with severe or chronically disabling mental illnesses and their family members. It has focused largely on interactions with public mental health services.

For *beyondblue: the national depression initiative*, a high priority has been to increase the roles of people with depression and anxiety by increasing community awareness, promoting destigmatisation and influencing public policy and healthcare services development. As people with these disorders commonly do not present for medical treatment,[5] or are managed largely within the primary care sector,[5,6] it is essential for *beyondblue* to use strategies that go beyond consultation with existing organisations. In this report, we describe the outcomes of the first year of a broad strategy designed to identify the major concerns of people with depression and their families and carers.

Methods

Consultative processes were designed to elicit information from a broad group of people with depression or anxiety and their families or carers. The specific mechanisms included public meetings, focus groups, website-based mechanisms (http://www.beyondblue.org.au — bulletin board, facilitated discussions, feedback, posting of consumer and carer experiences), and consultation with existing consumer and carer organisations. These processes were conducted nationwide and used strategies to ensure participation from a wide group of people in metropolitan, regional and rural areas.

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Public meetings

The public meetings were widely advertised as a process for increasing community awareness of depression and providing a forum for discussion of depression-related issues. The meetings included presentations by a specialist mental health professional, a consumer (and, in some instances, a carer) and a general practitioner, and a period for extensive discussion. Each major issue raised during the open feedback session was recorded electronically and displayed to the audience. At the conclusion of each meeting, evaluation forms were distributed requesting demographic information, ratings of the session and general comments. People were also encouraged to provide further feedback via the *beyondblue* website. There was no specific emphasis in the eliciting of negative or positive responses from participants; rather, we aimed to provide a mechanism to voice publicly the experiences of people whose lives had been affected by depression. Several consumers and carers were asked to prepare short pieces for this report (Appendix).

Website and written feedback

The *beyondblue* website was launched in April 2001 and includes a bulletin board focusing on key issues such as "experiences with antidepressant drugs" and "experiences with psychological treatments". The aim was to encourage the personal description of experiences and views on these topics, thereby enabling consumers and carers to report directly their narratives and perspectives.

Additionally, a large amount of written material had been received by *beyondblue* from individuals as well as organisations. Key perspectives have been included in the discussion presented here.

Focus groups

Focus groups were designed to enable in-depth discussion of key themes with smaller groups of participants. Participants for the focus groups were recruited via prior participation in community meetings, contact with the website, written contact with *beyondblue*, or participation in a current consumer or carer organisation. The recruitment process emphasised the representation of people from a variety of sources. Priority was given to participants who had recovered and resumed social and occupational roles. There was a deliberate attempt to limit the number of participants who had chronic or severe illnesses or who had ongoing high levels of use of specialist services. Most participants were consumers with experiences of both the primary and secondary healthcare systems. Carers, and consumers who were also carers, were also specifically recruited. For each focus group, 7–9 people were contacted to obtain 6–8 participants (allowing for non-attendance) per group. Participants were paid a nominal fee for their time.

The focus groups were conducted by one facilitator (B G McN) and followed a structured format. Four stem questions emphasising the ongoing difficulties faced by consumers and carers were used:

- How would you describe the impact of depression and/or anxiety on you and your family?
- What factors make this experience worse than it may already be?
- What factors would make it less severe?
- What do you consider to be the main areas of need for persons who experience depression and their families?

There were no specific questions designed to elicit positive experiences. The responses from the focus groups were collated by the facilitator from transcripts of audio recordings or notes taken by a scribe or the facilitator during the focus group sessions. These were later subjected to thematic analysis by the facilitator and an independent psychologist (N J H) with experience in conducting this type of analysis.

Results

Public meetings

Participants

Twenty-one public meetings (1529 participants; mean attendance, 73; range, 20–200) were held in a wide range of metropolitan (12 meetings; 894 participants [58%]), regional (6 meetings; 409 participants [27%]) and rural (3 meetings; 226 participants [15%]) settings across Australia. Formal evaluation forms were returned by 911 (60%) participants (603 [66%] females; 53 [6%] aged 15–24; 380 [42%] aged 25–44; 410 [45%] aged 45–64; 60 [7%] aged 65 years or older). Although the numbers of participants who were consumers, family members, carers, healthcare professionals or interested community members were not recorded, discussions indicated that a wide range of participants attended, some of whom had current or past experiences with depression (directly or indirectly) of varying severities.

