APPENDIX 7: FAMILY INTERVIEW (RESIDENT IS DECEASED)

COVERSHEET

(Obtain from facility records)

_____	_____	_____
Date of Interview	**Interviewer ID**	**Carer ID**
____/____/____	____/____/____	
Resident Date of Birth	**Resident Date of Death**	
____/____/____	_____	
Date of Admit to Aged Care		

Was resident under care of the Aged Care Facility during all of the last 7 days of life? _____

Resident Marital Status: Married Widowed Divorced Single, never married

Resident Sex: M F

Carer Name (First Last): _____

Carer Sex M F

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INTRODUCTION & SCREENING

Hello, may I speak to [CARER FIRST NAME]?

My name is [YOUR NAME] and I am working with [AGED CARE FACILITY] on a palliative care program for residential aged care facilities. I am so for your loss. As you are aware [RESIDENT] was enrolled in the facility's palliative care program. We were hoping to speak to family members such as yourself about your impressions of the palliative care provided by the facility. I realise this may be difficult to talk about but I wonder if I might ask you some questions. Is this a good time for us to talk?

[ ] YES ⟶	(CONTINUE WITH INTERVIEW – GO TO QUESTION 1)
[ ] NO ⟶	We will call you another time. When is usually a good time for you to talk? _____ [CONFIRM THAT CARER WILL BE CALLED AGAIN, AND TERMINATE INTERVIEW]

1. Can you tell me how you were related to [RESIDENT NAME]?

SPOUSE
PARTNER

CHILD
DAUGHTER-IN-LAW/SON-IN-LAW
PARENT
SIBLING
OTHER RELATIVE

FRIEND
OTHER (SPECIFY: _____)

INFORMED CONSENT

INTERVIEWER OR ADMINISTRATOR: IF NECESSARY MODIFY THIS INFORMED CONSENT STATEMENT BASED ON YOUR OWN INSTITUTION'S IRB.

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To make sure you have all the information about the study, I am going to read you a few sentences.

Your participation in this interview is, of course, voluntary. If you decide not to participate, it will not affect you in any way.

Your answers will be kept completely confidential. The information from this study will not be presented or published in any way that would allow the identification of any respondent.

It is important that your answers be accurate. Take your time and be sure to ask me if you are not sure what a question means or what kind of answer is wanted. It is very important that you answer as honestly and as accurately as you can. If there is any question you would rather not to answer, just tell me and I will skip it.

Do you have any questions before we begin?

May we proceed with the interview?

[ ] YES (CONTINUE THE INTERVIEW -- GO TO QUESTION A)
[ ] NO (THANK RESPONDENT AND TERMINATE INTERVIEW)

CHECKING THE FACTS

A. Where did [RESIDENT'S] death take place? [INTERVIEWER- IF NECESSARY, PROMPT UNTIL SITE IS IDENTIFIED]

[ ] AT HOME →	Was that in the resident's own home [ ], or in your home [ ], or in someone else's home [ ] ?

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[ ] IN A HOSPITAL →	Was that in the Intensive Care Unit, [ ] YES [ ] NO → Was that on a palliative care or ward? [ ] YES [ ] NO
[ ] AGED CARE FACILITY →	[ ] YES [ ] NO
[ ] HOSPICE →	Do you mean an inpatient hospice unit? [ ] YES [ ] NO
[ ] IN TRANSIT TO A MEDICAL FACILITY	
[ ] SOMEWHERE ELSE →	SPECIFY:
[ ] DON'T KNOW	

A1. And our information is that [RESIDENT] died on [DATE OF DEATH]. Is this correct?

[ ] YES
[ ] NO → In what month and year did (he/she) die? _____/_____

A5. We're interested in finding out where [RESIDENT] spent the last 7 days of (his/her) life. Let's start with where (he/she) was 7 days before (he/she) died. Where was (he/she)? For how many days was (he/she) there?

