

Rights to health information

Many carers of people with dementia experience concerns about being properly informed about the health care of the person they are responsible for. Disclosure of information about a person's health care by the healthcare provider is governed by the Privacy Act. The Act does recognise that family and carers may need health information to be shared when they are responsible for decisions about the person's care or treatment. This sheet explains what is allowed under the disclosure provisions of the Privacy Act, and how these provisions may apply to people with dementia, their families and carers

Can doctors share the health information of a patient with dementia with family or friends caring for them?

For people with dementia, family or friends caring for the person often need to manage the person's day-to-day health needs, such as taking regular medications and keeping doctor's appointments. In addition, they often play a key role in making decisions about the person's health care or treatment. This is because many people with dementia at some point in their illness become unable to understand or discuss issues relating to their care or treatment. They may no longer be able to make decisions about and provide consent for necessary treatments. To prepare for this possibility, it is recommended people have set out their general preferences in advance care directives and have organised powers of attorney.

Our health information is considered sensitive information under the Australian federal Privacy Act, and usually cannot be disclosed to another person by our doctor or healthcare provider without our consent. However, the Privacy Act does allow health information to be disclosed to others when a person lacks the capacity to provide such consent, within specified limits.

The Privacy Act regulates how organisations such as healthcare providers handle personal information. It contains ten 'National Privacy Principles' or 'NPPs' that set out how organisations may collect, use, disclose and store personal information.

Under NPP 2.4, if a patient is physically or legally incapable of giving consent, their healthcare provider can disclose their health information to another person

who is responsible for them. The healthcare provider can only disclose the information if they are satisfied that it is necessary for the patient's care or treatment, or if the disclosure is made for compassionate reasons. The disclosure must also not be against the patient's known wishes. No more information should be shared than is necessary for the patient's care, treatment or for compassionate reasons. The healthcare provider needs to decide whether these criteria apply in the circumstances.

NPP 2.4 only operates where a person is 'physically or legally incapable' of providing consent, or cannot communicate their consent. Consent means voluntary and informed agreement. A person may be physically or legally incapable of providing consent if they cannot understand the issues relating to the decision, and then use their judgement to form a view. Alternatively, a person may be capable of making such decisions, but unable to communicate their wishes. Both these situations can apply to people with dementia. The healthcare provider needs to determine whether the individual has capacity to make a decision and communicate it, or whether it is appropriate to disclose the individual's information to a person responsible for them.

A healthcare provider cannot disclose a patient's information to just anyone. NPPs 2.5 and 2.6 state who the provider can share information with when the patient is incapable of giving consent. Depending on the circumstances, a person who is responsible for the patient can be:

- their spouse, de facto or partner (same or opposite sex)
- their parent or guardian

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- their siblings or children (if they are 18 or older)
- a relative who lives with them (if they are 18 or older)
- a close friend, companion or personal carer
- their nominated emergency contact
- someone with a health-related 'enduring power of attorney'

Alternatively, the healthcare provider can disclose the patient's health information if one of the exceptions under NPP 2.1 permits the disclosure. This includes where a law requires or authorises disclosure (such as under a guardianship order), or where there is a serious and imminent threat to an individual's life, health or safety.

Access to accurate and up to date health information can be an important aspect of caring for a person with dementia. The Privacy Act permits this type of disclosure, but it does not require it – the discretion is left with the healthcare provider. If the healthcare provider decides not to disclose this information, they should explain to the person responsible why the disclosure is inappropriate in the circumstances.

Here is one example of how these regulations might apply for a person with dementia:

A man has had dementia for several years and has now been diagnosed with high blood pressure. When he visits his doctor, the doctor realises that the patient has been forgetting to take his blood pressure lowering medication. The patient is unable to consent to his doctor disclosing his health information to anyone else. However, the patient had listed his wife as an emergency contact when he first visited the practice, and his wife now accompanies him whenever he visits the doctor. His doctor tells the patient's wife what medication her husband needs to take, and when he needs to take it. His doctor also talks to the patient's wife about what activities he cannot do, such as driving a car and operating power tools. This is allowed under the Privacy Act because the information is disclosed to the patient's wife to ensure he receives appropriate care or treatment. However, the doctor does not tell the patient's wife about past conditions or treatments that have no bearing on his current care.

A disclosure for compassionate reasons could include a doctor telling a patient's partner or family about the patient's condition and their prognosis following an accident or during a serious illness. It could also include disclosing information to someone who the patient has nominated as an emergency contact, as long as reasonable steps are taken to verify that person's identity.

More information

An information sheet from the Office of the Australian Information Commissioner provides further information about the issues discussed here. *Information Sheet (Private Sector) 24 - 2008: Disclosure of health information and impaired capacity* is available at privacy.gov.au/materials/types/infosheets/view/6557

A related 'frequently asked question' (FAQ) is available at privacy.gov.au/faq/health/977

Information about the Privacy Act and its application in circumstances where a person is unable to give consent for disclosure of their health information is available at the website of the Office of the Australian Information Commissioner (OAIC): privacy.gov.au

FURTHER INFORMATION

Dementia Australia offers support, information, education and counselling. Contact the National Dementia Helpline on **1800 100 500**, or visit our website at dementia.org.au



Interpreter

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