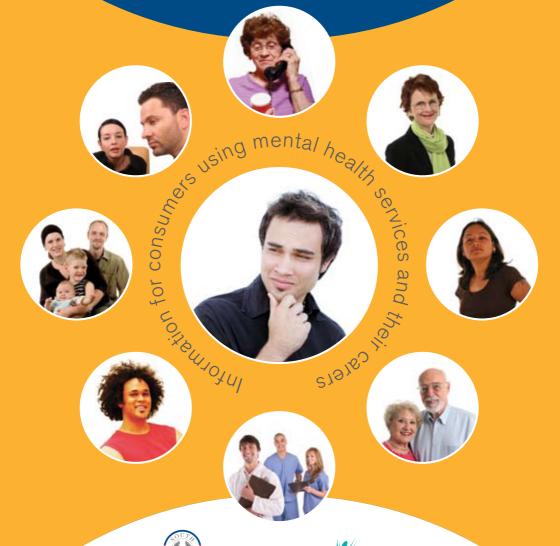
Privacy, Confidentiality and Getting the Best Care and Treatment Achieving the Balance



of South Australia
Department of Health

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If you need an interpreter, the *Telephone Interpreting Service* is available to assist you. Tel: 13 14 50. Also, you can ask your mental health service provider to explain this booklet by using the *Telephone Interpreting Service*.

Some words you might not know

Assessment The stage in health care practice where information

is gathered before a diagnosis, treatment plan,

or community support plan is made.

Carer Family members or friends who are seen by a

consumer as 'primary carer or support' persons helping them through the experience of illness.

Children and young people can also play caring roles.

Confidentiality The expectation that certain information is confined

to a relationship of trust and not shared with other

parties without permission of the consumer.

Consumer An individual who has experienced mental illness

and is receiving care and treatment for it.

Disclosure Telling somebody about an issue which

is likely to be sensitive in nature.

Health care The provision of services aimed at improving

a consumer's level of health.

Personal information Information which is about a consumer's identity,

contact details, personal history, occupation, living situation, health status and treatment.

Introduction

Public Mental Health Service All hospital and community based services which are a part of the public health system and are free to use. These are government run services.

Service Providers

The government employees who are responsible for a consumer's care. In practice, psychiatrists, mental health nurses, doctors, social workers, occupational therapists, psychologists, and consumer/ carer peer workers can all be seen as service providers.

Third party

Individuals and agencies other than a consumer and the public health service. Third parties are outside the relationship of 'confidence' between a consumer and the public health service.



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Introduction

What's this booklet about?

The information in this booklet is written for people who are receiving mental health care from public mental health services. It is also written for family members and friends who are supporting a person through an illness.

(In mental health care, the word 'consumer' is used for an individual who receives care and treatment. The term 'carer' is used for family members (or friends), who are seen by a consumer as primary support persons helping them through the experience of illness. These people may also be called 'primary carers')

The booklet has been written to provide information and ideas to help you in your communication with mental health professionals. It provides information about issues such as personal information, privacy, confidentiality and disclosure so that you are aware of the regulations that guide the sharing of information by health services.

For consumers, this information helps to point out your rights to privacy and confidentiality when using services.

For carers, the booklet explains how you can be involved in your family member's or friend's treatment.

You may also like to read the publication Your Rights and Responsibilities — A Charter for SA Public Health System Consumers, for general information about consumer rights in the public health system. See page 33.

¹ This definition is reflected in the Carers Recognition Act 2005. A person is not a carer only because they are a spouse, defacto partner, parent or guardian to the consumer. Carers provide ongoing care and assistance in an informal capacity. Volunteers or contracted service provider 'carers' are not regarded as carers within this document.

Privacy and sharing information in mental health — it's a balancing act!

Privacy and sharing information in mental health care are like a balancing act. On one side are the rights to privacy for a consumer, where it's important that personal information is kept in confidence. On the other side, high quality mental health care depends on the 'effective' sharing of treatment information, so that the different people and services involved in a consumer's care know how to best support that person.

