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So you have a 'Mental Illness'... What Now?

Our Consumer Place Resource Centre - Booklet One



*Oh My, four in five don't
have a mental illness??
All those poor
sane people...*

So You Have a 'Mental Illness'... What Now?

Our Consumer Place Resource Centre

So You Have a 'Mental Illness' ...What Now?

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So You Have a 'Mental Illness' ...What Now?

(Our Consumer Place Resource Centre Booklet One)

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Cartoons by Merinda Epstein (www.takver.com/epstein/)

Foreword

This booklet provides an introduction to mental health from the perspective of people who have been diagnosed with 'mental illness' (in this booklet, we call ourselves 'consumers').

It has been produced by Our Consumer Place (www.ourconsumerplace.com.au), a groundbreaking mental health resource centre run by consumers. Funded by the Department of Health (Government of Victoria) and auspiced by Our Community, we offer information and advice to individuals and groups who are providing or thinking about providing consumer developed initiatives (CDIs).

A number of issues introduced in this booklet are expanded in other booklets – check our website for more information.

Most of the available information on mental health has been written by other sorts of 'experts' – mental health professionals, mental health charities or researchers who are not consumers. This booklet is different – it is written by people with 'mental illness', based on our experience-based expertise. It is intended as an introduction to the issues that consumers have identified as being important for us.

This booklet provides an introduction in two senses: firstly, it introduces important aspects of the mental health system to those who have been diagnosed with 'mental illness' and want to know where to go next. It also provides an introduction to 'consumer perspective' – a way of looking at mental health that values the lived experience of those having been diagnosed with a 'mental illness' as a crucially important source of insight. In this sense, the information and views presented in this booklet are unlike the information and views presented in most other available information about mental health.

We want to stress, right from the start, that people with a diagnosis of 'mental illness' do not all have the same views (of course!); we disagree with each other on many points.

When people are diagnosed with 'mental illness', they can have a range of different reactions – some people feel lost, out of their depth or panicky about what will happen next. Others will hear the news with enormous relief – a diagnosis may explain things that were otherwise mysterious and troubling. Many of us may have a mixture of all of these emotions.

Over time, people move in different directions as they search for a path they want to follow. ***There is no right or wrong path.*** Some people want to find the best, most respected and accessible treatment. In Australia, this tends to mean working with mental health clinicians. Others rage against a



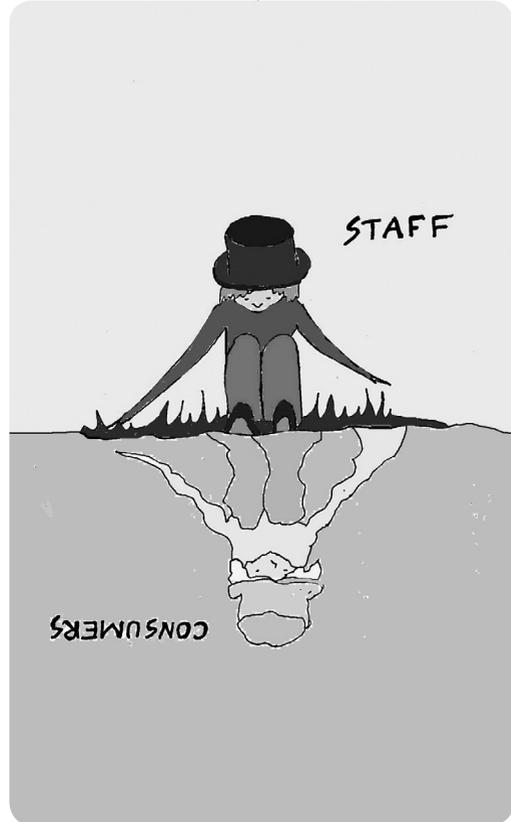
system that they find judgemental and damaging, pointing to loss of liberty and human rights abuses.

We know that you will find your own path – we offer this booklet in a spirit of “take what you like and leave the rest”.

Dedication & Acknowledgements

This series of booklets is dedicated to all people whose lives have been cut short by ‘mental illness’, and/or their experience of community prejudice and trauma.

Booklet One, *So You Have a ‘Mental Illness’ ... What Now?*, is dedicated to the life and work of Rhonda Black, who contributed in so many ways to its production. Her writing was crisp and witty, her intellect exceptional, and her life filled by an everyday, practical commitment to those in the community who had less than her. Unfortunately Rhonda died before this booklet was published.



We also owe a debt of gratitude to the Private Mental Health Consumer Carer Network (Australia), members of *The Maine Connection*, William Moon, Kenneth Holt, former Our Consumer Place staff members Cath Roper and Jon Kroschel, and all those who contributed information for this booklet. It has been a truly collaborative process. We thank all of you for your wisdom and insights.

Thanks also to the Department of Health (Government of Victoria) and Our Community for providing the funding and the support that allows Our Consumer Place to exist.

Merinda Epstein & Flick Grey

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Section One: Introduction



CONSUMER SUPPORT
STRUCTURES —





* What does 'consumer' mean?

What is a 'consumer'? Who is a 'consumer'
Am I a 'consumer'?

"The word consumer is far from perfect but it's the best we have available at the present time."

Our Consumer Place, drawing on the work of Alan Pinches,
Victorian consumer consultant

In this booklet the word 'consumer' has been chosen to describe people who:

- self identify as users of mental health services, and/or
- have been diagnosed with 'mental illness' and/or
- have been active within a mental health consumer/survivor/service user movement that is aiming to bring change – both radical and incremental – to the way people labelled with 'mental illness' are treated by services and society, and/or
- describe ourselves as a 'patient', 'client', 'consumer', 'service user', 'survivor', 'psych. survivor', 'sufferer', 'person with a psychiatric disability', or use reclaimed language (language that is used against us) such as 'mad', 'crazy', 'loony', 'nutcase' or 'batty'.

Simply put, you are a consumer if that is how you identify.

More detailed information about consumer language, perspective and activities is in the final section of this booklet, *Consumer Perspective – the basics*.



* **Some different ways to understand 'mental illness'**

Welcome to the debate! No need to hurry; it is sure to go on for a few hundred years yet

"I am interested in madness. I believe it is the biggest thing in the human race, and the most constant. How do you take away from a man his madness without also taking away his identity?"

William Saroyan, American writer, 1908-1981

In order to understand our own relationships with 'mental illness' it's useful to understand the many different approaches in the community. It is also important to understand that we all choose different ideas and different concepts to describe our experiences of mental distress. There are no 'facts' here but many choices.

In the Middle Ages distressed people were seen as witches and persecuted and from 18th Century until the mid 20th Century people were locked away in huge psychiatric asylums which were visited by bored members of the public as a source of entertainment. These places did not offer asylum.

Even today debates rage about how society deals with difference and not everyone involved in receiving, avoiding, providing or writing about mental health services comes with the same ideas and beliefs about the nature of 'mental illness' or even whether it exists at all.

Some of the ways people understand 'mental illness' are outlined below:

1. Medical Model

Since the 1950s the 'medical model' has become the dominant way of understanding emotional distress within mainstream thinking.

This model sees 'mental illness' as a medical problem to be solved by specially trained doctors (psychiatrists), clinical psychologists, behavioural therapists and pharmaceutical companies.

2. Social Models

There are also various ways of understanding mental distress as a social phenomenon. Dominant amongst these are approaches which concentrate on childhood trauma, neglect and abuse as fundamental

in understanding many forms of adult mental distress. Others see war, torture, social dislocation, sexual violence, bullying in the workplace, genocide and family violence as social determinants of many of the fears and 'behaviours' that are labelled 'mental illness'.

3. Psychosocial Models

This way of understanding 'mental illness' involves seeing it as a medical problem, but one that is linked with social and economic disadvantage. Issues such as homelessness, unemployment and isolation are seen as central to understanding the lives of people who have been diagnosed with 'mental illness'.

4. Anti-psychiatry

Anti-psychiatry refers to a number of different (and often conflicting) intellectual arguments against the 'medical model' and tends to be highly critical of diagnosis, pharmaceuticals and current mental health treatments such as electroconvulsive therapy (ECT) and involuntary 'treatment'.

The main thinkers within the anti-psychiatry movement, which emerged in the 1960s, were not consumers themselves but dissident psychiatrists, sociologists and social theorists. Anti-psychiatry is not as dominant as it was 30 years ago, but many of the key ideas have spread in various forms, and many have been taken up by consumers/survivors.

5. Alternative and Complementary Medicines

Many practitioners and consumers subscribe to models of healing which avoid conventional medications and therapies.

These alternative approaches include naturopathy, chiropractics, herbalism, traditional Chinese medicine, shiatsu, meditation and homeopathy. Some traditional doctors work in partnership with practitioners using alternative approaches.

6. Consumer Run Services, based on consumer expertise

This model is based on an assumption that the consumer body of knowledge is expert.

Consumer-run services take many forms, including peer-run crisis services, 'warm lines' (peer-run telephone counselling lines) and Intentional Peer Support. There are very few consumer-run services in Australia, but there are many different models around the world.



* Rethinking 'mental illness' as lived experience

If we look at madness differently, sometimes it makes sense, has value or is part of human variation

"Sometimes a breakdown can be the beginning of a kind of breakthrough, a way of living in advance through a trauma that prepares you for a future of radical transformation."

Cherrie Moraga, Chicana feminist writer

The most common way we are taught to understand 'mental illness' is as a 'biochemical imbalance in the brain.' Many consumers call this the medical model (see page 10).

Consumers in New Zealand have developed a wonderful website called 'Out of their Minds', which uses the insights of lived experience to explore other ways of thinking about 'mental illness'. They argue that the idea of 'mental illness' is "not just a phrase but a whole way of thinking," and suggest that it might be more useful to think about our *experience*, rather than 'symptoms.'

Whatever our beliefs about 'mental illness', it makes sense for us all to think of mental distress as an experience, at least as much as we think of it as a form of illness. This shift in thinking can make a big difference to our understanding of mental distress and people who experience it.

When we think of an illness, we tend to think of something:

- requiring hospital treatment
- that doctors know the most about
- that makes you dependent or weak
- that makes you broken, needing to be fixed
- with a prognosis, i.e. expectations of a return to wellness, ongoing disability, or death.

When we think of an 'experience', it can be something:

- good or bad, or both
- that can be learned from
- of value, e.g. when job-hunting, or helping others with something you have experienced
- that can be shared; that others can relate to



- unique, or universal, or somewhere in between
- that no-one else is the expert on it if they haven't had that experience.

When thinking about mental distress as an experience, it's a lot easier to recognise the positive as well as the negative aspects of it.

Valuing the experience

While we don't want to minimise how tough our experiences may be, it may be possible to find some value in them. It's well recognised in our community that we often develop insight after life challenges such as marriage break-ups, close brushes with death or the death of a loved one. The same value is almost never ascribed to the learning that follows challenges to our mental health. It makes sense to value these experiences – we learn a lot about ourselves and about the world when things go wrong, forcing us to face challenges head on:

"This includes experiences of severe anxiety, extreme highs or lows, hearing voices that no one else hears, and whatever else of the many and varied experiences usually labelled 'mental illness'."

Out of their Minds website

Acknowledgement: Our thanks go to 'Out of their Minds' (www.outoftheirminds.co.nz/), a New Zealand website which describes itself as "a new website exploring the value of mental distress, madness, 'mental illness', or whatever you want to call it". We have learnt heavily on their material to write on this topic.

* Thinking about 'recovery'

There are many different roads

*Here,
Surrounded by the sterile relics of sanity,
Lost in a labyrinth of refracted thought,
I sit ...*

Sandy Jeffs, Melbourne-based poet

The concept of 'recovery' from 'mental illness' deserves some reflection. At first glance, the path seems clear – similar to if we were recovering from an accident, physical illness or major surgery, we might need to rest, follow the advice of relevant medical professionals, take appropriate medications and gradually get our lives back to how they were before we "got sick". However, this image is simplistic even for recovery from physical problems, which may constitute a major transition, leading a person to rethink who they are and what they want in life.



For those of us who have experiences labelled as 'mental illness,' this is even more likely to involve some transition and rethinking of our lives. This is especially true when we have experienced catastrophic consequences – shattered self-esteem, difficulties functioning, social isolation, poverty, prejudice, loss of identity, hope and job opportunities, severed relationships with friends and family, and more.

We all have different ideas about what makes a good life, the meaning of our experiences of 'mental illness' and how we want to move forward from where we are. After many years of being consumers, listening to other consumers and reading many articles written by consumers, we've identified a continuum of responses, ranging from what could be called 'recovery through acceptance' at one pole, to 'recovery through resistance' at the other. Some of us tend towards one end or the other, while many others take a bit from both sides, developing our own understanding – accepting some things we have been told while rejecting others.

Recovery through acceptance

When we say "acceptance," we mean belief in the medical model of 'mental illness' or, perhaps, acceptance of past life events. This approach tends to lead to a fundamental respect for the assistance offered by the therapeutic professionals in our lives.

Consumers who follow this path tend to have found a diagnosis useful in understanding our experiences – it was more distressing not having a diagnosis! We tend to prefer behavioural approaches to psychiatry and psychology, recognising that learning new, practical skills is invaluable in our recovery. We also tend to respond to therapy that 'holds hope.'

Recovery through resistance

Recovery through resistance is obviously not encouraged by those who run the current systems in mental health. However, many of us have found strength and meaning in active (sometimes political) resistance to psychiatric labelling, psychiatric 'treatment' and psychiatric invasion of our lives.

For many people, psychiatric hospitals are iatrogenic (that is, they make us sick). Submitting to psychiatric power – often because we have been forced to – can be immensely disabling and disempowering. Many of us are still battling to recover our deep trust in ourselves.

Those who follow this path tend to prefer approaches that are politically-nuanced, collaborative, transparent, and transformative. We will often



reject traditional psychiatry and psychology. We may also reject the term 'consumer', preferring to call ourselves 'survivors'; we might also reject the term 'recovery', preferring to work towards transformation, either of ourselves or society. Trusting ourselves, rather than the systems that we critique, is central to our journey.

It's important to bear in mind that we won't all follow the same path. There is no 'right' or 'wrong' approach.

There are many roads

Another path that many consumers take is through creativity, exploring the richness of the inner world.

One consumer, Sandy Jeffs, says that "through creativity we can utter the unutterable, say the unsayable, speak the unspeakable and sense the insensible". Some examples of creativity in recovery are: the Penguin Artists (a Moonee Valley consumer-run group), the Splash Arts Studio (run through the North East Alliance for the Mentally Ill) and the Stables Studio (run through Prahran Mission) – all have websites you can find through a Google search.

Spirituality is also important to many consumers. For many of us, our 'recovery' involves seeking inner peace, greater wellbeing or a more direct experience of the sacred through religious or spiritual practices. For example, there are many 12-step programs (based on the model pioneered by Alcoholics Anonymous in the US in the mid 1930s) that take a spiritual approach to problems in life. This approach may be useful for mental health consumers.

*** Stigma, labelling, discrimination, oppression**

A consumer's view

"Many people think they are thinking when they are merely rearranging their prejudices."

William James, American philosopher and psychologist (1842-1910)

The challenges of having a 'mental illness' diagnosis are often exacerbated by the negative treatment we receive from the people around us. This is often described as 'stigma'. However, this might not be the most useful way to think about these issues – in fact, we believe that this way of thinking actually perpetuates problems!



What is “stigma”?

‘Stigma’ is a term that originally referred to a physical mark on a person, identifying them as disgraced; someone to be shunned from the community, typically because they had done something shameful (like commit a crime).

As it is used today, the concept of ‘stigma’ is quite confusing. ‘Stigma’ is a ‘thing’ rather than an action. ‘Stigma’ no longer refers to a visible mark, but is something to do with generalised negative attitudes towards a group of people. When we say (for example) that “there is stigma in the community against people with mental illness,” we are being very unclear about what this ‘thing’ is – who these negative attitudes come from and how or why they are perpetuated. The word ‘stigma’ makes it seem as if these attitudes are “just out there,” attaching themselves to the stigmatised group without anyone actually doing anything.

Does it matter what we call it?

We think it’s important to think very carefully about these issues if we are to truly change the way people with ‘mental illness’ are treated. In the context of mental health, the most common approach to combating stigma is to “educate the community”, teaching them to be better informed about the medical model of ‘mental illness’ – often along the lines of teaching people that “mental illness is an illness like any other,” or imparting basic information about specific diagnoses (sometimes called ‘Mental Health Literacy’).

There are two major problems with this approach. Firstly, there is a great deal of evidence to suggest that this kind of ‘education’ actually makes people *more prejudiced* – for example, not wanting to have contact with people with a diagnosis of ‘mental illness’ or believing that people with ‘mental illness’ are dangerous or unpredictable. There are many different theories about why this dynamic occurs, but no one knows exactly why.

Secondly, many of us see this approach as misrepresenting the cause of “stigmatising” attitudes – these approaches presume that the cause of stigma is “ignorance” (of the medical model), whereas many consumers believe that being labelled (i.e. given a diagnosis) itself causes stigma.

How else can we talk about these issues?

Some of us prefer the term ‘prejudice’ as it is clearer about the fact that *other people in the community* are prejudiced and that these people are the problem, not us. Others prefer terms such as ‘discrimination’ or ‘oppression’. Again, these terms make it very clear that other people (and



social institutions) are the ones at fault. They are also clear that there are acts involved, not just attitudes. The term 'oppression' is often specifically used to describe the use of forced 'treatment' – the term 'stigma' doesn't really work in this context! Talking in terms of 'oppression' makes it possible to talk about issues like forced 'treatment' in a context of human rights and self-determination. It also connects us politically with other forms of oppression, such as that experienced by indigenous groups or people with other disabilities.

Yet another approach draws on 'labelling' theory, and argues that psychiatric labels ('diagnoses') are themselves part of the problem. People who work in education, sociology and criminology have developed ideas about how labelling people is damaging, and part of the process of treating them as 'other'. Some consumers argue that a similar process happens in mental health – that the actual process of being labelled is itself discriminatory and oppressive.

Damaging language:

10 terms that are used against us

The way people use words can be damaging.
Here are 10 shockers but there are many more.

1. **'Manipulative'**: This term is used often, particularly by clinicians in hospital settings. Many consumers would argue, however, that what appears to be 'manipulation' is usually in fact an *ineffective* attempt to get needs met. It's an important life skill to be able to manipulate effectively.
2. **'Attention Seeking'**: Again, it seems that just about everyone who has been diagnosed with a 'mental illness' has been described as an 'attention seeker' at some point. It's meant to be a criticism but when you think about it, is there anyone in the world who doesn't need attention? Anyway, if you just turn the words around and say 'seeking attention', the meaning changes.
3. **'Non-compliant'**: This tends to be used as shorthand for saying someone disagrees with his/her doctor's recommendations. As consumers, we suggest that it signals that more communication is needed, or that the person is becoming more empowered to make independent decisions.