Themes

The key themes largely concerned healthcare services and responses of the wider community. Consumers and carers who related their experiences in these public settings commented directly on the personal relief associated with such disclosure. The value of such personal experiences for increasing community awareness and respect for people whose lives are affected by depression was also rated highly by the wider audience. Common themes are listed in Box 1.

In regional and rural settings, important healthcare service differences included the relative or absolute unavailability of specialist services and, in smaller centres, lack of access to GPs. The critical role of GPs in mental healthcare was more openly accepted in these communities. By contrast, in metropolitan areas, the barriers to specialist services were largely related to cost, and the central role of GPs was more frequently questioned.

The issues related to stigma were viewed somewhat differently in rural settings. While the difficulties of living with a mental disorder within a small community were highlighted, so too were the opportunities for a more cohesive and coordinated community response. The larger size of the audiences in small rural centres and the attendance of local politicians and dignitaries were notable. The impact of youth suicide on the local community was more openly recognised.

Website and written feedback

This mechanism provided both brief and detailed responses. Most of this material detailed personal experiences, but some included lengthy critiques of *beyondblue* or the “medical model” of mental illness. Others provided detailed information that proved invaluable in taking forward issues such as exclusion in insurance or overt barriers to care within specific healthcare systems.

Focus groups

Nine focus groups were conducted during a seven-month period (69 participants; average group size, 7.6; range, 6–9; 49 [71%] female) in each State and Territory in Australia (two focus groups were held in Victoria). The response rate of people invited to take part was very high, with only two people declining for reasons other than availability on a particular night. In broad terms, the focus groups disclosed similar themes to the public meetings. However, the groups provided a more in-depth level of understanding of the difficulties faced by consumers and carers. Key themes are detailed below. Direct quotes have been augmented by other written material.

Themes

Consequences of stigma and lack of awareness of depression as an illness: The personal, family, social, occupational and health consequences of the ongoing stigma associated with even common forms of mental illness, such as depression and anxiety, were highlighted. The inability of family members to appreciate the experiences of people with depression was emphasised. Family members, like members of the wider community, may not believe or understand that depression is an illness. Rather, they tend to see depression as normal sadness, a transient response to difficult circumstances or a self-correcting period of psychological distress. Such attitudes result in unhelpful comments such as “just pull your socks up” or “just put some lippy on, love”. Consequently, such attitudes often prevent the establishment of an empathic or supportive home environment. As people with depression withdraw from the wider world, they become more reliant on family and close friends.

> “I really don’t have anyone who understands. My great boyfriend of the last four years just doesn’t understand depression. He thinks I’m just sad.”
>
> “My family and friends didn’t understand, or didn’t want to know, one or the other.”
>
> “I have only told my family in the last month, and got the exact response I expected from my mother. I was told I should work through it.”
>
> “I wanted my partner to call the doctor but he was embarrassed and said there was nothing he could do.”

Specifically, the absence of any medical sign of illness was likely to contribute to a reluctance to accept depression as “real”. Consequently, community responses rarely indicated that persons with depression were accepted as being ill.

1: Common themes arising in the public meetings

For healthcare services:

- difficulty accessing family doctors with time, skill or commitment to mental health services;
- difficulty accessing specialist care for assessment or ongoing specific treatments;
- difficulty accessing non-pharmacological forms of care;
- difficulty accessing reliable and useful information about treatments provided (notably antidepressant drugs);
- lack of effective responses of healthcare services to emergency situations;
- lack of respect for concerns of carers;
- lack of continuity of care within healthcare services;
- lack of coordination of medical and psychological aspects of care;
- lack of availability and professional support for self-help and other non-professional care organisations;
- financial costs associated with accessing quality care; and
- over-reliance on a highly “medical” model of illness and recovery.

For barriers to wider social participation:

- stigma associated with even simple forms of depression or anxiety;
- overt and covert discrimination in the workplace;
- exclusion by the insurance industry; and
- difficulties in families who do not accept mental illness in a family member.

> “How often do you see flowers and chocolates brought into a psychiatric ward?”
>
> “Friends don’t understand. They don’t visit when I’m in hospital and they assume that I don’t want to socialise.”

