

Funding & Services Provided

12(b) Would your hospitals, or other Catholic Health facilities, support a patient at the end of life seeking terminal sedation?

St John of God Health Care (SJOG) response - Sedation may be used in exceptional circumstances at the end of life to alleviate distress that cannot be alleviated in any other way in a patient who is imminently dying. The dose of sedation used in these situations is kept to a minimum, and if necessary titrated vs effect to ensure comfort and alleviation of distress. In recent years the number of other options for symptom relief has reduced the need to consider this approach.

- i. **Under the PCOC assessments, patients and clinicians each rate the severity of a patient's pain, while only clinicians rate the severity of patients' psychological or spiritual problems.¹ Would the assessment of whether their symptoms are refractory be a matter for the patient or the doctor?**

SJOG response - The assessment of any symptom requires input from the patient and the clinician. Observation by members of the multidisciplinary team, family members and advocates can be a powerful mode of assessment where patient reports are unreliable or unobtainable.

- ii. **Department of Health issue guidelines for adults in the terminal phase.² Would medical practitioners in Catholic institutions follow similar guidelines?**

SJOG response - Yes, we advocate use of these guidelines.

- iii. **Would you say that the patient's level of distress should be the guiding factor in treatment? If not, what other factors need to be considered?**

SJOG response - Distress levels are one factor guiding treatment. Contributors to distress, and factors altering perception threshold (including a range of physical, psychosocial and spiritual factors) need to be considered. Management may be directed at minimising these contributors and does not necessarily involve medication. Consideration of non-drug measures to alleviate distress is equally important.

12(c) Are you aware if any of your hospitals, or other Catholic Health facilities, have ever had a patient request voluntary assisted dying?

SJOG response - Occasionally patients request assisted dying. Our approach then is to acknowledge the distress that has led to the request and explore why the request has been made, and then to address contributing factors. Often fear is a major factor, and acknowledgement, explanation and reassurance of continued presence and monitoring and adjustment of the management plan are all that is required.

Doctrine of Double Effect

13 Catholic Health Australia, in your submission you raised the doctrine of double effect and the protection under the Criminal Code³:

- a. **The provision you refer to is section 23A(2) of the Criminal Code and it is generally a defence if a person's act is unwilling; this is distinct from not intending the**

consequences of an act.⁴ The relevant provision protecting medical practitioners is s 259(1). Would you like to comment?

Catholic Health Australia (CHA) response - This is an ethical or moral principle, not a legal principle. It may provide grounds for a legal defence, but only in the circumstances noted below.

The question it seeks to answer is: “Is a doctor ethically or morally responsible for causing a patient’s death – that is, is the doctor culpable of killing the patient – if he/ she delivers a medical treatment that has two effects, one positive (eg pain relief) and the other negative (eg shortening of life)?”

The Principle answers “no” **if and only if**

- a) the specific treatment (eg specific medication or combinations of medications in this specific dose) is clinically indicated to deliver the pain relief required; and
- b) the treatment itself relieves the patient’s pain or discomfort directly (so if death occurs it occurs subsequent to the relief attained and not vice versa); and
- c) no better treatment is reasonably available or tolerable to the patient.

The Principle may provide grounds for a legal defence for the doctor only if the treatment applied is both medically indicated and necessary according to professional practice standards: that is, if in the view of most similarly experienced doctors in a similar situation, the same treatment should be applied. In such a case the law seems to favour the professional judgment of the doctor.

But if a doctor were to provide a clearly disproportionate treatment – eg a larger dose than clinically indicated at the time – and the patient dies as a result, the doctor might be considered to have directly intended the patient to die, and therefore might be open to litigation.

Proper application of the Principle of Double Effect is therefore ethically and legally quite distinct from any notion of ‘physician assisted dying’ or ‘voluntary assisted dying’, both of which are defined precisely as “an action which of itself and by intention causes the patient’s death.”

The Principle can be used to justify “**palliative sedation**”, defined as “the careful administration of appropriate medications in doses just sufficient to relieve distress. Such sedation is reversible. Death is not the goal.”

- b. In your experience how common is this doctrine relied upon in palliative care in WA?**

SJOG response - Rarely in a specialist context.

- c. Are the instances where death has occurred as a ‘negative side-effect’ of administering palliative medication recorded?**

SJOG response - The sequence of care, timing of any medication interventions, and the time of death are recorded.

