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?

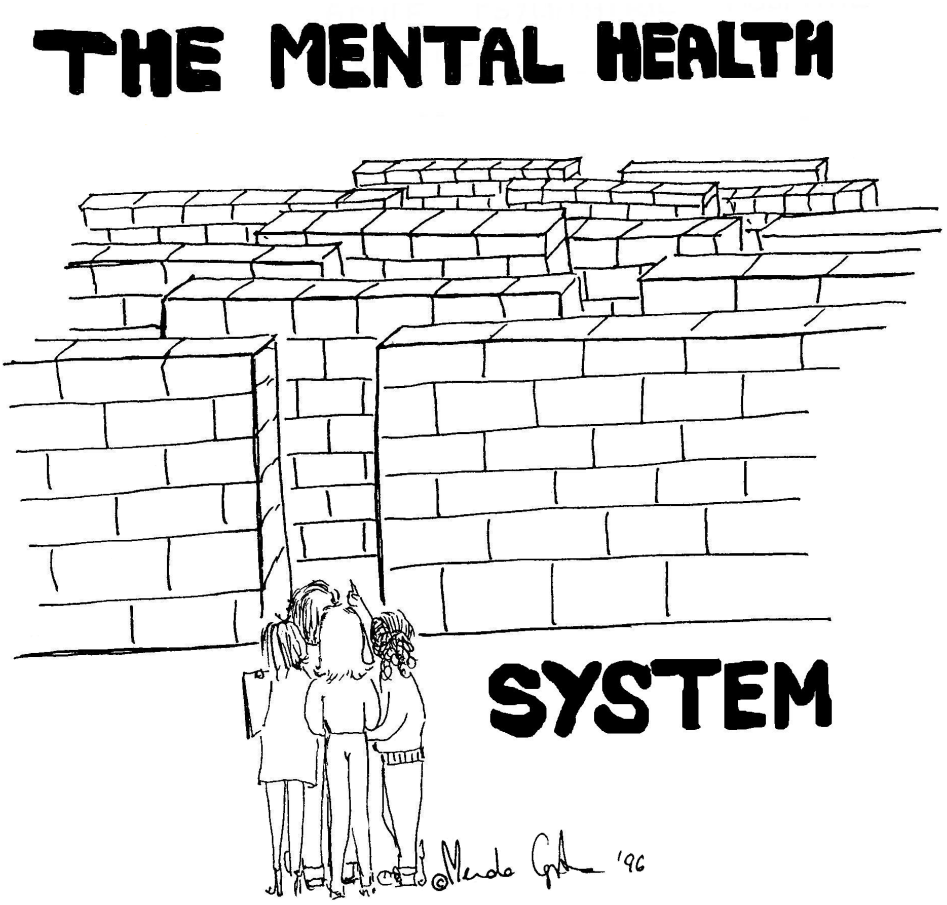
Once you get some initial information and have decided to see a psychiatrist, it's time to see if this person is right for you. At this time you may be vulnerable and perhaps scared not only of what is happening inside you but also about what others might think of you and what effect

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.



✷ 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).