

Learning from complaints about end of life and palliative care



The Health and Disability Services Complaints Office (HaDSCO) is an independent Statutory Authority providing an impartial resolution service for complaints relating to health, disability and mental health services in Western Australia and the Indian Ocean Territories.

HaDSCO's role dealing with end of life and palliative care complaints

Complaints about end of life and palliative care are an important area of work for the Office. HaDSCO staff add value by facilitating complaint resolution and the identification of service improvements. Such complaints are often brought by family members following the death of a loved one.

The complaints highlight how particular matters associated with the death of an individual remain unresolved. The motivation for making complaints is often to seek an explanation once there has been time to reflect.

Who can make a complaint?

A complaint can be made by:

- The person who received the service.
- A relative, representative or carer.
- A representative of a person who died.
- A carer, about a failure to comply with the *Western Australian Carers Charter* as set out in the *Carers Recognition Act 2004*.

What do the complaints highlight?

The complaints highlight:

- The levels of distress for individuals and family members during end of life care and during palliative care of loved ones.
- The need for patient-centred care and for the person to be made comfortable at the end of life.
- The individual circumstances of a patient are unique:
 - Cultural and personal circumstances are important considerations.
 - There may be matters which are particularly important to somebody (e.g., dietary requirements, concerns about falls, the location of the patient in the ward).
- The need for the individual and family members to be involved in decision making:
 - The importance of integrating a patient's values and circumstances into decision making.
 - Patient and family members often come from a well-informed position and have done their research.





- The need for regular and ongoing fit for purpose communication.
 - People and family members want to be informed about what to expect.
 - Some individuals want more communication than others.
- There can be misunderstandings about what end of life and palliative care mean, including amongst individuals and amongst health practitioners.
- There is a need for co-ordination of care across multi-disciplinary teams.
- Social workers and pastoral care support can assist.
- There are additional complexities where family members are out of the region or interstate.

How do we resolve the complaints?

HaDSCO often resolves end of life and palliative care complaints through conciliation. Conciliation brings the parties together and family members have an opportunity to express their experiences with service providers and health practitioners with an independent HaDSCO officer to facilitate the meeting.

Conciliations are undertaken within a confidential framework. Evidence of anything said or admitted during the conciliation process is not admissible in proceedings before a court or tribunal.

Conciliations are highly emotional experiences. They:

- Help with the healing process.
- Provide opportunities for family members and health practitioners to be heard.
- Help family members see the empathy and compassion of health practitioners.

The conciliation process assists both parties to be able to talk openly and freely about what occurred. Family members have expressed that the conciliation process provides a sense of relief.

HaDSCO can arrange for written explanations to be provided instead of a conciliation meeting.

Not all complaints are suitable for conciliation. Complaints are assessed by HaDSCO staff to ensure they are appropriate for conciliation. This will depend on what outcomes are being sought. The conciliation process is voluntary and both parties to a complaint need to agree to participate. Where complaints are not suitable for conciliation, they may be resolved through HaDSCO's negotiated settlement process. This is a paper-based approach involving the exchange of written information to assist in resolving the complaint. HaDSCO has separate Information Sheets on both processes.

What outcomes are achieved?

Complaints can be valuable feedback for service providers and can lead to quality improvements for other service users. Complaints can result in a number of outcomes including:

- Explanation.
- Apology.
- Change in policy or procedure.
- Refund or waiver of fees.
- Access to a service.
- Training or education for the service provider.

Many complaints are used as de-identified case studies for training purposes to assist in learning from complaints.





What can we learn from the complaints?

There are two component outcomes that can be derived from a complaint:

- The resolution of matters in dispute between the parties to a complaint.
- The opportunity for service delivery improvements.

Complaints can give an indicator of service delivery issues and trends in an organisation and can drive system changes. From one complaint, there can be redress for the individual and system changes for many others to improve service delivery.

Complaints highlight that the patient experience is key. A positive patient experience hinges on considering the patient's values and circumstances. Considering and respecting the values and circumstances of patients will improve interaction and the patient's experience overall. Sir William Osler stated that "A good physician treats the disease, the great physician treats the patient who has the disease."

Complaints about end of life and palliative care highlight the need for good communication between the parties. Based on the observations made in managing the complaints, the following tips may assist with communication.

Tips for patients and families:



- Acknowledge that this is an emotional time.
- If you want to know something, ask.
- Be prepared; have a list of questions and set out what you want to know.

- Listen carefully. If possible, have someone else with you to assist with understanding.
- Check you have understood. If you don't understand, seek clarification and get more information. Don't interpret or assume.
- Your values and circumstances are important. Communicate how they might influence decision making, however, acknowledge that health practitioners have a depth and breadth of clinical experience and expertise.
- Be ready to receive difficult messages.
- Ask who you can speak to if you have a concern or complaint.

Tips for service providers and health practitioners:



- Acknowledge the feelings and emotions of patients and their families.
- Ensure communication is fit for purpose. Avoid using complex words and jargon.
- Listen, engage and repeat. Ensure that the information discussed was understood.
- Everyone is entitled to be kept informed. Some people want more information. Anticipate and respond.
- Answer questions and provide information about what to expect.
- Ensure your non-verbal communication is appropriate for the situation.
- Ensure confidentiality; avoid disclosing information in open or public spaces.
- Consider and respect the patient's and family's values and circumstances. This will assist with communication and improve interaction, and the patient's experience overall.





The Health and Disability Services Complaints Office (HaDSCO) is an independent Statutory Authority offering an impartial resolution service for complaints relating to health, disability and mental health services in Western Australia and the Indian Ocean Territories. Our services are free and available to everyone who uses and provides health, disability and mental health services.

What we do

HaDSCO acts impartially and in confidence to support improvements to health, disability and mental health services through resolution and investigation of complaints and providing education and training to service providers in the prevention and resolution of complaints.

HaDSCO encourages that complaints are raised with the service provider in the first instance. A complaint can be lodged by the service user or nominated representative. If this proves unsatisfactory, a complaint can be raised to HaDSCO.

What you can complain about

Complaints may include allegations that a health, disability and mental health service provider has acted unreasonably:

- by refusing to provide a service.
- by providing a service that should not have been provided.
- in the manner of providing a service.
- by denying or restricting the consumer's access to records.
- by breaching confidentiality.
- by not effectively dealing with a complaint.
- by failing to comply with the Carers Charter, Disability Services Standards and Mental Health Care Principles.

HaDSCO is generally unable to deal with matters that are more than two years old, or that have already been determined by a court, registration board or tribunal. In these cases referrals to alternative organisations may be suggested.

Supporting improvement through complaint resolution

Complaints and enquiries: (08) 6551 7600

Free call: 1800 813 583 (free from landlines)

Admin: (08) 6551 7620

Email: mail@hadsco.wa.gov.au

Web: hadsco.wa.gov.au



Health and Disability Services
Complaints Office (HaDSCO)



Interpreter Service: 131 450 - tisonational.gov.au

National Relay Service:

1800 555 660 - relayservice.wa.gov.au