- d. Who decides if the need to relieve pain warrants accepting the risk of hastening death?**

SJOG response - With skilful titration of analgesia this should not need to be considered.

- e. Have you had patients or their substitute decision makers request an increase in palliative medication knowing the risk of a hastened death?**

SJOG response - Yes, but this is uncommon. Such requests are dealt with as for requests for assisted dying.

Palliative Care in Residential Aged-Care Facilities

14 A question for Catholic Homes WA - do you offer palliative care services at your residential care facilities?

(a) If not, how do patients access palliative care, specialist or otherwise, when it is required?

Catholic Homes response - Catholic Homes WA do provide palliative care services at our residential care facilities. At the facilities where we do not have Registered Nurses working 24 hours/day, we engage Silver Chain Hospice Service via referral from the GP. Silver Chain Hospice is available for staff to call 24 hours a day, 7 days a week, and will attend to administer medications – usually injectable, and via a NIKI pump when required. Staff will ring this service after hours and on weekends when there is no nurse at the facility. At our larger facilities where there is registered nurses 24 hours a day, we do not engage Silver Chain.

15 Are there patients in residential care facilities operated by Catholic Health Australia members who have been assessed as requiring palliative care or specialist palliative care?

CHA response - There will be residents in Catholic aged care services who have been assessed as requiring palliative care or specialist palliative care, but whether such residents continue to be cared for will depend on the capacity of each home to deliver the level of care that is required. This will sometimes depend on whether expert palliative care support is available from local public health authorities. Aged Care homes are not expected to deliver care beyond their clinical capability.

SJOG response - These patients can access support via the Metropolitan Palliative Care Consultancy Service.

16. Evidence suggests the number of aged-care residents and admissions appraised as requiring palliative care has trended downwards. However, it may be that the application of the Aged Care Funding Instrument (ACFI) has influenced these figures.⁵

(a) Are you able to provide comment, on the changes to the application of the ACFI for palliative care?

CHA response - There have been no changes to the ACFI question relating to palliative care (Question 10 of the Complex Health Domain) since ACFI was introduced in 2008. However, the ACFI is administered by individual providers which may have led to changes in provider claiming practices over time. CHA does not have evidence relating to claiming practices against the palliative care question. There have been recent changes to the weightings of other questions in the Complex Health Domain, in particular 'complex pain management'.

Catholic Homes response - The current ACFI system enables palliative care to be claimed in the complex health domain. To satisfy the evidence requirements as specified by the ACFI user guide, palliative care can only be claimed in the last week to days of life. They direct providers to the definition of palliative care (page 6 of the ACFI user guide under End of Life) as "care provided to the

resident in the last week or days of life". To resubmit an ACFI for a resident is an onerous process, so providers are likely to not do so to claim for palliative care, with the increase in funding for this claim only for days to one week, and is a very minimal increase in funding (if at all) in any event. Therefore if data relating to aged-care residents requiring palliative care is obtained from this source –ie. ACFI palliative claims, it is likely to be inaccurate.

(b) Are you able to provide comment on the suggestion that the number of aged-care residents and admissions appraised as requiring palliative care has been trending downward?

SJOG response - Palliative care needs are likely to be underreported. Non-specialists may lack the skills to be able to detect palliative care needs. Many care homes have been upskilled through the capacity building work undertaken by MPACCS. However, one of the challenges of this work is the rate of staff turnover in care homes.

CHA response - National data on claiming practice trends would be more appropriately directed to the Australian Government Department of Health.

(c) From your experience, are you able to comment on whether the number of aged-care residents and admissions actually requiring palliative care has decreased since 2012-13?

CHA response - CHA does not have access to trend data on the number of residents requiring palliative care.

17 In your submission you state aged-care facilities are ineffectively resourced to provide permanent palliative care expertise.⁶ Do your members engage the services of Metropolitan Palliative Care Consultancy Service in WA?

(a) If not, why not? OR

(b) If so, can you provide comment on the level and quality of service and accessibility?

Catholic Homes response - The Metropolitan Palliative Care Consultancy Service (MPaCCS) in WA is available to aged care facilities. The service is good, but is more a consultancy service operating during business hours Monday to Friday. Without a good GP who is available and accessible to staff (including outside of their usual round times), and who is prepared to meet with the family at the appropriate time – usually more than once as the resident deteriorates and approaches death (often after hours) it is very difficult to deliver good palliative care to residents in an aged care facility.