Continued...



4. **'Lacking Insight'**: This term is very like 'non-compliant'— a person is deemed to *have insight* when s/he seeks or accepts 'appropriate treatment.' Of course we all have our own insights but too often, in mental health contexts, the person with more power (the mental health professional) lays claim to the 'correct' insight.
5. **'Inappropriate'**: What is or isn't 'appropriate' is largely about social norms; arguably, it has more to do with social control than mental wellbeing.
6. **'Passive Aggressive'**: This seems to be a term of frustration when the skills of the clinician are being tested. In many consumers' experiences, it tends to be used in contexts where someone is struggling with expressing difficult emotions from the past (fear or anger, for example). Judgemental responses from professionals just add to the difficulty and make it harder to express these emotions.
7. **'Just behavioural'**: This term is used to distinguish between people who are considered legitimately 'unwell' (with a 'mental illness') and those who are just plain recalcitrant (often displaying traits associated with 'personality disorders'). As consumers, we argue that this language is dismissive, blaming and unhelpful.
8. **'Venting'**: Again, this term is often used in hospital settings. It describes a situation where a mental health professional has listened (or feigned listening), while a patient has shared something that is important to her/him (and possibly very intimate). The professional has then gone away and dismissed the communication as being unimportant or pathological.
9. **'Dependent'**: As adults we are not supposed to be dependent, so this term can cut deeply. The reality we must remember is that this so-called 'dependency' is often a product of the industry of psychiatry, which demands compliance with medication and medical mores on the one hand, and 'appropriate insight' on the other.
10. **'Splitting'**: is used in a derogatory way to describe consumers who the system, represented by 'The Treating Team', believes have the capacity to badly affect team unity; that is, to split the team. Apparently we do this by liking some members of the team and not others.

An exercise for a group of consumers might be to brainstorm all your most detested words, print a list and distribute it widely. It's even better when you can offer alternatives.



Section Two:

Getting your head around diagnosis

The issue of diagnosis is an important one for many consumers. For some people, the naming of what is happening in our lives as a specific, recognised mental illness is an important first step towards recovery.

Others strongly resist the 'medical model' (including diagnosis) as a way of understanding what is happening for us. There can be many reasons for this, ranging from a strong belief that what we are experiencing is social rather than psychological, to a belief that diagnoses are not as 'objective' as is often assumed.

Still others never receive a diagnosis, and yet may feel that their experiences or distress are related to mental health.

In this section, we explore the many different experiences and ideas consumers have about diagnoses.





* Some background to diagnoses

Mental illness classification systems and how they work

“The main thing diagnoses are good for is sussing out what your shrink thinks of you – Bipolar Affective Disorder means they like you. Unipolar means you’re boring. Borderline Personality Disorder means they hate you and Schizophrenic means you scare the shit out of them because they can’t keep up with your thinking.”

Persimmon Blackbridge, consumer painter & writer of Prozac Highway

Many of us have received a formal psychiatric diagnosis (or two ... or three) and for some of us it was a positive and enlightening process, even a turning point, in helping us to understand experiences that had previously been distressingly confusing.

On the other hand, many of us reject psychiatric diagnoses as misrepresenting our experiences, stigmatising and labelling, or profoundly disempowering.

And some of us feel a bit of both, being simultaneously critical of our diagnosis while using it as a tool in our own understanding. Of course, many of us have changed our relationships with psychiatric diagnoses over time.

It’s useful to understand the two main international psychiatric classification systems: the Diagnostic & Statistical Manual of Mental Disorders (DSM) and the International Classification of Diseases 10 (ICD10).

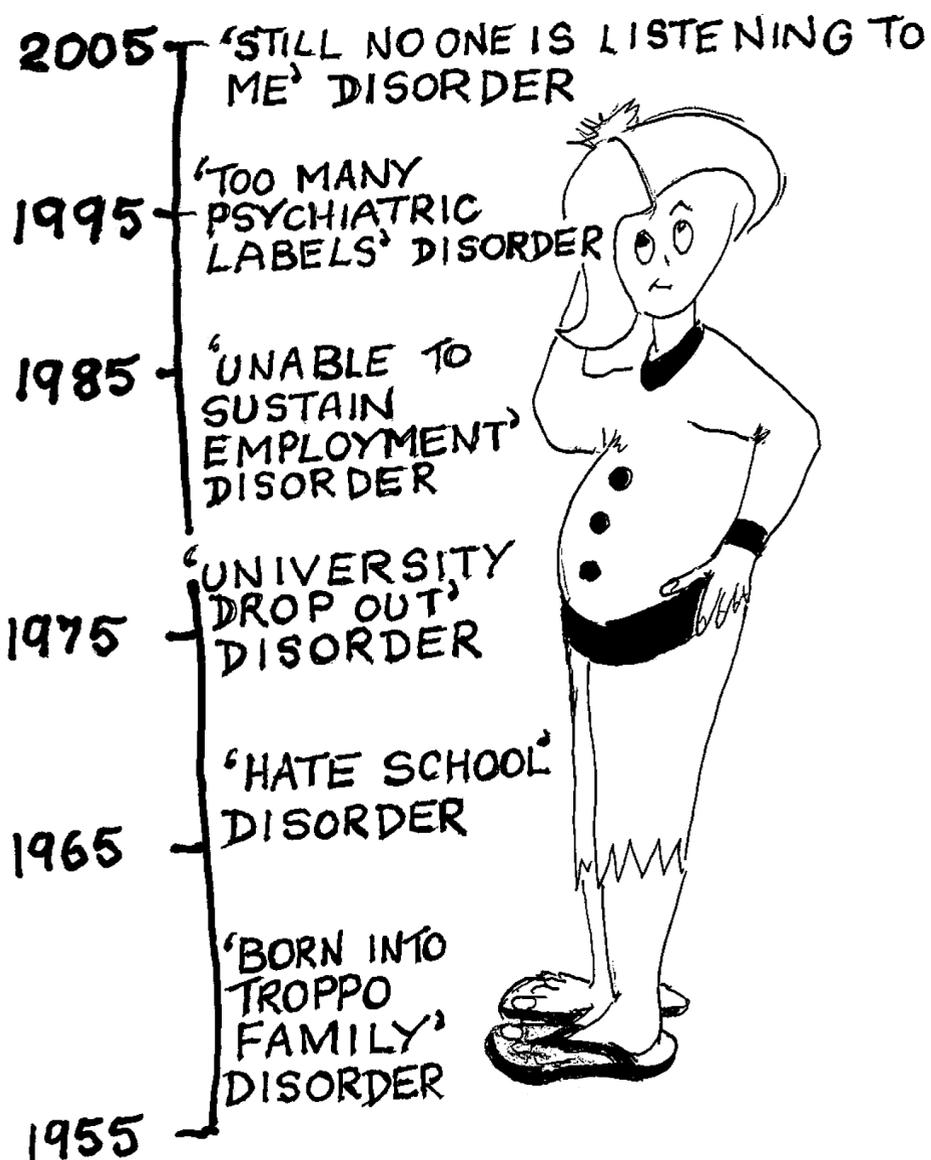
The Diagnostic & Statistical Manual of Mental Disorders (DSM)

published by the American Psychiatric Association (APA), is the system most commonly used in Australia. The most recent version (DSM-IV) was published in 1994, while a revised text version (DSM-VI-TR) was published in 2000.

Under the direction of American psychiatrist, Darrel Regier, the next edition of the DSM (V) is projected to be published in 2010/11. It is predicted to contain a suite of ‘new’ mental illnesses. At the time of publication of this booklet, there has already been considerable debate within the different groups of ‘experts’ looking at different groups of ‘illnesses’ about what is and is not a ‘mental illness’. There has also been a lot of debate about the cultural bias of the DSM.

A second classification system is the **International Classification of Diseases 10 (ICD10)**, published by the World Health Organisation





THE PROBLEM WITH DIAGNOSIS

(WHO). This system is also used around the world, especially Europe. Because most Australian states use the DSM more than the ICD, in this booklet we focus on the DSM. The most recent version of the ICD (the 10th edition) was published in 2002.

How these classification systems ‘work’

The DSM and the ICD are simply classification systems. They are intended to organise ‘mental disorders’ (or ‘mental behavioural disorders’) systematically so that there is some consistency between psychiatrists and/or clinical psychologists.

The DSM classification system lists symptoms for each disorder, although not every symptom need be present in each patient – clinicians count the number of symptoms that are present, and the DSM will specify how many are necessary for a diagnosis to be made; e.g. at least six out of a possible 10. (If only four are present this will preclude this diagnosis.)

The DSM system is observational, involving counting and naming in order to reach a diagnosis. It sounds simple, but more complex questions arise when you consider the interpretation of what this collecting and counting leads to, as we discuss in the next section.

*** Thinking critically about diagnosis**

“She’s got 14 diagnoses,” said the auctioneer.

“Any advance on 14?”

“When you are a Bear of Very Little Brain, and Think of Things, you find sometimes that a Thing which seemed very Thingish inside you is quite different when it gets out into the open and has other people looking at it.”

A.A. Milne, *The House at Pooh Corner*

Many of us want our pain named. Having no name gives ‘it’ power over us, power that we want to reclaim. It can be a huge relief to know we’ve got something real that makes sense. It is important to know that we’re not making it up and that something can now be done about it. Some people even give the experience a name to distance themselves from ‘it’, such as Sir Winston Churchill’s ‘Black Dog’.

On the other hand, some of us intuitively know that our mental distress is not a ‘thing’; that it doesn’t have the qualities of ‘thingness’. Rather, it’s an idea. Diagnosing us into categories of ideas may seem pointless. It can also be dangerous because the label can become us.



Ask clinicians up front what diagnosis you have

It's OK to ask the clinician what s/he has written in terms of a diagnosis. After all it's our diagnosis, not theirs. Some will simply tell you; others will dither. Some are very honest and say, "At this stage I'm really not sure."

Be aware that if your psychiatrist or psychologist has written any formal documentation for you (e.g. reports to courts etc.), they will have had to include a diagnosis. Sometimes we are the only person who doesn't know our own diagnosis! You can ask if you want to know.

If you are a public health 'patient' you will be diagnosed: it's mandated regardless of whether the clinician thinks this is useful or not. It is our right to know this diagnosis.

As mentioned earlier, many people find comfort in diagnosis, while others find it labelling and disempowering (and some experience a mixture of both).

Whatever your view, it can be helpful to apply some critical thought to your diagnosis. Here we offer some reasons to view psychiatric diagnoses with caution:

1. **Diagnoses themselves change:** The Diagnostic and Statistical Manual (DSM) is reissued every few years to reflect changing professional opinions. A famous example of this is that homosexuality was considered a mental illness until 1973.
2. **Professionals disagree amongst themselves about diagnoses:** There is a great deal of disagreement in the professional literature about the validity of current diagnostic categories.
3. **The process of diagnosis is not an objective one:** The process of diagnosis can be heavily influenced by the individual mental health professional's own perspective – ideas about particular diagnoses as well as feelings towards the person they are diagnosing. There is extensive anecdotal evidence to suggest that some diagnoses are associated with negative professional opinions. For example, one US website has observed: "BPD [borderline personality disorder] is a diagnosis clinicians give to patients who make them angry." It's not always this overt, but it is worth bearing in mind that the mental health professional is human, and will bring their own ideas and feelings to the encounter.
4. **Diagnoses are influenced by culture and context:** Certain diagnoses are more likely to be given to people from a particular cultural group/ social class/gender/age/sexual orientation. Diagnosis is also influenced by whether someone is in an institution, such as a prison facility.



5. **Diagnoses are not necessarily useful in terms of treatment:** Much of the thinking behind treatment selection is motivated by experience with the person, rather than their diagnosis.
6. **Keeping people out of services:** Because public mental health services are stretched to the maximum, diagnoses can be misused to keep consumers out of services. For example, in public services in Victoria it can be extremely hard to get access to any sort of service if we don't have a diagnosis of one of the schizophrenias, drug induced psychosis or bipolar disorder I.
7. **Diagnoses do not predict recovery:** Diagnoses are often falsely associated with unduly pessimistic prognoses (predictions for future progress). It's important to remember that people can and do recover.
8. **People change:** Many people who receive a psychiatric diagnosis have received multiple diagnoses over time. People also learn new skills and new ways of being in the world. A diagnosis should therefore not be viewed as a life sentence.
9. **Diagnoses contribute to stigma and discrimination (or “mentalism”):** Too often, people are seen as their labels. This is especially a problem because psychiatric labels focus on the difficulties people have, not on their strengths or individual personalities.
10. **Finally (and possibly most importantly):** A diagnosis tends to come from someone else (a mental health professional), who decides it is appropriate for you. You might not agree with your diagnosis.

Acknowledgement: Some of the material in this section has been adapted from work by Dr Coni Kalinowski, who, at the time of printing, was working as an independent psychiatric consultant in San Jose, California.

* Surviving a mental illness diagnosis

We all do it differently

“You can't empower me. All you are doing if you try is proving your power over me. The best you can do is to stop disempowering me and this is your responsibility.”

Merinda Epstein, consumer, cartoonist and 2004 Human Rights Award winner

There's no 'right' reaction to being given a diagnosis. There's no path we should be following.

You may experience one of the following reactions (or actions), or a combination, or move through them or up and down them from time to time.



1. **Acceptance of the diagnosis:** There are some of us who have found acceptance a relief. The diagnosis makes sense of our strange feelings and it can shed light on our 'behaviour'.
2. **Rejection of the diagnosis:** There is another group of us who find enlightenment, safety and health through rejecting medical classification. We believe that to subjugate ourselves to others' control over our lives is unbearable, and unhealthy. Often we learn how to play 'good patient games' to appease the services and their enforcement agencies but we know it is a game. We know our healing has come from resistance – not acceptance.
3. **Recognition of the seriousness of our distress:** Some of us have known for a long time that the distress we are experiencing is destructive and disabling but we can't get anyone – including mental health professionals – to take us seriously. One person has commented that the most insidious diagnosis she had ever had was, "*There's nothing wrong with you*". Being diagnosed can feel like our experience has finally been recognised as 'real' and legitimate, and so not being given a diagnosis can feel like our experience is 'not real' or somehow illegitimate. For those of us who have been in this position, a clinician who will take us on, give us priority and reinforce our own judgement that we need help is the first step to recovery.
4. **Peer support:** For some of us, getting together and comparing experiences with particular clinicians; describing clinical behaviour which is unacceptable; finding friends who have had similar experiences; and helping others who are going through a tough time are essential, life-enhancing experiences post diagnosis. Getting a diagnosis can open up this world of consumer support to us.
5. **Consumer Initiatives:** Some of us choose to become more formally organised. Planning for local initiatives to help other people; finding out more about our specific diagnosis; running education initiatives in schools and in the community; developing education packages for the media and for health professionals; and organising support groups and information nights are all potentially empowering activities.
6. **Reclaiming language:** For those of us who resent the loss of personal power over our circumstances, reclaiming language that has been used against us can be essential. This means starting to talk about ourselves as 'batty', 'lemons', 'nutcases', 'nutters', 'loonies' and so on. It can be empowering and can replace the language of diagnosis.
7. **Rejoice in our 'madness':** When we get together to celebrate 'madness' through culture, our own science, and learned wisdom through stories, art, friendship, determination and, of course, our very



own version of black humour, we can experience that side of madness that is truly emancipatory.

- 8. Competing with other diagnoses:** We must be careful because it's easy, when we are desperate, to get sucked into comparing our needs with others with different diagnoses. Lots of groups compete with each other, diagnosis against diagnosis, to gain a part of the insufficient resources available. We must try to avoid this. We are consumers and recognising everyone's needs regardless of their medical label is consumer perspective.

* **Why didn't I get diagnosed earlier?**

It could have saved me a lot of suffering

"Keeping an open mind is a virtue, but not so open that your brains fall out."

James Oberg, Space journalist

Many people – consumers as well as mental health professionals – speak about wasted time and senseless suffering due to the long delays some people experience before they get a diagnosis that makes sense to them. There are many reasons why these delays can occur:

Psychiatrists face more complexity as diagnosticians than most other kinds of doctors, since factors contributing to our distress might include 'scientific signals' but also issues like child abuse, domestic violence, body image, neglect, poverty and lack of economic security.

Evidence-based medicine has become the new catch cry and discussions around 'scientifically measurable things' like enzymes, hormones, brain chemistry are all testimony to this. However, these things can only ever tell half a story. Psychiatry is as much an art as it is a science. Often dismissed by the 'real science' specialists (such as surgeons), psychiatrists and their organisations are determined that their discipline be seen as an accountable 'science' – sometimes at the expense of the art and subtlety.

There may be other reasons for delays in diagnosis (or delays in finding out what our diagnosis is):

- **'Saving us' from discrimination:** Some clinicians, knowing the possibly dire consequences of having a 'bad' diagnosis such as 'borderline personality disorder' or 'schizophrenia', try to protect us by not telling us. Even though this is well intended it's a bad way to build trust. It is



dreadful when we only discover our diagnosis from the screen on our General Practitioner's computer.

- **Genuinely unsure:** We have to admit that some of us are very mixed up. Our histories are often just too complex. It sometimes takes the joint effort of us and a clinician to find a diagnosis that seems to fit and make sense; this can take a lot of time and a few false moves.
- **Some psychiatrists hate labelling us:** Some genuinely don't like classification systems and share all the same frustrations we have but in order to have a common language with their peers they are forced to use this sort of linguistic shorthand.
- **Some clinicians use not telling us as 'therapeutic':** They could possibly justify this by their own 'self talk' that our knowledge of our diagnosis could be detrimental to our health.
- **There could be some fear of litigation:** Some clinicians in some situations might be what we call 'practicing defensive medicine' – believing that the less they divulge, the less likelihood there is that they could possibly get sued.
- **Different diagnosis:** Many of us are given different diagnoses over time through different doctors, different types of therapists and different systems. This can make it hard for everyone.
- **Diagnostic Traits and Secondary Diagnosis:** Complicating matters further are the 'secondary diagnoses' that many of us receive. We could be diagnosed with bi-polar affective disorder with narcissistic personality disorder traits, or have a primary diagnosis of paranoid schizophrenia with a secondary diagnosis of chronic anxiety disorder. To be described as having "traits" means that we don't meet enough of the criteria for diagnosis, but do meet enough for this to be relevant to our treatment.
- **We always have the right to ask!** Remember that it is *your* diagnosis, not anyone else's. Don't be afraid to ask what it is.



Section Three:

Making medication work for you... ?

This section provides an introduction to some of the issues associated with psychiatric medications, from the point of view of consumers. While many of us have experienced medications as being life-enhancing, or even life-saving, we think that the role of medication in our lives is an issue that consumers should have more information about and control over.

Some of us have had powerful, mind-altering medications forced upon us, imposed on our lives and bodies against our explicit wishes. This is an incredibly serious issue. The effects of some psych. drugs are horrific.

