APPENDIX 7: FAMILY INTERVIEW (RESIDENT IS STILL LIVING)

COVERSHEET

(Obtain from facility records)

_____ _____ _____

Date of Interview **Interviewer ID** **Carer ID**

_____/_____/_____ _____

Resident Date of Birth

_____/_____/_____ _____

Date of Admit to Aged Care

_____

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. As you are aware, your family member [RESIDENT] is enrolled on that program. As part of our evaluation of the program we would like to get the family's viewpoint on the care their loved one has received over the last month. 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: _____)

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INFORMED CONSENT

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

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, or your family member's care, 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)

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CHECKING THE FACTS

A. Has [RESIDENT] resided at [AGED CARE FACILITY] for the last month? Did [RESIDENT] go anywhere else in the last month (hospital for instance)? [INTERVIEWER- IF NECESSARY, PROMPT UNTIL SITE IS IDENTIFIED]

[ ] AGED CARE FACILITY ⟶	[ ] YES [ ] NO NUMBER OF DAYS:_____
[ ] IN A HOSPITAL ⟶	[ ] YES [ ] NO NUMBER OF DAYS:_____
[ ] SOMEWHERE ELSE ⟶	SPECIFY: NUMBER OF DAYS: _____
[ ] DON'T KNOW	

A1.

INTERVIEWER:
DETERMINE WHETHER RESIDENT WAS UNDER CARE OF THE AGED CARE FACILITY DURING THE LAST MONTH.

IF YES ⟶ CHOOSE "IN THE LAST MONTH"
IF NO ⟶ CHOOSE "IN THE LAST MONTH WHILE [RESIDENT] WAS UNDER CARE OF THE AGED CARE FACILITY"

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DOMAIN QUESTIONS

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

C1. (In the last month/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 the last month/ 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 the last month/ 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 the last month/ 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 the last month/ While under care of the Aged Care Facility), how often did any doctor give confusing or contradictory information about [RESIDENT'S] medical treatment - always, usually, sometimes, or never?

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

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

[ ] YES
[ ] NO

C2a. (In the last month/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. Does [RESIDENT] have specific wishes or plans about the types of medical treatment (he/she) does or does not want?

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

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

[ ] YES
[ ] NO

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

[ ] YES
[ ] NO

D4. (In the last month/ 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) previously stated wishes?

[ ] YES
[ ] NO

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D5. Does [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. Does [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 D12)

D7. Have 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 [RESIDENT]'s symptoms.

D12. (In the last month/ 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)

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D12a. (In the last month/ 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 the last month/ 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 the last month/ 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?

[ ] YES
[ ] NO

D16. (In the last month/ 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 the last month/ 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)

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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 the last month/ 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 the last month/ 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

D21. (In the last month/ 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?

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

D22. (In the last month/ 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?

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

D23. (In the last month/ 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?

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

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D24. (In the last month/ 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?

[ ] YES
[ ] NO

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

[ ] YES
[ ] NO

D26. At any time while [RESIDENT] has been in the Aged Care Facility have you or your family received any information about what to expect in regard to (his/her) condition?

[ ] YES
[ ] NO

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

[ ] YES
[ ] NO

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

E1. (In the last month/ 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 the last month/ 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 the last month/ While [RESIDENT] was under care of the Aged Care Facility), did someone

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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 the last month/ while [RESIDENT] was under care of Aged Care Facility)?

[ ] YES
[ ] NO

E6. (In the last month/ While [RESIDENT] was under care of the Aged Care Facility), how much emotional support 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

E8. (In the last month/ 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 the last month/ 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 month/ 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 outcomes of care?

R

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

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

R

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

F3. (In the last month/ 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 month/ While [RESIDENT] was under care of the Aged Care Facility), how well did those taking care of [RESIDENT] make sure that [RESIDENT] was treated with dignity?

R

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

F5. (In the last month/ 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 the last month/ 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 palliative care needs 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
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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