SJOG response - The service is excellent, but limited in scope and is a 5 day, working hours service

From their website (<https://www.bethesda.org.au/MPaCCS.aspx>):

Metropolitan Palliative Care Consultancy Service (MPaCCS) is a mobile specialist palliative care team, focusing on capacity building of the palliative care sector workforce through training, education, assistance and mentoring where there are currently no specialist palliative care consultation services available for residents or patients at the following locations:

- *Mental health and psycho-geriatric facilities;*
- *Residential aged care facilities;*
- *Residential disability facilities;*

- Correctional facilities;
- Aboriginal and Torres Strait Islander medical service facilities;
- General practitioners (GPs) and consultants working in the above facilities; and
- Hospital staff engaged in the discharge planning for patients who will transfer to a facility or institution.

The service operates in a mobile manner and services the north and south metropolitan regions. The MPaCCS team seek to work collaboratively with GPs and other health care team professionals to ensure superior levels of patient outcomes.

Advance Health Directives

- 20 This question is for St John of God Health Care, but we will open it up after the initial response: You indicated in your submission a relatively low instance of advanced care plans or Advanced Health Directives being used.⁷ Can you comment on why you think this is the case?**

SJOG response - It takes a significant length of time to have these conversations properly, and often multiple conversations are needed before a patient is able to arrive at a firm decision regarding preferences for care, and any ceiling of intervention. In addition, many clinicians lack the skills and confidence to hold these discussions effectively.

- 21 St John of God Health Care also indicated that there are questions arising as to the validity of advanced care plans and AHDs when they are present.**

- a. Can you please explain what you mean by ‘questions of validity’ in relation to advance care plans as these are not statutory instruments?**

SJOG response - Can we be sure that what is written adequately reflects the patient's current wishes?

- b. What are the ‘questions of validity’ that arise in relation to AHDs?**

SJOG response – How confident are we that the patient was of sound mind when the AHD was written? Do the current circumstances sufficiently match the circumstances to which the decisions apply? Is there any reason to believe the patient's wishes may have changed since the AHD was written? Is the intent of the patient clear? (Wording can be ambiguous) Can coercion be reasonably excluded?

- 22 Do other witnesses have similar experiences with advanced care plans or Advanced Health Directives?**

- 23 Could anyone comment, just based on their experiences, on the proportion of patients in palliative care that have advanced care plans or Advanced Health Directives in place?**

SJOG response - Very small numbers with formal AHDs, but many more with verbally expressed or written advance care plans. The number of advance care plans is increasing. In specialist units and consultancy services it is usual to hold discussions about the patient's wishes for future care. Some patients prefer not to make any firm decisions in advance.

Other issues

24 This inquiry is looking at all aspects of the law on end-of-life choices – are there any specific areas not yet discussed that you think require change or improvement?

SJOG response - Current laws in relation to the prescribing of strong opiates in palliative care necessitate frequent medical appointments for patients even when pain relief needs are stable. This means care remains, at times, unnecessarily focussed on regular medical appointments at a time when the focus should be on quality of life and keeping medical intervention to a minimum. This has implications for patients and limits the capacity of healthcare services.

Good palliative care involves a thorough and frequent assessment of psychological state. Timely access to appropriate levels of psychological support is essential in order to address holistic care. Rapid access to psychological and psychiatric services is limited outside the context of inpatient specialist palliative care. In the absence of adequately addressing psychological distress, requests for assisted dying may be more likely.

Supporting carers keeps patients at home. Most care in the last year of life is provided by informal carers in the home. Access to community care to enable safe and supported discharge from hospital is becoming increasingly difficult, with waits of up to 12 months to access appropriate formal care packages. The burden on carers, causing carer fatigue and stress, frequently results in breakdown in care at home and admissions to hospital for social reasons. Addressing availability of care in the community will enable timely discharge from hospital and reduce the number of unnecessary admissions.

This in turn will enable specialist units to focus on more proactive care for patients with the most complex symptom control and psychological/ spiritual needs. These patients are currently often managed in acute hospital beds, with or without support from palliative care consultancy services. Failure to refer early to the palliative care team can result in unnecessarily long lengths of stay in hospital, and unnecessary/ inappropriate investigations and interventions.

Lack of access to rehabilitation services also disadvantages palliative care patients. Maintaining function is particularly important in this patient group, who decondition quickly in the context of advancing disease. Maintaining independence keeps people at home and reduces the overall cost of care.