Even those of us who have a choice about whether we take medications or not often feel disempowered by the lack of information, being discouraged to do our own research, or feeling like we are just expected to consume whatever has been 'prescribed' for us, regardless of what we experience, or understand (or don't understand!)

The intention of this section is to support consumers to be able to make more informed decisions about the role medications play (or don't play) in our lives.





* Introduction to psychiatric medications – a consumer perspective

From the horse's mouth!

*Little boxes on the hillside, Little boxes made of ticky-tacky,
Little boxes, little boxes, Little boxes, all the same.
There's a green one and a pink one, and a blue one and a yellow one
And they're all made out of ticky-tacky
And they all look just the same.*

Little Boxes, a song written by Malvina Reynolds in 1962

There are many ways to find information about medications from a medical perspective. However, here we provide a mental health consumer perspective on psychiatric medications. This is information that you will not necessarily get in the promotional or instructional material produced by drug companies or from benevolent non-consumer organisations.

First, a word on terminology: 'Medical Drugs' or 'Medications'?

Some of us feel strongly that we should use the term 'drug' because of the significant effects these substances have on our lives. Others dislike the association with illicit drugs, and feel more comfortable with the term 'medication.' We use both terms to reflect this diversity.

What is 'compliance' and why do clinicians talk about it so much?

This term basically means we (the consumers) do what we're told, which may include taking medications as we are told to when we are told to. It tends to be seen by clinicians, 'the system', family, friends, and even ourselves sometimes as essential to our wellbeing.

However, 'compliance' is sometimes not so wonderful. For many people it involves a loss of self-determination, which can cause many long-term, iatrogenic problems including what's known as 'institutionalisation'. We become institutionalised as we lose confidence in our own decision-making and put too much faith in clinical interactions with their 'warped' power relationships.

When medication is forced on us:

Some of us prefer not to use language around 'compliance,' especially



because many consumers have no choice. In this situation compliance is seen by many as 'social control'. That is, for some people forced 'treatment' is no longer 'treatment' at all. We have no choice, no self-determination – none of the things that make us fully human. Involuntary 'treatment' or the threat of it is used to coerce many people into staying on medications whether they want to or not.

Can we have a good life without medication?

Each of us will face this question and we will make different decisions. It will depend on your own experiences, attitudes and feelings.



SIDE-EFFECTS?

Why would anyone stop taking psychiatric medications?

Many of us have done it! There is no shame in experimenting with a drug-free life. There are usually complex personal stories behind a decision to come off psychiatric medications. It might work for you or it might not.

One reason for choosing to try coming off drugs is the terrible effects of some medications, including getting really fat (see next section), dreadful muscle spasms, uncontrollable shaking and trembling, farting a lot, dribbling, smelling more than usual, mood problems, and more. These can be debilitating and it's no wonder we don't want them!

Should I feel guilty or stupid because I trust my psychiatrist and want to keep taking medication?

Is it OK to find the medications useful? Of course! We all want and should be allowed to be the decision-makers in our own lives. If your informed decision is that the medications are useful, then that is great. It is the experience of many people that medications have saved their lives and this has to be a good thing!

Some political and ethical issues associated with psychiatric medication

Some consumers believe the behaviour of large pharmaceutical companies to be questionable, especially in developing countries where people may use medical drugs that have proved to be undesirable (or even dangerous) to people in more affluent countries for various reasons. Many also believe that some companies may have too much influence on major policy decisions and research in the mental health field.

Where to find out more about medication

1. **Consumer perspective:** Many consumers recommend a website called Crazy Meds: <http://crazymeds.us/> because it uses easy to understand language.
2. **Medical perspective:** There are many sources of information on medications from a medical perspective including: the instructions that come with medications; pharmaceutical company websites; the website of the Mental Health and Drug Division of the Department of Human Services; SANE Australia's plain English Guide to Medication and Other Treatments; and MIMS (Monthly Index of Medical Specialties), Australia's resource for doctors. This last one is expensive (around \$200) and can be difficult to understand, but is the most comprehensive information source.



* **Fat is a pharmaceutical issue***

Don't blame me for the effects of your drugs

"I'll have a plate of Olanzapine, Clomipramine and Sodium Valpoarte with some fat on the side please."

Merinda Epstein, consumer, cartoonist and 2004 Human Rights Award winner

There are many unwanted effects of taking medical drugs. Sometimes these are compensated for by the helpful effects of the medication. Often they are not.

Here, the focus is on fat. This is not to neglect other horrible effects such as Tardive Dyskinesia, shaking uncontrollably, walking funny, getting depressed, slowing the body down, and many more – some minor and some extremely dangerous.

However, fat is in the news at the moment, the 'Obesity Epidemic' is attracting funding, but few people are talking about the links with psychiatric medications.

Fat can be fought by exercise, but ...

We know physical activity can help get rid of unwanted fat. Also, endorphins are found within our body's chemical structure and when they are produced through exercise they are a natural way to produce a feeling of 'contentment' for some or a way of feeling 'a bit better' for others. However, there are some practical realities:

- When we are really fat, most of us are hesitant to be seen exercising publicly;
- It is hard to explain to others the weight gaining effects of most psychiatric medications. Sometimes we haven't even told people about our diagnosis of 'mental illness';
- Exercising often works much better if you can do it in a group but many of us have lost our community to 'mental illness' and so there is no longer a natural community to which we belong;
- Going on 'exercise excursions' with Psychiatric Disability Rehabilitation and Support Services (PDRSS) can be excruciatingly embarrassing

*This is a play on the title of a famous text, *Fat is a Feminist Issue*, written by British psychotherapist Suzie Orbach and first published in 1978. It was updated and re-released in 2008.



for some of us (some have commented that it makes them feel like they are back at school). We are also very vulnerable to being publicly embarrassed, unfortunately even by well-meaning PDRSS staff.

- Gyms are prohibitively expensive for people on Disability Support Pensions (DSPs).

Other activities

Similar situations arise around other activities that might be useful for some overweight consumers. These include getting food from health food shops and eating lots of good quality vegetables, fruit and less junk food.

It is almost always assumed that the problem is with our ignorance so people try to 'train us' to eat better but the issue is often not that we don't know what we should be eating (most of us do know), the problem is often poverty. People with psychiatric disabilities often end up living in poverty.

Many of us are in and out of work because of episodic illness and some of us can't work at all because of what some people call our 'symptoms'. Of course this is not universal. People diagnosed with 'mental illness' can also get on very well in the world but there is also a group whose struggle is mighty.

It's hard not to feel infantilised and patronised during an education session on 'good food choices' given by some young, well dressed occupational therapist who wouldn't know poverty if s/he walked into it. Poverty can mean that we can't even contemplate the joy of buying birthday presents for our family; however, we can still get a little bit of pleasure from a bag of hot chips.

This is about culture and survival – not about being 'good' or 'bad'. Try not to add an extra layer of shame by beating yourself up about what you eat or how you look. Shame, we know, is particularly bad for our mental health.

Whose responsibility?

Sure, we can all take responsibility for the decisions we make in life but it is naïve and unfair to expect distressed and disempowered people to take on this responsibility that belongs largely (pardon the pun) to powerful corporate entities.

Pharmaceutical companies should be putting much more time and energy into making their products less harmful to the already fading personal images of beauty and dignity that accompany the portrayal of 'mental illness.' Self esteem is crucial to where we want to go next on our journey.



* Talking about medication – who’s in control?

Would you like some power with that pill?

Don't ask the doctor, ask the patient.

Yiddish proverb

As discussed earlier, taking medication can be an extremely helpful or profoundly disempowering experience (or, indeed, both).

Whatever our experiences, it can be helpful to feel as if we can take some control over our own interactions with medication, rather than being subjected to the wishes of others.

Here are five ways we can have more power when discussing medication with professionals.

1. Thinking differently about medication:

- **Medication is a tool.** Recovery is hard work and takes more than pills alone. There are many non-drug coping strategies that can be used with or without medication, including love, solitude, art, avoiding alcohol and street drugs, nature, prayer and work. Like any tool, medication should be something that you actively use, rather than passively 'take'.
- **Using medication is not a moral issue** and it is not a sign of weakness to use medications.
- **Learn about your medications.** It is easy to be intimidated by all the jargon that is used. Try to get more informed (use the Consumer Resources outlined on page 101).

2. Thinking differently about yourself:

- **Trust yourself.** You know more about yourself than your psychiatrist will ever know. If you are experiencing unwanted drug effects (such as a feeling of apathy, constipation, loss of sex drive or double vision) trust your perception. Check with the pharmacist or with friends and check books or trusted websites.
- **It's your recovery.** Too often people say that "the drug made me feel better". Don't give the drug all the credit! Even if it was helpful, don't overlook other things you have done to get well and stay well.

- **Your questions are important.** Anyone who has taken psychiatric drugs for some time is likely to have questions – don't be frightened to ask:
 - *Is it worth (still?) taking these medications?*
Have my needs changed over time?
 - *Am I addicted?*
 - *What is the "real me" like now?*
What would I be like if I didn't take these medications?
 - *Are there non-drug methods I can learn to reduce my symptoms instead of using medications?*
 - *Are there any long-term studies on the medication I use?*
Am I at risk? Do I want to take this risk?

3. Thinking differently about psychiatrists and other professionals:

- **Most psychiatrists are too busy for our own good.** Don't assume that your psychiatrist has full knowledge of your treatment history. It's good to keep your own records as well.
- **Psychiatrists are not experts on everything and sometimes psychiatrists are wrong.** It's good to get a second opinion when in doubt, and remember that psychiatrists are trained in *medical* matters. You might supplement medicine with other things that are important to you; for example, spirituality.

4. Being prepared before meeting with your clinician:

- **Set your agenda for the meeting,** rather than simply reacting to what s/he does or doesn't do. Organise your thoughts, concerns and questions, write them down, and bring them with you.
- **Be specific.** The more specific we can be in our communications, the more control we have.

5. Taking charge of the meeting with your clinician:

- **Record what you need to from the meeting.** You can bring a note pad and pen and take notes or tape-record the meeting (with permission, of course). Psychiatrists take notes, so why can't you? Tape-recording can be useful if you have trouble taking everything in during meetings.
- **Announce your agenda at the beginning of the meeting.** If you have prepared, then you know what you want to get out of the meeting.



Communicate this so the meeting addresses these issues.

- **Bring a friend or advocate, if you want to.** Many people bring a friend or support person when they see a dentist or have a physical exam. It makes sense to bring a friend to a meeting with a psychiatrist.

Acknowledgement: Most of this material has been adapted for Australia from an article by Patricia Deegan, *Reclaiming your power during medication appointments with your psychiatrist* (2008). The complete article is available at: www.power2u.org/articles/selfhelp/reclaim.html



Section Four:

Navigating the mental health system

Navigating the mental health system can be challenging and daunting. This is not only because of the bureaucratic maze of public provision, but also because there is often a mismatch between what is described in pamphlets or websites and what actually exists in reality.

Often, by the time we even start thinking about services, we are desperate. Public mental health services are under-funded and so have become a competing place for the extremely desperate. This is complicated by the fact that some people are locked up in psychiatric hospitals against their will.

This section offers some realistic suggestions, from the perspective of consumers, about where we can start looking for help.





* **Where to start?**

The mental health system can be confusing, especially if you're distressed already

"The distance doesn't matter; it is only the first step that is difficult."

Marie Ann de Vichy-Chamrond (Marquise du Deffand), French hostess (1697-1780)

For many of us our first step towards getting help is a very difficult one. It can be so hard to know whether what we are experiencing is 'just normal stress' or something more than this. Some of us are ashamed that we don't seem to be dealing with our lives better and others are quite scared about what is happening.

Because of widespread social prejudice many of us have never spoken to anyone about our thoughts, fears and sometimes strange behaviour. Although it is difficult, it can be worth finding someone to work with you (e.g. a friend, a GP, a fellow consumer, a professional advocate) to navigate the system – the mental health system can seem like an incomprehensible maze!

Public vs Private

First of all, it's helpful to understand the difference between the public mental health system, and the private system.

The public system is free, but can be very difficult to access, for various reasons (see the section on 'Why can't I get help?'). The structure of the public system is outlined below.

The private system includes psychiatrists, clinical psychologists and other counsellors in private practice, private mental hospitals, and some other services that are accessible only to people with private health insurance (see the section on 'What services are provided through private health insurance?'). The government subsidises some of the costs of accessing services in the private system through the Medicare Rebate system (see next page).

There are also other avenues discussed at the end of this section.

First port of call

The first port of call for many is our GP (general practitioner). A GP will be able to refer us to an appropriate mental health professional (e.g. a



psychiatrist or psychologist), and might be able to help us find one who bulk-bills, or meets specific needs we might have (e.g. a preference for a female clinician or someone who specialises in our sorts of experiences). For more information on finding the right professional for you see the section on – 'How do I find the right mental health professional for me?'

If we want to see a psychiatrist or access the Medicare Rebate, we need a referral from a GP. A GP may also be able to help us access services through private health insurance.

Medicare rebates

While some people are able to afford private mental health services (e.g. a psychologist in private practice), many of us rely on the government's Medicare rebates, which significantly subsidise the costs. Unfortunately, many clinicians charge what's called a "gap" fee – money you have to pay in addition to what Medicare will rebate. This means that private services still aren't accessible/enough for many of us. If you want to know more about the Medicare rebate, it might be good to talk with a GP.

What public mental health services are provided in Victoria?

In reality, public mental health services are only able to work with a tiny minority of people. An inability to help us might have nothing to do with a service thinking we don't matter, even if it feels like that. Restrictions are associated with various factors, including service capacity limitations, triage processes (the way in which patients are prioritised for services – see the section on page 47 for more on this), and strict diagnostic criteria.

Public mental health services are also mainly structured according to particular "catchment" areas (the geographical region in which we live), and our age – Child and Adolescent (0-18 years); Adult (16-64 years); and Aged Persons (65+).

The main ways consumers access adult public mental health services are through:

- **Crisis, Assessment and Treatment Team (CATT):** These are teams of clinicians (usually two people) who come to us in times of crisis, either to enable us to access an acute unit, or to support us as needed... Well, that's the theory – unfortunately the reality doesn't always quite match! (See the section on 'CAT Teams').
- **Acute Units:** These are inpatient services designed for intensive intervention (usually with strong doses of medication). The vast majority of 'patients' in public acute units are people who are there

against their will – it is incredibly difficult to get into an acute unit voluntarily (see the section on ‘Why can’t I get help?’).

- **Community Mental Health Services:** These are the hubs of clinical services in the community. While these are theoretically open to all consumers, resource allocation means that services are almost exclusively devoted to people who have been in an acute unit and are now “back in the community”.
- There are also some specific, state-wide services, for example specialising in eating disorders, personality disorders and mood disorders. However, the experiences of many have been that these services have a much higher demand than they are able to meet.

What else is out there?

It used to be easier to get to see a mental health worker in a Community Health Centre (CHC) than a designated public mental health service because their definitions are broader. Unfortunately many regions, both urban and rural, lost their local Community Health Centres in health shake-ups over the past 15 years. Like Community Mental Health Centres, they are geographically defined – ring 03 9096 0000 for your local CHC.

There are also alternative and complementary therapies you could find out more about. There are so many different approaches (e.g. naturopathy, Bowen technique, acupuncture, reflexology, etc.). They may work for some people and not for others.

Finally, there are also completely different ways to respond to our experiences – e.g. spirituality, creativity, self-help groups and consumer groups.

*** How do I find the right mental health professional for me?**

Finding the right ‘fit’ for you

“In my profession, the customer is always wrong ... It’s a therapist joke.”

Dr Paul Weston, psychotherapist in the HBO television series, *In Treatment*

Finding the right mental health professionals (when we actually get to choose!) can be a challenge, partly because the search almost always begins at a time when we are emotionally distressed.



Here are a few ideas to consider when searching for the right clinical relationship. Although we are focusing on psychiatrists, much of this information is also relevant to finding a psychologist, or another type of clinician.

What is ‘Doctor Shopping?’

While it may have negative connotations when used by others, to many consumers, the term ‘doctor shopping’ is about assertively searching for the clinician who has the attributes we are looking for.

First we must decide whether a psychiatrist is the way we want to go. In order to do this we need to have an understanding of what some of the other clinicians offer and how we can access them. This issue is covered in much greater detail in another booklet in this series.

The next step is to find the best professional relationship we can. Sometimes we prefer to trust the information and referrals our GP (general practitioner) gives us. Others prefer to ask our GP for what we want. Neither approach is right nor wrong, they are just different.

The role of GPs in referrals to psychiatrists

You need to get a referral from a GP to see a psychiatrist. GPs often have a set of specialists whom they have sent people to before. Sometimes they rely on professional reputation or feedback from patients. Their criteria for making particular referrals can be rather rudimentary, such as, *“other patients say she’s very nice”*.

GPs may react in different ways when we ‘doctor shop’. Because many are not used to ‘their’ patients being involved in making decisions in this way it is important to act assertively but not rudely and show the GP that we have really thought about it. Some GPs will be grateful for our guidance, others will be threatened.

Finding the right psychiatrist

Below are some issues you can think about when you start your search for a psychiatrist. Try not to feel rushed. Do it at your own pace and within your present capacities.

What am I looking for?

- *Do I know the difference between a psychiatrist and a clinical psychologist or counsellor? What else is out there? Am I sure a psychiatrist would be the greatest help?*



- *Would I be prepared to take medical drugs, with their unwanted effects?*
- *Does the person I'm looking for need to have a specialist interest in, for example, childhood trauma?*
- *Is the gender of the psychiatrist important?*
- *What about their reputation in the field? Do they have a public profile? Is this good or bad?*

Logistical questions:

- *Can I afford a private psychiatrist? How often could I afford to consult a private psychiatrist?*
- *Is location important? (Note that many private psychiatrists tend to be located in the more affluent suburbs of Melbourne. There are few in the western and northern suburbs and even fewer in rural and regional areas.) Inconvenient location can prove a problem because of frequency of visits but people usually say that if the relationship is a good one, this is secondary. Distance from public transport is also worth investigating.*

Once someone has been tentatively chosen:

- *Is the person properly qualified and registered as a psychiatrist?*
- *Have there ever been any complaints made about her/him or his or her practice? You can easily get this information from the Medical Registration Board.*
- *What sort of approach (e.g. behavioural or psychotherapy) would suit me best? Remember that psychiatry can be considered an art as well as a science. Sometimes psychiatrists use eclectic practices that can be hard to describe. It is extremely difficult to give informed consent to something that can't be explained to you – but this does not necessarily mean it isn't any good. (Note that while much information about different approaches is available online and in books, very little of this is from consumer perspective.*

See the Consumer Resources section for some useful listings of consumer perspective materials.)

What next?

