



# Participant information sheet

**PROJECT TITLE:** *My Story, Our Journey*

**HUMAN RESEARCH ETHICS COMMITTEE APPROVAL NUMBER:** H-2023-163

**PRINCIPAL INVESTIGATOR:** Dr Jaklin Elliott

Dear Participant,

You are invited to participate in the research project described below. There is a lot of information so you can watch or listen to it by scanning this QR code, or if you would rather we went through it with you in person or on the phone, you can call us on 0468 571 630.



## **What is the project about?**

In this project, we hope to better understand what it is like for people making decisions about where and how someone will be cared for as it gets harder for them to care for themselves—typically (but not always) when a person is in the later stages of an illness or becoming more unwell. Sometimes (but not always), this coincides with knowing that a cure is unlikely for that person, so everyone is wanting to help them get the best care they can—to live as well as they can, as long as they can.

We know that care is often provided by family or close friends and that changing circumstances sometimes mean that new (sometimes easy, sometimes difficult) decisions have to be made—and that these decisions will affect both those providing care and those receiving care. So, we want to know what things are important to people and their carers/family in making those decisions and what happens before and after they do, especially over time.

From hearing your stories about your experiences and combining them with similar stories in this research project, we hope to be able to let others know what things might look and feel like, and what might be helpful for them when they are facing similar decisions.



## Who is undertaking the project?

This project is being led by University of Adelaide researcher, Dr Jaklin Elliott. It is part of a 5-year program trying to find out the best way to help people, families, and communities get the care that they need, especially when dealing with a life-limiting illness, and perhaps beginning to think about the care they might want at the end of life. This research has been funded by The Hospital Research Foundation Group: Palliative Care. Other partners are listed at the end.

## Why am I being invited to participate?

You are being invited as

- you are aged 18 years or over;
- you have been told that doctors cannot cure your illness;
- you find you are needing more help to care for yourself and/or needing frequent medical care;
- someone who cares for you and helps with making decisions about your care may also like to talk with us about these things (this could be either with you, or separately, whichever worked for you all);
- you were born in a country where English was not the main language and still speak that language at home; and
- you and your carer are able to talk about your experiences.

## What am I being invited to do?

First, we invite you to read this through and talk about it with someone else.

As part of this project, we invite you to talk with one of our researchers about what choices you have been making or facing, and what that has meant for you. We will ask you to share your experiences and what has been important to you before, during, and after making decisions. We hope to meet with you regularly over time to keep up with how you are going and what has been happening. If we haven't heard from you after three months, we will get in touch with you to see if we can make a time for our next visit. We will always fit in with what will work best for you.

We also ask you to name a chosen family member or carer to participate in the study with you. They will also be interviewed, and you can choose to be interviewed together



or separately. Interviews will take place at a location that is convenient to you, for example: your home, a community space, your carer's home, or via telephone or video call (such as Zoom). There is a separate Participant Information and Consent Form for your chosen family member/carer in an envelope that you can give them so they can decide if this is right for them. To be part of this research study, both you and a carer need to join up. With your permission, we will audio and video record our meetings.

As part of our first meeting, we will listen to your stories and draw a diagram capturing important moments, feelings, things, people, and places. We will revisit this diagram at each meeting to explore where and how things are changing and what decisions you've been faced with. We'll ask you if you'd like to share anything else important to you, for example, a photo and will keep a copy in a folder we will provide to you. We will give you copies to keep or share with others if you wish.

### **How much time will my involvement in the project take?**

We think that each visit will last no more than 90 minutes but we will stop each when it suits you. We hope to share your journey from the time of our first meeting to the end of our study in March 2026 or when you aren't able or don't want to continue meeting with us.

### **Are there any risks associated with participating in this project?**

Sometimes talking or thinking about what is happening now and what might happen in the future can be upsetting. If you do get upset when we are there, we will support you and listen to you, and can pause or stop—whatever is best for you. If you are still upset, you can contact your own health professional (your GP perhaps) or the following organisations for support.



Grief Line 1300 845 745



LifeLine 13 11 14



GriefLink <https://grieflink.org.au/>



MyGrief [https://www.grief.org.au/ACGB/Bereavement\\_Support/MyGrief.aspx](https://www.grief.org.au/ACGB/Bereavement_Support/MyGrief.aspx)



You and your family member/carer may have different things to say or different views on the same situation. That is absolutely OK. We are not looking for a right or wrong answer or trying to get you to agree—each of you are unique and will have your own story. We can always stop talking about something if it is difficult, and we will check in with you at the end of our meeting. If we are worried about you, we will follow up with a phone call and help you contact the right people to help if needed.

### **What are the potential benefits of the research project?**

Being part of this study may not directly benefit you, but we hope that your stories will show us what might be most useful to help others in your situation to get the care they need to live as well as they can. It could also help healthcare professionals know what kind of care and support is important at this time of life so they are better able to provide that.

### **Can I withdraw from the project?**

It is up to you if you want to be part of this project. You can withdraw or let us know not to keep something you've already shared any time before the end of the project in March 2026 or when you don't want to or can't be part of the project (whichever comes first). Whether you stay in the project or withdraw, your care will not be affected.

### **What will happen to my information?**

We will keep everything you share with us safely stored in a secure, locked location at the University that only our researchers can access. We will change important personal information like names and places, to try to protect your identity. We know, however, that sometimes stories are so unique and personal that someone might be able to guess who they are about. We'll do our best to prevent that but can't promise that no-one will identify you as someone in our study. Similarly, you may be recognised through photos we collect; we will ask you if we can share these with others as they are, or with images of people or things blurred out so they can't be identified.

