



Government of Western Australia
Department of Health



Consumer Survey: End-Of-Life Care in Residential Aged Care Facilities and Nursing Homes in Western Australia.

We are conducting research to better understand peoples' experiences with palliative and end-of life care in Residential Aged Care Facilities (RACFs), also known as Nursing Homes.

If one* of your family members or friends died in an RACF/Nursing Home in WA between 2021 and 2024, we invite you to have your say and share your experiences in this survey.

This study has been approved by the **University of Western Australia** (Ref: 2023/ET000833). Your participation is entirely **voluntary**. Any information you provide remains **anonymous**.

We estimate the survey will take approx. **30 minutes to complete**. If you have any questions about the survey, please email jennifer.lowe@perron.uwa.edu.au, or call **08 6457 0312**.

The survey is divided into 8 sections. We will ask questions about you, your relative and the support you received whilst caring for your relative and the period following their death.

Previous survey respondents have told us they benefited from being able to share their experiences, but if you do become distressed whilst completing this survey, contact details for **bereavement support services in WA** can be found at perroninstitute.org/agedcare.

Instructions for **returning your completed survey to us via post** can be found on **Page 17** of this document. We are accepting survey responses until **Tuesday, 30 April 2024**.

Thank you for your valuable contribution towards improving end-of-life services.

**If more than one relative has died in an RACF/Nursing Home in WA between 2021 and 2024, please complete the survey with your most recent experience in mind. If you wish to share more than one experience, please complete an additional survey for each relative.*

This survey has 8 sections:

Section 1 – Is about you as the family, carer or close person to the person who died

Section 2 – Is about your relative who has died

Section 3 – is about how you were introduced to palliative care

Section 4 – Is about the care received in a nursing home/residential aged care facility (RACF)

Section 5 – Is about informal/community support you received while your relative was alive

Section 6 – Is about the circumstances around your relative’s last period of life and death

Section 7 – Is about the support you received after your relative died

Section 8 – Is about sharing more comments on your experience

Section 1: Tell us about yourself.

1.1	Are you?	<input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> Other
1.2	What is your age?	----- years
1.3	What is your current marital status?	<input type="checkbox"/> Never married <input type="checkbox"/> Married/partnered <input type="checkbox"/> Separated or divorced <input type="checkbox"/> Widowed <input type="checkbox"/> Other (<i>Please specify</i>) -----
1.4	What is your cultural background?	<input type="checkbox"/> Australian <input type="checkbox"/> Other English speaking <i>(For example: British, New Zealander, etc.)</i> <i>Please specify:</i> ----- <input type="checkbox"/> Non-English speaking <i>(For example: Italian, Malaysian, etc.)</i> <i>Please specify:</i> -----
1.5	Are you from an Aboriginal and/or Torres Strait Islander background?	<input type="checkbox"/> Yes <input type="checkbox"/> No

1.6	What is your highest level of education?	<input type="checkbox"/> No formal education <input type="checkbox"/> Primary school <input type="checkbox"/> High school <input type="checkbox"/> Diploma/certificate/trade qualification <input type="checkbox"/> University degree
1.7	Currently, what is your main employment situation (please tick one box only)	<input type="checkbox"/> Working full time <input type="checkbox"/> Working part-time <input type="checkbox"/> Carer (full time) (of home, family, etc.) <input type="checkbox"/> Student (full-time) <input type="checkbox"/> Unemployed <input type="checkbox"/> Retired <input type="checkbox"/> Other (<i>Please specify</i>) -----
1.8	What is your residential postcode?	 ----- (<i>E.g., 6050</i>)
1.9	What was your relationship to your relative who died? You were their ... ? (Please tick most relevant)	<input type="checkbox"/> Wife/husband or partner <input type="checkbox"/> Mother/father <input type="checkbox"/> Sister/brother <input type="checkbox"/> Daughter/son <input type="checkbox"/> Daughter-in-law/Son-in-law <input type="checkbox"/> Friend <input type="checkbox"/> Other (<i>Please specify</i>) -----
1.10	Were you the main family carer?	<input type="checkbox"/> Yes <input type="checkbox"/> No
1.11	How long had you been caring for your relative?	At home: ----- Months In other settings: ----- Months
1.12	Overall, how would you describe your involvement in your relative's care whilst at home, before admission to a nursing home/RACF?	<input type="checkbox"/> Day-to-day hands-on <input type="checkbox"/> Intermittent hands-on <input type="checkbox"/> Rare hands-on <input type="checkbox"/> Provided no hands-on care but still close <input type="checkbox"/> Other (<i>Please specify</i>) -----

Section 2: Information on your relative who has died.

