

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).

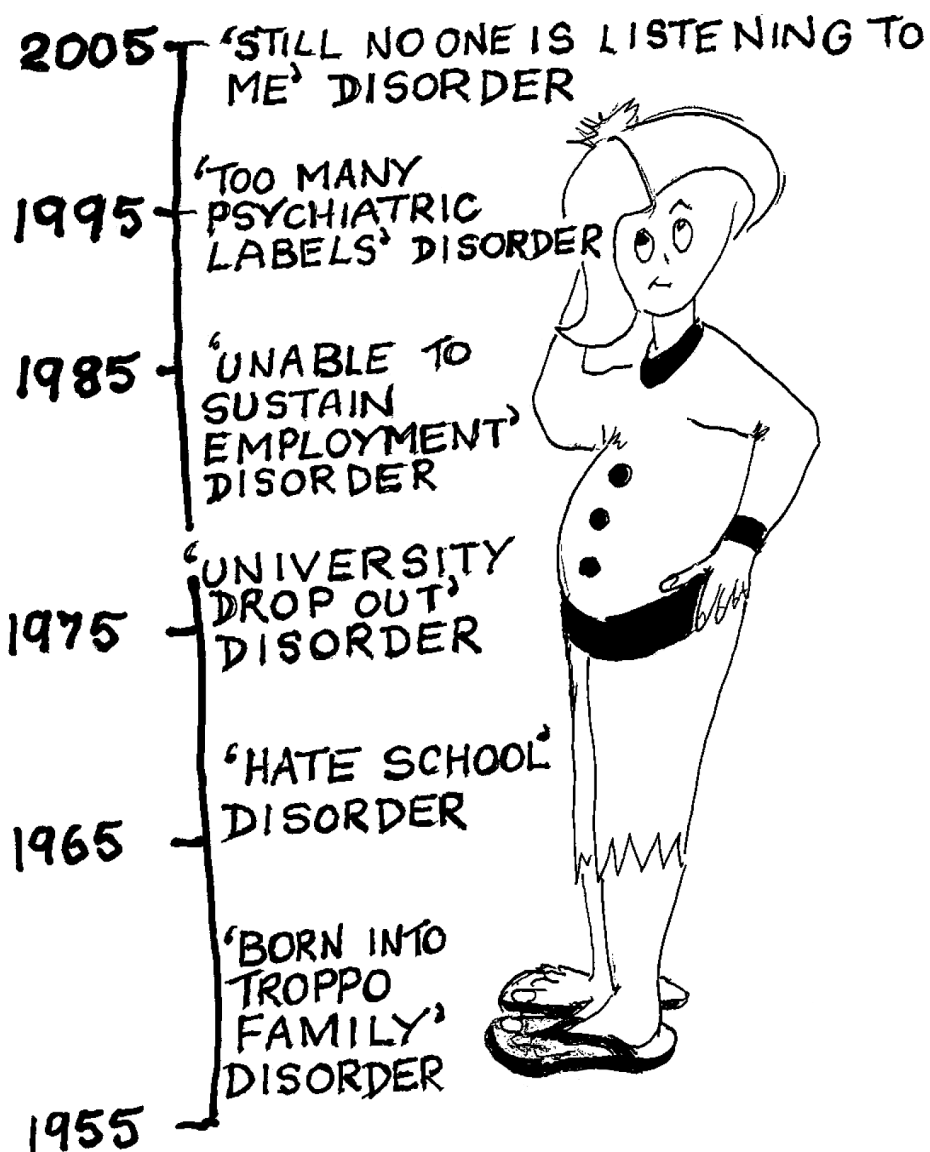
The Diagnostic & Statistical Manual of Mental Disorders (DSM)

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.

