

27 February 2017

Senator Rachel Siewert  
Committee Chair  
Senate Standing Committees on Community Affairs  
PO Box 610  
Parliament House  
CANBERRA ACT 2600

Dear Senator Siewert

**Re: Complaints mechanism administered under the Health Practitioner Regulation National Law (National Law)**

I would like highlight improvements that could assist in a fairer, quicker and more effective complaints process from a consumer and carer perspective.

#### *Care relationships*

Care relationships are multifaceted and dynamic. Carers advocate for the health, safety, wellbeing, dignity and inclusion of the person they share a care relationship with, and are health consumers in their own right. There are 239,100 primary carers in Victoria:

- 41% care for their partner
- 29% care for their child (including adult children)
- 21% care for their parent, and
- 9% care for another relative or friend.<sup>1</sup>

#### *Carer health and wellbeing*

Research has demonstrated carers who provide high levels of informal care and are also employed are at risk of substantial negative health impacts.<sup>2</sup> In addition to the health impacts of caring, 37% of primary carers report having a disability themselves,<sup>3</sup> and can face significant psychological distress.<sup>4, 5</sup> Improving carer quality of life can lead to improvement in patient quality of life.<sup>6</sup>

#### *Tasks performed by carers engaged with the health system*

Families increasingly are expected to provide complex care at home to ill relatives. Such care requires a level of caregiving knowledge and skill unprecedented among lay persons, yet family caregiving skill has never been formally developed as a concept in nursing.<sup>7</sup>

Carer tasks may include:<sup>8, 9, 10, 11, 12</sup>

- transportation to appointments
- advocacy for information and basic services
- accessing services or resources
- coordinating care among healthcare professionals
- facilitating care transitions (e.g. hospital to home, to hospice or residential aged care)
- making medical decisions when the patient cannot (via medical treatment decision making hierarchy as legislated)
- providing continuity between an array of diverse health care professionals
- symptom management (expectation to assess and monitor patients for symptom changes, or new symptoms, monitor patients for side effects for therapy, symptom exacerbation)
- communicating with doctors, nursing and allied health staff
- assisting with personal care and hygiene
- procuring, administering and managing medication, and
- managing patient controlled analgesia pumps, epidural catheters, home infusions and PEG feeding.

### *The importance of carer advocacy*

The list above is not meant to be exhaustive. It serves to provide some practical examples of the range of tasks undertaken by carers. One of the most important tasks carers undertake is advocacy, as this provides a natural safeguard to the person receiving care, when interacting with the health system.

This is especially important where the person receiving care has a communication or cognitive disability. For example, researchers at UNSW recently revealed that people with an intellectual disability are twice as likely to suffer a potentially avoidable death when compared to the general population. Dr Julian Trollor, lead author, said 'people with an intellectual disability will often experience communication difficulties in consultations, often a person with disability struggles to be enabled to be part of the conversation, struggles to be included in decisions around healthcare, and struggles to communicate their health care needs to the person they are seeing'.<sup>13</sup>

The advocacy and safeguarding role of carers in these care relationships is therefore critical. Carers play a vital role in raising concerns and reporting complaints; however, carers are not always supported in this role.

Carers do not always feel included in the complaints process. Some carers who have raised complaints regarding the person they care for felt they did not receive adequate communication and information throughout the complaint process. Further, the additional psychological distress placed on the carer going through the complaints process is seldom acknowledged.

**Recommendation One:** Data collection on complaints should recognise complaints made specifically by carers; and should trigger the inclusion of information on carer support services in future correspondence with the complainant.

In the 2015–16 financial year Australian relatives made a total of 596 complaints to AHPRA, representing 10% of all complainants (patients represented 33% of all complainants).<sup>14</sup> While this data is useful, if it was further broken down to carers as a notification category, this would duly highlight the important role carers play in the health care system, especially in relation to patient advocacy and safeguarding.

Further, if complaints data captured those complaints made by carers, the relevant authority could include information on available carer support services, which carers may not be currently accessing. This is especially important if the nature of the complaint is psychologically distressing, as carer support services provide funded counseling and emotional support for carers.

This is consistent with two principles in the statement for Australia's carers defined in the Australian *Carer Recognition Act 2010*:

- the relationship between carers and the persons for whom they care should be recognised and respected
- carers should be considered as partners with other care providers in the provision of care, acknowledging the unique knowledge and experience of carers.

Principles of this nature are also enshrined in the Victorian *Carer Recognition Act 2012*.

**Recommendation Two:** Carers Victoria recommends that consumer and carer representatives are included in projects or programs that seek to improve the experience of the complainant.

Carers Victoria acknowledges the work that AHPRA has undertaken to improve communication with complainants and their experience throughout the complaints process, which has been informed by a notifier survey.<sup>15</sup>

In future projects and programs it would be desirable to include consumer and carer representatives, to ensure their experience of the process is not only considered, but also informs the design of the resultant changes, as they are the end users.

**Recommendation Three:** Carers Victoria recommends AHPRA leads the development of simple web based tool or app that enables consumers to select responses to determine which agency they should lodge their complaint with.

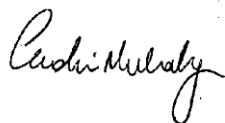
Presently, consumers are required to determine which entity they should make a complaint to and navigate the complaints process for each; including individual health services, the Victorian Health Services Commissioner (VHSC), the Mental Health Complaints Commissioner (MHCC) and AHPRA (this varies for other states and territories).

Carers Victoria acknowledges the development of a brochure for consumers on where to direct their complaint.

If a user friendly tool was available on the websites of health services, which navigated the process for them based on pro-forma questions this would ameliorate some confusion with navigating this complex process. This tool could also act as a central referral gateway, submitting a form to the appropriate agency. A central referral gateway would have the benefit of a central data collection point on complaints made to multiple health services and agencies.

If you would like to discuss this matter further, please contact Policy Advisor, Rachel Vanstone, on 0408 595 740 or [Rachel.Vanstone@carersvictoria.org.au](mailto:Rachel.Vanstone@carersvictoria.org.au)

Yours sincerely



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**Chief Executive Officer**

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- <sup>2</sup> Kenny, P. et al (2014), The physical functioning and mental health of informal carers: evidence of care-giving impacts from an Australian population based cohort, *Health and Social Care in the Community*, 22(6) 646-659.
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- <sup>5</sup> Collins, A. et al. (2016), Lived experiences of parents caring for a child with life-limiting condition in Australia: a qualitative study, *Palliative medicine*, 1-10.
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- <sup>9</sup> Wilkinson, A. (2010), the carer experience in end-of-life cancer caregiving: a discussion of the literature, *Cancer forum*, 34(2).
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- <sup>13</sup> Worthington, E. (9/2/2017), people with intellectual disabilities twice as like to suffer preventable death, study finds, ABC news.
- <sup>14</sup> AHPRA, (2016), Annual Report 2015/16 supplementary tables, p 20.
- <sup>15</sup> AHPRA, (2016), Annual Report 2015/2016, p 8.