2.1	Gender	<input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> Other	
2.2	Age at death	----- <i>years</i>	
2.3	Date of death	----- Day / Month / Year	
2.4	Postcode (of home before entering the nursing home/RACF)	----- <i>(E.g., 6050)</i>	
2.5	What type of life limiting illness did your relative have? <i>(You can tick more than one box)</i>	<input type="checkbox"/> Frailty because of old age <input type="checkbox"/> Dementia <input type="checkbox"/> Heart disease <input type="checkbox"/> Lung disease <input type="checkbox"/> Cancer <i>(Please specify)</i> ----- <input type="checkbox"/> Other Neurological Disease <i>(such as MND, MS, Parkinson's. Please specify)</i> ----- <input type="checkbox"/> Other <i>(Please specify)</i> -----	
2.6	Approximate year you started caring for your relative for any of these illnesses? For example, 2019.	Frailty because of old age	----- <i>(e.g., 2019)</i>
		Dementia	----- <i>(e.g., 2019)</i>
		Heart disease	----- <i>(e.g., 2019)</i>

		Lung disease	----- (e.g., 2019)
		Cancer	----- (e.g., 2019)
		Other neurological disease	----- (e.g., 2019)
		Other disease	----- (e.g., 2019)
2.7	Did your relative have an Advance Care Plan, Advance Health Directive, Enduring Power of Guardianship or Goals of Care in place? (You can tick more than one box)	<input type="checkbox"/> Advance Care Plan <input type="checkbox"/> Advance Health Directive <input type="checkbox"/> Enduring Power of Guardianship <input type="checkbox"/> Goals of Care <input type="checkbox"/> Other, e.g. My Values website (Please specify) ----- <input type="checkbox"/> No formal documents <input type="checkbox"/> Not that I was aware of	

Section 3: Introduction to palliative care

3.1	During your relative's illness, did you look for information about palliative care?	<input type="checkbox"/> Yes <input type="checkbox"/> No
3.2	Was it easy to find this information?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable

3.3	Where did you find this information about palliative care? (You can tick more than one box)	<input type="checkbox"/> Website (<i>Please specify</i>) <hr/> <input type="checkbox"/> Pamphlet (<i>Please specify where obtained</i>) <hr/> <input type="checkbox"/> RAC staff <input type="checkbox"/> GP <input type="checkbox"/> Specialist <input type="checkbox"/> Other healthcare practitioner (<i>Please specify</i>) <hr/> <input type="checkbox"/> Family member <input type="checkbox"/> Friend <input type="checkbox"/> Other source (<i>Please specify</i>) <hr/> <input type="checkbox"/> Not applicable
3.4	Which source provided the best information and why?	
3.5	<p>Was your relative seen by a visiting palliative care team* while in nursing home/RACF?</p> <p><i>*In WA, there are specialist palliative care teams of doctors, nurses, social workers, and other clinicians that visit Residential Aged Care Facilities and Nursing Homes to provide extra support to residents, families, and staff. These visiting palliative care teams in WA include MPaCCS from Bethesda Palliative Care Unit, WA Country Heath Palliative Care and Silver Chain.</i></p>	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't Know <input type="checkbox"/> Not applicable
3.6	Was your relative able to access this visiting palliative care team as soon as he/she wanted or needed to?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable <i>Please feel free to make additional comments below:</i> <hr/>

Section 4: The care received at nursing home/residential aged care facility (RACF)

4.1	What is the name of the nursing home/RACF?	<input type="checkbox"/> In the Perth metropolitan area: <i>Please write the name of the service below:</i> <hr/> <input type="checkbox"/> In a regional or rural area: <i>Please write the name of the service below:</i> <hr/>
4.2	What suburb or town is the nursing home/RACF in?	<hr/> <i>(E.g., Perth)</i>
4.3	Postcode (of the nursing home/RACF, if known)	<hr/> <i>(E.g., 6050)</i>
4.4	What date was your relative admitted to the nursing home/RACF?	<hr/>
4.5	Was there an option to stay with your relative overnight?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know
4.6	If no, would you have liked to stay?	<input type="checkbox"/> Yes <input type="checkbox"/> No
4.7	Was there a cost involved to stay with your relative?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know <input type="checkbox"/> Not applicable