PLACE (7 DAYS BEFORE): _____ NUMBER OF DAYS: _____

[AS NEEDED: Did (he/she) go anywhere after that? Where was that? How long was (he/she) there? CONTINUE THROUGH THE DAY OF DEATH]

PLACE: _____ NUMBER OF DAYS: _____

PLACE: _____ NUMBER OF DAYS: _____

LAST PLACE: _____ NUMBER OF DAYS: _____

INTERVIEWER CHECK: "IN THAT LAST WEEK" OR "WHILE UNDER CARE OF THE AGED CARE FACILITY"

DETERMINE FROM THE COVER SHEET WHETHER RESIDENT WAS UNDER CARE OF THE AGED CARE FACILITY DURING THE LAST 7 DAYS OF HIS/HER LIFE.

IF YES → CHOOSE "IN THAT LAST WEEK"
IF NO → CHOOSE "WHILE UNDER CARE OF THE AGED CARE FACILITY"

NOTE: LAST WEEK = LAST 7 DAYS

DOMAIN QUESTIONS

These next questions are about [RESIDENT'S] experience during (his/her) (last week/while under care of the Aged Care Facility).

C1. (In [RESIDENT'S] last week/While [RESIDENT] was under care of the Aged Care Facility), did you talk with any of [RESIDENT'S] doctors yourself?

[ ] YES
[ ] NO (SKIP TO C2)

C1a. (In that last week/ While under care of the Aged Care Facility), was there ever a problem understanding what any doctor was saying to you about what to expect from treatment?

[ ] YES
[ ] NO

C1b. (In that last week/ While under care of the Aged Care Facility), did you feel that the doctors you talked to listened to your concerns about [RESIDENT'S] medical treatment?

[ ] YES
[ ] NO
[ ] HAD NO CONCERNS

C1c. (In that last week/ While under care of the Aged Care Facility), how much information did the doctors provide you about [RESIDENT'S] medical condition - would you say less information than was needed, just the right amount, or more than was needed?

[ ] LESS THAN WAS NEEDED
[ ] JUST THE RIGHT AMOUNT
[ ] MORE THAN WAS NEEDED

C1d. (In that last week/ While under care of the Aged Care Facility), how often did any doctor

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give confusing or contradictory information about [RESIDENT'S] medical treatment - always, usually, sometimes, or never?

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

C2. (In that last week/ While under care of the Aged Care Facility), was there always a doctor in charge of [RESIDENT]'s care?

[ ] YES
[ ] NO

C2a. (In that last week/While under care of the Aged Care Facility), was it always clear to you which doctor was in charge of (his/her) care?

[ ] YES
[ ] NO

D1. Did [RESIDENT] have specific wishes or plans about the types of medical treatment (he/she) did or did not want while dying?

[ ] YES
[ ] NO (SKIP TO D5)
[ ] DON'T KNOW (SKIP TO D5)

D2. To the best of your knowledge, did [RESIDENT]'s doctor or the medical staff who cared for (him/her) while under care of the Aged Care Facility speak to (him/her) or you about (his/her) wishes about medical treatment?

[ ] YES
[ ] NO

D3. Did (his/her) doctor or the medical staff who cared for (him/her) while under care of the Aged Care Facility speak to (him/her) or you about making sure (his/her) care was consistent with (his/her) wishes?

[ ] YES
[ ] NO

D4. (In that last week/ While under care of the Aged Care Facility), was there any medical procedure or treatment that happened to (him/her) that was inconsistent with (his/her)

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previously stated wishes?

[ ] YES
[ ] NO

D5. Did [RESIDENT] have a signed legal form such as [FOR QLD: Enduring Power of Attorney; FOR NSW: Enduring Guardianship; FOR SA: Enduring Power of Guardianship/ Medical Power of Attorney; FOR WA: Enduring Powers of Guardianship] naming someone to make decisions about medical treatment if (he/she) could not speak for (him/her) self?

