

While volunteering for Aged Care Volunteer Visitor Scheme (ACVVS), the person you visit may experience a life-limiting illness or dying. This is a normal part of life and research shows that people who have consistency in their social network around them at this time can help to improve their quality of life.

Palliative care is available to anyone experiencing a life-limiting illness, dying, grief and to their caregivers. Palliative care is not simply a clinical team, service or timeframe. Palliative care is an approach to care that focuses on quality of life, rather than mainly focusing on cure.

Palliative care can help care recipients with their health, social, emotional and/or spiritual needs that may arise during this stage in life. This may include planning ahead, compassionate conversations, symptom management, equipment support, understanding treatment and care options, staying socially connected, sharing stories, legacies or memory making, care for the carer and much more.

Outline of the Role of the ACVVS Volunteer in Palliative Care

- **Companionship:** Continue providing emotional and social support to the care recipient (CR), with non-medical tasks.
- **Consistency:** Be a calming presence during this sensitive time.
- **Listening Ear:** Allow the CR to express feelings without judgment.
- **Memory Making and Storytelling:** Listen to the CR's life stories and support and encourage them to write these down or share with others (if appropriate).
- **Helping them Focus on their "What matters most":** Helping the CR identify and prioritise the simple things that bring them joy (for example, feeling sunshine on their face, being in nature, or enjoying a cup of tea).

'What If?' Scenarios

- **Meeting Family Expectations:** Meeting family expectations: Explain your role as a volunteer, emphasising that you are there to provide companionship and support, not medical care, counselling, or advice.
- **Family Conflicts:** Maintain neutrality, inform your ACVVS Coordinator if tensions arise.
- **Community/Home Visits:** If the family or CR asks for additional support, refer them to the Coordinator.
- **Uncertain Situations:** If you're unsure how to respond or feel uncomfortable, contact the ACVVS Coordinator immediately.
- **Offering of a Gift:** Politely explain you are unable to receive gifts and inform your ACVVS Coordinator.

This resource has been developed by the Palliative Care SA project in collaboration with the Southern Volunteering ACVVS team

Communication

- **Do More:**

- Speak calmly and demonstrate empathy.
- Use open-ended questions like, “How are you feeling today?” or “What would you like to talk about or do today?” or “Tell me about.”
- Be comfortable with silence; it creates space for memory recollection and storytelling.
- When it’s closer to the end, consider reading to the CR or offering a gentle hand massage (with CR consent).

- **Do Less:**

- Avoid making assumptions about their diagnosis, prognosis, emotions, or beliefs.
- Avoid sharing your own stories, unless invited to do so. Comparisons aren't always helpful.
- Avoid saying, “I know how you feel.”

Boundaries and Self-Care

- **Setting Boundaries:**

- It’s okay to say no to requests outside your role, including an increase in visits to a level where you feel uncomfortable.
- You are not expected to take the place of professional care services or a carer. If you or the CR have concerns about the level of care, speak with your ACVVS Coordinator.
- Communicate honestly with your ACVVS Coordinator if overwhelmed.

- **Self-Care Tips:**

- Practice mindfulness or relaxation techniques after visits with your CR. Ensure you identify your own ‘What Matters Most’ priorities and consider creating a self-care plan
- Seek support if needed; it’s okay to feel emotional.

Grief and Bereavement

- **Remind Yourself:**

- When someone dies, we grieve the loss of the person and everyone does this differently. There is no timetable for grief.
- As an ACVVS volunteer, you formed a connection with the person who died, and it’s completely okay for you to grieve their loss. Rituals can help to process the grief (i.e. light a candle for them or listen to their favourite music).

- **Support Available:**

- Contact your ACVVS Coordinator for guidance and use free counselling services offered to you.
- Connect with peers who understand the challenges of this role.

Continue your Learning

- Visit your relevant **Palliative Care** state/territory peak body website for more information and linkages (i.e. palliativecaresa.org.au).
- Visit **CareSearch**: Australia’s palliative care knowledge network (caresearch.com.au).