On most occasions, this balance of privacy and sharing information is something that should be decided by consumers. Sometimes though, service providers need to make a decision about this balance without a consumer's agreement. This especially happens when a person is too unwell to give consent for the sharing of information. It also happens when there are safety issues involved.

This situation is common to all health care. Public health services and service providers have a 'duty' to:

- make sure that a consumer's rights to consent and privacy are maximized where possible
- *act in the interests* of achieving the best possible care and treatment for the consumer
- *prevent risks* which could be harmful to consumers, carers and other community members.

Introduction

Making 'balanced' decisions about privacy and information sharing is something that you need to be involved in. As a consumer or a carer, this booklet encourages you to be proactive in talking with service providers about how information will be shared in your situation and how you can feel more in control of privacy matters. Learning about the rules governing privacy and disclosure is an important part of consumer and carer involvement in health care.

Did you know that a consumer's rights around privacy change when they are receiving treatment under the Mental Health Act? Do you need to know more? See pages 17 and 24.



This is about me! What are my rights to privacy?

There are many laws and Department of Health policies which describe how your personal information needs to be used, shared and kept private as it is collected by service providers. The following section lists your rights to privacy as set out under these rules.

Confidentiality

You have the right to have all identifying personal information kept confidential to those service providers involved in your treatment.

Under the South Australian Health Commission Act 1976 and the Mental Health Act 1993, service providers in the public health system are required to keep your personal information confidential. They are not able to disclose your information to any third parties² without your consent unless required or authorised to do so by the law or their employer. This would normally involve a 'duty of care' situation or a public safety issue. Service providers face serious penalties for breaching these laws.

Your information will be shared with other health service providers only on a 'need to know' basis. This will happen when they are asked to become involved in your assessment or treatment plan. For instance, it is standard practice for public hospitals to provide a discharge summary to your General Practitioner when you leave the hospital.

Some of your health information may be used to plan for future services and to help service providers to improve the quality and safety of these services. Wherever possible, any information used for these purposes should not identify you.

² Third party services, for instance private psychologists, non government accommodation services and other government providers will have their own methods for seeking your consent to release personal information.



Personal information.

As a consumer of a mental health service, your personal health information may be used in teaching students and trainees under the supervision of staff.

In these circumstances, your information will be treated confidentially by students, trainees and their teachers.

Your personal health information may also contribute to health care research. All research undertaken by public health services is approved by an ethics committee and performed in accordance with National Health and Medical Research Council guidelines.

Respect

You have the right to have your personal information treated respectfully by service providers.

Respect is a fundamental part of providing best practice health care. Your information should be used in a professional manner and only in the interests of providing high quality treatment and care.

Involvement of others

You have the right to decide who can be present during your treatment and health care.

This right means that you choose who can be invited to be a part of your care (i.e. third party persons and agencies). You can ask carers, advocates and other organisations to become involved and represent your interests to service providers.

In most cases, you can also refuse permission for third parties to become involved. In this situation it is important to weigh up the likely benefits and costs of not involving another person or service which your public service provider recommends.

Private conversations

You have the right to have conversations about your treatment held in private settings.

Your service provider should make sure that conversations about your health or any other personal matters are held in private rooms, or quiet areas.

Personal disclosure

You have the right not to tell a service provider about issues which are very personal to you.

There may be questions that service providers ask which you don't want to answer. These questions may bring up painful memories or may seem irrelevant to you. In these cases, it is important to understand that this information will be important for your care and recovery. We encourage you to ask about sensitive questions so that you can be more informed about the health care assessment and your involvement in providing information.

Accurate records

You have the right to have your information recorded accurately and kept up to date.

Service providers are obliged to enter highly accurate information on your health care records. If you find there is some information which doesn't seem right to you, ask your service provider to check your current and previous records for consistency.

If at any time you are unsure about what will happen to any information you have disclosed to service providers, you are able to ask them for an explanation.