[ ] YES
[ ] NO
[ ] DON'T KNOW

D6. Did [RESIDENT] have a signed legal form such as [FOR QLD: Advance Health Directive; FOR NSW: Advance Health Care Directive; FOR SA: Advance Directive/Anticipatory Direction; FOR WA: Advanced Health Directive or Living Will] giving directions for the kind of medical treatment (he/she) would want if (he/she) could not speak for (him/her) self?

[ ] YES
[ ] NO
[ ] DON'T KNOW

INTERVIEWER CHECK: DOES D5= YES **OR** D6 =YES?

[ ] YES
[ ] NO (SKIP TO A8)

D7. Had you or [RESIDENT] discussed (his/her) [FOR QLD: Enduring Power of Attorney or Advance Health Directive; FOR NSW: Enduring Guardianship or Advance Health Care Directive; FOR SA: Enduring Power of Guardianship/ Medical Power of Attorney or Advance Directive/Anticipatory Direction; FOR WA: Enduring Powers of Guardianship or Advanced Health Directive or Living Will] with a doctor caring for (him/her) while under care of the Aged Care Facility?

[ ] YES
[ ] NO

Now I want to ask some specific questions about when [RESIDENT]'s health started to get worse and

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(his/her) symptoms while (he/she) was under the care of the Aged Care Facility.

A8. About how many days or weeks before (he/she) died did [RESIDENT] lose consciousness?

_____ DAYS OR _____ WEEKS

[ ] NEVER LOST CONSCIOUSNESS

INTERVIEWER CHECK: IS A8 GREATER THAN OR EQUAL TO ONE WEEK OR, IF LESS THAN ONE WEEK, LONGER THAN THE TIME THE RESIDENT WAS UNDER THE CARE OF THE AGED CARE FACILITY?

[ ] YES (SKIP TO D18)
[ ] NO

D12. (In that last week/ While under care of the Aged Care Facility), was [RESIDENT] on medicines to treat (his/her) pain?

[ ] YES
[ ] NO (SKIP TO D15)
[ ] DON'T KNOW (SKIP TO D15)

D12a. (In that last week/ While under care of the Aged Care Facility), did (his/her) doctor or the medical staff who cared for (him/her) tell you about how (his/her) pain would be treated, in a way that you could understand?

[ ] YES
[ ] NO

D15. (In that last week/ While under care of the Aged Care Facility), did [RESIDENT] receive too much, too little, or just the right amount of medication for (his/her) pain?

[ ] TOO MUCH
[ ] TOO LITTLE
[ ] RIGHT AMOUNT

D15a. (In that last week/ While under care of the Aged Care Facility), was there ever a time when one doctor or nurse said one thing about treatment of (his/her) pain and another said something else?

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[ ] YES
[ ] NO

D16. (In that last week/ While under care of the Aged Care Facility), did (he/she) have trouble breathing?

[ ] YES
[ ] NO (SKIP TO D17)
[ ] DON'T KNOW (SKIP TO D17)

D16b. How much help in dealing with (his/her) breathing did [RESIDENT] receive - less than was needed, or about the right amount?

[ ] LESS THAN WAS NEEDED
[ ] RIGHT AMOUNT

D17. (In that last week/ While under care of the Aged Care Facility), did (he/she) have any feelings of anxiety or sadness?

[ ] YES
[ ] NO (SKIP TO D18)
[ ] DON'T KNOW (SKIP TO D18)

D17b. How much help in dealing with these feelings did [RESIDENT] receive - less than was needed or about the right amount?

[ ] LESS THAN WAS NEEDED
[ ] RIGHT AMOUNT

D18. (In that last week/ While under care of the Aged Care Facility), was there any problem with doctors or nurses not knowing enough about [RESIDENT'S] medical history to provide the best possible care?