Once you get some initial information and have decided to see a psychiatrist, it's time to see if this person is right for you. At this time you may be vulnerable and perhaps scared not only of what is happening inside you but also about what others might think of you and what effect



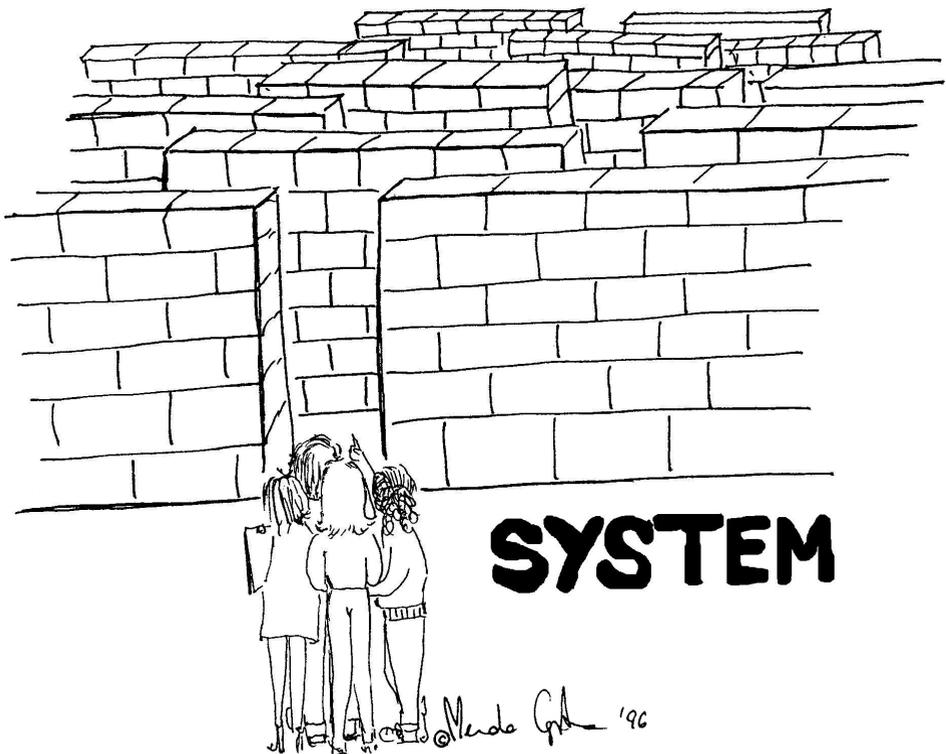
the psychiatric consultations might have on you. All this is normal.

What clinicians call the 'clinical relationship' is important and this is always evolving. It's one of those intangible things that we recognise as important but find hard to describe. It is easier to describe when it's bad.

We strongly recommend you approach any therapeutic relationship with an awareness that the first few sessions might be a 'trial run' and that you might decide this person isn't right for you.

It's worth thinking through what Plan B would be if you decide a particular approach doesn't feel right for you. Many of us have found that it is harder to leave a therapeutic relationship the longer you are in it, so these can be very real challenges.

THE MENTAL HEALTH



* Why can't I get help?

Mirror, Mirror on the wall, who's the sickest of us all?

"... the doors of health services swing open for chest pains when arteries are blocked but swing shut if life threatening physical symptoms are caused by psychological blockages ..."

Professor Patrick McGorry, Australian of the Year 2010

Public mental health services only provide services for a tiny minority of people. In reality, these services are under-resourced and overwhelmed.

Triage and intake are the processes by which the system decides who has priority in accessing services (more on this below). And it's important to note that priority does not always go to those who actually *want* access.

So while on the one hand there are many people who are desperate for help but are missing out on services, on the other there is a group of people whose human rights are being threatened as they are forced to endure a 'treatment' regime they do not want.

There is a third group as well: those who want help but don't want the services that are currently offered – they may have been traumatised by services in the past, or seen friends and family traumatised or become 'addicted' to these services. They may be wary of what they view as 'social impediments' in their lives being reinterpreted as 'psychological problems' or 'psychiatric problems'. As a result, they may seek alternatives to the current system, which unfortunately may be even more poorly resourced.

Triage and Intake

Triage and *Intake* are similar processes – they involve deciding who will get services and who won't, based on certain criteria (most commonly diagnosis). The process is called *triage* when it's about emergency services (e.g. CAT Team or acute unit admissions), *intake* when it's about non-crisis services.

What does this mean in practice?

In practice, the most important criteria used for admission are:

- diagnosis (regardless of distress),
- 'dangerousness', and
- the likelihood of self harm.



People who have been labelled as having psychotic illness (the schizophrenias, some forms of bi-polar affective disorder, psychotic depression, schizo-affective disorder, and so on) are much more likely to be admitted and incarcerated against their will in an acute psychiatric unit than others. Most units are locked and more than 80% of inpatients are there involuntarily.

On the other side of the equation, some people find it extremely difficult to get any help at all unless they have a lot of money, because the public system defines them, against their will, as 'not serious enough', 'bad patients', or a 'bad influence on acute unit and generally difficult'.

This can lead some of us into a position where self-harming behaviours become necessary to receive services. This is obviously an awful position to be put in.

It's important to understand that a refusal to help us has nothing to do with a service thinking we don't matter, even if it feels that way.

It is also worth noting that many GPs are aware of the gaps in the mental health system and may be as frustrated as we are about the lack of services. Many of us have "educated" our GPs as they struggle with us through the process of navigating this often frustrating system.

*** When we have no choice**

The Mental Health Act 1986 (Vic) makes it possible for people to be 'treated' against their will

"The ethical system (if I can call it that) that drives the involuntary treatment system is paternalism, the idea that one group (the one in power, not oddly) 'knows' what is best for another group (which lacks power). The history of our civilisation is, in part, the struggle against paternalism and for self-determination."

Judi Chamberlin, psychiatric survivor, activist, speaker and educator (1944-2010)

As mentioned earlier, it is very difficult to get into a public mental health service in Victoria unless you are admitted involuntarily. This can be viewed as either 'good' or 'bad' depending on your circumstances, beliefs and past experiences.

Involuntary 'treatment' involves losing self-determination and choice about your medical needs. It can be one of the most awful, galling, frightening

experiences that can be endured. If we had committed a crime, at least we would have received a trial!

Powerlessness leads to the corruption of hope for many of us. It is questionable whether forced services can actually be called 'treatment'. Many of us believe we lose as much as it's possible to gain.

How is involuntary admission decided?

There are five criteria for a person to be admitted involuntarily, and then held under the *Mental Health Act 1986 (Vic)*. This often isn't explained to us (whether we meet the criteria or not). In order for us to be involuntarily detained we must fulfil **all five** criteria:

1. The person appears to be mentally ill [sic]; and
2. the person's mental illness [sic] requires immediate treatment and that treatment can be obtained by the person being subject to an involuntary treatment order; and
3. because of the person's mental illness [sic], involuntary treatment of the person is necessary for his or her health or safety (whether to prevent a deterioration in the person's physical or mental condition or otherwise) or for the protection of members of the public; and
4. the person has refused or is unable to consent to the necessary treatment for the mental illness [sic]; and
5. the person cannot receive adequate treatment for the mental illness [sic] in a manner less restrictive of his or her freedom of decision and action.

If you need further clarification of these criteria, you can ring the office of Victoria's Chief Psychiatrist, The Mental Health Review Board, the Mental Health Legal Centre, or the Victorian Mental Illness Awareness Council (VMIAC) – see the Consumer Resources section for contact details.

What are my rights?

The Mental Health Legal Centre has a very useful booklet for people held against their will in psychiatric units. Every acute unit and every community service is supposed to display copies of it. If there aren't any, speak to the Consumer Consultant (if there is one) or staff and ask them to get some in. These booklets are easy to read.

When we are better informed we can sometimes be more empowered to control our own circumstances. Copies are available from the Mental Health Legal Centre, www.communitylaw.org.au or 9th Floor, 10 -16 Queen Street, Melbourne VIC 3000, phone (03) 9629 4422.



Community Treatment Orders (CTOs)

CTOs enable us to leave a locked ward under the supervision of a mental health service which is given powers under the *Mental Health Act 1986 (Vic)*. Victoria has many people on CTOs because it once prided itself on using this mechanism to get people out of oppressive regimes in psychiatric hospitals. At the beginning it was seen as progress towards greater freedom but today it no longer fulfils this task.

While we may not be in hospital, a CTO is very restrictive. Some of us don't even have control over where we live and we certainly do not have control over what medications we are given, when appointments are made, which doctors we see or what service we use.

People on CTOs are assigned 'case managers' and the name itself gives away the truth – our lives are being managed by others without our wish or consent. (And, by the way, we're not 'cases' – we're people.)

* What services are provided through private health insurance?

Making the most of private psychiatric services

"Sticks and stones may break my bones but I have private health insurance!"
Anon

Private health insurers pay for services provided by private hospitals, and these days some other services as well. Any 'out of pocket' expenses (the money for which you will not be compensated) will be dependent upon the level and type of cover you choose.

Check before you use a service if you're covered, and to what extent you're covered. You may choose to use the service even if you won't be able to get the full rebate but at least you will know what you're up for.

What services are paid for?

The services for which private health insurers can pay has expanded a lot due to changes to federal legislation in 2007. The changes introduced 'broader health cover' which means that you no longer need to be an 'admitted' patient of a private hospital to get access to private health benefits. This means that people with private health insurance now have access to a larger range of services, many of which could be provided in a community setting.



Note, though, that some of the private health insurance plans that are most affordable don't cover psychiatric services and from April 1, 2010 some plans which previously covered inpatient psychiatric services of a private hospital now may not. Also, check with your doctor to see whether they work in the private sector. Some psychiatrists see private patients but do not see patients in private hospitals. Inquire about this earlier rather than later.

Private services include:

- **Acute inpatient services:** All private hospitals with mental health 'beds' offer a range of treatment and care in an inpatient setting. If a psychiatrist believes we need to be in hospital, he/she will arrange with the private hospital for us to be admitted.
- **Day patient programs:** Private hospitals offer a range of programs you can attend whilst you remain at home. You can generally attend as a day patient on a half or full day basis, depending on what program will help.
- **Outreach services:** These services are offered to people who have been in hospital as inpatients. A trained clinician will visit you in your home to see how you are going with things like managing your medications, home, and finances. They can come weekly, fortnightly or monthly depending on your psychiatrist's instructions. If you are not coping very well or are becoming unwell they might come more frequently. If they think you need to go to hospital, they can contact your psychiatrist. These services are paid for by the health insurers to the private hospital and will not cost you anything, so long as you have the appropriate insurance coverage.
- **Case Management:** Some health insurers offer members with a long history of mental illness and hospital stays a telephone-based case management service. This service is staffed by clinicians who telephone regularly to talk about things like managing medications, recognising early warning signs, and who you can turn to if you are becoming unwell. They also offer a 24-hour, seven-day-a-week point of contact. If you give permission, they will involve your psychiatrist in the service. If you have the right coverage, the health insurers pay for these services and they will not cost you anything.

Concerns and problems with private health insurance companies

You must remember to always check with your health fund before you access any services at a private psychiatric hospital to make sure that you are covered.



If you have any problems, enquiries, or complaints regarding your health fund, private hospital or medical practitioner about a health insurance arrangement, you can contact the independent service of the Private Health Insurance Ombudsman (PHIO), Complaints Hotline: 1800 640695 (free call anywhere in Australia) or the Private Health Insurance Ombudsman, Level 7, 362 Kent Street, Sydney NSW 2000. Telephone: (02) 8235 8777.

* **Crisis, Assessment and Treatment Teams (CAT Teams)**

The mental health ambulances ... sort of

"I asked the CAT Team to be quiet as they came up my path. I held my finger to my lips and said, 'Shhh,' because I was worried about the neighbours hearing us. I didn't want my mental illness broadcast. This was interpreted as me shutting up 'my voices'. They took me to hospital."

A consumer's experience with CATT

Crisis, Assessment and Treatment Teams – often referred to as 'CAT Teams' are teams (usually two people) of clinicians who visit people in their homes.

They have two roles: (1) to assess whether someone needs to be in hospital (an acute unit) and (2) to provide brief, intensive support in people's homes if needed, when either an acute unit stay is not warranted or a 'bed' cannot be found. In practice, the 'treatment' part of the acronym seems to have disappeared over the last decade.

How do you contact them?

Anyone can call the CAT Team, including friends and family. The police or community services can call them on our behalf and sometimes do so, even when we don't want them to.

CAT Teams are attached to local urban and regional/rural Area Mental Health Services so you have no choice which team will respond. You can find out which services are in your area at the Mental Health Branch website: www.health.vic.gov.au/mentalhealth/services/index.htm

First Contact: The Triage Clinician

Whoever is referring us to the CAT Team will initially speak to the Triage



Clinician. This person is responsible for making decisions about who has a “serious” problem and who doesn’t (see the section on ‘Why can’t I get help?’ on page 47).

- **Referring ourselves:** Remember, decisions will be made while we are talking to the triage clinician on the phone. What they conclude from ‘how’ we are saying things is often as important as ‘what’ we are saying.
- **Referrals from friends and family:** The Triage Clinician might ask to speak to us. S/he might want to know whether the referring person has our permission.
- **Medical referrals:** If the referral is coming from our GP or psychiatrist there is a much greater likelihood that the triage clinician will act promptly. However, this is not always the case and some general practitioners find the whole process as frustrating as we do.
- **Referrals from police:** If there is a perceived risk to self and/or others – e.g. a referral from police – the Triage Clinician will treat this as a priority.

What happens next?

If, after listening to us (or whoever contacted him/her), the Triage Clinician deems our situation ‘urgent,’ action will be taken immediately. Sometimes we – as the subject of the call – still won’t know anything about what is going on. If our situation is deemed less urgent the Triage Clinician might advise us over the phone. (Unfortunately, this advice might be patronising and/or unhelpful ... many of us have experienced being told to “go for a walk”, “put on the television”, “have a bath” and so on.) The CAT Team might ring later.

The assessment

If the CAT Team decides we need to be in hospital (usually as an involuntary admission) they will become preoccupied with trying to find a ‘bed’ and working out the logistics, including transporting us to the hospital – with police, in their own vehicle, or organising family or friends.

On the other hand, they may assess that we are safe to stay where we are, and in these cases usually they leave us with a list of phone numbers and contacts. This can be intensely frustrating – it can feel as if our debilitating emotional pain is being fobbed off with platitudes.

Admission to hospital and follow ups

The actual admission to hospital will often be made by the consultant



psychiatrist on duty at the hospital. CAT Teams also follow us up after we leave hospital. This is only for a very short time. Sometimes we may want more of them than they can give and they have the difficult task of telling us that this is not what they do.

Emergency Crisis Assessment and Treatment Team (E-CATT)

Members of E-CATT work in Emergency Departments of public hospitals, rather than travelling out to people's homes, but they fulfil a similar role to ordinary CATTs.

Every person who comes in to hospital who is considered in need of psychiatric assessment is seen by the E-CATT member before s/he is discharged.

The ideal vs the reality

Consumers' experiences with CATT teams vary enormously. For some of us, the CAT Team has been respectful, responsive and effective, even life-saving. For others, the CAT Team has been invasive, coming into our homes, either against our wills, or in ways that are deeply disrespectful. Others have struggled to be taken seriously by CAT Teams, partly because CATTs are under-resourced and have to make tough choices every day about their priorities (this has led to some consumers describing CATTs as "Can't Attend Today" teams). And some who have had the CAT Team visit them have been left wanting a great deal more in terms of effective crisis support. The reality is extremely mixed.

*** How to stay as safe as you can as a patient in a psychiatric hospital**

Both agents of social control and nurturers of the very ill

"Being a 'good patient' helps you get out of hospital, being a 'bad patient' helps you get a life."

Judi Chamberlin, psychiatric survivor, activist, speaker and educator (1944-2010)

Often we are told that everything is up to us in relation to safety, recovery, relationships, insight, side effects, weight gain, indeed all aspects



of 'success' as a patient. Yet those of us who have been through 'the system' know that our destiny is often determined by social forces and institutions that are outside our control.

We are fortunate if we have a senior clinician who will advocate for us, or an Advance Directive (see the section on page 75 for more on this).

But the truth is that psychiatric institutions can be hazardous. Recognising these realities can be a place to start in keeping ourselves safe. Some things to consider include:

- **Our own histories:** The incidence of childhood trauma, abuse, neglect, and chaos is much greater among those of us with 'mental illness' than it is in the general population. This can have a significant impact on our experience of the mental health system. In the chaotic world of a psychiatric acute unit, those of us who have a history of childhood trauma are at particular risk. The hospital environment may mimic what we experienced as children. We can try talking to staff about this but be aware that staff in these settings may have been taught to 'observe' rather than really listen.
- **Gender:** There are no single-gender psychiatric units in Victorian public hospitals. Women who were abused sexually or physically as children, who live in situations of family violence, or who have been sexually assaulted may feel particularly vulnerable in such settings. Some, but not all, women have been calling for women's-only psychiatric units to increase their safety.
- **Who has the keys?** Keys are an obvious and highly visible presence in an acute psychiatric unit. While they're supposed to make people feel safe, they often have the opposite effect. It's a good idea to think about (and write down) what you need to feel safe. For example: being locked up in a seclusion room against your will might make you feel intruded upon, harmed, disrespected as a human being, and very unsafe; but being allowed to use such a room when you know you are at risk of harming yourself might be quite different.
- **'Good and Bad Patients':** People can react differently to the experience of being in an acute unit. Some may become compliant (becoming 'good patients'); others may lash out in reaction to their powerlessness (and be labelled 'bad patients'). It's important to remember that not all 'good patients' are powerless. Many of us sensibly behave in subservient ways in order to achieve our goals such as 'getting out' or 'staying in' or 'getting our children back'. It's a unique form of communication which can replace assertiveness in these strange places. Remember that there is no 'right' or 'wrong', 'good' or 'bad' way to behave in this context.



- **Unsafe Staff:** It is often difficult to talk about inappropriate staff behaviour. Even when other staff are critical of their colleagues they are often reluctant or afraid to take action – careers are at stake. All staff have a responsibility to report behaviour that is sexually inappropriate, takes advantage of their position of trust, or is violent. It is undeniable that abuses of power have occurred in the past and continue to occur. If you have seen or experienced any staff behaviour that is, in your opinion, reportable, contact the Mental Health Legal Centre or the Victorian Mental Illness Awareness Council (see the Consumer Resources section for contact details).



Section Five:

Let's talk money

Money is an issue for many people diagnosed with 'mental illness', although how we are affected differs substantially.

Medications can be a significant cost, especially if we are on multiple medications, or if our medications are especially expensive. In this section, we outline from a consumer perspective how the government supports us with the cost of medications through the Pharmaceutical Benefits Scheme (PBS).

For many of us, our ability to work has been impaired by our 'mental illness' and we may be relying on the Disability Support Pension. This is not easy, so we offer some advice from the experts – us!