In turn, depression was still largely perceived as personal inadequacy rather than an illness.

> “Physical illness happens to me, but depression is perceived to be a weakness within me.”
>
> “Anything to do with the mind is about who you are — that promotes the stigma.”

The impact of stigma was often seen in attitudes towards seeking medical care or continuing appropriate treatments.

> “. . . took a *lot* to finally talk to my GP about the fact that I was depressed. Before, I only went to the GP when I was able to be ‘up’ for her.”
>
> “I’ve had insensitive doctors give me the ‘no pain no gain’ speech so many times it makes me puke!”

The stigma experienced by people taking medications was particularly severe and a strong pressure existed (even from family members) to discontinue treatment.

> “Very reluctant to mention to anyone that I am on antidepressant medication. There is still a very high stigma attached.”
>
> “I ran out of my tablets and was just too depressed to be bothered to go out and get any more and also, to be truthful, I felt angry because I was on them . . .”
>
> “I’m a bit, no a lot, concerned that I am going to take this drug for a long time. Makes me feel pathetic that I require a chemical to stay out of the black.”

Unmet needs in healthcare settings: A fundamental lack of understanding was also felt to be characteristic of healthcare providers. Consumers faced significant frustrations when they presented their deeply personal experiences to healthcare professionals.

> "Depression for one person is not the same as depression for another — they just can't all give the same treatment for everyone all the time."

> "I feel like my basic humanity has been denied."

This frustration was fuelled by encounters with a healthcare system that appeared poorly planned or unwilling to address the specific needs of people with depression.

> "I feel like healthcare professionals are just in this to meet their needs, not mine."

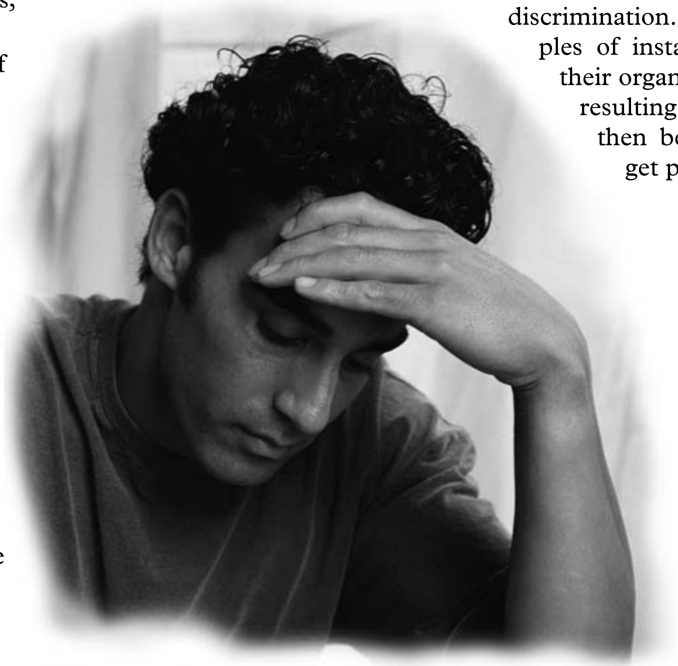
> "I now believe the health professionals do more to stigmatise the illness and they alienate patients from loved ones, the people they need most."

As a result, the experience of seeking appropriate treatment was likened to a persistent battle both for consumers and carers.

> "The carers have to spend their time just trying to keep the peace."

Perhaps the greatest difficulties existed for people who had a dual role, being both a consumer and carer. Consumers who were also carers talked about the lack of credibility that they sometimes had with healthcare professionals when they ask for help for someone they were caring for.

> ". . . the double burden of being a consumer and carer can make me feel there is no end to the nightmare."



The lack of responsiveness of emergency services was frequently raised. For example, a man who had self-mutilated as a result of severe depression presented to a casualty department and was told by the triage nurse, "You'll have to wait, we only treat sick people here."

Most people's first contact with healthcare services was through their GP. While many reported positive responses, it was not uncommon for people to receive demeaning responses.

> "I spoke to my GP about my feelings, but was assured that I didn't have postnatal depression. [I was told] I was just dealing with an unhappy baby and that anyone in my position would be feeling that way."