4.8	Were your relative's values respected and taken into account?	<input type="checkbox"/> Always <input type="checkbox"/> Most of the time <input type="checkbox"/> Some of the time <input type="checkbox"/> Never <input type="checkbox"/> Don't know <i>Please feel free to make additional comments below:</i> <hr style="border-top: 1px dashed black;"/>
4.9	Was your relative's cultural background respected and taken into account (e.g., cultural traditions recognised and enabled to continue/occur?)	<input type="checkbox"/> Always <input type="checkbox"/> Most of the time <input type="checkbox"/> Some of the time <input type="checkbox"/> Never <input type="checkbox"/> Don't know <input type="checkbox"/> Not applicable <i>Please feel free to make additional comments below:</i> <hr style="border-top: 1px dashed black;"/>
4.10	Were your relative's spiritual and/or religious beliefs respected and taken into account?	<input type="checkbox"/> Always <input type="checkbox"/> Most of the time <input type="checkbox"/> Some of the time <input type="checkbox"/> Never <input type="checkbox"/> Don't know <input type="checkbox"/> Not applicable <i>Please feel free to make additional comments below:</i> <hr style="border-top: 1px dashed black;"/>
4.11	Did the nursing home/RACF ask you or your relative about Advance Care Plans, Advance Health Directives, Enduring Power of Guardianship or Goals of Care?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know
4.12	If no to 4.10 , did the nursing home offer to assist your relative to have one of these documents?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know <input type="checkbox"/> Not applicable
4.13	If yes to 4.10 , were your relative's wishes in these documents taken into account by the nursing home/RACF?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know <input type="checkbox"/> Not applicable

4.14	If no to 4.12 , why do you think their wishes were not taken into account?	-----
4.15	How much of the time was your relative treated with respect and dignity by the staff?	<input type="checkbox"/> Always <input type="checkbox"/> Most of the time <input type="checkbox"/> Some of the time <input type="checkbox"/> Never <input type="checkbox"/> Don't know
4.16	How much of the time was your relative treated with compassion and kindness by the staff?	<input type="checkbox"/> Always <input type="checkbox"/> Most of the time <input type="checkbox"/> Some of the time <input type="checkbox"/> Never <input type="checkbox"/> Don't know
4.17	In your view, did the members of the team work well together?	<input type="checkbox"/> Yes, definitely <input type="checkbox"/> Yes, to some extent <input type="checkbox"/> No <input type="checkbox"/> Not sure <i>Please feel free to make comments below:</i> -----
4.18	What are your views of the general competence and skills of the staff?	<input type="checkbox"/> Very competent <input type="checkbox"/> Competent <input type="checkbox"/> Incompetent <input type="checkbox"/> Very incompetent <input type="checkbox"/> Don't know <i>Please feel free to make comments below:</i> -----
4.19	Were you able to get the information you needed from nursing home staff, or a satisfactory explanation of why the information wasn't available?	<input type="checkbox"/> Always <input type="checkbox"/> Most of the time <input type="checkbox"/> Some of the time <input type="checkbox"/> Never <input type="checkbox"/> Don't know <i>Please feel free to make comments below:</i> -----

4.20	Were you able to discuss any worries and fears you may have had about your relative's condition, treatment or tests with the staff?	<input type="checkbox"/> I had no worries or fears to discuss <input type="checkbox"/> Yes, I discussed them as much as I wanted <input type="checkbox"/> Yes, I discussed them, but not as much as I wanted <input type="checkbox"/> No, although I tried to discuss them <input type="checkbox"/> No, but I did not try to discuss them <i>Please feel free to make comments below:</i> <hr/>
4.21	Did the nursing home/RACF have a plan for your relative's care if their condition was to decline out of hours ?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know
4.22	Approximately, how many Emergency Department (ED) visits to deal with symptom problems did your relative have:	While a resident at nursing home/RACF? <hr/> During the last month of their life? <hr/>
4.23	Were these ED visits helpful to your relative?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know <input type="checkbox"/> Not applicable <i>Please feel free to make additional comments below:</i> <hr/>
4.24	Did the nursing home services work well together with the GP?	<input type="checkbox"/> Yes, definitely <input type="checkbox"/> Yes, to some extent <input type="checkbox"/> No, they did not work well together <input type="checkbox"/> Don't know <input type="checkbox"/> Not applicable <i>Please feel free to make additional comments below:</i> <hr/>

