

Defending the Right to Autonomy and Self Determination: Advance Directives for Mental Health

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Advance directives—what are they?

The Mental Health Legal Centre (MHLCC) maintains a strong position that each consumer knows best about the lived experience of their 'illness' and that decisions made by others on their behalf will never adequately substitute for the decisions people make for themselves about their own lives.



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Advance directives for mental health provide a vital mechanism to inform mental health services about the person's preferences for treatment, care and other important lifestyle issues when they are distressed or unwell during a mental health crisis. In other words, the advance directive allows the person's 'voice' to be heard at a time when they may be least able to make their wishes known (Scheyett et al 2007).

Typically advance directives contain special information outlining the person's unique circumstances including psychiatric and other treatment choices as well as broad practical life management arrangements, for example the care of children, pets, accommodation, hospital visitors and employment (Topp and Thomas 2008).

The legal status of advance directives

Some recent decisions by courts in New South Wales (Hunter v A 2009) and Western Australia (Brightwater v Rossiter 2009) have confirmed the general principle that the law will enforce an advance directive to refuse medical treatment where a person has lost capacity to give or refuse consent, provided the directive was made while the person retained decision-making capacity and there was no evidence to show otherwise. It is beyond the scope of the article to consider the test of capacity in detail.

Suffice it to say the law presumes adults 18 years and over have capacity to make decisions. The test of capacity in general requires assessment of the person's ability to understand and retain the information relevant to the particular decision, the ability to weigh up or process that information and to communicate a decision.

Although advance directives for mental health have not been specifically considered by any Australian court, the position regarding psychiatric treatment is less promising. The two key legal obstacles to enforceable advance directives for mental health are the wide ambit of clinicians' coercive powers under mental health legislation and the contrived regime of substitute decision-making when a person lacks the capacity to make decisions in a mental health crisis. In Victoria, the Mental Health Act 1986 (MHA), gives the authorised psychiatrist the power to detain and/or treat a person against their will under the involuntary treatment provisions which effectively 'trump' any advance decisions—one of the key criteria for involuntary treatment is that the person is 'unable to consent to or *is refusing* treatment' (emphasis added) (Section 8(1)(d)). In other words, a person does not have the same right to refuse psychiatric treatment in the way that they may refuse treatment for a physical condition.

Moreover, the decision of a person appointed as a medical enduring power of attorney under the Medical Treatment Act 1988 (Vic) is irrelevant when it comes to involuntary treatment under the MHA—the authorized psychiatrist proposing the treatment becomes the substitute decision-maker, effectively 'consenting' to the treatment on the person's behalf (see sections 3 and 12 AD MHA).

Whatever their legal status advance directives for mental health can make a significant contribution to the wellbeing of people living with psychiatric disability. As one consumer notes:

People are starting to be seen as the experts of their illness and condition and are able to plan for a crisis in advance. Developing advance directives helps to reduce the stress caused by an admission to hospital and helps a person to establish an empowering, therapeutic relationship with health and social-care professionals from day one of their admission (MHLC 2006).

Underlying human rights principles

Originally conceived as a means of promoting autonomy and self-determination in general health care, particularly relating to end-of-life decision-making (Airedale v Bland 1993) advance directives are now increasingly being recognised as a key component of a legal framework that engenders respect for the inherent dignity of people with mental illness.

These fundamental human rights principles find expression in key instruments such as the Victorian Charter of Human Rights and Responsibilities (see for example Section 10(c)—Freedom from treatment without consent) and the United Nations Convention on the Rights of Persons with Disabilities (Disability Convention).

Article 12 of the Disability Convention requires State Parties to 'recognise that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life'. In reality however, while there are a range of legal options to exercise one's autonomy to make general health care decisions in advance of impaired capacity—such as appointing enduring powers of attorney or executing a Refusal of Treatment Certificate—these are denied to people with mental illness when it comes to psychiatric treatment.

Genevra Richardson (Richardson 2007, p.72) notes the inherent discrimination in a system that fiercely guards the autonomy of people in general health care to refuse treatment, while refusing to embrace the same rights for people with mental illness to refuse psychiatric treatment (see also Wand and Chiarella 2006, p.125). Mental illness is, after all, episodic in nature and most people retain capacity to make a range of decisions aside from occasional periods of impaired capacity.

Viewing mental health law through a human rights lens provides fertile ground for advance directives for mental health to gain currency in a meaningful way through policy and law reform. The Attorney General has asked that the Victorian Law Reform Commission (Commission) independently evaluate the legal framework for guardianship and powers of attorney. The

reference provides scope for supported decision-making more broadly, including advance directives as a tool of autonomy for people with disabilities. The Commission is due to report its findings and recommendations by 2011.

Consumer experience

People living with mental illness are often frustrated by the refusal of service providers to acknowledge and respect their expertise gained from hard personal experience. Understanding the perspective of consumers, particularly those with an experience of involuntary detention, can challenge the culture of service delivery to people with mental illness. Advance directives for mental health can challenge the inevitable imbalance of power between consumer and clinician, to enhance patient self-determination and create better outcomes for the person.