This sense of not being taken seriously was not limited to consumers, but was frequently reported by carers.

> "I suffered two years of *hell* and when I consulted a GP I got no help. I lost my rights to depression and have become cynical of the medical profession . . . I wish someone had told me 'Don't let loved ones be treated for depression by health professionals that won't involve a family member'."

The burden of care was generally underestimated in caring for people with depression.

> "No, I didn't suffer depression but my husband of 30 years did. In many ways I suffered more than him. He doesn't remember or believe he suffered depression."

> "My fiancé became my carer. He would arrive home from work each day afraid he'd find me hanging somewhere, or in a pool of blood. He was the only thing that kept me alive and only just. He was the only person who supported me, carried me, throughout my illness."

Discrimination in the workplace: The inability or unwillingness to view depression as an illness has major repercussions in the workplace, resulting in overt and covert discrimination. Participants gave many examples of instances where they had informed their organisation of their depressive illness, resulting in an inability to get work, or then being undermined and unable to get promotions.

> "If you tell someone you've got a problem, they wouldn't employ you. End of story. You are not qualified, you're overqualified, you're too old, you're too experienced."

> "I missed out on that promotion last year, I've missed out on one again last week, I've got to stand up and fight them. Mainly for me, and prove to them too that I might have a mental illness but I can still damn do the job!"

> "At first I told one lie after another and in the end I decided to come clean and tell the truth, so I told the truth and I've decided it's the worst thing I think I've ever done for future prospects in that company."

In addition there were also examples of consumers who had lost their jobs as a direct consequence of their depressive illness.

> "I was asked to chart the days that I would be taking off sick over the rest of the year. When I said that I can't do that — I ended up losing my job."

Discussion

The major theme elicited by our consultation processes was the stigma experienced by people whose lives had been affected by depression. This issue dominated experiences with the healthcare system and barriers to participation in the wider society. Although the experience of stigma is widely reported by people with psychotic, severe or chronic mental disorders,[3,4] the extent of these experiences for people with common forms of depression and anxiety is

2: A consumer and carer agenda for people whose lives have been affected by depression and related disorders

A. Within healthcare services

- Development of more responsive primary and specialist care sectors;
- Education of healthcare professionals to ensure that they do not contribute to the stigmatisation of people with depression or anxiety;
- Development of improved information resources for people provided with treatments;
- Provision of more information about services and treatments available;
- Advocacy for improved access to non-pharmacological forms of care at low cost to consumers;
- Advocacy for better professions-based responses to the maldistribution of specialist services;
- Support for the development of accessible self-help, mutual support and other non-professional care agencies;
- Promotion of the key roles of carers, particularly to primary care professionals;
- Promotion of a broader model of recovery from illness than that associated with the medical notion of 'remission of symptoms';
- Development of novel measures of service quality and mechanisms for collecting such data routinely within healthcare services; and
- Development of measures of consumer- and carer-based concepts of clinical recovery that can be incorporated in treatment and healthcare services research.

B. Broader community priorities

- Reduction of stigma through increasing community awareness and the promotion of the experiences of people with depression or anxiety;
- Workplace and schools-based education programs;
- Development of depression prevention programs, particularly for young people;
- Development of education resources for the wider community concerning common symptoms of depression or anxiety, as well as how to go about accessing appropriate care; and
- Initiating response to formal barriers, such as exclusion from life and income protection insurance.

surprising. Many of the people reporting these experiences had only received treatment in the primary care sector. Most had resumed active lives and returned to work. However, the responses of the community and the healthcare services to people with depression and anxiety appear not to differ greatly from the responses to people with psychotic or chronic forms of mental illness. All face major ongoing barriers to social participation and many report being demeaned by their experiences with healthcare service providers.

