

# **PATIENT-RATED SEVERITY OF DISTRESSING SYMPTOMS EXPERIENCED IN TERMINAL PHASE OF PALLIATIVE CARE**

**WA Palliative Care Services, July-December 2016**

**Patient-rated Symptom Assessment Scale (SAS)\* scores at beginning of patient's terminal phase (percentages)**

| Symptom Distress Score          | Inpatient Setting |               |                |                  | Community Setting |               |                |                  | Weighted Average |               |                |                  |
|---------------------------------|-------------------|---------------|----------------|------------------|-------------------|---------------|----------------|------------------|------------------|---------------|----------------|------------------|
|                                 | 0<br>(Absent)     | 1-3<br>(Mild) | 4-7 (Moderate) | 8-10<br>(Severe) | 0<br>(Absent)     | 1-3<br>(Mild) | 4-7 (Moderate) | 8-10<br>(Severe) | 0<br>(Absent)    | 1-3<br>(Mild) | 4-7 (Moderate) | 8-10<br>(Severe) |
| Difficulty sleeping             | 93.3              | 3.2           | 2.7            | 0.8              | 81.2              | 7.7           | 10.4           | 0.7              | 86.6             | 5.7           | 7.0            | 0.7              |
| Appetite problems               | 96                | 2.4           | 1.1            | 0.5              | 94.6              | 2             | 2.2            | 1.2              | 95.2             | 2.2           | 1.7            | 0.9              |
| Nausea                          | 95.5              | 1.8           | 2              | 0.8              | 92.8              | 3.7           | 3.5            | 0                | 94.0             | 2.9           | 2.8            | 0.4              |
| Bowel problems                  | 92.5              | 4.1           | 2.6            | 0.8              | 89.4              | 6.8           | 3.7            | 0.1              | 90.8             | 5.6           | 3.2            | 0.4              |
| Breathing problems              | 73.6              | 13.6          | 9.6            | 3.2              | 67.3              | 16.6          | 13.4           | 2.6              | 70.1             | 15.3          | 11.7           | 2.9              |
| Fatigue                         | 88.8              | 4.2           | 4.1            | 2.9              | 80                | 1.2           | 12.9           | 5.9              | 83.9             | 2.5           | 9.0            | 4.6              |
| Pain                            | 64.5              | 22.7          | 10.2           | 2.6              | 54.4              | 25.7          | 18.1           | 1.8              | 58.9             | 24.4          | 14.6           | 2.2              |
| <b>Totals</b>                   |                   | 52            | 32.3           | 11.6             |                   | 63.7          | 64.2           | 12.3             |                  | 58.5          | 50.1           | 12.0             |
| No. of terminal phases reported | 665               |               |                |                  | 837               |               |                |                  | 1502             |               |                |                  |

\* describes the patient's level of distress relating to individual physical symptoms. The symptoms in the scale are the seven most commonly experienced by palliative patients: difficulty sleeping, appetite problems, nausea, bowel problems, breathing problems, fatigue and pain. The instrument is designed to be a patient-rated tool but also allows for rating by proxy (e.g. family, carer or clinician).

**Source:** Connolly A, Allingham S, Pidgeon T, Clapham S, Quinsey K and Foskett L (2017) *Patient Outcomes in Palliative Care: Results for Western Australia, July – December 2016, detailed report*. Palliative Care Outcomes Collaboration, Australian Health Services Research Institute, University of Wollongong, Tables 35 and 36.

## ELIGIBILITY TO ACCESS VOLUNTARY ASSISTED DYING (VAD)

1. **Age** 18 or over.
2. **Capacity** Legally capable of making decisions.
3. **Condition** A grievous and irremediable medical condition, where:
  - a. The illness, disease or disability is serious, progressive and incurable
  - b. The patient is in an advanced state of irreversible decline
  - c. Natural death due to the condition has become reasonably predictable
  - d. The patient is enduring intolerable physical and/or psychological suffering that cannot be relieved under conditions acceptable to the patient.
4. **Requests** to access VAD have been made on three occasions and are:
  - a. Free and voluntary
  - b. Without external pressure and coercion
  - c. Fully informed as to all available treatment options other than VAD
  - d. Enduring over a period of at least a week from first to last request.

5. **Assessment** as to fulfilment of the above criteria has been carried out by two independent medical practitioners between the first and last requests.

### Notes

1. Should both independent medical practitioners agree that

- a. the patient's medical condition has undergone or is likely to undergo unacceptable deterioration before the expiry of a week from the first request
- b. at least one day has elapsed since the practitioners have reached that agreement

the third request may be made before the elapse of one week since the first request.

2. Should legal capacity be lost

- a. after the second request and before the third
- b. where an Advance Health Directive requesting VAD was in place before the first request
- c. all other eligibility requirements remain in place

the third request may be lawfully acted upon.

## **STATUTORY SAFEGUARDS FOR PERSONS REQUESTING ACCESS TO VAD**

- 1.** All eligibility requirements must be met in accordance with the previous list.
- 2.** The patient must not be suffering from untreated active major depressive illness.
- 3.** Both independent medical practitioners must provide written reports stating that all eligibility requirements have been met, and that the patient is not suffering from untreated active major depressive illness.
- 4.** The second request must be in writing, signed and dated, before two independent witnesses who must then also sign and date the request.
- 5.** The third request must be made verbally to the medical practitioner who will activate the VAD process.
- 6.** An opportunity must be afforded the patient to withdraw the third request, and their express consent to VAD must be confirmed, before the VAD process is activated.
- 7.** Each assisted death must be reported to a statutory authority, with all relevant documentation retained and available for medical auditing purposes.
- 8.** Both medical practitioners must be accountable in the auditing process for the contents of their written reports.
- 9.** The medical practitioner who activates the VAD process must be accountable in the auditing process for its outcome.