



Your Right to Know: Consumer and Carer Participation and Involuntary Mental Health Care

BY PUBLIC ADVOCATE, DR JOHN BRAYLEY

Mental health care is just another part of the overall health care system. Many of the same rights apply. Two key rights are the right of a patient to be given information about their illness and the right to participate in decisions about health care. These principles apply no matter what type of health problem you have and what type of decision that you need to make – whether it is a decision about getting treatment for a physical illness such as high blood pressure, or a decision about getting treatment for mental illnesses such as anxiety, depression or psychosis.

How can such rights exist when a person is receiving involuntary mental health care either in the community or in hospital? How can a person exercise these rights if a person is unwell in hospital and possibly sedated by medication? This article looks at some practical ways you can consider to uphold your rights in this situation. These strategies are based on provisions in the new South Australian Mental Health Act 2009 which came into operation last year.

Before going through the practical suggestions it is worthwhile spending time on the reasons why it is so important for consumers and carers to be informed and have their say about treatment.

Patient Safety: The Right to Know and the Right to Choose

A major reason why health consumer rights is important is because it has been shown that consumers involved in decisions about their care are more likely to get the right treatment and better results. Consumers who know what should be happening in their care and are confident to speak up when something is about to go wrong can also stop errors happening. Avoidable errors can occur in even the best clinics and hospitals. Informed consumers speaking up means safer care. The right to participate in care is now part of the Australian Charter of Healthcare Rights.

If consumers are very unwell and cannot speak up for themselves, the role of carers can be critical. They can let staff know what a person needs and speak up when there is a problem. The eyes and ears of carers also makes for safer care. Carers can become advocates and rights watchdogs for consumers; for example when a consumer is first unwell and may be subject to practices such as restraint or seclusion.

Supported Decision Making

A key recent document is the UN Convention on the Rights of Persons with Disabilities. This entered into force in 2008. It applies to people who have disabilities secondary to any illness, including mental illness.

Article 12 of this Convention is titled 'Equal Recognition before the Law'. This article says that all people should be assumed to be able to make their own decisions. Article 12 also dictates that if decision making is taken away from a person – for example, when a person

is receiving involuntary treatment under a detention order or a community treatment order – it is still necessary to respect the rights, will (wishes) and preferences of the person. While some decisions that are made may be against a person's wishes, it is likely that many other decisions about treatment can still be made in accordance with what a person wants. For example, a person may be detained in hospital against their will, but still be able to be fully involved in the choice of treatments, both talking therapies and drug treatments.

Article 12 of the Convention also underpins supported decision making. If a person is unwell they may need support to make their decisions. With this support it may still be possible to make decisions without requiring someone else such as a doctor to take over the decision making – which is known as substitute decision making. For supported decision making to work, there needs to be a 'supporter' – someone who can be available when a person is unwell, attend key appointments, and help the person make a decision. The supporter may be a family member, or friend.

Practical strategies: Your right to know

Your right to obtain information is based in law. A guiding principle of the Mental Health Act 2009 is that patients (together with their family or other carers or supporters) are provided with comprehensive information. This can be about illnesses, treatment, services, alternatives and orders (Section 7 (1) (i)). You should expect to be told detailed information. If you are not told what you need to know, then it is important to ask.

If you have difficulty asking questions someone else may be able to do this for you – a family member, friend, supporter or advocate.

If you have been subject to an involuntary treatment order you should get a clear explanation about the reasons why the order has been put in place as well as your rights, including your rights to appeal the order.

Your right to be involved in treatment decisions.

The Mental Health Act 2009 requires that treatment be based on a comprehensive treatment and care plan. This plan should be developed in consultation with patients, family, or other carers and supporters (Section 7 (1) (c) (i) and Sections 39-41).

This is the opportunity for consumers and carers to be part of decision making. The plan will describe what services will be provided and should cover key treatment decisions such as choices of medication and, for people in hospital, discharge planning.

Your will and preferences should be taken into account when this plan is developed. Voluntary inpatients have the power to consent or refuse to any part of the plan. People on involuntary orders should still expect to have a significant input.



Your right to having a supporter present.

The Mental Health Act 2009 has a key provision that enables supported decision making. Section 47 of the Act entitles a patient to have another person's support when they meet with their doctor or treatment centre staff. This person may be a guardian, relative, carer or friend. The consumer can nominate who they wish to be their supporter. Advocates and community visitors can also act as supporters.

The benefit of having a supporter can be two fold. First the supporter can assist a consumer to express their views. In addition to this, the supporter will hear information directly from the health professional. After the interview the supporter can help a consumer to make their own decisions by discussing this information.

Having a supporter present is an entitlement under legislation that should be available 'wherever practicable'. Consumers and supporters should not be hesitant in asking for this. It may require asking for an appointment time to be made ahead for key interviews so that all parties can be present. The Act does permit the medical practitioner in charge of a person's care to impose 'reasonable limits' on a supporter's access to a patient. The medical practitioner can also exclude a support person during medical examination and treatment according to their own discretion.

If a supporter is unable to access a patient then this matter could be discussed with the Office of the Public Advocate.

Supporters could have a key role in discussions about detention and meetings to consider the treatment and care plan. Not everyone will have a person who can act as a supporter. This is why other options of using an advocate or community visitor have been included in the Act. Selecting a supporter and having an agreed view about the supporter's role could be arranged ahead of time.

The Office of the Public Advocate would welcome feedback on how people have fared using this part of the Act, as it may currently be under utilised.

Accessing advocacy

If you have made a decision but no one is taking notice of it, an advocate may be needed. The Disability Advocacy and Complaints Service of South Australia is an organisation that provides significant advocacy services to mental health consumers in South Australia. The Office of the Public Advocate can also help put you in contact with an advocacy service.

The future

Strategies to provide for supported decision making include helping people access support when unwell and having advanced directives in place beforehand. In 2008 the Advanced Directives Review led by a former Minister of Health, Hon Martyn Evans, recommended that South Australia develop a new Advance Directives Act. It advised that such an act contain a legally recognised Ulysses Agreement.

A Ulysses Agreement is a record of an agreement between a patient, their treating health professional, relatives and others, about how treatment is to be provided and arrangements made during future episodes of mental illness. Such agreements can be a vehicle for acting on a person's own wishes rather than relying on doctors and others to make decisions.



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There is now work being done on developing a new Advanced Directives Act that will hopefully contain a Ulysses Agreement which will complement the other measures in the Mental Health Act 2009.

The Office of the Public Advocate enquiry service is available to answer consumer and carer questions about the Mental Health Act 2009. We would also welcome your impressions of how the Act is operating; and specifically whether consumers and carers are given the information that they require and then are involved in key decisions. The Office can be contacted on 8342 8200 or by email opasa@opa.sa.gov.au.

For further reading about the Mental Health Act:

Mental Health Act 2009 Overview, *MIFSA News* August-September 2010, page 16 www.mifsa.org

Office of the Public Advocate Fact Sheets 2, 12 and 13 www.opa.sa.gov.au

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Forward notice

Dr Brayley will be the Guest Speaker at the MIFSA Monthly Forum
27 July 2011; 1 pm – 2.30 pm

Go to page 12 for details about Forums being held in April and May