

## **Mental Health Legal Centre Inc. Advance Directives**

The Mental Health Legal Centre 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. Self-determination is crucial to anybody's ongoing wellbeing. Advance directives provide a more formal means than currently exists, for the declaration of the treatment preferences and carrying out instructions of service users.

We are keen to promote ways that maximise the opportunity for consumers to claim their own power and sovereignty at all times.

Advance Directives are one important way that mental health services can be better informed not only about the wishes and preferences of each person, but also consumers in general. It is critical that the service system can demonstrate an understanding of the perspective of people with a psychiatric disability regarding decision-making processes and the experience of being a recipient of mental health services, particularly if under involuntary detention.

Advance Directives are one way that consumers can seek to maintain authority over their own lives in a way that will in both the long and the short term keep them well. The MHLC is committed to working with people to design Advance Directives in a way that leaves them with maximum autonomy, dignity and control but without deception about the limitations of the law as it presently stands.

The right to refuse unwanted medical treatment is deeply enshrined and respected for those deemed having a capacity to consent. However, those people subject to provisions of the Mental Health Act, are at risk of involuntary treatment.

The message coming through loudly and clearly from consumers is that the introduction of Living Wills or Advance Directive which have some legal force would mean an improvement in the recognition of their rights. In our view the introduction of some form of Advance Directive must be pursued with appropriate legal status to ensure that they are considered and respected.

There is also a strong view that, even if they are not legally enforceable, they may be of value for people in both the process of development of the document, and the possibility that mental health workers will give them serious consideration even if they are unenforceable. It is our overwhelming experience that non-enforceable principles of aspiration will be vastly less effective than enforceable rights.

It is the view of the MHLC that Advance Directives are also relevant and ought to be available to people who would like to have certain treatment from a Mental Health Service or for that matter would like to choose one treatment option over another, and where possible to choose their practitioner or case manager.

Furthermore consumers raise the possibility that Advance Directives as a tool could be used in relation to many other issues associated with a crisis situation eg. temporary responsibility for childcare during a crisis, vetting of visitors, passing on important information – for instance who the consumer wants staff to talk to and who they don't. If extended more broadly than treatment an Advance Directive could address problems regarding continuity of care, discharge planning and support in all aspects of a person's life. It may well be that opening

up to scrutiny the question of what is judged clinically 'best', through the lens of consumer preference and instruction could influence the upholding of such rights as users' being involved in their own treatment.

People with psychiatric disability very quickly lose their right to participate in decision making. What people experience is that once they are deemed incapable of consenting, they are excluded from meaningful participation in many life decisions. Participation and consultation are cornerstones of the National Mental Health Strategy. The principle that people should be given the opportunity to influence the treatment they receive, and their preference should be granted wherever possible, is enshrined in the United Nations Principles and National Mental Health Standards, even where they are deemed to be involuntary under mental health legislation<sup>1</sup>. To the extent that Advance Directives can create the maximum participation possible, they are desperately needed.

## **Discussion:**

### ***Advance directive in practice***

In Victoria common law regarding Advance Directives suggests that when a person is deemed to be 'competent', their Advance Directive will be respected<sup>2</sup>. However, once a person is defined as 'incompetent' the Advance Directive holds a much weaker position. This causes considerable problems because what consumers think they're doing when making an Advance Directive is putting in place something that will be there for them if they do become very distressed and ill later on. One of the problems that comes from present discussions of Advance Directives is that they might inadvertently be setting consumers up to have an expectation that may not be realistic given the systemic discrimination which operates within mental health institutions. Realistically perhaps, OPA argues that Advance Directives have very limited legal spaces in Victorian law at the moment and that the untested nature of them makes the more legally viable option, the completion of a Refusal of Treatment Certificate (RTC) under the *Medical Treatment Act*. A Refusal of Treatment Certificate (RTC) however, is only concerned with consumers who do not wish to receive treatment. This raises two sets of problems:

1. The Refusal of Treatment Certificate (RTC) can, like the Advance Directive, be overturned by the Supreme Court or VCAT; and
2. Consumers' wishes are essentially about many things (and many potential things) and not just about refusal of treatment. Lifestyle decisions about safety of children during crisis, who to share medical information with, which visitors people want and things like agreements on the overt signs of mania that the consumer, issues that would not be within the ambit of a RTC.

### ***Advantages irrespective of validity***

One of the most important things that an Advance Directive can do is encourage discussions between patients and healthcare professionals and patients and their families about important health care

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Ref the OPA document here: [eg restricts discussion to those seeking to refuse treatment](#)

<sup>1</sup>The National Standards for Mental Health Services provide in Standard 11.4.2 that, though legislation may sanction involuntary treatment, under all circumstances the Service must make every attempt to obtain informed consent prior to the administration of any treatment.

