

## Response ID ANON-NSV3-CY48-J

Submitted to **Draft WA End-of-life and Specialist Palliative Care Strategy 2018-2028 Consultation**  
Submitted on 2017-12-12 17:12:01

### About You

#### 1 Are you providing your views as an individual or on behalf of a group / organisation?

Group / organisation

#### 2 In what capacity are you providing your views for this consultation?

Peak body representative

**Other:**

Carers Association of WA Inc.

#### 3 What health setting do you represent when providing your views for this consultation?

I do not represent a health setting

**Other:**

### Your Feedback

#### 4 Please rate the extent to which you agree/disagree with the following statements.

**Statements - The Strategy is applicable to the end-of-life care sector:**

Agree

**Statements - The Strategy is applicable to the specialist palliative care sector:**

Agree

**Statements - The VISION in the Strategy will inform the end-of-life care sector to 2028:**

Agree

**Statements - The VISION in the Strategy will inform the specialist palliative care sector to 2028:**

Don't know /Not applicable

**Statements - The PRIORITIES outlined in the Strategy are clear:**

Strongly Agree

**Statements - The Strategy provides direction for future initiatives and service provision:**

Agree

**Statements - Overall, the Strategy is achievable in the defined time frame (2018-2028):**

Don't know /Not applicable

**Please provide any rationale, comments or suggestions you have related to the above statements.:**

The vision does not specifically mention carers, only patients and family, please note comments in Qu, 5 below regarding the need to consider carers as a cohort as separate to family.

#### 5 If you have identified any weaknesses in the Strategy, please describe them below and provide suggestions as to how these could be addressed.

**Weaknesses:**

There is inconsistent reference in relation to the terms family, friends and carers throughout the document. This should be used consistently throughout to prevent any confusion for the reader.

The definition of family in the Reference document glossary includes the definition of a carer, however family (whether relatives or family of acquisition) are not always in a caring role. We believe that carers should be defined separately to family in the document to acknowledge that carers are entitled to certain rights and provisions that family who are not in a caring role will not be. For example Centrelink benefits, access to services from Carers WA including carer counselling (including bereavement counselling) and rights under the Carers Recognition Act 2004. This is also important in encouraging carers to identify themselves as being in a caring role so that they access the supports available to them which they may not if they only identify with their familial role and not their caring role.

#### 6 If you have identified strengths in the Strategy, please describe them below.

**Weakness solutions:**

The Strategy is very inclusive of families throughout all the priority areas (including carers as per the definition in the document) . NB: Please see other comments in our response about defining carers as separate to family.

The Strategy describes the Carers Recognition Act 2004 in the Reference document; Section 10. Appendices, page 18. We would recommend also including The Carers Charter in this section, or if not in this document in upcoming Priority plans. Additionally the WA Carers Strategy (<https://www.dlhc.wa.gov.au/Publications/Pages/WA-Carers-Strategy.aspx>) could be added to the list of national and state strategies.

**7 Please provide any other comments or suggestions you have about the Strategy.****Comments:**

It was noted that the Working Group for the strategy had no Carer Peak Body Organisation Representation, this would have been valuable with regards to providing the carer perspective on the Draft Strategy. Whilst we acknowledge that the Strategy is a high level document, it would be also be of value to have had Consumer or Carer lived experience representation on the group in line co-design/co-production principles. Carers WA would like to be involved as the peak body for carers in Western Australia in any subsequent development of priority plans. Carers WA are also able to recruit carers with relevant lived experience through the WA Health funded Carer Representation Program.

Page 25 of the Draft Strategy (Priority area 3: Connected care) has a case study which states ' Reducing Carer fatigue was addressed', it would be helpful to know how this was achieved.

Page 27 of the Draft Strategy (Priority area 4: Family and carer support) Refers to families in the introduction of this section, but does not mention carers specifically anywhere else in this section; again, family members are not always in a caring role.

Case study 4 under this section has little focus on the wife caring for her husband apart from being assessed alongside husband and being offered respite; it would be useful to source a case study which comes more from the carer perspective in this section. It is important that carers are assessed in their own right as having distinct needs from the patient. It is pleasing to see reference to the Carer Support Needs Assessment Tool (CSNAT) under reference 23 and 25, however the reference to Carer Assessment could be strengthened in this section. Also under this section, carers and families having equitable access to respite, can have challenges. We hear regularly from carers that there are a number of issues in accessing respite (these were supported by :

1. The family cannot afford it
2. It is not available where they live
3. The person with care needs is resistant to a stranger coming into the home or going into residential respite care
4. Respite providers may not be able to provide the complex nature of care required.

These issues need to be addressed if carers are to achieve meaningful support.

Additionally this section refers to families having access to support and referral to local, community, and non-specialist palliative carer organisations, however there is no mention of referral to specific carer supports . It would be useful if not in this document, then in the Priority Plans to specifically mention Carers WA, who can provide a Carer Advisory Service and statewide Counselling (including bereavement counselling).

In the Reference Document, section 6. Care values and supporting factors; the core value of care centered on the patient and family, does not refer to carers, suggest include carers here.