* Understanding the Pharmaceutical Benefits Scheme (PBS)

Reading between the lines of the glossy pamphlets

"May the holes in your net be no larger than the fish in it."

Irish Blessing

The Pharmaceutical Benefits Scheme (PBS) is an Australia-wide scheme that is designed to make medicines more accessible to all. It is funded by the Federal Government, which also has responsibility for the PBS Safety Net.

What is the PBS Safety Net?

The Federal Government recognises that some people and families accumulate greater pharmaceutical costs than others. The Safety Net is an attempt to help with some of these costs. Thresholds enabling people to qualify for a PBS card are reached when a family or individual can show proof that they have spent a specific amount of money on medications in a calendar year. Most medications are then free (if you are a concession card holder) or greatly reduced in price.

The importance of record-keeping

If you want to make the most of the PBS Safety Net you'll need to keep good records. You can ask your pharmacist to keep a record for you and they will give you a card to record any medications dispensed at other pharmacies. Good record-keeping can be difficult but it can make life easier at the other end.

Check if medications you are prescribed are on the PBS

Any registered doctor (including doctors in Community Health Centres and hospitals) can supply PBS-registered medications. It's good to always check that any medication dispensed to you is added to your Safety Net Threshold.

Sometimes doctors prescribe medications that are not registered with the PBS (which means they will cost a lot more). If this happens, it's good to ask your doctor some questions:

- Is there a generic drug alternative? If not, why not?



- What are the benefits of this particular medical drug? (*Is it so important that it's worth taking out a second mortgage on my house?*)

Sometimes it may well be important to get this particular drug, but make sure you ask the question.

The 20-Day Rule

Note that if you buy a PBS medication within 20 days of the previous script being filled for that same medication the cost may not count towards your PBS threshold, and if you have already reached the threshold you may still have to pay for this second script.

The whole family is included

On your PBS card you can include your spouse or de facto partner, family members under the age of 16 and under your care, and dependent full-time students under the age of 25. Their medication costs will be added to yours when calculating whether you have reached the threshold for free or cheaper medications. Some consumers think this is unfair for people who are single – especially since our experiences of 'mental illness' may well have impacted on our social and emotional resources (as well as our financial resources!).

Authority Script

Some medications are only available on the PBS for certain diagnoses. This requires your psychiatrist or GP to ring the PBS and obtain 'authority to prescribe' before they give you the script.

When doctors ring up to get scripts authorised there is a special code that they give. The bureaucrat in Canberra asks the clinician questions about the diagnosis to which the doctor is only required to answer 'yes' or 'no'. This means that the clinician can prescribe medications without divulging our diagnosis to us. Remember, you can always ask.

A consumer perspective of problems with the PBS

Some consumers see the PBS as propping up drug companies (and using our taxes to do so!), because the government pays the drug companies the difference between what we pay and what the drug company charges for the drug.

Another problem with the PBS is the lack of means testing. Consumers tend to have less money on average because we may be relying on the Disability Support Pension, or can only cope with part-time work, or have



had our careers interrupted by 'mental illness'. Medicines are extremely expensive and the jump from \$5.30 for people with concession cards to the price paid by everyone else in the community is enormous. This is multiplied because many of us are on several different medications. This means that there is a huge incentive to try to keep our Health Care Card benefits – we may feel as if we're being punished if we come off a Centrelink benefit or are able to work more hours. It is our experience that many consumers are trapped in poverty because of the costs associated with our medications. For this reason, we believe the PBS Safety Net should be means tested.



I'll have two acres
of asylum, one
respectful psychiatrist
and someone to talk
to who is interested
in recovery please!
I have \$10.20 cents left
from my pension.



* The Disability Support Pension (DSP)

Information from the experts: us!

"If you think about it, the most amazing thing of all is that some people do manage to live 'successfully' each week with the amount of money many people throw into the small change bowl on the dressing table."

G.K., consumer

The Disability Support Pension (DSP) is the money paid to people who are unable to work because of their disability. This includes psychiatric disability.

The way the DSP is administered puts a lot of restraints on the way people live and what they can earn on top of the pension. Although it is possible to earn money the rules are very tight and if you don't get it right there can be dire consequences. Find out as much as you can when you first start receiving the pension. If you don't understand it can be a good idea to speak to someone else who has had to learn how to live on the pension.

For those of us who rely on the DSP as our primary or only form of income there are some special issues that might relate to our level of disability, the unpredictable nature of our 'mental illness', some of the structural factors put in our way by Centrelink, and the distress related to exploring other options when we have a stress-related disability.

While it's wonderful to live in a country where there is a government safety net, living on the DSP is not easy. Some consumers have described Centrelink as iatrogenic – it can be such a frustrating system that it can send us crazy if we're not already so!

Expertise on the DSP comes from two separate forms of knowledge:

- The rules and regulations set by Centrelink and government authorities themselves and
- The daily reality of the lived experience.

It is essential to be familiar with Centrelink and other government rules to avoid the sudden cessation of payments. Filling in forms and returning them to Centrelink by due dates is absolutely critical if unnecessary interruptions are to be avoided.

Some hints from the 'experts' (us!):

Keep organised records:

- Get organised (if you are not an organised type of person get someone to help you).
- Get everything in writing and keep copies of all papers that you lodge or submit.
- Record the date, time and receipt number of any telephone calls and interactions with the Centrelink office.
- Keep Centrelink updated on any personal or financial changes to your circumstances, particularly income as overpayments can incur an extra penalty fee.

Prepare for interviews:

- Consider taking somebody along with you to Centrelink interviews to ensure that you are not "steamrolled" or feel compelled to sign something with which you disagree. Choose someone who you trust to be strong if needed.
- Allow plenty of time for appointments and take a book or magazine to read to settle any nerves while you are waiting.

Understand the system:

- Request an appointment with a social worker if you feel 'lost' in the system or are brushed off by busy counter staff.
- Enlist the services of an advocate or specialist organisation to inform you of your rights to avoid them being breached (see the Consumer Resources section).

Simple things that can make all the difference:

- Reassure yourself that the person beside you in the queue is probably just as scared and confused as you are. Know you're not alone!
- Read signs carefully to ensure that you go to the right place and ask someone for directions if you're unsure.
- Don't forget to take a ticket if that's how it works at your Centrelink office!





Section Six:

Rights & supports

This section provides information about an assortment of different supports that might be useful for consumers in various different situations. The law impacts on those of us with 'mental illness' in various ways, and it's not always clear to us what our rights are, or whether our rights are being upheld. In some situations, it might be helpful to enlist the help of either an advocate or legal representation. At other times, there may be things you might want to do for yourself, such as access your medical records, communicate with those around you about your 'mental illness' or set down in writing what you would like to happen in case you get mentally 'unwell'. These are the kinds of situations where it may be especially helpful to have a consumer perspective on what your options are.





* Letting others know what you need

This is what I need you to be

“Don't walk ahead, I may not follow. Don't walk behind, I may not lead. Just walk beside me and be my friend.”

Albert Camus, French existentialist philosopher (1931-1960)

There are a few important things to remember when relating to people you are close to, with whom you work, with whom you live, or people who play some sort of 'caring role' in your life.

The first thing to note is that if you don't let people know what you need they might get it 'wrong'. One of the hardest things for people to do is to guess what you need from them when things have gone off the rails. Many people are frightened and when they are frightened, things can happen which are not useful. These include:

- Giving you advice that you don't want – e.g. the dismissive “just get on with your life”;
- Acting as though nothing has happened: pretending you haven't been absent when you return to work after a prolonged episode or a stay in a psychiatric hospital;
- Trying to 'hide' you when you have not asked to be hidden;
- Speaking on your behalf when you have not asked for it;
- Wanting to understand everything you do and think as part of your 'illness'.

Think through for yourself what you **do** need from those around you – who you need to do what and when. Then ask people for it. Ask people to respect your knowledge of yourself.

Have a discussion about communication

If you know that you communicate differently when you are 'crook', reflect about that and write a list. Perhaps you lose your cool more easily; maybe you become self obsessed. Let people know what you need in response to these changes. Be honest. Pre-arranging strategies collaboratively is very useful even when it sometimes doesn't go to plan.

Work

If you are 'out' (i.e. public) about your diagnosis, it is possible to write a



Workplace Advance Directive which instructs your workplace colleagues and, especially, those who have management responsibilities, what to do if things go pear shaped.

If you work in a mental health setting it's very important to think through these issues because your workmates are also clinicians. Things can go wrong for you at work once clinicians have witnessed what they might call 'an episode'. It can be a good idea to set down ways of dealing with this in collaboration with those who have responsibility for the workplace and the 'safety' of everyone who is employed.

You can write an Advance Directive for any other part of your life too (see page 75 for more on this topic).

Other health professionals

It may also be important to let other clinicians, such as physicians and surgeons, know what you need from them.

They'll know you have been diagnosed with a 'mental illness' – it will be part of the referral process. But being medically trained does not insulate people from society's prejudices. Some of us just avoid the subject and act as sane as possible. Others find it more useful to let mainstream clinicians know we don't want to be treated differently. These are decisions we all have to make individually.

'Caring' and society's expectations

Society puts many expectations on 'carers'. Sometimes this is in a financial sense but often for us the more important and troublesome aspect is the impact this has in a relational sense. 'Carers' are often expected to be (publicly at least) only interested in the needs of the people they 'care for'. This leads many 'carers' to believe that they have to speak about our needs when they are speaking in public, rather than their own. The media and other institutions consolidate this in the public's minds.

This is problematic because:

- It gives both the community and us the impression that 'carers' know what we need better than we do. This sometimes makes us very angry because it infantilises and disempowers us.
- It means that some 'carers' feel under-appreciated and this can cause a whirlpool of resentment that becomes a flashpoint, particularly when they are feeling judged unfairly by a society which tells them they ought to have no needs of their own.



Symbolically returning power to the consumer

If we know that there are times when we do need to be 'cared for' it's sometimes helpful to have a small ritual which marks the end of these times and which gives us back our own lives: something simple like the exchange of a stone or a small plant.

* Using an advocate

Not pre-judging, finding the right people and justice – this is what it's all about

"It seems to me that whereas power usually means power-over, the power of some person or group over some other person or group, it is possible to develop the conception of power-with, a jointly developed power, a co-active, not a coercive power."

Mary Parker Follett, pioneer theorist on management theory (1868-1933)

An advocate is someone who supports you to accomplish a particular specific goal of your choosing, often in part by speaking on your behalf.

Who is an advocate?

An advocate can be *almost anyone* – e.g. a friend or a paid support worker: someone you trust.

Professional Advocates are independent workers whose job is to help us get our message across on particular issues.

Who uses advocates?

Many people use advocates at various times. For example, you might:

- hire a lawyer/legal advocate, to represent you before a court;
- use a union organiser/advocate in a dispute with an employer;
- employ a real estate agent when negotiating a house sale with a buyer;
- take a relative with greater English language proficiency to a Centrelink appointment.

Even children may have experienced using an advocate; for example, getting Mum to ask Dad for something rather than asking for themselves.



Why use an advocate?

Using an advocate does not mean you are unskilled or incapable of speaking for yourself. It may reflect the fact that when issues are very important and personal to us it can be hard to think objectively and calmly. It may be that we don't have all the specialised knowledge needed to get our goals met. In the context of mental health, it's often a combination of these two.

When issues involve specialised knowledge, it can help to have skilled, effective support. This is why most lawyers who are brought before a court themselves hire their own lawyers, or why skilled advocates sometimes need advocates themselves – not because they lack skills but because no one has all the specialised knowledge that might ever be needed.

Some examples of where an advocate can be helpful

Example 1: Someone is being held as an 'involuntary patient' in a psychiatric unit. They have been in the hospital for a long time and no one has re-assessed their involuntary status. Their claims to have been treated unfairly have fallen on deaf ears. They may seek the support of an advocate who has specialised knowledge of the *Mental Health Act 1986 (Vic)*

Example 2: Sometimes, people stop listening to us once they learn we have a psychiatric diagnosis. This may exacerbate our mental distress. Many of us don't divulge our 'mental illness' at work because of such prejudices. But sometimes this privacy is impossible, especially if we have been absent from work. Having a professional advocate on our side can be helpful in ensuring we are heard.

Example 3: The degree of prejudice in the mental health workforce and services is also an important issue. Sometimes we need a professional advocate because we believe we are being treated prejudicially by the very people who are employed to provide care for us.

What does an advocate do?

Most advocates believe that their job is to address specific issues – to listen to what we want to accomplish, maybe help a little in clarifying or separating out issues, and then present options or offer advice (and, where needed, personal support) to accomplish the goals we choose. Sometimes an advocate will speak on our behalf in a particular context.



The ultimate goal of advocacy is justice – a ‘fair go’ for all. If we, the people the advocate assists, get the same opportunities to pursue our goals and partake in our community as any other person would want, then many advocates would feel they had done their jobs adequately.

* Getting legal representation

What’s the law got to do with it? Well, lots, actually

“Of all tyrannies, a tyranny exercised for the good of its victims may be the most oppressive.”

C.S. Lewis, English author (1898-1963)

People with a diagnosis of ‘mental illness’ may need legal support for many different issues: discrimination, dealings with State Trustees, violation of our rights, resisting forced ‘treatment’ or involuntary detainment in a psychiatric institution, as well as matters that anyone else may have to deal with – everything from criminal matters to traffic fines.

Dealing with the legal system can be incredibly stressful and can be made more difficult by the effects of our ‘illness,’ medication or life circumstances.

While this booklet does not seek to dispense legal advice, here we outline some introductory issues and point towards some legal supports you might be able to access, with a particular focus on people held involuntarily under the *Mental Health Act 1986 (Vic)*.

The context

Because of the coercive nature of some mental health ‘treatments,’ the interface between the law and medicine is far greater in mental health than it is in many other areas of disability or health.

The *Mental Health Act 1986 (Vic)* is a piece of legislation that enables forced ‘treatment’, commitment and restraint against your will. This legislation is presently being revised by the Legislation Review Team. The Act can be found on the Victorian Mental Health Branch website or the Office of the Chief Psychiatrist.

The Mental Health Review Board is the legal entity which makes decisions in relation to the *Mental Health Act 1986 (Vic)*. The Board consists of three people: the chair, who is usually a lawyer, a psychiatrist and a community member. The *Mental Health Act 1986 (Vic)* makes it



impossible to keep people against their will or on Community Treatment Orders (CTOs) indefinitely. For more information on this do an internet search for 'Lacking Insight – Involuntary Patient Experience of the Victorian Mental Health Review Board' or look on the Mental Health Legal Centre website.

Community Treatment Orders (CTOs) are an important part of Victorian legislature. CTOs give legal power to impose psychiatric 'treatment' and can be very restrictive. They sometimes come with a 'residence clause' which restricts where we can live. For more information on this, do an internet search for 'Thomas Nerney, Challenging Incompetence: The meaning of Self-Determination'. See page 50 for more on CTOs.

Legal supports

The Mental Health Legal Centre has responsibility to represent those of us who are on Community Treatment Orders (CTOs).

Victorian Legal Aid picks up the responsibility for working with and representing those of us who are inpatients, held against our will in psychiatric institutions and forced to have 'treatment' we don't want.

Note that access to both of these supports is means tested, and Legal Aid is also assets tested.

Private lawyers

Anyone who can afford it can engage their own lawyer to represent their interests.

Much of the work in this area refers to the *Mental Health Act 1986 (Vic)* but there are many other issues that people diagnosed with mental illness might retain a lawyer for. These include issues to do with discrimination and privacy.

What to expect from a lawyer

When representing people before the Mental Health Review Board a lawyer must act on instructions, according to our expressed wishes, rather than any other sense of what might be "in our best interests".

They should then tell us what the likelihood is that this result will be achieved – this is called advising us, and they do this by referring to the law and also to their knowledge of previous times that they have worked with someone who had similar issues to ours.

A lawyer will not tell you what to do but will simply advise you, so you need to ask questions of them to ensure that they fully understand the implications of your instructions. Lots of us say it is great to have someone on our side but also *someone who knows the law*, so that if we are detained under the *Mental Health Act 1986 (Vic)* they will know the legal arguments that can be used.

How to get in touch

See the Consumer Resources section of this booklet for information about how to contact the community legal centres mentioned in this article. Community legal centres may also be able to put you in touch with a private lawyer with appropriate experience, if that is what you require. The Mental Health Legal Centre engages lawyers from large law firms on a pro bono basis and runs an evening clinic.

*** Accessing your medical records**

We all have different ideas about how much we want to be privy to

*They kept this great dossier all full of me,
Famous or infamous I was numbered and labelled.
My whole life story for 'L plate doctors' to see.
FOI gave me the right. My story enabled.
What had been written by those medical sages?
Squished like a book mark between the pages.
I was the last one to really find out.*

G.B., consumer

Freedom of Information Act

The *Freedom of Information Act 1982* is an Act of the Victorian Parliament. It covers access to any patient files for services that are provided by the public health system in Victoria. You can apply to the relevant public hospitals for access to your current psychiatric record or get the appropriate forms from the Mental Health Legal Centre. (Some older records are archived by the Department of Human Services.

To find out how to contact this department go to www.health.vic.gov.au/healthrecords)



Costs

There are two costs associated with making a Freedom of Information (FOI) request under this Act:

- **Application Fee:** This fee is a fixed cost which is non-refundable. People on pensions or small incomes (“impecunious”) can have these fees waived. At the time of writing the FOI application fee was \$22.70.
- **Access Charges:** Access charges relate to the costs of providing the information requested, covering things like photocopying.

Health Records Act

The Health Records Act 2001 is an Act of The Australian Parliament. It covers access to files held by all “health service providers”, including: all medical practitioners (including general practitioners and psychiatrists); private and public psychiatric hospitals; allied health service providers; complementary health service providers; nursing services; community health centres; pharmacists; day programs; pathology services; supported residential services; and all disability service providers, including all Psychiatric Disability Rehabilitation and Support Services (PDRSS).

Getting access to your file

Getting to ‘see’ your file is not always straight forward. As part of both the *Freedom of Information Act 1982* and the *Health Records Act 2001* there are clauses which give individual health service providers and institutions the right to delete parts of your file before you access them.

Access can be denied and information can be deleted if it is considered that:

- the information will be detrimental to your mental or physical health;
- a third party will be disadvantaged by release of information that concerns them;
- another person’s privacy is considered to be at risk; or
- release of information may endanger a third party.

Protecting yourself when you access your files

Many of us are scared about seeing what has been written about us. You may well find yourself on the receiving end of thoughtless words, linguistic shortcuts and what you believe to be incorrect information. This can justifiably make you angry or upset.

Many people ask someone to be with them when they open their file. Sometimes people ask a clinician to go on this journey with them.



Sometimes people who have experienced similar things can help us channel these intense feelings into advocacy, creativity, activism or black humour. These are all very helpful at such times.

Consumer groups are also useful. It's good to remember we are not alone.