Accessing records

You have the right to access, view and seek amendments to your healthcare records.

The Freedom of Information (FOI) Act 1991 enables you to access your medical record and any other document kept by mental health services. Given this right, many service providers will allow you to see your records without going through the formal application processes under the Act.

If a service provider does not respond to this request, you can use the formal application process. Most health services will be able to provide you with an application form. The application will be free if you are receiving a Commonwealth benefit. However, if you are working, the application fee is \$24.70 (as at December 2006). Another person can also make this application on your behalf if you nominate them.

If you believe that details in your record are incorrect, out-of-date or misleading, you can ask for an amendment or for a note to be added to the record which describes your perspective on a matter.

If you would like any further information, please ask to speak to the Freedom of Information Officer at your service. Information and forms are also available at the following website: www.archives.sa.gov.au/foi/.



What if I become unwell? -Planning in advance

The preceding pages point to many decisions you can make about how your information is shared by the people involved in your treatment.

At an early stage in your contact with services, you are encouraged to speak with your carers and service providers about the issue of information sharing. Many consumers find it is a good idea to make agreements with these people about what information should be shared should they become unwell and are less able to give informed consent.

This issue is important because different laws can come into play if you become significantly unwell. If you are detained under the Mental Health Act, service providers can make various decisions which affect you privacy. See page 17.





Making a Ulysses Agreement

Your preferences as to how information is shared amongst those involved in your care can be recorded via a written agreement (called a 'Ulysses Agreement') which is signed by you and those in the agreement (usually a carer and service provider).

Ulysses Agreements are not legally recognised in South Australia. However, they can provide an informal way for you to express your wishes about what should happen in future situations.³

Following are some arrangements that you can make with the individuals and agencies involved in your care:

- My carer should be consulted and involved in treatment planning if I am in hospital
- My carer can call mental health services for assistance, even though I might be upset about this during an episode of illness
- My public service providers are able to speak to my accommodation workers about my treatment plan. This can be extended to other workers from the community who are involved in my treatment
- Certain people can be involved but they should only be able to access some general information about my treatment, not any information about my personal history.

Any agreements should specify a time span during which the listed plans apply.

³ These agreements do not override treatment plans or privacy matters made in respect to the Mental Health Act (1993).

Planning for the care of your children

We encourage consumers to make sure arrangements are in place for the care of children. There is a resource available, the Supporting Our Family Kit, which encourages adults to talk with their children about mental illness and to help keep the family well connected in times of illness. Care plans for children can include:

- The names of your children and family contact details
- The names of care givers who can look after your children in case you need to go into hospital
- A list of belongings (toys, clothes, medication) that children need to take if they need to stay with a care giver or other family member
- The contact details of a child's school and their general practitioner
- The names of health workers who are supporting your recovery and can be a point of contact for the children
- Details of regular sporting or hobby groups the children attend.

The kit is available from Children of Mentally Ill Consumers (COMIC). Tel: (08) 8221 5160. It is also available online at: www.bowstat.com/comic/.

There are many resources available to help families talk about the nature of mental illness and recovery. The website of Children of Parents with a Mental Illness (COPMI), Tel. (08) 8161 6859, has a very useful resource section. The address for this site is: www.copmi.net.au/common/download.btml.



Making an Advanced Directive

Legally appointing another person to make decisions in the event of loss of mental capacity is a way of planning ahead to ensure that your wishes are followed.

There are various forms of advanced directives. In South Australia, legally recognised advanced directives include:

- Medical powers of attorney (under the Consent to Medical Treatment and Palliative Care Act 1995). This enables you to appoint an agent with power to make decisions on your behalf about medical treatment. You are also able to specify conditions about what the agent can or cannot do.
- Enduring powers of attorney (under the Power of Attorney and Agency Act 1984). This enables you to appoint an agent to manage legal and financial affairs. You are also able to specify conditions about what the agent can or cannot do.
- Enduring power of guardianship (under the Guardianship and Administration Act 1993). This enables you to appoint an agent to make decisions about lifestyle, accommodation and medical care. Again, you are able to specify conditions about what the agent can or cannot do.