4.25	Did the nursing home services work well together with the visiting palliative care team?	<input type="checkbox"/> Yes, definitely <input type="checkbox"/> Yes, to some extent <input type="checkbox"/> No, they did not work well together <input type="checkbox"/> Don't know <input type="checkbox"/> Not applicable <i>Please feel free to make additional comments below:</i> <hr style="border-top: 1px dashed black;"/>					
4.26 How would you assess the overall level of support given in the following areas from those who cared for your relative at the nursing home?							
		Excellent	Good	Fair	Poor	Don't know	Not applicable
	Relief of pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Relief of symptoms other than pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Spiritual support to your relative	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Emotional support to your relative	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Emotional support to you as family, carer or friend	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Practical assistance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Information on your relative's condition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Inclusion of your relative in care decisions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Inclusion of you in care decisions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4.27	Overall, did you, your relative and your family receive as much help and support from the nursing home/RACF as you wanted?	<input type="checkbox"/> Yes, we received as much support as we wanted <input type="checkbox"/> Yes, we received some support but not as much as we wanted <input type="checkbox"/> No, although we tried to get more help <input type="checkbox"/> No, but we did not ask for more help <i>Please feel free to make comments below:</i> <hr style="border-top: 1px dashed black;"/>					

4.28	Overall, the care received from the nursing home was:	<input type="checkbox"/> Excellent <input type="checkbox"/> Good <input type="checkbox"/> Fair <input type="checkbox"/> Poor <input type="checkbox"/> Don't know <i>Please feel free to make comments below:</i> <hr/>
4.29	Based on your experience what would you improve and why? <i>(Were there other services not provided in the nursing home that were needed?)</i>	<hr/>

Section 5: Informal/community support you received while your relative was alive. Please tell us about support you received from the community while caring for your relative who died.

5.1	What sources from your own social/community networks supported you while your relative was in the nursing home/RACF? (can tick more than one)	<input type="checkbox"/> None <input type="checkbox"/> Members of your family <input type="checkbox"/> Friends <input type="checkbox"/> Neighbours <input type="checkbox"/> Community groups (church, sports...) <input type="checkbox"/> Not for profit organisation <i>(Please specify)</i> <hr/> <input type="checkbox"/> Other <i>(Please specify)</i> <hr/>
5.2	How helpful was this support in general?	<input type="checkbox"/> Very helpful <input type="checkbox"/> Quite helpful <input type="checkbox"/> A little bit helpful <input type="checkbox"/> Not helpful <input type="checkbox"/> Not applicable
5.3	What was most helpful?	<hr/>
5.4	What was least helpful?	<hr/>
5.5	Was there other support that you needed from your own networks but didn't receive?	<hr/>

Section 6: Circumstances around your relative’s last period of life and death.

6.1	Where did your relative die?	<input type="checkbox"/> Nursing home/RACF <input type="checkbox"/> Hospital ward <input type="checkbox"/> Palliative care room on hospital ward <input type="checkbox"/> Hospital ED <input type="checkbox"/> Hospital intensive care unit <input type="checkbox"/> Hospice/Palliative Care Unit <input type="checkbox"/> Other (<i>Please specify</i>) <hr style="border-top: 1px dashed black;"/>
6.2	Where did your relative prefer to die? (last preference)	<input type="checkbox"/> No preference <input type="checkbox"/> Not discussed/don’t know <input type="checkbox"/> Nursing home/RACF <input type="checkbox"/> Home <input type="checkbox"/> Hospital <input type="checkbox"/> Hospice/Palliative Care Unit <input type="checkbox"/> Other (<i>Please specify</i>) <hr style="border-top: 1px dashed black;"/>
6.3	Did their preference change over the course of their illness?	<input type="checkbox"/> Yes <input type="checkbox"/> No <i>Feel free to make comments below:</i> <hr style="border-top: 1px dashed black;"/>
6.4	Where did you prefer your relative to die?	<input type="checkbox"/> No preference <input type="checkbox"/> Not discussed/don’t know <input type="checkbox"/> Nursing home/RACF <input type="checkbox"/> Home <input type="checkbox"/> Hospital <input type="checkbox"/> Hospice/Palliative Care Unit <input type="checkbox"/> Other (<i>Please specify</i>) <hr style="border-top: 1px dashed black;"/>