The United Nations Principles for the Protection of Persons with Mental Illness and Improvement of Mental Health Care provide in Principle 11(9) that where treatment is authorised without the persons consent, every effort shall nonetheless be made to inform and involve the patient.

<sup>2</sup> Consumers are doubtful about this. Respected in the way that patients in a psychiatric hospital are respected? they ask with some cynicism. Perhaps it is better to suggest that this is respect-in-principle rather than respect-in-practice.

issues. Through this process important documents can be drawn up which can give services detailed and accurate directions about what the consumer does and does not want to happen when they next get sick or mentally distressed. This might or might not be to the point, which psychiatrists deem the person not to have 'capacity'. Consumers who have studied the idea of Advance Directives emphasise the importance of the pre-signing discussion, however they are divided on whether it is in their interests to give others power (either legally or, perhaps morally) to make decisions for the consumer when they are unwell (but before they have lost 'capacity') that they have carefully pre-thought and documented when well. Consumers need to think about the sorts of circumstances that might arise. The legality of the agreed document is, as OPA suggests, might give important guidance to the treating team and other important people who care about the consumer. It is within these contexts that several issues arise.

One of these is the encouragement of more widespread use of Advance Directives by consumers who may never have been involuntarily detained but may have experienced horrible things, which they wish to avoid in the future when they are admitted as voluntary patients. The participatory development of an Advance Directive document which becomes part of a consumer's history could be (if handled well<sup>3</sup>) a very important way for consumers to make known what they do and do not want to happen to them during periods of crisis (regardless of their status as an involuntary or voluntary patient)

### ***Cautions***

In this paper, the term Advanced Directive is being used to cross a range of different health care scenarios including death and dying. Our interest as the Mental Health Legal Centre is to understand the potential for Advanced Directives more specifically in the mental health area, looking at decisions that can be made when a person is well for times in their life cycles when they become distressed or unwell. It is a slightly different scenario and one we think is important. The point is made however that this is tricky territory. A person might develop an Advance Directive with full intentions of honouring it when they become unwell however they might change their minds. If we accept the Ulysses principle then the role of the Advance Directive is to hold the person to the decision they made when they were 'well' ethical problems arise for us. Taking instructions from our clients at the time when they need legal support is a sacrosanct part of the practice of the Mental Health Legal Centre. If clients change their minds it is the duty of our solicitors to act on these new instructions.

### ***Safeguards***

#### ***The role of advocacy***

When the consumer nominates someone to act on their behalf it means choosing carefully. It should not be a service provider. It should be someone who has good advocacy and negotiation skills, is assertive, who the consumer trusts with their life. It also needs to be someone who is physically, geographically, available, and at short notice. This nominated person needs to be someone who can cope with strong feelings, from all sides, if it becomes a situation, for example, where an aspect of the Advance Directive is not being adhered to. It would work best if your nominated agent shared your values and understood your health and treatment preferences. Not everyone has access to such a person.

It may be that at present it would be unwise to promote the use of Advance Directives without also promoting the need for highly skilled advocates who could act on behalf of the consumer, particularly in the case of attempting to uphold treatment preferences, where there is disagreement.

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<sup>3</sup> Consumers argue that a consumer driven Advance Directive is quite different from an Individual Service Plan (ISP) or Treatment plan, which may or may not truly be drawn up collaboratively between the consumer and staff. The risk with Advanced Directives is, handled poorly, that they could slip into having exactly the same problems of tokenism as ISPs.

## Legal perspective

The OPA paper examines three Victorian Acts, relevant to a discussion of Advanced Directives in Victoria, *Medical Treatment Act 1988*, *Guardianship & Administration Act 1986* and *Mental Health Act 1986*. The discussion paper states that the Mental Health Act overrules patients' rights to self-determination, when they are admitted as an involuntary patient and overrules an Advance Directive. This capacity of the Mental Health Act to gazump other legal provisions must inform any discussions about Advance Directives and must be clearly articulated to consumers both those who might (in the future) be thinking about developing Advance Directives for themselves and those who are engaging in the present debate. It would be important for users to fully understand the workings of their State legislation regarding their rights, before drafting an Advance Directive.

A medical practitioner who administers medical treatment to a 'competent'<sup>4</sup> adult without their consent violates the right to self-determination and could be criminally liable. OPA argues that Advance Directives and the right to refuse treatment are logical extensions of the right to self-determination. At the time a person is deemed (by psychiatrists) not to have 'capacity' is the time when they and those around them need to consider their wishes and respect a forethought refusal.