As one consumer said, 'I have to make a commitment to [advance directives]. I have to be active in my own treatment and recovery, because I've found that that works better'.

At a consumer forum convened by the Mental Health Legal Centre in 2006, one consumer described their story of preparing an advance directive:

...[A]fter an episode of illness where I was dragged to hospital... I didn't know about the consumer movement, the Mental Health Act or advance directives, but I did know that I needed to take control of my own life. I changed what was happening with my treatment and got better fairly quickly. I discussed the changes with a psychiatrist who then thought that just maybe I had been right.

Out of frustration I decided to make a sort of advance directive which I just called a letter for my file (quite an ignorant thing to do as I really didn't know that it had no official clout at the time). I knew that in general health you could say that you did or didn't want certain treatments.

I virtually interviewed psychiatrists when I felt well ... to see if they would look after me the way I wanted and needed to be looked after. I did know that people weren't hearing me and that what was happening was making things worse and not better. It also seemed like a way to have people take notice when I was feeling like I may be seen as having more credibility—when I was 'well'.

The Mental Health Legal Centre's research

The MHLC is presently undertaking research in Victoria into advance directives with a view to making recommendations for law reform and practice and further research. Unlike some other Western countries (e.g. the United States, New Zealand and Scotland) these documents do not enjoy legal recognition and are not legally enforceable in Victoria or Australia. The project is a qualitative study; issues are explored and information collected through individual interviews and discussion groups.

The research aims to identify the benefits, challenges and opportunities presented by advance directives from the perspective of consumers, clinicians and other stakeholders in Victoria. The findings of the research will be used to make recommendations for further research, law reform and practice to enable respect and recognition of advance directives.

Advance directives can make a difference

What consumers have said about the strengths of advance directives (MLC 2006):

- Taking control both personally and at work was a turning point for me after a particularly bad patch with my mental health.
- It was very thought provoking. You really had to think about what is good for you and you had to relive some of the past to remember what wasn't good for you. I found it empowering; you could stand up for yourself.
- I had been in the hospital a couple of times and had been coerced into several treatments, including shock treatments, and I wanted it made very clear that this was not an option. I felt safer. I felt I was advocating for myself. It took away some of the 'if'.
- I feel it has worked. I'm lucky—my psychiatrist fully respects my wishes (even if he doesn't agree—actually I asked him once what he would do differently) The couple of times at work when people have been unsure about how I am doing they have looked at my protocols and talked to me before thinking or acting further.
- I am not at all interested in a substitute decision maker. I want to make my own decisions.
- I believe I have a moral right to make these decisions even if I don't as yet have a legal one so to speak that can't be overridden.
- I am not asking for people to agree with my choices. I am asking them to respect them— there is a difference.

For more information on advance directives for mental health, the MHLC's research or to access the MHLC's draft online proforma document, go to: www.communitylaw.org.au/mentalhealth or contact Catherine Leslie catherine_leslie@clc.net.au

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References

Court decisions:

Airedale NHS Trust v Bland, 1993 AC 789 AC 789, per Lord Goff at 894–5, available at: <http://www.bailii.org>

Brightwater Care Group v Rossiter, 2009 WASC 229, available at <http://www.austlii.edu.au>

Hunter and New England Area Health Service v A 2009 NSWSC 761, available at <http://www.austlii.edu.au>

Legislation and treaties

Charter of Human Rights and Responsibilities Act 2006 (Vic), available at <http://www.legislation.vic.gov.au>

Making an advance directive

There is no single, set way to go about drafting an advance directive for mental health, particularly given advance directive documents are not prescribed in legislation. The MHLC has developed a draft online proforma document which is one way for consumers to make their own advance directive for mental health. This document, together with relevant information is available by following the 'Advance directives' links on the MHLC's website: www.communitylaw.org.au/mentalhealth

Key aspects of the MHLC document are:

- It can be filled in online and printed out (though not saved electronically);
- It provides prompts for useful information to include—personal information; key clinicians; primary support persons; what works in terms of medication, care and treatment; what has not worked in the past; other health issues; accommodation, and life style issues and any other information that the person wants known;
- It includes provision to record that the person has appointed other people such as enduring powers of attorney/guardianship;
- It also includes provision for the person signing the document to have it witnessed by a lawyer, clinician or allied health worker to attest that the person making the directive understands and intends the effect of the decisions contained in the document, and importantly, provides for the person to withdraw an advance directive, which must also be signed and witnessed;
- It suggests that storage of the directive be on the person's medical record and with key people named in the document (either wholly or in part);
- It recommends review of the document at least every 12 months.

The MHLC also welcomes feedback about the document and the accompanying information.

Medical Treatment Act 1988 (Vic) available at <http://www.legislation.vic.gov.au>

Mental Health Act 1986 (Vic) available at <http://www.legislation.vic.gov.au>

United Nations Convention on the Rights of Persons with Disabilities, 13 December 2006, (entered into force 3 May 2008) available at: <http://www.un.org/disabilities/default.asp?navid=12&pid=150-->

Journal articles & other sources

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