6.5	Were you or others close to your relative given enough help and support by the nursing home care team at the actual time of their death?	<input type="checkbox"/> Yes, definitely <input type="checkbox"/> Yes, to some extent <input type="checkbox"/> No, not at all <input type="checkbox"/> Don't know <i>Feel free to make comments below:</i> <hr/>
6.6	After your relative died, did staff deal with you or others close to your relative in a sensitive manner?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know <input type="checkbox"/> Not applicable, I didn't have any contact with the staff <i>Feel free to make comments below:</i> <hr/>
6.7	Was your relative involved in decisions about their care at the end of their life as much as he/she would have wanted?	<input type="checkbox"/> Involved as much as he/she wanted to be <input type="checkbox"/> He/she would have liked to be more involved <input type="checkbox"/> He/she would have liked to be less involved <input type="checkbox"/> Don't know
6.8	Were you involved in decisions about your relative's care at the end of their life as much as you would have wanted?	<input type="checkbox"/> I was involved as much as I wanted to be <input type="checkbox"/> I would have liked to be more involved <input type="checkbox"/> I would have liked to be less involved <input type="checkbox"/> Don't know
6.9	Were any decisions made about your relative's care that they would not have wanted?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know <i>Feel free to make comments below:</i> <hr/>
6.10	Were any decisions made about your relative's care that you did not want?	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Don't know <i>Feel free to make comments below:</i> <hr/>

6.11	Overall, and taking all services into account, how would you rate your relative's care at the end of their life?	<input type="checkbox"/> Excellent <input type="checkbox"/> Good <input type="checkbox"/> Fair <input type="checkbox"/> Poor <input type="checkbox"/> Don't know
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Section 7: Support you received after your relative died.

7.1	Since your relative died, have you talked to anyone from health and/or social services about your experience of their illness and death?	<input type="checkbox"/> Yes <input type="checkbox"/> No, but I would have liked to <input type="checkbox"/> No, but I didn't want to anyway <input type="checkbox"/> Not sure
7.2	Were you offered information about grief and bereavement services that might be helpful following the death of your relative?	<input type="checkbox"/> Yes <input type="checkbox"/> No, but I would have liked it <input type="checkbox"/> No, but I didn't want it anyway <input type="checkbox"/> Not sure
7.3	Did staff contact you (by phone, post, or home visit) within the weeks following the death of your relative to find out how you were coping, and discuss any questions you might have had?	<input type="checkbox"/> Yes <input type="checkbox"/> No
7.4	Did staff contact you (by phone, post, or home visit) about 6 months after the death of your relative to find out how you were coping and discuss any questions you might have had?	<input type="checkbox"/> Yes <input type="checkbox"/> No
7.5	Overall, did you and your family receive as much help and support as you wanted from health and/or social services after your relative died?	<input type="checkbox"/> Yes, we received as much support as we wanted <input type="checkbox"/> Yes, we received some support but not as much as we wanted <input type="checkbox"/> No, although we tried to get more help <input type="checkbox"/> No, but we did not ask for more help <input type="checkbox"/> We did not need help <input type="checkbox"/> Other (<i>Please specify</i>) <p>-----</p>

7.6	What sources from your own social/community networks have supported you after your relative's death? (you can tick more than one)	<input type="checkbox"/> None <input type="checkbox"/> Members of your family <input type="checkbox"/> Friends <input type="checkbox"/> Neighbours <input type="checkbox"/> Community groups (church, sports...) <input type="checkbox"/> Not for profit organisation (<i>Please specify</i>) <hr/> <input type="checkbox"/> Other (<i>Please specify</i>) <hr/>
7.7	How helpful was this support in general?	<input type="checkbox"/> Very helpful <input type="checkbox"/> Quite helpful <input type="checkbox"/> A little bit helpful <input type="checkbox"/> Not helpful <input type="checkbox"/> Not applicable
7.8	What was most helpful?	<hr/>
7.9	What was least helpful?	<hr/>
7.10	Was there other support that you needed but didn't receive?	<hr/>

Section 8. Please use the space below if there is anything more you would like to say about your experiences.

PLEASE RETURN YOUR COMPLETED SURVEY VIA POST TO:

Professor Samar Aoun, Perron Institute
QEI Medical Centre, 8 Verdun Street, Nedlands, WA 6009