



# National Register of Palliative Care Consumers and Carers

## FACT SHEET

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Palliative Care Australia (PCA) is the national peak body for palliative care. We represent all those who work towards high quality palliative care for all Australians. PCA truly believes in the important contributions palliative care consumers and carers can make to improve palliative care. The National Register of Palliative Care Consumers and Carers gives a voice to those living with a life-limiting illness, people who are receiving palliative care, their family, carers and the palliative care volunteers who support them. The ultimate goal is to improve the quality of, and access to, palliative care throughout the country.

### **What is the National Register of Palliative Care Consumers and Carers?**

The National Register is designed to foster opportunities for palliative care consumers and carers to engage in the development of palliative care health policy, service delivery and reform activities at a national or jurisdictional level.

### **How do you become a consumer representative?**

Recruitment of members occurs through a review process on an annual basis (or as needed). The call for applications will be promoted through our e-newsletter and website. A selection panel will then make selections based on the skills, experience and commitment outlined in each application.

### **Who is eligible to be a consumer representative?**

- Consumers - people receiving palliative care for a life-limiting illness
- Carers - people who have provided care in the past or are currently caring for a person receiving palliative care
- Family members of a person who has or is currently receiving palliative care
- Volunteers – people with experience caring as a volunteer for a person receiving palliative care

### **How many consumer representatives are on the National Register?**

The National Register currently consists of six palliative care consumers and carers from across Australia. We aim to develop a diverse and representative group, and will continue to expand membership on an annual basis. To find out more about our current members visit the [website](#).

### **What specifically will consumer representatives do?**

Our palliative care consumer and carer representatives use their lived experience and communication skills to share their stories and provide input into public policy and service delivery related to palliative care in Australia. PCA has an ongoing schedule of support and training opportunities for members of the National Register. This will provide members with sector insights, developing their knowledge of palliative care issues and networks, and empowering them to participate in strategic decision making and input into policy, health service design and relevant projects.

Representatives may be positioned on national committees, boards, working groups and evaluations, or advise on the development of a new project, program or service. They may also submit reports (verbal or written) following representative activities for data collection.

### **What if a consumer representative is unwell or does not want to take part in a project?**

Participation in individual opportunities is at the discretion of each consumer representative. If a consumer representative is unwell or believes they cannot contribute in a meaningful way they may choose not to participate or withdraw themselves. In these cases PCA will work with the organisation to identify another suitable consumer representative.

### **How long is the term for a consumer representative on the National Register?**

There is no required term for participation, however we do encourage consumer representatives to remain on the National Register for a period of between one to five years.

### **Will consumer representatives get paid?**

PCA strongly believes in the important contributions and insights that Consumers and Carers can provide and organisations are encouraged to recognise these contributions through appropriate remuneration and reimbursement of travel, accommodation and associated project costs. PCA will work with each organisation before the promotion of a project to ensure conditions are reasonable. Project details will be shared with consumer representatives before the start of the project.

PCA will cover consumer representative's expenses related to attending any PCA training and education opportunities, however consumer representatives will not be remunerated for their time to attend these activities.

### **How will consumer representatives be paid?**

Payment to consumer representatives will be facilitated through the engaging organisation's existing processes for reimbursement and remuneration. Consumer representatives are encouraged to seek their own individual advice with respect to the taxation implications of receiving payments for contributions as a consumer representative.

Consumer representatives may be asked to provide an invoice which includes either:

1. Their Australian Business Number; or
2. A statement by a supplier which outlines the reason for not quoting an Australian Business Number

### **Flexibility & Support**

PCA acknowledges that some consumer representatives may face barriers inhibiting their participation in training, projects and travel, especially where they are currently receiving palliative care or are providing support for a person receiving palliative care. Accordingly, PCA will work with consumer representatives to ensure we are supportive and flexible to accommodate the diverse needs of each individual. This may include covering the costs of travel and accommodation to allow a carer to travel with the care recipient, or utilising video conferencing and other technology solutions.

### **Who do I contact if I have questions about the National Register?**

If you have any questions about the National Register please contact Tim van Ierschoot, Community Engagement Coordinator, on 02 6232 0700 or [pca@palliativecare.org.au](mailto:pca@palliativecare.org.au).

**THANK YOU FOR YOUR CONSIDERATION - YOUR VOICE MATTERS**