## The UK Mental Incapacity Bill

The Bill lays out a single definition of capacity that requires capacity to be assessed according to each decision that needs to be taken. This means that individuals will not be labelled 'incapable'; rather they would only be regarded as lacking capacity for certain decisions at the time that decision needs to be taken. The approach to establishing whether someone has capacity used in the Bill is underpinned by the belief that whenever possible individuals should continue to make as many of their own decisions as possible. The starting point is always that the person has capacity and the Bill states that 'all practicable steps' must be taken to help the person make the decision before they can be regarded as lacking the capacity to make that decision. (*Department for Constitutional Affairs UK 2003*)

Some states in USA have explored the idea of Advance Directives more thoroughly. However we are concerned that there has been a tendency for them to take into account such factors as the consumer's "comprehension" of illness and prognosis. It is argued that these facts are important to establish a successful outcome for the patient seeking to have their Advance Directive complied with. Determining what is and how to get a 'successful outcome' for a patient is tricky and imposes a best interest model, so often opposed to the instructions of the person.

Furthermore, there are a number of factors related to completing an Advance Directive, which can make them a difficult document for the Courts to uphold which include<sup>5</sup>:

- Possible advances in medical technology, not evident at the time of making the directive. In other words, somebody may say that they want this and don't want that based on the knowledge of the time, but in fact the treatment may be much, much less intrusive than it was at that time, by the time that the Advance Directive is called on to be used.
- The requirement of a certain level of knowledge about the illness and the likely chances of recovery that may not generally be known or considered when the Advance Directive is made.

These issues particularly impact on the directives of people with psychiatric disabilities.

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<sup>4</sup> Competent is used here in all its legal glory. Consumers don't like it and point out that it should only be used with great care and respect and consumers' concerns about the language should always be acknowledged. This is yet another example of a legal word which can potentially make an individual or a whole class of people feel deficient and dehumanised. It must also be used with great care and adequate explanation

<sup>5</sup> Reference to OPA

- In Victoria common law strengthens Advance Directives made when a person is 'competent'<sup>6</sup> however, once a person is defined as incompetent the Advance Directive holds a much weaker position. Consumers believe that an Advance Directive is putting in place something that will be there for them in the event of an emergency but in reality these wishes may be easily disregarded. One of the problems that comes from present discussions of Advance Directives is that we need to be realistic and mindful about the current legal validity such a document would have. 'Perhaps Advance Directives have very limited legal spaces in Victorian law at the moment and that the untested nature of them makes the only legally viable option, the completion of a Refusal of Treatment Certificate (RTC) under the *Mental Treatment Act*.<sup>7</sup>

### ***Medical Treatment Act - Refusal of Treatment Certificate (RTC)***

This instrument comes into effect when the person does not wish to receive any treatment, as highlighted above, and results in a tenuous document able to be overturned and unable to incorporate the wishes of the person in all aspects of their life.

One of the most important things that an Advance Directive can do is encourage discussion between patients and healthcare professionals and patients and their families about important health care issues. Through this process documents can be drawn up which can give services detailed and accurate directions about what the consumer does and does not want to happen in an emergency. Consumers who have studied the idea of Advance Directives emphasise the importance of the pre-signing discussion however they are divided on whether it is in their interests to give others power (either legally or, perhaps morally) to make decisions for the consumer when they are unwell (but before they have lost 'capacity') that they have carefully pre-thought and documented when well. Consumers need to think about the sorts of circumstances that might arise. The legality of the agreed documents is, as the paper suggests, suspect but nonetheless they might give important guidance to the treating team and other important people who care about the consumer.

Widespread use of Advance Directives by consumers who may never have been involuntarily detained will strengthen the respect for such documents and educate practitioners to consider and implement a persons wish as to their treatment (regardless of their status as an involuntary or voluntary patient)

The OPA document applies Advance Directive to a range of different health care scenarios including death and dying. Our interest at the Mental Health Legal Centre is to understand the potential for Advance Directives more specifically in the mental health area, examining at decisions that can be made when a person is well for times in their life cycles when they become distressed or unwell. It is a slightly different scenario and one we think is important. The point is made however that this is tricky territory. A person might develop an Advance Directive with full intentions of honouring it when they become unwell however they might change their minds. If we accept the Ulysses principle then the role of the Advance Directive is to hold the person to the decision they made when they were 'well' ethical problems arise for us. If clients change their minds we believe new instructions must be heard new facts and circumstances considered.

However, it would seem that the 'competency' required depends on the consequences attached to the decision made by the patient. The more important the decision, the higher the level of 'competency' that must be established. The argument is put forward that there is a difference between looking at a decision that appears to be not a very good decision and deciding that a person is necessarily incompetent for making that decision. A bad decision does not necessarily indicate decisional incapacity. We all make good and bad decisions daily but most of us do not do so under the gaze of the Mental Health Act.

