



Ms A Sanderson, MLA  
Chair, Joint Select Committee  
on End of Life Choices  
Parliament House  
4 Harvest Terrace  
WEST PERTH WA 6005

Dear Ms Sanderson

Thank you for your invitation dated 15 September 2017 to provide a submission to the Joint Select Committee (the Committee) on End of Life Choices.

The Health and Disability Services Complaints Office (HaDSCO) is an independent Statutory Authority offering an impartial resolution service for complaints relating to public and private health, disability and mental health services in Western Australia and the Indian Ocean Territories. HaDSCO is established under the *Health and Disability Services (Complaints) Act 1995* (HaDSC Act) and also has responsibilities under Part 6 of the *Disability Services Act 1993* and Part 19 of the *Mental Health Act 2014*.

Having regard to the Committee's terms of reference, HaDSCO is aware that there are mechanisms currently in place, such as Advanced Health Directives and an Enduring Power of Attorney, which enable individuals to plan for decisions about their medical, surgical, dental and healthcare treatment to be made on their behalf, in circumstances where they are unable to make these decisions for themselves. Whilst HaDSCO cannot comment on the type of legislative change required in respect of End of Life Choices, it can by virtue of its role, offer some information that may be of assistance for this consideration.

From time to time, HaDSCO receives complaints about end of life issues or palliative care in the context of the provision of a health service, as defined in section 3 of the HaDSC Act. A health service relevantly means any service provided by way of —

- (a) diagnosis or treatment of physical or mental disorder or suspected disorder; and
- (b) health care, including palliative health care; and
- (c) a preventive health care programme, including a screening or immunization programme; and
- (d) medical or epidemiological research, and includes any —
- (e) ambulance service; and
- (f) welfare service that is complementary to a health service; and

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- (g) service coming within paragraph (a), (b) or (c) that is provided by a person who advertises or holds himself or herself out as a person who provides any health care or treatment; and
- (h) prescribed service,  
but does not include an excluded service.

Section 4 of the HaDSC Act sets out the guiding principles for the provision of health services. These are:

- (a) quality health care, given as promptly as circumstances permit; and
- (b) respect for the privacy and dignity of persons receiving health care; and
- (c) the provision of adequate information on services provided or treatment available and the effects and costs of treatment, in terms that are understandable; and
- (d) participation in decision making affecting individual health care; and
- (e) informed choice in the acceptance or refusal of treatment or participation in education or research programmes; and
- (f) reasonable access to information in records relating to personal use of the health care system, except information that is expressly prohibited by law from being disclosed or information contained in personal notes by a person giving health care; and
- (g) the protection of personal health records and personal information from disclosure except for proper purposes.

With regard to complaints received about end of life issues and palliative care in the context of the provision of a health service, complaints are usually received by family members or carers of deceased people or on behalf of people receiving palliative care. Section 25 of the HaDSC Act sets out what complaints can be about. A complaint must allege that one or more of the following has occurred —

- (a) a provider has acted unreasonably by not providing a health service for the user;
- (b) a provider has acted unreasonably in the manner of providing a health service for the user, whether the service was requested by the user or a third party;
- (c) a provider has acted unreasonably in providing a health service for the user;
- (d) a provider has acted unreasonably by denying or restricting the user's access to records kept by the provider and relating to the user;
- (e) a provider has acted unreasonably in disclosing or using the user's health records or confidential information about the user;
- (f) a manager has acted unreasonably in respect of a complaint made to an institution by a user about a provider's action which is of a kind mentioned in paragraphs (a) to (e) by —
  - (i) not properly investigating the complaint or causing it to be properly investigated; or
  - (ii) not taking, or causing to be taken, proper action on the complaint;
- (g) a provider has —
  - (i) acted unreasonably by charging the user an excessive fee; or
  - (ii) otherwise acted unreasonably with respect to a fee;
- (h) a provider that is an applicable organisation as defined in section 4 of the *Carers Recognition Act 2004* has failed to comply with the Carers Charter as defined in that section.

HaDSCO manages complaints using a resolution based approach relevant to the matters under consideration. Complaints involving end of life issues and palliative care involve sensitive matters for family members. HaDSCO staff manage them with care ensuring that those making the complaints feel comfortable and supported during the complaints process. Complaints are resolved through negotiated settlement, conciliation and investigation. Through these resolution options, including for complaints about end of life issues and palliative care, a range of outcomes may be achieved. These include the issuing of apologies, provision of explanations, changes to policies and procedures and staff training.

Service providers generally show a strong willingness to participate in complaints resolution. The outcomes can assist families to understand the reasons for clinical decisions that are made having regard to clinical standards and policies within a clinical governance framework. One of HaDSCO's key functions is to review and identify the causes of complaints, and to suggest ways of removing and minimising those causes.

Having regard to the guiding principles set out under section 4 of the HaDSC Act, as listed above, when dealing with complaints about end of life issues and palliative care, HaDSCO is particularly interested in reviewing the quality of health care provided; the ability for the patient or family member or guardian to participate in decision making to enable them to make informed choices about treatment; and the provision of information to the relevant parties.

In accordance with the *Health Practitioner Regulation National Law (WA) Act 2010*, HaDSCO is required to consult with the Australian Health Practitioner Regulation Agency (AHPRA) about complaints concerning registered health professionals relating to health, performance or conduct matters. The consultation process provides a mechanism through which a determination can be made about which is the more appropriate agency to manage the complaint. This is also a key aspect of HaDSCO's management of a complaint about end of life issues and palliative care.

I trust that the above information demonstrates HaDSCO's role in dealing with complaints which involve end of life issues and palliative care.

Thank you for the opportunity to provide this information.

Yours sincerely

**SARAH COWIE  
DIRECTOR  
HEALTH AND DISABILITY SERVICES COMPLAINTS OFFICE**

23 October 2017