Every piece of your information (e.g., the video, the timeline diagram, photos, anything else) will be labelled as yours and we will ask what you would like to happen to each thing when your part of the study has finished. You might want to share it with others in the study, or not. We will only share exactly what you tell us with people you tell us to.



We will only keep your name and any contact details so we can call you or send you things as part of the study and will delete them at the end of the study. We will keep your consent form separate and only the lead researcher Jaklin Elliott and the Program Manager Belinda Evans will be able to access that.

We will also ask you if we can keep your stories and share them with researchers doing similar research in the future. You don't have to agree to this. If you do, researchers will be able compare your stories with others' stories, to see if things are different or the same across time and space. We will only do that if you tell us we can and we will remove any personal identifying information as we described earlier. If you say 'no, you cannot share my stories,' we will only keep these and consent forms for 5 years after the end of the study—we have to do that according to our university rules. We will then make sure they are safely destroyed in line with our university rules.

We plan to share the important things we find through publishing in academic journals or presenting at conferences. We will also let community leaders know, so they can share through things like newsletters or community events. Finally, we may share through media stories or on the internet.

Finally, we will only use your information as we've described in this participant information sheet and we will only share it in line with what you agree to, unless the law tells us otherwise.

To say thank you for sharing your stories, you will receive a gift card for \$100 at our first meeting, and at the end of your time in the study along with copies of things you shared with us all presented in your own personal folder.

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

If you have any questions, you can contact the lead researcher:

Dr Jaklin Elliott on 8313 3855 or 0468 571 630

or via email at [Jaklin.elliott@adelaide.edu.au](mailto:Jaklin.elliott@adelaide.edu.au),

### **What if I have a complaint or any concerns?**

The study has been approved by the Human Research Ethics Committee at the University of Adelaide (approval number H-2023-163). This research project will be conducted



according to the NHMRC National Statement on Ethical Conduct in Human Research 2007 (Updated 2018). If you have questions or problems associated with the practical aspects of your participation in the project or wish to raise a concern or complaint about the project, then please talk with Dr Jaklin Elliott, as the Principal Investigator. If you wish to speak with an independent person regarding concerns or a complaint, the University's policy on research involving human participants, or your rights as a participant, please contact the Human Research Ethics Committee's Secretariat on:

Phone: +61 8 8313 6028

Email: [hrec@adelaide.edu.au](mailto:hrec@adelaide.edu.au)

Post: Level 3, Rundle Mall Plaza, 50 Rundle Mall, ADELAIDE SA 5000

Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.

### **If I want to be part of this project, what do I do?**

If after reading this, you would like to be part of this project, please contact the University researchers (details below) to arrange your first interview. At this interview, the project will again be briefly described to you, and you will have the opportunity to ask any questions. If you choose to proceed, we will ask you to sign the attached Consent Form. The first interview will then start, and we'll agree on how we'll organise the next interview and stay in touch.

Thank you for taking the time to read this information.

Yours sincerely,

Dr Jaklin Elliott



For questions, more information, or to register interest, contact us through:

Phone: 8313 3855 or 0468 571 630

Email: [Jaklin.eliott@adelaide.edu.au](mailto:Jaklin.eliott@adelaide.edu.au)

Internet website - use the **QR code** 

or URL:

<https://health.adelaide.edu.au/public-health-and-palliative-care/get-involved>



### Research Partners

Flinders University, The University of South Australia, La Trobe University, Western Sydney University, Multicultural Communities Council SA, Palliative Care SA, ACH Group, Barossa Hills Fleurieu Local Health Network (LHN), Central Adelaide Palliative Care Service, Flinders and Upper North LHN, Northern Adelaide LHN, and the State-wide Palliative Care Clinical Network.



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## Consent form: My Story, Our Journey

1. I have read the attached Information Sheet and agree to take part in the following research project

|                                |                              |
|--------------------------------|------------------------------|
| <b>Title:</b>                  | <i>My Story, Our Journey</i> |
| <b>Ethics Approval Number:</b> | H-2023-163                   |

2. The research worker has explained the project to me, including what I will be doing. I've been able to ask any questions about the project and what I will be asked to do. I freely agree to be part of this study.
3. I was able to have someone in my family or a friend here while the project was explained to me.
4. I understand what this research is trying to find out, but also know that I may not gain any benefit from being part of it.
5. I agree to complete the activities that were described in the Information Sheet, that is, to have interviews with the research worker about every three months for as long as I want to up to March 2026.
6. I know that the project also includes interviews with my chosen carer/s.

Name: \_\_\_\_\_

Name: \_\_\_\_\_

7. I know that the findings from this project might be shared in academic journals, in news stories, on the project website, at conferences, or other associated research dissemination activities.
8. I have been told that the researchers will change any identifying information about me in any published materials, but they can't promise that no-one will recognise me.
9. I know that that all information about me that I provide can be removed from the study when I don't want to or can't be part of the project, or before the end of the project in March 2026 (whichever comes first), but not after.



10. I agree that our interviews can be audio or video recorded.

Audio Yes  No  [Please tick yes or no]

Video Yes  No  [Please tick yes or no]

11. I agree that the information I provide in this study (e.g., videos, images, transcripts) can be used by these or other researchers in other research projects that build on or are similar to this project, but only as I consent to throughout the project.

[Please tick one]

Yes  No

12. I understand that no-one else will see my information, unless the law says so.

13. I know I should keep a copy of this signed consent form with the attached Information Sheet.

**For me (the participant) to complete:**

Name: \_\_\_\_\_ Signature: \_\_\_\_\_ Date: \_\_\_\_\_

**Researcher/Witness to complete:**

I have described the nature of the research to \_\_\_\_\_

*(print name of participant)*

and in my opinion they understood the explanation.

Signature: \_\_\_\_\_ Position: \_\_\_\_\_ Date: \_\_\_\_\_