Can we correct the things that we believe are wrong in our file?

If information in our file is inaccurate, out-of-date, misleading or incomplete, we can apply to have an amendment added. The original information may not be removed though.

There is no legal right to change what has been written about us. We do have the right to add to our file. However, be careful and prepared. Sometimes, in a system where everyone is attuned to detecting pathology, it is possible that attempts to set the record 'straight' will be seen as further evidence that we are 'sick'.

*** Advance Directives – telling others what works for us**

They might not be legally enforceable yet but they can still be useful

“Be who you are and say what you feel because those who mind don't matter and those who matter don't mind.”

Dr Suess, American's children book author (1904-1991)

Advance Directives are one way that we can communicate with others about our needs. An Advance Directive is a document that you can write to communicate clearly what you want – both in terms of mental health treatment and your life more generally.

This can be very useful if at a later time you are less able to communicate your wishes. This is a concept borrowed into mental health from general health, where Advance Directives are legally binding and used in end-of-life decision making.

In the context of mental health, an Advance Directive is not legally binding, but it means that people around you making decisions about your life (e.g. friends, family, lovers, colleagues, clinicians, etc.) have a clearer idea about what you need. Preparing an Advance Directive is also a way to increase your autonomy.



If written and (preferably) signed off by a psychiatrist to say you were of 'sound mind' when you wrote it, an Advance Directive can be a useful tool.

Here are five things you should know about Advance Directives.

1. An Advance Directive should clearly state what works for you and what doesn't.

For example, it might include contact details for your GP, whether you have any allergies, who you do not want to visit you, which treatments do more harm than good, and what is likely to make you dissociate.

Advance Directives can also detail more mundane, but important, things like who needs to be contacted to feed your cat. Some people write Advance Directives that are specific to a particular part of their life; for example, a 'Workplace Advance Directive' to reassure and guide work colleagues.

2. Advance Directives can come in different forms.

Advance Directives come in two different forms. The first is to appoint a proxy decision maker who you trust and who you know will defend what YOU want to happen strongly, sometimes under difficult circumstances. The second is for you to write an instructive document. This is called an 'Instructive Advance Directive'. There are pros and cons to each approach.

It's important to note that Advance Directives are very different from Treatment Plans. An Advance Directive is owned and controlled by the consumer; and clinicians, lovers, family or friends may be asked to read and sign off on the document.

By contrast, a Treatment Plan (mandated under the *Mental Health Act 1986 (Vic)*) is typically written by a clinician and the consumer only signs off on it. 'Carers' now have a legal right in relation to a Treatment Plan – consumers ourselves have much less autonomy with a Treatment Plan than with an Advance Directive.

3. In Australia, an Advance Directive is not legally binding.

It's essential that we know that while an Advance Directive can be useful, it is **not legally enforceable** in Victoria. In some other parts of the world (e.g. parts of Scotland and the U.S.A.) they are legally binding.

Some groups in Australia are pushing for greater legal recognition of Advance Directives – for example the Mental Health Legal Centre in Melbourne is lobbying for specific laws outside and beyond the *Mental*

Health Act 1986 (Vic) so that people who are 'informal' or 'voluntary' patients can use them with more confidence.

4. They need to be kept up to date.

Circumstances can change, so we need to update our Advance Directives frequently. We may need the document well after we last drafted it and it can be unclear to other people whether they should follow the old one or not. This clarity is important.

We are also responsible for distributing up-to-date copies of our Advance Directive. Always keep one copy in a secure place that others can find if needed.

Keep careful track of where your Advance Directive goes. As the law stands at the moment there is nothing in Victorian privacy legislation to make sure this document is kept private.

5. The journey can be as important as the destination.

Some people say that the process of working out clearly for themselves exactly what their needs are and then sharing them with the important people in their lives can be a very important process.

More information on preparing an advance directive is available from the Mental Health Legal Centre – see the Consumer Resources section for contact details.

A hand-drawn sketch of a psychiatric file page, divided into two columns. The left column contains patient information and clinical notes, while the right column contains dates and observations. Several areas are redacted with black ink.

NAME: Ms JAN ATTENTION SEEKER
DATE OF BIRTH: 21/11/75
DIAGNOSIS: [REDACTED]
RECORD NUMBER: 472180:2010

PRESENTATION
MS ATTENTION-SEEKER PRESENTED AS A RATHER PLAIN LOOKING WOMAN IN HER THIRTIES, ALTHOUGH SHE CLAIMED SHE WAS FEELING "SUICIDAL" SHE COULD NOT IDENTIFY A CLEAR PLAN!!

HISTORY
MS SEEKER HAS A PRIMARY DIAGNOSIS [REDACTED] SHE HAS A HISTORY OF CHRONIC LYING [REDACTED] CLAIMING [REDACTED]

MANAGEMENT
MS ATTENTION-SEEKER WILL BE ADMITTED FOR ASSESSMENT ONLY. [REDACTED]

13.3.2009 AM
PREDICTABLY JAN'S BEHAVIOUR IS CHAOTIC. SHE DESCRIBES THE SITUATION AS "NO ONE IS LISTENING TO ME". SHE IS PERMITTED TO VENT FOR 10 MINUTES EVERY TWO HOURS. [REDACTED]

13.3.2009 PM
CAREFUL OBSERVATION FOR SELF-HARMING BEHAVIOUR. DO NOT REWARD. BAN BEDROOM DURING THE DAY. WATCH FOR HER MANIPULATING OTHER PATIENTS. [REDACTED]

GETTING TO "SEE" YOUR PSYCH. FILE

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* The human rights agenda

The UN Convention on the Rights of Persons with Disabilities

"If everyone howled at every injustice, every act of barbarism, every act of unkindness, then we would be taking the first step towards a real humanity."

Nelson DeMille, American author

The *UN Convention on the Rights of Persons with Disabilities* – sometimes referred to as the CRPD or just the Disability Convention – is new international law designed to promote and protect the rights of people with disabilities.

After four years of negotiations, it was adopted by the UN General Assembly in December 2006 and became international law in May 2008 after 20 countries ratified it. The Australian Government ratified the Convention in July 2008, which means that it accepts it as international law and agrees to abide by its obligations.

How is disability defined?

Disability is defined in the Convention as an evolving concept that includes: *"those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others"* (Article 1).

Although some mental health consumers don't like thinking of themselves as having a disability, it's clear that the definition given above explicitly includes people with mental health difficulties (sometimes called 'psychiatric disability', or the currently preferred term 'psychosocial disability') in the Convention.

The Convention incorporates the **social model of disability**, rejecting the commonly held view of disability as an individual's medical problem, to be addressed through welfare or charity. Instead, disability is now framed as a social, human rights issue: societies are obliged to eliminate the many obstacles – physical, social and attitudinal – that restrict the full inclusion and participation of people with disabilities in their communities.

The Disability Convention has been described as a "paradigm shift" for all people with disabilities. At the heart of this shift is the recognition

that people with disabilities have the same rights as everyone else in the community. It does not create any new human rights for people with disabilities but prohibits any discrimination on the basis of a person's disability or medical condition.

How does this affect me?

The main benefit of the Convention is not as a law that we might use in a courtroom but as an advocacy tool to campaign for the rights of people with disabilities. One of the most important rights asserted in the Convention is the equal recognition before the law of all people with disabilities "on an equal basis with others" (a phrase that appears frequently throughout the Convention).

This right underpins the other major component of the Convention's paradigm shift, which is the shift to a supported rather than substituted decision-making model (see below), and possibly the abolition of involuntary psychiatric treatment.

Under the old *substituted decision-making* approach, someone would be appointed to make decisions on behalf of the person with a disability. In mental health, the psychiatrist becomes the substitute decision-maker when a person is put on an involuntary treatment order. Substituted decision-making not only denies a person their legal personhood it also has a long history of abuses and harmful consequences.

Under the *supported decision-making* approach, a person never loses her/his legal personhood in this way. Rather, whenever a person needs assistance to make decisions, for whatever reason, the obligation now is to provide whatever supports the person needs to make his/her own decision. The cornerstone of supported decision-making is the right to make your own decisions based on free and informed consent.

For a copy of the Convention and more information, visit the UN website at www.un.org/disabilities





Section Seven:

Consumers supporting each other

Many people who are diagnosed with 'mental illness' in our culture end up as targets for cultural ignorance and mistrust. It's easy to become isolated under these circumstances. Coming together to meet, tell stories (including comparing notes of services past and present) and to share food can be an enlightening and empowering experience. Regaining a sense that we are entitled as much as anyone else in the community to a fulfilling life is an important message we can reinforce with each other.

Groups of consumers meet for different reasons. Some want to absorb as much professional knowledge as they can and part of the group experience is to bring clinicians into the group to talk about issues that concern the group. Other groups form around a dissatisfaction with services (or the lack of them). There are many other reasons why groups form and this section is an introduction to this important issue.





* Benefits of consumer developed and run groups

What people who have been part of developing consumer-run groups have learnt

*Although there is nothing happy about being ill
I have no right to complain because
it appears to me that, thanks to nature,
illness is a means to give us new life and hope,
to heal us, rather than constituting an absolute evil.*

Vincent van Gough, Dutch artist (1853-1890)

This section of the booklet has been written collaboratively by the current active members of The Maine Connection, a consumer-run group in Castlemaine, Victoria.

Below the group has identified some of the many benefits of being a member of a consumer-run group, and what they have learned in the process of setting up such a group:

- **Knowing Yourself:** Getting diagnosed with a mental illness changes your life. A self-run support group provides a regular opportunity to think and talk about how you've changed and how your world has changed. Other people's stories and reflections help you understand your own place in the world.
- **Knowledge of 'Mental Illness', 'Mental Health' & 'Recovery':** 'Mental illness', 'mental health' and 'recovery' are all very loosely defined and there is plenty of argument about the definitions. There are no physical tests to determine 'mental illness' or 'mental health', and 'recovery' mean different things to each of us. Informal discussion groups help people understand and define their own levels of distress and wellbeing, and enable us to make decisions about our own recovery journey.
- **Knowledge of the system – improving mental health services:** Discussions about our own circumstances and those of others, plus stories of our experiences with the mental health system, invariably raise ideas about ways in which the system could be improved. They also help people form ideas about ways of minimising their own risk of relapse into unwellness.



- **Normalising your condition:** Stigma, prejudice and discrimination stem from a fear and mistrust of difference. Increasingly it is clear that 'mental illness' is more the rule than the exception in society, and that it is the *extent of distress* experienced by people rather than the existence of *symptoms* which determine whether or not an individual receives a diagnosis. Freely discussing symptoms, medications, side-effects and the *experience* of 'mental illness' can work wonders in removing that sense of difference.
- **Regaining control of our lives:** One of the most distressing effects of a diagnosis of 'mental illness' can be a loss of trust in ourselves. In many cases, other people lose trust in us too, and as a result we may lose some control over our lives. Mental health services can add to this sense of not being in control of our lives by using involuntary 'treatment' and insisting that we follow *their* programs if we wish to receive a service. Finding the support of others that we can relate to helps us to regain a sense of ourselves, our strengths and our human value.
- **Building self-confidence and esteem:** Self-confidence and self-esteem are based on our perceptions of ourselves. If we have lost those through the diagnosis of 'mental illness' and all the consequences of that, we need to develop new ways of 'seeing' ourselves, and new ways of understanding who we have become.
- **Moving on:** We believe that a consumer run service is the fastest and most effective way of finding ourselves again – not who we were, but who we have become.
- **Developing a community:** Communities take time to develop. Despite members' insistence on inclusiveness, it took more than 12 months before we were confident that we wouldn't be 'taken over' by new members. Only after that did we distribute flyers advertising our existence and welcoming new people. Early days were spent determining what we wanted to be.
- **Rebuilding social networks:** Consumer communities may often be necessary as a part of re-establishing yourself in the world, but they are rarely enough. Many of us have experienced rejection by the wider community and until our social networks branch out into that wider society, we can't realise our potential. For many, stepping outside the consumer community is best done with friends. We have found that bringing the community into the Maine Connection whenever we can has also worked for us.



- **Creating a safe place for ourselves:** Creating a feeling of safety for people is essential. Sharing food initiates contact and is familiar and welcoming. Confidentiality (“What’s said in the group stays in the group”) is essential for people to feel safe. A friendly environment, casual and informal talk, including everyone in conversation, tolerating different points of view, and respectful behaviour by and to everyone are simple but effective ingredients in developing a feeling of safety.
- **Exercising your sense of humour:** Laughter is therapeutic, and consumer support groups ought, above all, be fun.

* Choosing the group that’s right for you

Understanding the difference between self-help, advocacy and activist groups

“We’re all mad here!”

From *Alice in Wonderland* by Lewis Carroll

Self help, advocacy and activist groups, in the context of mental health, are not all the same but sometimes one group might fulfil a number of roles or change through time.

It is important to understand some of the differences because much of the angst that emerges in groups stems from the differing expectations of members and how they see the role of the group.

Self help groups emerge when people recognise what can be gained from coming together with other people who have had similar experiences. In an Australian context they:

- might be ‘illness specific,’ bringing together different people with a similar diagnosis, with many having a majority of members who use private mental health services;
- might concentrate on the individual person within the group, personal growth, helping each other overcome adversity and supporting members, especially through difficult times.
- tend to be less publicly critical of the medical establishment than other types of consumer groups. Rather, they might see their public role as fighting ‘stigma’ in the community and educating the public about their





**THE
SKY
IS THE
LIMIT**

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particular illness, often calling on medical experts to speak at meetings and offer 'professional advice'.

- tend to be interested in medical research and new treatments rather than issues like psychiatry as a means of social control or the role of drug companies in medical research.

Advocacy groups sometimes materialise from self-help groups as people become more and more frustrated with 'the system', poor communication and the prejudice they face in the community.

Sometimes it is easy to see this move from self-help to advocacy as a progression. This is not necessarily true. Many groups achieve both. Sometimes people simply don't want to get any more involved than just having friends to talk to who have 'been there, done that'.

Advocacy groups recognise the importance of effects like social exclusion, prejudice in the community, bad clinical practice, and systemic lack of communication skills.

These groups want to make a political difference, i.e. to change the power relationships within services and the community. They are reformers rather than survivors of 'the system'.

Activist Groups are rare in Australia, although they are common around the world. The most influential activist group is the World Network of Users and Survivors of Psychiatry (WNUSP). Rather than being reforming in nature they tend to be revolutionary. They;

- are a progression from the 'anti-psychiatry movement' in the 1970s (see page 11);
- often take a strongly political stance that psychiatry perpetrates atrocities and damages people;
- tend not to take part in many of the bureaucratic opportunities offered to consumers because they find these not only tokenistic and a waste of time but also just nibbling around the edges of a huge problem of social control and State abuse of power which they believe lies at the base of all psychiatry.

Activist groups tend to have an interest in psychiatry and the law, major institutions like the United Nations, international political debates, radical discourse and disrupting both clinical and consumer events that they find unacceptable.



* Consumer networking in rural Victoria

Special things to consider when communities are small and rural

"Perhaps the best time for networking is Mental Health Week with everyone holding an activity, but then again, isn't every week Mental Health Week?"

Kenneth Holt, consumer

For many consumers there are important differences between living in a country town or regional centre and living in a city. For one thing, one country area can stretch for hundreds of kilometres and mental health services are severely stretched. When these country distances are taken into account, coupled with lack of mobility and poor public transport and communications between towns, real networking problems becomes apparent.

Often consumers meet each other in hospitals and clinical services in the city or a regional centre; the nature of this setting can in fact inhibit the development of consumer run initiatives. Interaction is occurring in a space that is not 'owned' by consumers and we know that this 'ownership' is fundamental to successful group cohesion and autonomy to make decisions which are empowering. Furthermore, services might be in the same geographical area as defined by the Victorian Mental Health Branch but if one person lives in Wonthaggi and another in Cann River it can be hard to maintain contact. This is accentuated by the costs of keeping in contact from home, where all the calls are charged at high rates.

The result is that consumers who live on farms or in very small communities are largely isolated from other consumers. This remoteness and lack of connection is exacerbated by transport and communication difficulties.

Large regional centres and medium towns often support their own Psychiatric Disability Rehabilitation Support Service (PDRSS), which provides drop-in community based activities. As part of their charter, many PDRSS encourage community participation – people moving on from relying heavily on PDRSS services for friendships and community to form their own groups. Not all consumers want to branch out on their own but some do.

Help from PDRSS in forming a consumer run group can sometimes also be a curse. Some non-government institutions have trouble letting people experiment, fail, experiment again, get bigger, have a slump and then grow again. These are all attributes of any group anywhere; however, when we



are talking about consumers being allowed to fail and rebound this is fraught with problems of judgements over “who’s responsible”. People working in the mental health sector often talk about the concept of ‘Duty of Care’ whilst many consumers are now talking about ‘Dignity of Risk’. Balancing these two ideals and ideas is incumbent on regional and rural support services and the consumers who rely on them.

Despite the challenges, there are many exciting initiatives run by and for consumers in rural areas. However, there are few opportunities to learn from each other. In part this is because PDRSS services are often run by different non-government providers. It’s worth noting that for a relatively small amount of money consumers wanting to start support and/or advocacy groups could travel to and see successful groups working, bring in key consumer expertise to talk about what they do, and engage Our Consumer Place.

Email is an excellent way to bridge some of the barriers created by distance in rural areas (though it must be acknowledged that not all consumers are computer literate). The Victorian Mental Illness Awareness Council (VMIAC) runs a mental health chat room site (see the Consumer Resources section for details). Leaving chat rooms aside, there are also excellent ways to acquire friends from your living room through such programs as Facebook and Twitter. These are mainstream, non-mental health sector sites.

Many PDRSS hold programs for consumers – for example, community lunches, men’s groups, women’s groups and outings – providing a friendly environment for people to socialise as an aim. Transport difficulties are usually solved by the PDRSS staff. These activities may be great for some consumers but they can also create the potential for “*small town syndrome*”. Consumers socialise within a small base of people whom they know extremely well but are not exposed to other groups of consumers in other towns and in other PDRSS areas. These internal activities can also contribute to the ghettoisation of ‘the mentally ill’. We might get to know local consumers very well but our horizons can be limited by prejudice in our own communities.

This ghettoisation can, unfortunately, also contribute to us becoming outcasts and sticking together even more. The Victorian Mental Illness Awareness Council (VMIAC) plays a major role in bringing people diagnosed with ‘mental illness’ to Melbourne. Sharing meals brings people together, allows us to meet consumers from all over Victoria and have an experience of city life.

To find out more about these events find the Victorian Mental Illness Awareness Council in the Consumer Resources section.





Section Eight: Consumer Perspective – the basics

Very few humans live a life totally segregated from other human beings. We live a communal existence pulled together by history, culture and social structures such as systems of government, families, and organised religions. Having been defined as having a 'mental illness' and experiencing the social institutions that this places in our path, including forced detention and 'treatment' we might not want, inevitably reshapes the way we see the world.