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<sup>6</sup> Consumers are doubtful about this. Respected in the way that patients in a psychiatric hospital are respected? they ask with some cynicism. Perhaps it is better to suggest that this is respect-in-principle rather than respect-in-practice.

<sup>7</sup> Reference to OPA document

### ***Guardianship and Administration Act 1986***

An Advance Directives can also be overturned by a Guardian appointed under the Guardianship and Administration Act 1986. This Act provides for an appointed decision maker to consent to various treatments including medical and dental treatment where a patient is unable to do so. What this would mean is that an Advance Directive made in common law would have to be respected while the patient was 'competent', but once the patient lost 'capacity', the person responsible for their care (person responsible<sup>8</sup>) could make a decision that goes against the Advance Directive if s/he did not consider the Advance Directive to be in the best interests of the consumer. This neutralises the effect of an Advance Directives and also denies the person the right to have their wishes respected. At a time when the person may be unable to either make decisions or communicate their decisions to other people, these wishes are crucial, and in our view there is a duty of care to consider them. Given this, it is reasonable for consumers to come to the conclusion that the whole process might be a bit of a charade.

The Act has other impacts on the effectiveness or otherwise of an Advance Directive, an Administrator under the Act can make decisions which will effect life style issues which may have been considered and incorporated by the person and must therefore be respected. It also raises the obvious reality that Advance Directives and the accompanying documentation needs to be routinely updated and not 'allowed' to become out of date. The consumer needs to maintain 'control' of this process.

Currently the law in Victoria under the Guardianship and Administration Act allows that a 'person responsible' may override a patient's common law Advance Directive with their own decision as long as they still act within the patients best interests, under S37 of the Act. This interpretation would deny an 'incompetent patient' their autonomous right to decide what will happen to them and therefore deny them the fundamental right of self-determination. However, if a person has made a legally valid Refusal of Treatment Certificate (RTC) under the Medical Treatment Act this decision has to be respected by the 'person responsible' because a doctor cannot act contrary to the RTC without committing an offence under the Act. It is our view that an Advance Directive must be similarly respected.

### ***Mental Health Act 1986***

One of the criteria for the admission of an involuntary patient is that the person has refused or is unable to consent to what is perceived to be necessary treatment for their 'mental illness'. Straight away this challenges the effectiveness of an Advance Directive refusing psychiatric treatment, for example, made by this person when they were considered 'competent' because it reinforces the evidence that the person is mentally ill. To date, no cases have arisen in Victoria that have involved an involuntary patient having drawn up an Advance Directive while 'competent'. This still needs to be tested but it suggests that until such a case should arise, it would seem to indicate that the consumer remains an involuntary patient regardless of any Advance Directives they may have made. Such an interpretation would impact on the patients right to self-determination.

The paper discusses the right of mental health consumers to refuse health treatment that is not psychiatric treatment and how an Advance Directive can be used in relation to psychiatric treatment. We are concerned about refusal of treatment but also refusal of specific treatment, for example ECT. Under the Act a person needs to give informed consent to the ECT even if they are being detained involuntarily, informed consent is not necessary if the nature of the mental disorder that a person has is such that the performance of ECT is urgently needed (s73.4). This means that if the treatment is considered to be urgently needed then the patient's consent or any Advance Directive will be overridden.

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<sup>8</sup> Person responsible is the name given to the person who is, in law, responsible for making decisions for an 'incompetent' consumer under the Guardianship and administration Act.

If an involuntary patient refuses to consent to necessary treatment or is 'incapable' of consenting to treatment for his or her 'mental illness', then, consent in writing may be given by the authorised psychiatrist, thus the psychiatrist's consent prevails over any Advance Directive of the patient. The Act is silent as to the effect of a valid Refusal of Treatment Certificate (RTC) in relation to an involuntary patient who refuses to undergo psychiatric treatment. Presumably if a person cannot give informed consent (ie. is deemed to be 'incompetent' under the Mental Health Act) then their directive probably would not be honoured, especially if the treatment was considered to be urgent. The Act does provide procedures to be followed in relation to a patient who is 'incapable' of providing informed consent, however, these procedures are not designed to take the patient's Advance Directives or their best wishes into account. If we are going to be serious about Advance Directives, they would need to be strengthened by the Act.

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### **Electronic Mail**

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Cohan, Kathryn <Kathryn@PersonFirst.org>, email (27 January 1999)

Hack, Randolph <unitedsel001@Hawaii.rr.com>, email (27 January 1999)

Mason, David <DavidMason@HREOC.GOV.AU>, email (8 February 1999)

Sandra Oliver-Jobling <freckles@ne.com.au>, email (16 January 1999)

Strong, Ria <strong@madnation.org>, email (16 January 1999)

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