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 infantalises 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.

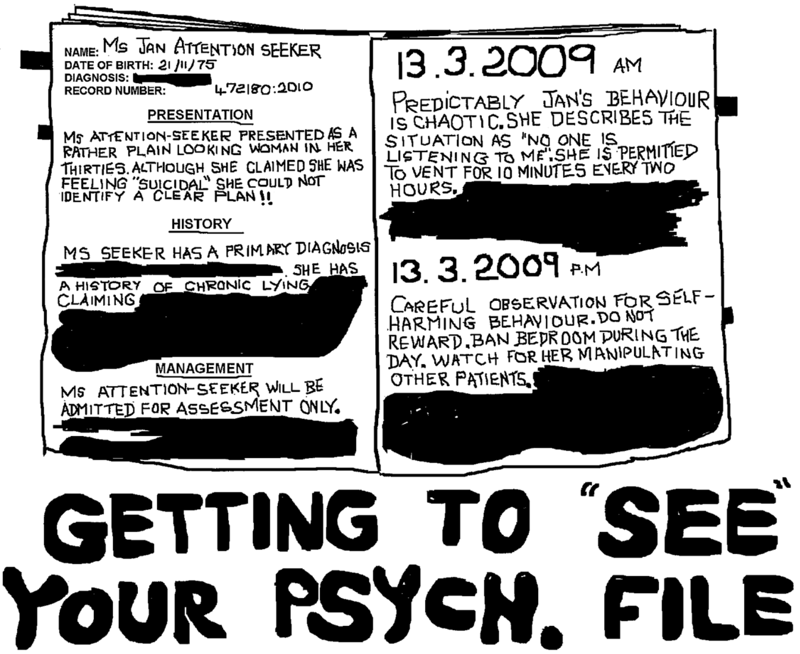
We are also responsible for distributing up-to-date copies of our Advance Directive. Always keep one copy in a secure place that others can find if needed.

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.



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 P.M

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

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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**