[ ] YES
[ ] NO

D19. (In that last week/ While under care of the Aged Care Facility), was there ever a decision made about (his/her) care without enough input from (him/her) or (his/her) family?

[ ] YES
[ ] NO

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D21. (In that last week/ While under care of the Aged Care Facility), how often were [RESIDENT'S] personal care needs - such as bathing, dressing, and changing bedding - taken care of as well as they should have been - would you say always, usually, sometimes, or never?

①

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

D22. (In that last week/ While under care of the Aged Care Facility), how often was (he/she) treated with respect by those who were taking care of (him/her) - always, usually, sometimes, or never?

①

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

D23. (In that last week/ While under care of the Aged Care Facility), how often was [RESIDENT] treated with kindness by those who were taking care of (him/her) – always, usually, sometimes, or never?

①

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

D24. (In that last week/ While under care of the Aged Care Facility), was there enough help available to meet (his/her) personal care needs, like bathing, dressing, feeding, and going to the bathroom?

①

[ ] YES
[ ] NO

D25. (In that last week/ While under care of the Aged Care Facility), was there enough help with medications and getting dressings changed?

①

[ ] YES
[ ] NO

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D26. At any time while [RESIDENT] was in the Aged Care Facility did you or your family receive any information about what to expect while (he/she) was dying?

[ ] YES
[ ] NO

D26a. Would you have wanted (some/more) information about that?

[ ] YES
[ ] NO

D26b. How confident were you that you knew what to expect while [RESIDENT] was dying - very confident, fairly confident, or not confident?

[ ] VERY CONFIDENT
[ ] FAIRLY CONFIDENT
[ ] NOT CONFIDENT

D27. At any time while [RESIDENT] was in the Aged Care Facility did you or your family receive any information about what to do at the time of (his/her) death?

[ ] YES
[ ] NO

D27a. Would you have wanted (some/more) information about that?

[ ] YES
[ ] NO

D27b. How confident were you that you knew what to do at the time of death - very confident, fairly confident, or not confident?

[ ] VERY CONFIDENT
[ ] FAIRLY CONFIDENT
[ ] NOT CONFIDENT

D28. At any time while [RESIDENT] was in the Aged Care Facility did you or your family receive any information about the medicines that would be used to manage (his/her) pain, shortness of breath, or other symptoms?

[ ] YES
[ ] NO

D28a. Would you have wanted (some/more) information about the medicines?

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[ ] YES
[ ] NO

D28b. How confident were you that you understood about the medicines that would be used to manage (his/her) pain, shortness of breath, or other symptoms - very confident, fairly confident, or not confident?

[ ] VERY CONFIDENT
[ ] FAIRLY CONFIDENT
[ ] NOT CONFIDENT

These next questions are about <u>your</u> experience (during [RESIDENT'S] last week/while [RESIDENT] was under care of the Aged Care Facility).

E1. (In [RESIDENT'S] last week/ While [RESIDENT] was under care of the Aged Care Facility), how often were you or other family members kept informed about [RESIDENT'S] condition – always, usually, sometimes, or never?

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

E2. (In [RESIDENT'S] last week/ While [RESIDENT] was under care of the Aged Care Facility), how often did you have concerns about [RESIDENT'S] personal care needs – such as bathing, dressing, and changing bedding- being met when you were not there - always, usually, sometimes, or never?

[ ] ALWAYS
[ ] USUALLY
[ ] SOMETIMES
[ ] NEVER

E4. (In [RESIDENT'S] last week/ While [RESIDENT] was under care of the Aged Care Facility), did someone talk with you about your religious or spiritual beliefs?

[ ] YES
[ ] NO (SKIP TO E6)

E4a. Was this done in a sensitive manner?

[ ] YES
[ ] NO

E4b. Did you have as much contact of that kind as you wanted (in [RESIDENT'S] last week/ while [RESIDENT] was under care of Aged Care Facility)?