As many of these people are not compelled to seek treatment, the widespread experience of stigma contributes significantly to delays in seeking treatment, reluctance to access specialist care and reluctance to continue medical treatments. The widespread lack of empathy and understanding from the general public, employers, insurers and other social institutions may be underpinned by ignorance rather than active discrimination,[7,8] and is consistent with broader surveys of community attitudes in Australia.[8-10]

The reported attitudes of healthcare providers are serious evidence of professional failure to view mental disorders as major *general health* concerns. Many of the experiences portray a healthcare system that has not given sufficient consideration to issues such as access, cost, physical characteristics of treatment settings, integration of medical and psychological care, natural history of illness, disability due to illness, ongoing personal and social needs and factors that predict long-term recovery.[11,12] Consumers and carers perceived services as focusing largely on reducing danger of self-harm or promoting remission of symptoms rather than promoting notions of personal recovery, long-term outcomes or return to full social participation. A recent international review[13] of Australia's National Mental Health Strategy (1993–2003) noted that consumers and carers:

> ". . . are still not fully satisfied with the rate of progress [in terms of change in mental health services] as their expectations of *service responsiveness and quality* still outstrip their direct experience." [p 15, emphasis added]

Through both traditional (eg, consultation with representative organisations) and novel (eg, consultation via the Internet and community meetings about depression) strategies, we sought to actively recruit people with depression and their families whose perspectives may not have been included previously. We believe that this resulted in highlighting perspectives that have not received adequate public attention. This has assisted us to develop an agenda for promoting consumer and carer issues for people whose lives have been affected by depression or related disorders (Box 2).

A limitation of our approach is that we did not recruit a representative sample of people attending primary or secondary care services. Participants might have been more likely to have had negative experiences. Further, as the focus groups did not specifically seek reports of positive experiences, the overall picture might not be as bleak as the experiences highlighted here. An alternative approach, at least with regard to experiences with healthcare services, is to assess consumers' experiences of care quantitatively. Studies of this type have been conducted in association with the Australian National Survey of Mental Health and Wellbeing, and suggest that many people with depression and anxiety do have their basic needs for care met by healthcare services.[14]

Consistent with international reviews of the situation in Australia,[13] it is time to move from tokenism to a more mature state in which the role of consumers and carers is respected and affirmed. It is our intention to continue to expand the breadth of this consultation process and provide more in-depth and ongoing analysis. Additional priorities are to promote mechanisms (and methods) for ongoing consumer- and carer-based monitoring of the quality of services provided[12] and to include key measures of consumer- and carer-based concepts of meaningful outcomes in future treatment and healthcare services research. By working with consumers and carers, *beyondblue* gives a public voice to people whose lives have been affected by depression. We are committed to increasing community awareness of depression and destigmatising the illness, so that ultimately the well is *not so steep, nor so deep*.

Acknowledgements

Bernard McNair wishes to acknowledge the support of his employers Wesley Mission Sydney and, in particular, Rev. Dr Gordon Moyes AM and Mr Mark Caldwell for their support of work with *beyondblue*. We also thank Ms Laurie Flynn of Columbia University, New York City, for her invaluable input and support into the focus group program.

We would also like to express our gratitude to the consumers and carers who have provided feedback and shared their thoughts and feelings via *beyondblue* community forums, focus groups and website. The editorial assistance of Cristina Ricci was greatly appreciated.

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Appendix: Experiences of people whose lives have been affected by depression and related disorders

1. Fay's story

My experiences with healthcare services/providers have been varied. However, in the vast majority of cases, it has been negative, and often to the extreme. Trying to find a general practitioner who is *au fait* with mental illnesses is very difficult. Those who do have some knowledge and compassion about the predicament of mental illness are very often extremely busy and cannot generally afford you the time needed. I saw several psychologists and psychiatrists before I found the psychiatrist who led me to discover the positive, creative, passionate, well person I am now.

Mental illness is not only life threatening from the point of view of suicide or falling from a building with the notion that you can fly. I am a diagnosed sufferer of mental illness; however, I am also a mother. On two separate occasions, the lives of my daughters have hung in the balance because of doctors and their staff disbelieving the concerns I held for my children's health, patronised and shunned until I found doctors who cared for my children instead of stigmatising me. The first occasion saw my baby daughter hospitalised, only a few hours left to live from severe dehydration. On the second occasion my teenage daughter had an emergency appendectomy, suffering complications of gangrene.

The problem is magnified when, as a mentally ill parent, you present with a mentally ill teenage child for treatment. Evidence of your child's self-harm is often not enough for doctors to accept the fears of the consumer parent. My daughter was denied care on the occasion I phoned the mobile treatment team. They would not believe my concerns for my daughter, questioning my mental state. She went on to cut her wrists later that evening.