(If you have not appointed an enduring power of guardianship and you become incapable of making your own decisions, the matter may be referred to the Guardianship Board. This may result in a guardian being appointed for you.)

Once made, these above directives only come into force when you become incapable of making your own decisions.

For further information

The Office of the Public Advocate has a more detailed fact sheet on advanced directives. This is available online at: www.opa.sa.gov.au (under publications).

These services below have application forms for advanced directives and should be able to provide information about getting the process started.

Legal Services Commission

Offices are at Adelaide, Elizabeth, Modbury, Noarlunga, Port Adelaide and Whyalla. Telephone legal advisory service: 1300 366 424 (9am-4.30pm, Monday—Friday).

Website: www.lsc.sa.gov.au

Service SA, Government Information Centre

77 Grenfell Street, Adelaide. Tel: 13 23 24, Fax: 08 8204 1909 Website: www.info.sa.gov.au

Consumers

What happens under the Mental Health Act?

The Mental Health Act (1993) has a number of additional rules around privacy and disclosure which affect your rights. This section describes when disclosure can be made without your consent.

Disclosure without consent If you are detained under the Act, service providers:

- may disclose your identity and relevant personal information to third parties who are essential in contributing to your care and treatment. These parties include the Guardianship Board, your primary carer(s), medical practitioners from the private sector, police and ambulance officers
- must inform persons who have a 'proper interest in the matter' whether you have been admitted or detained under the Act and, if so, the date of your admission to, and discharge from, a hospital



Service providers working under this Act recognise that these disclosures can only be made when they are based on your best interests and to persons who have a proper interest in the matter. If each of these criteria are not met, then a disclosure will not be made to carers or other relatives.

Service providers also recognise your 'best interests' as something which is influenced by the variable course of mental illness. There may be variations in your capacity to consent appropriately to information sharing. This capacity must be weighed at each point of time, taking into consideration any real, potential, immediate and future risks to your well being and the community more broadly.



Consumers

Are there other laws affecting my privacy?

There are a number of other laws which mean that aspects of your personal information can be communicated to third parties without your consent.

These laws have been made in the interests of public safety, where not to make a disclosure would place community members at risk.

Disclosure without consent

The various laws that require disclosure to third parties include:

- *Duty of Care.* Where a service provider needs to disclose information to a third party in order to avoid a real risk of injury to a consumer, or other member of the public. Any disclosure for reasons of 'duty of care' is determined on a case by case basis
- *Child protection.* Professionals are obliged to report information about a current situation where a child is at risk of abuse or neglect
- *Public health*. The diagnosis of certain diseases needs to be reported to public health authorities
- *Firearms*. Health professionals are obliged to advise the Registrar of Firearms where a person's mental health is likely to affect their safe use of a firearm
- *Motor vehicles*. Doctors need to advise the Registrar of Motor Vehicles if a person's mental health is likely to affect their ability to drive safely
- *Various legal orders*. Disclosure can be enforced by legal orders such as subpoenas, summonses, discovery orders etc.

In all of these cases, service providers can only disclose information that is relevant and sufficient to the Act or law in question.

In most cases, service providers should inform you about any disclosures they have made under these laws.

For young consumers

If you are under 16 years of age, the general rule is that your parents or guardian will be able to exercise your rights to privacy on your behalf.

If you are 16 years or older, you can make decisions about your own medical treatment and information sharing (Section 6 –Consent to Medical Treatment and Palliative Care Act 1995).

In some cases, children under 16 can consent to treatment arrangements directly, without needing their parents to consent. For this to occur, two doctors need to agree that the child understands the implications of the treatment and agree that it is in the best interests of the child.

It is important that you and your parents discuss the directions of your treatment and make sure everyone listens to each other's point of view. Your service provider should be able to help this discussion.