This combination of extreme events created by others' defining us as 'mentally ill' and our own personal history, leaves most of us seeing the world differently from others who have not had these experiences. This is the basis of consumer perspective.

It is also the fabric which knits us together in opposition to some of the ways we have been defined and treated and this, in turn, fashions our movement for social change.





* Some thoughts about the term ‘consumer’

This debate belongs to people diagnosed with ‘mental illness’.

“From antiquity, people have recognised the connection between naming and power.”

Casey Miller and Kate Swift, authors

Consumer thinkers since the 1970s – when the word ‘consumer’ gained currency – have been discussing the pros and cons of this term. It is a very interesting discussion and a summary of it can be found on Our Consumer Place website (www.ourconsumerplace.com.au). Some of the main issues include:

1. **The language is contested:** many consumers themselves dislike the term, often for radically different reasons. For example, some people regard it as a euphemism adopted by policymakers and services to appear inclusive. Others find the term too political, i.e. not representing their relationships with clinicians. Still others dislike the association with consumption.
2. **The language is contextual:** some people employ the word ‘consumer’ when they are engaged in advocacy or activism but choose to use the word ‘patient’ when in hospital because this more accurately describes their current context. Others use the term ‘consumer’ when working with policymakers, but prefer terms like ‘mad’ or ‘survivor’ in other contexts.
3. **The language varies internationally:** outside of Australia, other terms may be more common, e.g. ‘user’ or ‘survivor’.
4. **The language is our language:** it is up to us to ensure that we continue to discuss and debate its relevance and efficacy and we should have the right to self-definition.
5. **The language is useful politically:** it is useful to have a term to describe ourselves collectively. It is unrealistic to say we are all ‘just people’, as tempting as this may be.
6. **The language is consistent with consumer groups across all health sectors but not in other sectors.** For example, in the Psychiatric Disability Rehabilitation and Support Sector (PDRSS) the most



common terms are 'participant', 'client' or 'resident'. The movement for change in the disability sector also uses different language.

The discussion about language reflects contemporary debates about where mental health sits and where we can gain greatest traction in terms of power. This debate is gaining momentum as consultation continues into what we want of a new Australian-wide consumer body.

As Melbourne consumer Alan Pinches' work suggests, the word 'consumer' is far from perfect but it's the best we have available at the present time.



* What is ‘consumer perspective’?

The lens through which we see the world

“We don’t see things as they are; we see them as we are.”

Anaïs Nin, French author (1903-1977)

Consumer perspective is a way of looking at life through eyes that have been categorised as ‘mad’ or distressed enough to require intervention from a mental health professional.

Such a perspective is acquired as a result of receiving, or being unable to receive when you wish to, services in the mental health system. It is based on a belief that as individual consumers we are **‘the experts’** about our own life and carry the wisdom to best articulate our own needs if we are accorded the time, space and means to do so.

Sometimes consumer perspective is called ‘the expertise of **lived experience**’ which is often under-recognised and even undermined by the social institutions that govern contemporary social life.

It’s an idea that developed out of a collective consciousness and political solidarity that grew from the consumer/survivor movement and provides a way of looking at the world from the point of view of a group that has been marginalised and discriminated against.

Consumer perspective is about ‘belonging’ and reclaiming citizenship using the language and terms defined by the group for itself.

Consumer perspective is also:

- that ‘hard to define’ camaraderie that draws people together in an acute unit and the recognition that any oppression we face is a shared oppression;
- an intangible recognition that happens in services which leads us not to ‘dob on’ each other;
- the allowance we give everyone to define what is happening for them in their own way;
- a healthy questioning of taken for granted definitions of ‘professionalism’;
- knowing and believing in the concept of consumer ‘common-sense’;
- a historically wary way of looking at the world.



Consumer perspective is **not** about:

- interpreting others' behaviour using the tools supplied by the medical establishment;
- blindly accepting the language supplied by the medical model;
- assuming any one of us can speak for others;
- setting up our own groups and organisations which merely imitate the inequitable power relationships we have experienced in services;
- assuming that any of us is different and somehow better placed to mentor others whom we perceive and categorise as less able.

Acknowledgement: Some of the material in this section has been adapted from: Epstein, M., & Shaw, J. (1997), *Developing effective consumer participation in mental health services: The report of the Lemon Tree Learning Project*, VMIAC

* **How are 'consumer views' different from 'consumer perspective'?**

We have an infinite number of different views within consumer perspective

I wonder if I've been changed in the night? Let me think: was I the same when I got up this morning? I almost think I can remember feeling a little different. But if I'm not the same, the next question is 'Who in the world am I?' Ah, that's the great puzzle!

Lewis Carroll, *Alice in Wonderland*

While the idea of 'consumer perspective' can be understood as singular, consumer views can never be understood in this way. There are as many different views as there are individuals diagnosed with 'mental illness'!

This is important to keep in mind because people often confuse an individual consumer's experience with 'consumer perspective' (so, for example, if one consumer is happy with a service, they might say "consumers are happy with our service"). This has implications for consumers representing other consumers.

We can offer our consumer perspective – speaking from the lived experience, and stressing the importance of this lived experience being respected. Our views are shaped by:

- **Social Institutions:** We use this term to include governments, the family, the media, legal systems, etc. It is impossible to live in the social



world without being influenced by social institutions. Each of us is affected differently, depending on our position within these institutions.

- **Personal History:** Our own personal history affects our views too. This includes our childhood, whether we lived through child abuse or neglect, sexual abuse, absent parents or anything else that deeply affected our ability to operate within the institutions of our community. Personal history doesn't stop with childhood – we make it every day, and every day it continues to make us.
- **World View:** The modern world is fast changing, fragmented and stressful. To survive as individuals and as a culture we need a way to understand new information – sometimes called our “world view”. It helps us see the big picture, make decisions about what information is important and what can be discarded; what becomes a priority; what is worth fighting for; whether we are convinced by medical definitions of what is happening in our lives and whether we choose to become politicised as consumers or whether we put our energy somewhere else.

* Introduction to the consumer/survivor movement

From personal experience to collective action

The World Network of Users and Survivors of Psychiatry recognises and respects madness as part of human diversity and therefore respects the rights of those who experience reality differently to others.

World Network of Users and Survivors of Psychiatry

The consumer/survivor movement is a social movement (like the environmental movement or the feminist movement) – a collective of people with a common desire for social change, e.g. to change society's treatment of us, or how the mental health system works.

Our desire to be part of a social movement tends to arise out of personal experiences of injustice. As with any movement, there are differences between people's views, interests and priorities.

Who is part of the consumer movement?

It might be useful to think of the consumer movement as something



people choose to identify with. You can be part of the consumer movement without being an activist (someone whose work – paid or unpaid – is dedicated to changing social conditions), but there are many wonderful consumer activists out there!

You are part of the consumer movement if that is how you think of yourself.

What 'basic ideas' do we share?

People who see themselves as part of a movement are usually committed to making the world a better, fairer place and recognising that success takes group effort. Our political development, particularly overseas, was influenced by civil rights movements and disability activists as they struggled for self determination; equal rights before the law; removing discrimination; and improving access to what we need in order to take up our citizenship rights.

Some of us have also been influenced by the writings of anti-psychiatrists (like RD Laing, Foucault or Thomas Szasz) or consumers/survivors who have reflected on their own experiences of injustice. See the list of consumer perspective writings in the Consumer Resources section for more references.

Why be part of a movement?

On a practical level, more can be achieved through a group than on an individual basis. Also, the difference between feeling alone with our views or feeling part of something larger can be both liberating and empowering.

What does the consumer movement do?

The slogan "Nothing about us without us" has been adopted by the disability movement (of which we are a part). This speaks to the range of things we do: community education, reconceptualising what 'mental illness' is, influencing policy, improving access to and quality of services, campaigning for human rights and against discrimination, providing peer support and alternative services, to name a few. We all have different priorities, but there's much work to be done.

What has the consumer movement achieved?

In Australia, the consumer movement has championed the notion that people diagnosed with 'mental illness' can and do recover. We have raised issues about human rights and have fought for consumer participation



at all levels of service delivery and policy development, which is now reflected in all national and state mental health strategies. We have also added our knowledge to what is understood about mental health.

Internationally, the movement has been represented at the United Nations, including playing a key role in the development of the *UN Convention on the Rights of Persons with Disabilities (CRPD)*. Overseas, consumers/survivors have established peer-run services, fought involuntary “treatment”, raised awareness around pharmaceutical companies’ power, and campaigned for ‘madness’ to be respected as part of human diversity.

Where is our history?

The Victorian consumer/survivor movement has a long and rich history of fighting for the rights of our fellows in this state. Very few people know about it. It has never been documented and this is tragic. Without our history we can’t know where we are going.

It also means that we are losing precious insight with each new generation of consumers, advocates and activists; we are losing the potential to build on what we already have. History is important for self-reliant groups and communities.

What is the future of the consumer movement?

So long as we live in an imperfect world there will be social movements. Some major current issues include forced treatment under the *Mental Health Act 1986 (Vic)*, violations of consumers’ rights, tokenistic representation of consumer voices and fighting for our right to self-determination.

How can I get involved?

There are many ways to get involved – you might want to start by checking out the Our Consumer Place website (www.ourconsumerplace.com.au) and contacting the Victorian Mental Illness Awareness Council (see the Consumer Resources section for contact details).

You might be interested in other consumer/survivor groups – there are a huge variety, local, national and international – or you might be interested in starting something yourself. Our Consumer Place can help you find what you’re looking for, or (if you are interested) help you to start up something new!





Section Nine: Consumer resources

Here we provide some information to enable you to find material written by consumers. This material can sometimes be hard to find because it will often not come up using traditional internet search engines.

Some of this writing fits into the category of 'grey literature,' which means that it is local, often hand photocopied, not put on the web, and only known to a specific group of consumers. This is a problem that Our Consumer Place is starting to address through our online Clearinghouse (www.ourconsumerplace.com.au/clearinghouse).





* Some books recommended by consumers

What consumers have to say about life with a 'mental illness'

"If I have lived by any maxim as a reporter, it was that every person is an expert on their own circumstances."

Joseph Lelyveld, Journalist, *New York Times*

These publications have been recommended to Our Consumer Place by consumers.

We have not read all of them and so can't 'recommend' them. We simply hope they might be useful for other consumers, recognising that there are many other published works that deserve to be included too.

Some comments from the people who recommended the books or other descriptive notes are provided to provide some guidance about content and tone.

Recovered, Not Cured: A Journey Through Schizophrenia, Richard McLean, 2003.

A frank and funny guide to recovering from a psychotic illness told with startling frankness.

Broken Open, Craig Hamilton, 2004.

A great account of Craig's battle with bipolar and recovery from it – great because Craig is able to reflect on his life and then make the connection between that lived experience and the technical diagnosis and stages of recovery.

How I Stayed Alive When My Brain Was Trying to Kill Me: One Person's Guide to Suicide Prevention, Susan Rose Blauner, 2002.

Susan Blauner speaks of her own story whilst at the same time discussing strategies and things that helped her in her recovery. This was an inspiring book that made recovery seem like a real possibility.

Poems from the Madhouse, Sandy Jeffs, 2003.

A powerful collection of poetry about schizophrenia. Sandy Jeffs invites the reader into the paradoxical world of insanity: the confusion and clarity, the courage and the fear, the bleak despair and the black comedy.

Healing Tears, Linette Bone, 2001.

This fine and powerful selection of poems is one that we all should read and take to heart.



I Had a Black Dog, Matthew Johnston, 2005.

Artist and writer Matthew Johnstone has lived with depression. Here he shows that the Black Dog can be a terrible beast, but with the right steps can be brought to heel. See also Living with the Black Dog, Matthew & Ainsley Johnstone, 2008, written for partners, family, friends and colleagues of people with depression.

Get Me Out of Here: My Recovery from Borderline Personality Disorder, Rachel Reiland, 2004.

"What the hell was that?" raged Rachel Reiland when she read the diagnosis written in her medical chart. As the 29-year old accountant, wife, and mother of young children would soon discover, it was the diagnosis that finally explained her life.

Bipolar and the Art of Roller-Coaster Riding, Madeleine Kelly, 2000.

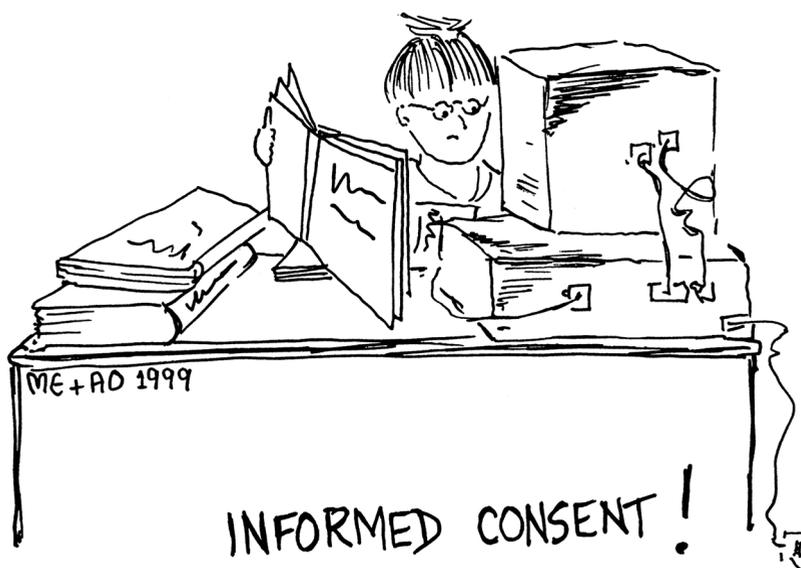
Madeleine was diagnosed with bipolar in the middle of her medical degree and therefore was able to explain the manifestations of bipolar in layman's terms, which she supported with diagrams and graphs.

A lifelong journey: staying well with manic depression/bi-polar mood disorder, Sarah Russell, 2005.

The book does not claim a quick fix-it or one fix fixes all approach, but there are many common strategies that seem to help many people.

Taming the Black Dog, Bev Aisbet, 2000.

A simple guide to managing depression ... Including a unique blend of wit and information, it is an invaluable guide for both chronic sufferers of depression as well as anyone with a fit of the blues.



* **Some ‘survivor’ writings recommended by consumers**

Transformation through resistance

Ko taku rourou, Ko tau rou rou, Ka ora te tangata
With my resources, And your resources, Everyone will benefit
A New Zealand Maori Proverb

These publications have been recommended to Our Consumer Place by consumers.

As with the books listed on the previous pages, we have not read all of them and so can't 'recommend' them. We simply hope they might be useful for other consumers, recognising that there are many other published works that deserve to be included too.

Here we represent a very small fraction of the literature that comes from a 'survivor' perspective. These books offer insights into our political base as a movement.

Some comments from the people who recommended the works or other descriptive notes are provided to provide some guidance about content and tone.

Toxic Psychiatry: Why Therapy, Empathy and Love Must Replace the Drugs, Electroshock, and Biochemical Theories of the “New Psychiatry,” Peter Breggin, 1991.

‘Toxic Psychiatry’ remains Dr Breggin’s most complete overview of psychiatry and psychiatric medication

Coming off Psychiatric Drugs, Peter Lehmann (editor), 2004.

The world-wide first book about ‘Successfully coming down from psychiatric drugs’

Models of Madness, Psychological, Social and Biological Approaches to Schizophrenia, John Read, Loren Mosher and Richard Bentall (editors), 2004.

Is schizophrenia an illness? Is madness preventable? This controversial, but carefully researched, book argues that what psychiatrists call ‘schizophrenia’ is not an illness. ‘Models of Madness’ shows that hallucinations and delusions are understandable reactions to life events.

Madness Explained, Psychosis & Human Nature, Richard Bentall and Allen Lane, 2003.



This work argues that we cannot define madness as an illness to be cured like any other, and that labels such as 'schizophrenia' and 'manic depression' are meaningless, based on nineteenth-century classifications.

Alternatives Beyond Psychiatry, Peter Lehmann (editor), 2007.

The book highlights alternatives beyond psychiatry, current possibilities of self-help for individuals experiencing madness, and strategies toward implementing humane treatment. Sixty-one authors – (ex-) users and survivors of psychiatry, therapists, psychiatrists, lawyers, social scientists and relatives from all continents – report about their alternative work, their objectives and successes, their individual and collective experiences.

This is Survivor Research, Angela Sweeney, Peter Beresford, Alison Faulkner, Mary Nettle & Diana Rose (editors), 2008.

This book marks the coming of age of user- and survivor-led research. It maps out the why, what and how of an important strand of research whose influence is growing in strength.

Voices of Transformation: Developing Recovery-Based Consumer/Survivor Organizations, The Empowerment Centre, Boston, 2009.

This new manual is a step-by-step guide to those working to create statewide consumer organizations ... The manual demonstrates the process of moving from finding an individual voice to developing a collective voice that increases the ability to influence mental health policy and practice on the local, state and national level.

On Our Own: Patient-Controlled Alternatives to the Mental Health System, Judi Chamberlin, 1978.

A classic in the consumer literature field, this tells Judi's story as a patient in both public and private hospitals. The story explores her experiences while being a patient as well as the lessons she learned while using services controlled by the patients themselves.

A Fight to Be – A Psychologist's Experience from Both Sides Of The Locked Door, Ron Bassman, 2004.

Tells of Ron Bassman's descent into a psychiatric abyss and his ultimate triumph to live a purpose-filled and self-directed life.

Healing the Trauma of Abuse, Mary Ellen Copeland, 2000.

This workbook offers women who have suffered sexual, physical, or emotional abuse crucial skills for coping, self-understanding, and self-care.

* Our favourite websites

Good places to start your search for information on consumer perspective

"That doesn't make a particle of difference," replied Charlotte. "Not a particle. ... Do you understand how there could be any writing in a spider's web?"

From *Charlotte's Webb* by E.B. White

Here are some of Our Consumer Place's favourite websites.

Our Consumer Place, www.ourconsumerplace.com.au (Victoria, Australia) "is a resource centre, by consumers for consumers, offering information and advice to individuals and groups in who are involved in consumer developed initiatives (CDIs)."

Victorian Mental Illness Awareness Council (VMIAC), www.vmiac.com.au (Victoria, Australia) "is a not-for-profit organisation providing support, advocacy and referrals to people who are experiencing, or have experienced in the past, emotional or mental distress."

National Empowerment Centre, www.power2u.org (USA) "is filled with practical information that will help you recover if you have been labeled with a mental illness. ...We envision a future when everyone with a mental illness will recover."

World Network of Users and Survivors of Psychiatry (WNUSP), <http://wnusp.rafus.dk> is an international organisation of users and survivors of psychiatry working to influence the direction of human rights and disability.