Consumers who are carers . . . we live this terrible, frightening, lonely predicament.

2. David's experience

I am a "consumer" of mental health services, having had two episodes of suicidal "depression", first in 1979 and again in 1995–1999. During this most recent period I received a variety of treatments, some of which helped, some not at all and some that made things worse. During and since this most recent episode I have learned much about depression and was initially excited by *beyondblue*, but have been disappointed to find that what *beyondblue* is telling us about depression is very different from my own experience of it.

My own recovery, now more than two years strong, only began when I bravely (some said foolishly at the time) stopped taking the medications that were truly making my crisis worse — my two serious suicide attempts occurred while I was taking these drugs. I found that I had to somehow reconcile the conflict between my deepest, innermost sense of self with my sense of self in the world in which I lived — the conflict between the "in-here" and the "out-there". I was very fortunate to receive some spiritual (not religious) and psychological counselling which has helped me with this.

I am now drug free and very content with my life and have resumed part-time work as a university lecturer. I am also free and willing to share my story in the hope that it may possibly help some others.

3. Ingrid's story: "Everything happens for a reason"

I am just emerging from a painful hibernation, my psychological prison.

I tried to sleep my life away and, like an alcoholic, reached for another refill of ice-cream and chocolate. Not loving myself enough to control the intake or care about the consequences. I had no energy or desire for anything. Food was comfort and sleep, refuge. For weeks I tried to climb out of my emptiness and kept telling myself I would get over this, everything happens for a reason. I knew I would eventually come out; I always do.

Usually a typical extrovert, I have it all: a loving partner and four-year-old daughter. I run a successful, rewarding business, and lead a full social life, until a cloud descends.

A positive from having re-occurring depression is my ability to connect with others with similar challenges.

Many of my family members, friends, and business associates have been struck with varying forms of mental illness. These spirits are mothers, fathers, daughters, and sons, often intelligent, educated, married, single, professionals, students, of varying ages . . . all with humbling stories.

In sharing experiences, these voices echo similar sentiments. People's reactions to their admissions of mental imperfections.

> ". . . other people are in a far worse predicament . . . snap out of it . . . what have you got to be depressed about? . . . Think positive. . . . Life has been so good to you . . . People used to be tougher in our day . . ."

If it were only that easy!

Treatments and success rates have been as mixed as the personalities that mental illness strikes. Some have reported positive outcomes, many others have not. Sadly, a number of people appear reluctant to seek treatment or guidance.

I owe my sanity, gratitude and life to my partner and psychiatrist. They have been my spiritual leaders for the last 18 years, picking me up when I fall, helping me brush off the dirt from my knees, and standing up and walking proudly forward.

4. Janne's experience

Mental illness and the provision of care by primary healthcare services are gaining greater significance and Commonwealth support.

My medical and mental health needs have been cared for by my general practitioner for over 10 years. I see a psychiatrist regularly. I trust and value both, and the fact that I am alive today is testimony to their diligence and care.

Depression and anxiety disorders impact on my life each day, always there.

I receive my care from the private sector. I do not have access to a multidisciplinary team, case manager or community services. My general practitioner attempts to fulfil this role. Her links to psychiatric services are limited. She is skilled and trained sufficiently, which partly fills this void. I know she has been financially disadvantaged in providing that care.

My mental health issues are complex and need specialist ongoing intervention. However, the role that my general practitioner plays is crucial. Her approach is different from that of specialist medical practice.

She cares and monitors my medical and physical needs, some of which are medication or anxiety related. We look at the burden of day-to-day needs, as well as relationship, social and work difficulties. She knows my personal and family histories and medical illnesses. She knows my family and the impact that my mental health issues have on them.

We continue to maintain an ongoing relationship, because that is the role of a general practitioner. She deals with me, the whole person, and offers me true holistic care, for the long term.

I have felt the impact of mental illness with the loss of friends, discrimination in the workplace in South Australia, a State with no redress, and areas such as declined life insurance.

She gives me time, support and hope. She is an essential cog in the medical wheel. She keeps me alive, she accepts *me* — something I value beyond words.