There are some useful websites available which talk about family issues and mental health. These include Reachout—www.reachout.asn.au, and the Maze—www.maze.sa.gov.au.





'I want to be involved' Carer participation in mental health care

Families and carers are at the centre of providing assistance and support to many consumers in the community. Carers assist by sharing social networks, friendships, love and hope. Carers are often involved in helping consumers with appointments and treatment, transport, medication issues, daily activities and accommodation.

The South Australian Public Health System encourages the involvement and support of family and other carers in the care of individual consumers. The recent Carers Recognition Act 2005 (Schedule 1.4) recommends that service providers aim to meaningfully include carers in the "assessment, planning, delivery and review of services that impact on them".

This statement recognises the importance of carers and family relationships in supporting consumers through an experience with illness. It also reflects that a 'team approach' to health care, where consumers, carers and service providers work together, is likely to assist the consumer's recovery.

For most situations, your involvement in care will depend on the agreement of the consumer and the communication of this agreement to service providers. From this agreement, there are various steps you can take in helping consumers, and requesting information from service providers.

Becoming involved

With the agreement of a consumer, you can be involved in discussion and decision making with public service providers.

In your initial contact with services, it is important that you and the consumer let the service provider know that you are the consumer's 'primary carer'. This means explaining the type of care you are providing and will provide to the consumer. The service provider should note your name and role within the consumer's health records for future reference, so that other staff understand your relationship with the consumer.

From here, being involved can occur in a number of ways. You can attend appointments with a consumer, after both of you have let the service provider know that you will be present. If a consumer is in hospital you can also ask to talk with a service provider, or arrange to be present in a case conference. In this situation, the service provider will check with the consumer to see if they're happy for your involvement before proceeding.

If for some reason a consumer prefers not to have you involved for all, or certain stages of his or her care, you can ask the service provider to explore issues of participation and information sharing with the consumer in a future conversation.

Gaining knowledge

You can ask for information about mental health care and how to develop skills for the caring role in mental health.

Service providers do their best to meet your information and educational needs as carers. The information you can ask about includes:

- the nature of the illness
- treatment and medication issues
- how to respond to disturbing behaviours
- where to find and access practical assistance.



How information is used

You can seek an explanation about how any personal information about a consumer will be used and recorded by service providers.

Service providers often ask carers questions about a consumer's behaviour and activity, especially during times when the consumer is unwell. These questions are a part of making a correct assessment. You can ask about the relevance of any questions if you do not understand their purpose and want to know how the information will be used. Also, you do not have to provide sensitive information about the consumer if you do not want to.

You need to be aware that the information you provide to service providers about a consumer will generally be made available to this consumer. Providing information as an anonymous person is possible only in some circumstances. If you have any concerns about a consumer having access to the information you have provided, you should discuss this with the service provider.

You can be involved in a consumer's care under the Mental Health Act. Please read the next section.



How does the Mental Health Act apply to me?

The Mental Health Act (1993) is a law which authorizes the way mental health care is provided in South Australia. Generally, the Act focuses on health care for consumers who have a serious mental illness and require hospital based treatment for their own health and safety or for the safety of the community. The Act enables consumers to be legally detained for treatment purposes.

Carer involvement in health care under the Act

In providing health care under this law, service providers must ensure that consumers "receive the best possible treatment and care" (Section 5) and make decisions about treatment which are in the consumer's best interests.

In arranging treatment, service providers need to manage the consumer's personal information respectfully and appropriately. Disclosures of personal information can only be made to specific agencies and people who are essential to the consumer's care.

Consumers who are very unwell may not be able to provide effective consent to these disclosures. People experiencing psychosis for example, may not think they are unwell and may not see the need for treatment or the involvement of essential services. The Act therefore enables service providers to act on behalf of the consumer and the community until the consumer's mental health improves.

If you are the 'primary carer' for the consumer, you may be seen as having a proper interest in ensuring the best possible treatment. It is likely that you will play an important role in the consumer's recovery. As such, service providers may invite your involvement in treatment discussions and disclose relevant personal information to you about the consumer's health.