Consumer Operated Services Program Multisite Research Initiative, www.cstprogram.org/cosp (USA). "The primary goal of this program is to establish how effective consumer-operated services are in improving outcomes for consumers of mental health services. This web page provides more information on the program."

National Mental Health Consumers' Self Help Clearing House, www.mhselfhelp.org (USA). Resources, training and links. "This was the first national technical assistance centre of its kind."

Mind Freedom International (MFI), www.mindfreedom.org (USA), is designed to "unite in a spirit of mutual cooperation for a nonviolent revolution of mental health human rights and choice".



Collective of Self Help Groups in Victoria (COSHG),

www.coshg.org.au/, is “a network of self-help and social action groups. These groups are made up of and controlled by people who are directly affected by a particular issue”.

PEOPLE WHO, www.peoplewho.org/, for “people who experience mood swings, fear, voices, visions”.

Peer to Peer Resource Centre, www.peersupport.org (USA). “The Centre serves people living with all kinds of mental illnesses, including depression, bipolar disorder, anxiety disorders, schizophrenia, and other illnesses.”

Consumer Organization and Networking Technical Assistance Centre, www.contac.org (USA), is “a resource for consumer/survivors/ ex-patients and consumer-run organizations across the United States, promoting self-help, recovery, and empowerment”.

Intentional Peer Support, www.mentalhealthpeers.com (USA). “Peer support in mental health grew out of a movement that challenged the structures, practices and theories of traditional mental health services.”

Icarus Project, <http://theicarusproject.net> (USA), is structured around autonomous local groups. “The Icarus Project envisions a new culture and language that resonates with our experiences of ‘mental illness’.”

Working to Recovery, www.roncolemanvoices.co.uk (Scotland) is a consultancy and training organisation, with links to recovery resources. Ron Coleman was also influential in the development of the Hearing Voices Network in the UK.

Shaping Our Lives – National User Network,

www.shapingourlives.org.uk (UK). “Shaping Our Lives National User Network is an independent user-controlled organisation, think tank and network.”

Mary-Ellen Copeland Wellness Recovery Action Plan, www.mentalhealthrecovery.com (USA). “Getting well and staying well is the focus of Mary Ellen Copeland – author, educator, and mental health recovery advocate. Mary Ellen’s work is based on the study of the day-to-day coping and wellness strategies.”

Out of their Minds, www.outoftheirminds.co.nz (NZ), “aims to explore views on madness, mental distress or ‘mental illness’ that are often ignored by mainstream media. The site features artists and thinkers interviewing themselves about the value they see in their experiences of mental distress, and about what comes out of their minds.”

All quotes are taken from the websites listed.



* Internet browsing from a consumer perspective

Finding information from mental health consumer perspective

Mentor: "Someone whose hindsight can become your foresight"

Anon

If you have browsed the internet for information about mental health, you may have discovered that there is a lot out there! However, very little of this material has been written by consumers.

If you want information written from a consumer perspective, here are 10 phrases that will help you narrow your search. These may be combined with more common terms (like *mental health, psychiatric* or *services*).

Instead of "Patient": Alternative words and phrases that are more likely to offer a consumer perspective include: *consumer, psychiatric survivor* or *survivor, user, ex-patient, CXS* (Consumer, Ex-patient, Survivor). E.g. you might search for *survivor mental health services*.

Reclaimed language: Some consumers have reclaimed (previously) offensive psychiatric language – words like *mad, madness, nutters, crazy, loopy, batty, nutcase*, etc. Many consumer-run sites use these terms.

Instead of "Diagnosis" and "symptoms": If you are searching for a particular diagnosis or specific symptoms, you are more likely to get a consumer perspective if you add a phrase like *story, personal story* or *individual experiences*. So, for example, you might search for *mood disorder personal stories*, or *self-harm experiences*, or *hearing voices personal experiences*.

"Lived Experience": Many consumers refer to particular lived experiences, rather than diagnoses. E.g. you might search for '*Lived experience mental illness*'. Other useful phrases include: *narrative, accounts, first hand experience, individual understandings, testament, story, perspective*. Another way of generating phrases might be to think in terms of experiences that are shared by many consumers – for example, *powerlessness* or *forced institutionalisation*.

"Trauma": Trauma plays/has played a significant role in the lives of many people diagnosed with mental illness. Some useful search terms include: *childhood trauma, abuse, trauma psychiatric acute unit, violence trauma psychiatry* and *iatrogenesis*, which means illness caused by health services or doctors.



“Peer Support”/ “Self Help”/ “Intentional Peer Support”:

Internationally, there are many consumer-run supports and services – you can find these by adding *peer support* or *self help* to your search terms. More specifically, you may want to search for *Intentional Peer Support* or *Wellness Recovery Action Plan* – both of which are consumer-developed initiatives.

Research: If you are looking specifically for research from a consumer-perspective, some useful phrases include: *research narrative*, *participatory action research*, *consumer directed research*, *ethics mental health survivor research*, and *consumer user evaluation*.

Consumer Groups: Many of the terms listed above will lead you to consumer groups, but here are some more searches you might want to add: *Our Consumer Place*, *Victorian Mental Illness Awareness Council*, *Consumer/Survivor/Ex-patient movement* (Australia and world); *Consumer/survivor groups*, *Mental Health Consumer Group*.

Consumer Delivered Service: If you want to find examples of services delivered by consumers, try searching terms like *consumer developed initiatives*, *consumer run service*, *consumer operated service*, or *consumer managed service*. For specific examples, try the word *consumer* with *respite* or *crisis centre* or *service* or *outreach*.

Consumers who work in services: Try the phrase *mental health* and also *consumer advocate*, *consumer consultant*, *consumer role*, *peer support worker*, *peer specialist*, *consumer consultant*, *Personal Helpers and Mentors Scheme (PHAMS)* or *Consumer Advisory Group (CRG)*



* Useful Supports

Navigating through a maze of community support agencies

If you have come to help me, you are wasting your time. But if you have come because your liberation is bound up with mine, then let us work together.

Often attributed to Lilla Watson, an indigenous teacher and activist, who has said she was “not comfortable being credited for something that had been born of a collective process”.

Australian Human Rights Commission: Handles complaints, writes reports and can be a powerful presence on our side. Has link to the UN Convention on the Rights of People with Disabilities.

www.hreoc.gov.au | (02) 9284 9600

Australian Psychological Society (APS): Peak body for counselling and clinical psychologists in Australia.

www.psychology.org.au | (03) 8662 3300 | Toll free 1800 333 497

Community Health Services (Public Health Services): These health centres are not mental health specific. They are regionally defined (although many regions no longer have them). Generally have a holistic approach to health.

http://health.vic.gov.au/communityhealth/service_provider/community_health_directory.htm | (03) 9096 8762

Community Mental Health Services: Services that are run as part of the public, state-run, mental health system but are not based in a public psychiatric unit or hospital. They are zoned geographically but it can be incredibly hard to get services unless you have been in an acute unit, or have a diagnosis of psychosis.

www.health.vic.gov.au/mentalhealth/services/ | 1300 767 299

Disability Act 2006 (Vic): Protects the human rights of people with disabilities in our community. At this stage people with psychosocial disabilities are excluded from this Act.

www.dhs.vic.gov.au/__data/assets/pdf_file/0017/152450/disact_easy_read_info_sheet_01_190907.pdf

Federation of Community Legal Centres: Peak body for over 50 Victorian community legal centres (CLCs). CLCs are independent community organisations that provide free legal services to the public,



focusing on helping clients who face economic and social disadvantage.

www.communitylaw.org.au | (03) 9652 1500

Mental Health Act 1986: The piece of legislation under which people diagnosed with 'mental illness' can be detained and 'treated' involuntarily. This can only happen in public mental health services.

www.health.vic.gov.au/mentalhealth/mh-act/index.htm

Mental Health Legal Centre: Provides a free and confidential legal service to anyone who has experienced 'mental illness' in Victoria whose legal problem relates to their 'mental illness.' Has an excellent website for consumers, offering useful and specific guidelines to follow to make an Advance Directive. The lawyers at this centre have experience in assessing situations to see if a claim of discrimination is worth pursuing. Be aware that their services are in strong demand and a means test applies.

www.communitylaw.org.au/mentalhealth | (03) 96294422

Mental Health Review Board of Victoria (MHRB):

A statutory tribunal established under the Mental Health Act 1986 to conduct reviews of, and hear appeals by, psychiatric patients being treated involuntarily either as inpatients or on Community Treatment Orders. It is made up of a panel of three people: an independent psychiatrist, a lawyer and a lay person.

www.mhrb.vic.gov.au | (03) 8601 5270

National Mental Health Consumer & Carer Forum

(NMHCCF): The combined national voice for mental health consumers and carers participating in the development of mental health service and sector development in Australia. Auspiced by the Mental Health Council of Australia

www.nmhccf.org.au | (02) 62853100

National Register of Mental Health Consumers and Carers:

Made up of over 60 mental health consumers and carers with experience working as representatives and training in leadership, advocacy, policy development, communication and other topics. These representatives are available to be members of national committees, boards, planning groups and evaluation groups as consumer or carer representatives.

www.mhca.org.au/the-national-register-of-mental-health-consumers-and-carers | (02) 6285 3100

Office of the Chief Psychiatrist: Responsible (amongst other things) for investigating any complaints in relation to public psychiatric services in Victoria.



www.health.vic.gov.au/chiefspsychiatrist | 1 300 767 299

Office of the Health Services Commissioner: Responsible (amongst other things) for arbitration or disputes between doctors and consumers.

www.health.vic.gov.au/hsc/ | 1 800 136 066

Office of the Public Advocate: Promoting the rights, interests and dignity of people with a disability. E.g. Oversees the Community Visitors Program – volunteers representing people with 'mental illness' in dealing with the police.

www.publicadvocate.vic.gov.au | 1 300 309 337

Our Community: A world-leading social enterprise that provides advice and tools for Australia's 600,000 community groups. Auspices Our Consumer Place.

www.ourcommunity.com.au | (03) 9320 6800

Our Consumer Place: Consumer-run mental health resource centre. We offer information, advice and support to individuals and groups who are developing consumer-directed projects. We offer training, for example in Intentional Peer Support, and produce consumer-perspective resources where none yet exist, including this booklet.

www.ourconsumerplace.com.au | (03) 9320 6839

Personal Helpers and Mentors Program (PHAMS):

Hosted by the Australian Government, PHAMS aims to provide increased opportunities for recovery for people who are isolated and on the receiving end of prejudice in the community. Many, but not all, PHAMS workers are consumers.

www.fahcsia.gov.au/sa/mentalhealth/progserv/PersonalHelpersMentorsProgram/Pages/default.aspx

Pharmaceutical Benefits Scheme: The scheme through which the Australian Government subsidises the cost of prescription medicine, making it more affordable for all Australians.

www.health.gov.au/pbs | 1 800 020 613

Pharmaceutical Society of Australia (PSA): The national professional organisation for pharmacists in Australia. This is a place to go if you have trouble with pharmaceutical related problems including understanding the Pharmaceutical Benefits Scheme.

www.psa.org.au | (03) 9389 4000



Private Mental Health Consumer and Carer Network:

Advocates for improved private mental health services, advises on issues affecting people with a mental health problem or 'mental illness' and their families, and increases the involvement of individuals, families and other interested parties in mental health matters.

www.pmha.com.au

Royal Australian & New Zealand College of Psychiatry

(RANZCP): Responsible for training psychiatrists and regulating psychiatry in Australia. All practicing psychiatrists need to be registered – registrations can be checked through the RANZCP. The organisation can also check if a psychiatrist has ever been investigated for malpractice.

www.ranzcp.org | (03) 9601 4924

The Maine Connection: Consumer-run group in Castlemaine, Vic.
0400 975 680

University of Adelaide Library: Provides a useful, up-to-date resource for those of us who are looking for books written by people diagnosed with 'mental illness'.

www.adelaide.edu.au/library/guide/med/menthealth/biog.html

Victorian Human Rights & Equal Opportunities

Commissioner: Responsible for protection and advocacy for people with disabilities including psychiatric disabilities, for example, complaints against Medicare.

www.equalopportunitycommission.vic.gov.au | 1300 292 153

Victorian Legal Aid (VLA): Provides legal representation to people in need. Services are means tested, which means you have to show that your financial need is legitimate. The services provided by legal aid for people diagnosed with 'mental illness' include: free legal information over the phone; lawyers on duty at many courts and tribunals across Victoria; and funding cases. Victorian Legal Aid also produces a large selection of valuable pamphlets, including Patients' rights: a self help guide to the Victorian Mental Health Act.

www.legalaid.vic.gov.au | (03) 9269 0120 | 1800 677 402

Victorian Mental Illness Awareness Council (VMIAC):

Peak lobby group for consumers of mental health services in Victoria. Also provides advocacy services for consumers.

www.vmiac.com.au | (03) 9380 3900



Victorian Privacy Commissioner: Sets standards for the way Victorian government organisations, statutory bodies and local councils collect and handle your personal information.

www.privacy.vic.gov.au | 1300 666 444

Welfare Rights Unit: Advocates for the right of people to have adequate income security and the rights of people in relation to the system that provides this income security (welfare).

www.welfarerights.org.au/offices/Melbourne.aspx | (03) 9416 1111



* Glossary/Index

Words matter, so it's important to be clear and transparent about how we use them

"In inpatient (hospital) psychiatry, the best way to tell the patient from the psychiatrist is by who has the keys.

In outpatient (office) psychiatry, the best way to tell the patient from the psychiatrist is by who has the key words."

From *The Untamed Tongue* by Thomas Szasz, academic, American psychiatrist and radical critic of psychiatry

We know that words have power. They strongly influence the way we perceive and think about the world, and hence how we act in the world.

Here, we offer a guide to how we use some of the words in this booklet. This is not intended to define the 'right way' of using words, but is intended to demystify some important terms in the context of mental health, suggest a consumer perspective on these words, and to provide clarity for how we are choosing to use words in the context of this booklet.

Rather than providing summaries, where we have explored the issues in the booklet, we point to the relevant section.

Acute Unit: see 42, p51

Advance Directive: see p75

Advocacy: see p69, p87

Anti-psychiatry: see p11

Behavioural Therapy: A specific type of therapy, usually short-term, that focuses on learning new behaviours in the 'here and now' rather than any form of analysis from the past. It has what medical researchers call an 'evidence-base' but does not suit all of us.

CAT Team: see *Crisis, Assessment and Treatment Team*

Community Health Centre (CHC): see p43

Community Mental Health Service: see p111

Community Treatment Order (CTO): see p50

Complementary medicine: see p11

Compliance: see p17, p31

Consumer: see p9, p93

Consumer perspective: see p95

Consumer/survivor movement: see p97

Consumer views: see p96

Crisis, Assessment and Treatment Team (CATT): see p42, p52

Diagnosis: see p19, p28

Diagnostic and Statistical Manual of Mental Disorders (DSM): see p21

Disability Support Pension (DSP): see p62

Dissociate: Believed to be a mental process that severs a connection to a person's thoughts, memories, feelings, actions, or sense of identity. It is often a response to trauma, particularly trauma in childhood, and can be quite disabling. One theory is that it enables the mind to distance itself from past experiences that are too much for us to process at the time.

Iatrogenic: Describes medical practice that makes patients unwell.

Intake: see p47

International Classification of Diseases 10 (ICD10): see p21

Involuntary admission/ 'treatment': see p49

Labelling: see p17

Lived experience: 'Lived experience' describes the set of knowledge that comes not from academia but from our day-to-day lives. We believe this is a crucial source of insight. This term was brought to Australia by carers but consumers have now picked it up as well.

Means test: Our 'means' is what we have in money and in assets (things like houses, cars etc.). Many services (Community Legal Services and some government services, for example) apply a 'means test' so that they can put their limited funding towards those who are most in need.

Medical Model: This is the most prominent way of understanding 'mental illness' in Australia at this time. The 'Medical Model' emerged in the middle of the 19th Century and holds that problems with thinking, mood and 'behaviour' are part of a 'brain disease'. This enables people to think of classifications of diseases, treatment and medical outcomes.

Medication: see p29

Mental Health Literacy: A course originally designed by Professor Tony Jorm at the Australian National University that attempts to teach lay



people about a 'Medical Model' understanding of 'mental illness'. Some consumers think it's useful, some don't. It doesn't incorporate other ways of thinking about mental 'illness'.

'Mental illness': We put this expression in quotation marks throughout this booklet to indicate that we don't all necessarily agree with this way of framing our experiences. This expression is based on the 'medical model'. While some of do find the 'medical model' useful, many of us question this whole concept. Despite the many critiques, we have chosen to use this expression because it is still the dominant way in which most people in society understand these experiences. There are so many ways to understand our experiences, so no single expression is correct or universal.

Pharmaceutical Benefits Scheme (PBS): see p59

Private mental health system: see p41

Psychiatric Survivor: see survivor / psychiatric survivor

Psychosocial disability: see p11, p78

Psychosocial Disability Rehabilitation and Support Services (PDRSS): Services provided by the non-government sector, including post-crisis/recovery services such as housing and outreach programs. PDRSS services are generally funded by a range of different financial sources including state and federal sources, fundraising activities and charitable trusts.

Public mental health system: see p41, p47

Recovery: see p13

Self-help groups: see p85

Social exclusion: Exclusion of certain groups of people in our community from the everyday activities of a community – things that the rest of us take for granted. 'Social exclusion' is sometimes overt (obvious) and sometimes covert (hidden). If people feel uncomfortable with someone they are likely to exclude them to make themselves feel more comfortable. People diagnosed with 'mental illness' are often excluded because of others' discomfort or unwarranted fear.

Social model of disability: see p10

Stigma: see p16

Supported decision-making: see p79

Survivor/psychiatric survivor: A term commonly used by people who are activists in mental health. The 'psych. survivor' language often refers to people having 'survived' the psychiatric system, rather than having 'used' it. While we have not written from this position, we believe that radical critique is necessary and also helps less radical voices to be heard.

Therapy: We have observed a tendency for many of the activities we engage in while recovering from 'mental illness' to be described as 'therapy' – especially in the context of inpatient psychiatric units or Psychiatric Disability Rehabilitation and Support Services. This kind of approach can turn activities that we might just want to dabble in or enjoy purely for their own sake into something that is done because it is 'good for us'. This can lead workers in these services to 'encourage' (or coerce) us to participate, even when we have no desire to, which drains the activities of any joy or intrinsic value for us (e.g. art therapy, "gardening therapy," even "cleaning therapy")

Transformation: A new idea coming from the psych/survivor movement, that is an alternative to 'rehabilitation' or 'recovery'. Transformation implies that we can come out of a horrible place with new insights, new ways of dealing with life, greater hope and so on. This is not 'recovery' because we are not wanting to return to who we were.

Treatment Plans: The term used in Victoria to describe the document that is supposed to be written by staff in collaboration with the patient/consumer. In other states these documents are called Management Plans, which might be a more accurate description.

Triage: see p47