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[ ] YES
[ ] NO

E6. (In [RESIDENT'S] last week/ While [RESIDENT] was under care of the Aged Care Facility), how much support in dealing with your feelings about [RESIDENT'S] death did the doctors, nurses, and other professional staff taking care of (him/her) provide <u>you</u> - less support than was needed or about the right amount?

[ ] LESS THAN WAS NEEDED
[ ] RIGHT AMOUNT

E7. (In [RESIDENT'S] last week/ While [RESIDENT] was under care of the Aged Care Facility), did a doctor, nurse, or other professional staff taking care of [RESIDENT] talk about how you might feel after [RESIDENT'S] death?

[ ] YES	→	Was it done in a sensitive manner? [ ] YES [ ] NO
[ ] NO	→	Would you have wanted them to? [ ] YES [ ] NO

E8. (In [RESIDENT'S] last week/ While [RESIDENT] was under care of the Aged Care Facility), did a doctor, nurse, or other professional staff taking care of [RESIDENT] suggest someone <u>you</u> could turn to for help if you were feeling stressed?

[ ] YES
[ ] NO

RATINGS

Now we would like you to rate some aspects of the care [RESIDENT] received (in that last week/ while (he/she) was under care of the Aged Care Facility). For each of the following questions, I'm going to ask you to use a scale from 0 to 10, where 0 means the worst care possible and 10 means the best care possible.

F1. (In the last week of [RESIDENT'S] life/ While [RESIDENT] was under care of the Aged Care Facility), how well did the doctors, nurses, and other professional staff who cared for [RESIDENT] <u>communicate</u> with (him/her) and the family about the illness and the likely

R

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outcomes of care?

[0 1 2 3 4 5 6 7 8 9 10]

F2. (In the last week of [RESIDENT'S] life/ While [RESIDENT] was under care of the Aged Care Facility), how would you rate how well those taking care of [RESIDENT] provided medical care that respected (his/her) wishes?

R

[0 1 2 3 4 5 6 7 8 9 10]

F3. (In the last week of [RESIDENT'S] life/ While [RESIDENT] was under care of the Aged Care Facility), how well did those taking care of [RESIDENT] make sure (his/her) symptoms were controlled to a degree that was acceptable to (him/her)?

R

[0 1 2 3 4 5 6 7 8 9 10]

F4. (In the last week of [RESIDENT'S] life/ While [RESIDENT] was under care of the Aged Care Facility), how well did those taking care of [RESIDENT] make sure that [RESIDENT] died with dignity - that is, died on (his/her) own terms?

R

[0 1 2 3 4 5 6 7 8 9 10]

F5. (In the last week of [RESIDENT'S] life/ While [RESIDENT] was under care of the Aged Care Facility), how well did those taking care of [RESIDENT] do at providing emotional support for you and [RESIDENT'S] family and friends?

R

[0 1 2 3 4 5 6 7 8 9 10]

And now an overall rating...

F6. On a scale of 0 to 10, where 0 means the worst care possible and 10 means the best care possible, what number would you give the overall care that [RESIDENT] received in [RESIDENT'S] last week of life/ while [RESIDENT] was under care of the Aged Care Facility)?

[0 1 2 3 4 5 6 7 8 9 10]

We have finished the interview now – thanks so much for your time.
Sometimes talking about the death of a loved one can stir up some emotions.

I have some numbers of people and organisations you can talk to if you would like further support or information. Would you like these numbers?

Lifeline (24/7): 13 11 14 Beyond Blue: 1300 22 4636

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Australian Centre for Grief and Bereavement: 1800 642 066

Ask if they would like a specialist palliative care nurse to call them (QLD: Kris McAnelly; SA: Peter Jenkin; WA: Teresa Prior) – let them know they can call sometime in the next week and if they have immediate needs for support they should call Lifeline or make an appointment with their GP.

Your GP is also able to assist you with any issues of grief or distress.

Thanks again for your time. Goodbye.

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