You can also request to become involved by explaining your role as a primary support person in the consumer's life and requesting that service providers take this into account.

Decisions about carer involvement are the responsibility of service providers working under the Act and are made on a case by case basis.

Additionally, these decisions are influenced by the variable course of mental illness. There may be variations in a consumer's capacity to consent appropriately to information sharing. This capacity must be weighed at each point of time, taking into consideration any real, potential, immediate and future benefits and risks to the consumer's well being and the community more broadly.

Defined obligations of service providers

When a consumer is detained under the Act, service providers have defined obligations to:

- inform persons who have a 'proper interest in the matter' whether the consumer has been admitted or detained under the Act and, if so, the date of their admission to, and discharge from, a hospital
- notify a relative about the consumer's transfer between hospitals, providing this disclosure is in the consumer's best interests
- provide a relative with a statement of patients' rights under the Act, providing this disclosure is in the consumer's best interests.

In carrying out these obligations, or when requested to provide this information, service providers will need to check with you that you have a proper interest in the consumer's care.

Working together

The outcomes of mental health care are often far better when consumers, carers and service providers work effectively together and are able to work to a shared treatment plan.

Carer involvement doesn't mean that everything that a consumer discloses with their service providers is open to their carers. Certain limits need to be agreed to which respect the privacy of the consumer. Examples include details about the consumer's relationship with other family members, or current partners, or the inner feelings of the consumer about family life.

Involvement means that all parties have an awareness of the basic plans that are being put into place. It also encourages parties to have further discussions about what information can be shared and in how much detail.

For Young Carers

Children and young people often provide care-giving roles for their parents. This is very common in single parent families, but can happen in any family. It is natural for these children and young people to have questions about their parent's illness and when they are going to get better.

If you are a young carer, it is important for your helping role to be acknowledged by service providers. It is also important to be included, where appropriate, in meetings where the care of your parent is being planned.

Service providers should be able to help you understand what is happening and offer you a chance to ask questions about the causes of mental illness and how treatment works. They can also talk with you about making plans if your parent becomes unwell at home.



The other important thing is to talk about your own situation and to plan activities which are fun for you.

If you need help to talk about these things, the Carers SA offers support to young carers. Their phone no. is 1800 815 549. The Young Carers Web Page is available at: www.carers-sa.asn.au/yc/.

The Kids Help Line is also a place to get some help. Telephone 1800 55 1800 or look up: www.kidshelp.com.au.

There is written information available from the website of Children of Parents with a Mental Illness (COPMI). Their website is available at: www.copmi.net.au.





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Consumers and Carers

If I'm not happy... how do I make a complaint?

Ways of making a complaint

If you have a complaint about aspects of a service provider's communication, or bis or her decisions about privacy matters, there are a number of ways you can make a complaint. You can:

- speak to the service provider concerned and express the reasons for your dissatisfaction
- ask to speak to the service provider's team leader about the matter
- contact the patient or consumer advisor in the health service and make the complaint directly to this person
- contact or write to the General Manager of the Health Service where you receive your mental health care, and make the complaint.

You can also use these ways to compliment the service!

If taking any of these actions, it is very useful to ask another person to support you to voice your concerns. Examples of support people include carers, workers from an advocacy service, members of your support group or people working as consumer consultants in the mental health system.

Service providers need to take all complaints seriously. Efforts should be made to negotiate a solution to the issue which is satisfactory for you and the health service.

The Health & Community Services Complaints Commissioner's website has useful tips for preparing to make a complaint to a health service. You can also ring the Commissioner's Office for advice.

If you are still unhappy, you can lodge a complaint with:

The Health and Community Services Complaints Commissioner

Mail address: PO Box 199 Rundle Mall Adelaide 5000.