5. Janice's experience

My father had breakdowns, abused me mentally and sexually. I grew up being made to feel responsible for him. Sometimes in a world of my own I protected myself from situations I couldn't handle. The mental health system of 50 years ago failed him and us as a family.

I grew up, married, had children, but postnatal depression didn't exist 35 years ago and there was no help for the dark times, the self-hating times, the terror that I would end up like my father. I would lock myself in my room, or the kids outside, in case I hurt them. There were times I did. I was known as a bitch among the in-laws. No help from my husband as he worked a job and helped on the family farm. My own family, so used to the way we grew up, thought my problems were just an extension of that period. I consulted medicos one after the other — no help. I was fighting for my sanity and no one was listening.

Ten years into my marriage, finally a psychiatrist diagnosed and believed I had depression. Amazing! I had a crisis earlier in 2001 and in desperation rang the mental health number. Another doctor was found. At last, light at the end of the tunnel. Life without the terrible rages and the self-loathing is good; my mind seems to be free of the fuzz that constantly inhabited it. I enjoy reading properly again. To experience calmness and the self-confidence I so desperately wanted is wonderful.

Some of those who put obstacles in my way and refused to help me now struggle out of their own terrible depths of depression and breakdowns. As I genuinely hope and pray for them the hopelessness and bitterness I lived with for so long is dissipating at long last. My husband and kids have always believed in me. Now, at 55, I am also able to believe in myself.

6. AC's story: "Dancing with the enemy"

I suppose I am fortunate to have entered a new era, particularly during the past decade, when depression is recognised as a serious affliction of the mind that affects men, women and children alike, of all ages, with no class distinction. It is and has proven to be the most nebulous of illnesses, where trial and error dominates in the field of medication. This, for some sufferers, is a never-ending process.

My illness I believe to be chemical. Over a period of 15 years from the age of 37, I have recognised a problem and have sought the advice and ongoing treatment of many psychiatrists, including professors, and been administered many different types of drugs, including antidepressants, mood stabilisers and anti-anxiety medications. I have read much literature and experienced much professional discussion.

Unless one has "felt" the pain of nothingness, the absolute lack of emotion, the black bottomless hole out of which one cannot climb and the absolute hopelessness of life, then how can one understand the confusion each individual depressed person is experiencing? When I was at my lowest ebb, day became night, so that I hoped I would never wake up.

Since February this year I have been experiencing intense psychotherapy with absolute sanction from my psychiatrist and general practitioner, who consult each other if the need arises. These sessions, now two hours per week, have changed my life. I am becoming a realist; my dependence on medication is real but not as significant. These sessions are intense to the extreme and I often suffer anxiety, which I am learning to deal with.

It is common to hear people say, "You look fine! What's your problem? Do something!". Have those people ever looked into the eyes of sufferers, dull and lacklustre? Do they see a smile or a tear? No. They save their compassion for the physically afflicted. I have not suffered much physical pain, but for me mental anxiety must be almost the worst of all.

Think about what I say. I write from first-hand experience and I would hope that my fellow sufferers get the necessary balance they should have as their right in humanity, otherwise we will have pills coming out of our ears and no final solution!

7. Alison's story

Depression can leave you feeling very alone, in a dark world which appears to be a whirlwind of emotions that at times does not seem to end, though I have learnt through my experience there are rays of light which pierce the darkness, delivering much-needed support and messages of hope.

My rays of light came from my work colleagues in particular. Instead of staying silent about the way I was, I spoke out. Despite not knowing what reaction to expect, I knew that it was one of the many steps I had to take to help myself.

Looking back, the support I received from fellow staff members was essential to my return of good health. It made the days when all I wanted to do was stay in bed easier to overcome, because I knew that I was going to a safe environment where people cared for each other. Slowly, days of wanting to stay in bed diminished, especially as I became more involved in the work I was doing. My colleagues lifted my spirits through their comments of acclaim for my work. All of a sudden I had a sense of achievement that I could be proud of.

My family was another source of light, and I sing their praises. Although I did not always feel their support in the early days, as time passed it grew more and more evident to me that it was not only there, but it was strong and unconditional. This realisation allowed me to not only have hope, but the knowledge that I am not alone and that I am part of a family who cares for each other, no matter what happens.

Support and hope from these two groups of people helped me to beat the cycle. ❑