Enquiry service Tel: 08 8226 8666, Monday to Thursday 10.00am to 4.00pm

Toll free number for SA: 1800 232 007

Interpreters can be organised by the Commissioner

Website: www.bcscc.sa.gov.au

You can also approach various *professional registration bodies*. (Ring to ask for details for correctly lodging a complaint)

Medical Board of South Australia Tel: 08 8132 6444

Website: www.medicalboardsa.asn.au

Nurses Board of South Australia Tel: 08 8223 9700

Website: www.nursesboard.sa.gov.au

South Australian Psychological Board Tel: 08 8443 9669

Website: www.sapb.saboards.com.au

The Council of Occupational Therapists Tel: 08 8443 9375

Registration Boards (Aust. & NZ) Inc. Website: www.cotrb.saboards.com.au

Pharmacy Board of South Australia Tel: 08 8357 8992

Website: www.pharmacyboard.sa.gov.au

Consumers and Carers

Agencies which can support your concerns

The Office of the Public Advocate

Level 8 ABC Building, 85 Northeast Rd. Collinswood 5081

Tel: 08 8296 7575, Toll free: 1800 066 969

Website: www.opa.sa.gov.au

Carers SA

58 King William Road, Goodwood, South Australia 5034

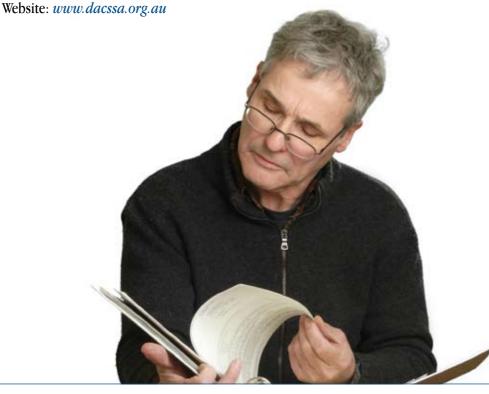
Tel: 08 8271 6288, Toll free: 1800 815 549

Website: www.carers-sa.asn.au

Disability Advocacy and Complaints Service of SA Inc

3/178 Henley Beach Road, Torrensville 5031

Tel: 08 8234 5699, TTY: 08 8234 2229, Toll free: 1800 088 325



Where can I get more information?

The following information is specifically about consumer and carer rights in the public health system.



Consumers and Carers

Your Rights and Responsibilities

-A Charter for South Australian Public Health System Consumers

Available from the Department of Health Tel: (08) 8226-6717

Website: www.health.sa.gov.au

Mental Health-Statement of Rights and Responsibilities (2000)

(Commonwealth policy on consumer rights in mental health). Available from the Commonwealth Department of Health and Ageing. Tel: (02) 6289 1555 (Central Office), Freecall: 1800 020 103

Website: www.health.gov.au/internet/wcms/Publishing.nsf/Content/mental-pubs

Relevant Laws and Acts on mental health care, privacy and disclosure

- Carers Recognition Act (2005)
- Children's Protection Act (1993)
- Consent to Medical Treatment and Palliative Care Act (1995)
- Duty of Care (Common Law relating to negligence)
- Firearms Act (1977)
- Freedom of Information Act (1991)
- Guardianship and Administration Act (1993)
- Medical Practice Act (2004)
- Mental Health Act (1993)
- Motor Vehicles Act (1959)
- Ombudsman's Act (1972)
- Power of Attorney and Agency Act 1984
- Public and Environmental Health Act (1987)
- South Australian Health Commission Act (1976)

These Acts can be found on the web at:

www.parliament.sa.gov. au/dbsearcb/acts-list. htm

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This document can be downloaded from the HCA website http://www.bcasa.asn.au/ Follow the link to publications.

Steering Committee Alan Bottrill, Gerald Graves, Maureen Healey, Nicki

Hirst, Rebecca Horgan, Ann Smith and Vic Kollosche

Project management Mark Loughhead

Graphic design Wayne Cunningham—Stereotype Design

www.stereotypedesign.com.au

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Privacy, Confidentiality and Getting the Best Care and Treatment