

Treasured Lives

Enabling independent ageing for older Tasmanians living with challenges related to hoarding and/or maintaining a healthy home.

Information sheet for families and carers

What's the research about?

This research is being done to help us understand how to support Tasmanians to stay living in their homes as they get older, and how to support their families and carers. In particular, we want to understand what it's like for Tasmanians who need support to manage their home, or the home of someone they care for, because of challenges related to hoarding and/or maintaining a healthy home.

The researcher is Lindsey Fidler. She works for Anglicare Tasmania's Social Action and Research Centre. The Social Action and Research Centre undertakes research and talks to Government about making changes that will improve the lives of Tasmanians.

What do we mean by 'challenges related to hoarding and maintaining a healthy home'?

When we say 'hoarding', we mean when someone is unable to resist acquiring items, and/or has challenges sorting or discarding things, even when this leads to cluttered living spaces. It may also lead to living spaces being unsafe and them being unable to use rooms in their home for the purposes they are designed for.

When we say 'challenges related to maintaining a healthy home', we mean when someone is living in an environment which has become unsanitary and may impact on their health and wellbeing. This could be because of an accumulation of rubbish, decomposing food, or excessive grime, dust and mould. Things like cooking, bathing and sleeping may become difficult because of the condition of the home.

Can I take part?

Lindsey would love to hear from you if you have caring responsibilities for and/or are related to an older person living with challenges related to hoarding and/or maintaining a healthy home. By 'older person', we mean someone aged 50 and over, or 45 and over if they are of Aboriginal or Torres Strait Islander heritage.

What would I need to do?

There are two ways of participating in the research. You can either complete an online survey, or you can talk to Lindsey about your experiences in an interview. That interview can be via videoconferencing, by phone or face to face in an appropriate venue.

The survey and the interviews will cover the same questions. The interviews will offer an opportunity for participants to go into more detail about their own experiences and those of the person they care for or are related to. If there is more than one older person in your life who has challenges related to hoarding and/or maintaining a healthy home, we would

recommend participating in an interview. This will enable you to separately explore your experiences in relation to each person you are thinking of.

Both the survey and the interviews will explore your experiences of and reflections on trying to provide support for someone in this situation. That will include your understanding about what's happening for them, the impacts on your relationship with them, and the impacts on your own life. It will explore the supports you receive, or would like to receive, and what you feel is needed in Tasmania to address this issue.

We are looking to interview 10-15 households or individuals who either live in Tasmania or have a relative/someone they care for in Tasmania. We hope another 30 individuals will complete the online or paper survey.

Completing the survey

You can complete the survey through this link here:

<https://www.surveymonkey.com/r/TreasuredLivesFC>.

Or, you can contact Lindsey to request a paper survey and a pre-paid return envelope.

We expect the survey to take between 10 and 40 minutes to complete, depending on how much you want to share. The online survey will be open until the **end of October 2020**.

Participating in an interview

If you would like to take part in an interview, please let Lindsey know. Her details are at the end of this information sheet. The meeting will last between one and two hours depending on how much you want to say. The interviews can be via videoconferencing, over the phone, or face to face in an appropriate environment. That might be in one of the places you go for support, a community centre, a library, or somewhere else. It's up to you. You can bring someone else with you to the interview, if you would like someone you know and trust to be there with you. Interviews will be held until the **end of October 2020**.

How will what I say be used?

Taking part in this research is confidential. **This means that your name will not be used.** It also means that if you are interviewed in a group, what others say is confidential too. The information will be used by Lindsey in her report and in her public talks about the research. What we find through the project will be used to talk to the Government and other agencies about how to support older Tasmanians and their families and carers when there is an issue with hoarding. The report will be published by Anglicare and posted on the website.

The research is due to be completed by March 2021. You will receive a copy of the final report and a summary of it, if you have been interviewed. For those who complete the survey, you can contact Lindsey if you would like to receive a copy.

How will information about me be stored?

All the research information is stored in a secure filing cabinet and a password protected computer system. The only people who can access this information are the Researcher and the Social Action and Research Centre's Coordinator. It will be held for seven years after the project is finished. After this time all project information will be shredded or deleted.

The research team may consider a follow-up project to test the research findings with those living with challenges related to hoarding and/or maintaining a healthy home. To accommodate this, we would like to ask your permission to use what you say in any future related projects. What you said would still be confidential and not identifiable as you. You do not have to agree to us using your data for future related projects, and this will not affect your participation in this current project. You just need to tell us on the consent forms so that we know what we can do.

How will my time be recognised?

If you are interviewed, you will receive a \$50 voucher to spend as a thank you for your time and input. We will also pay for any other costs you have in taking part in the research, such as travel to our meetings and child care.

What if I don't want to take part, or I change my mind about taking part?

Whether you decide to take part in the research is totally up to you. It will have no impact on any existing support and services you may be receiving. If you decide to take part in an interview and then change your mind, that's fine too. You can simply let the Researcher know that you no longer want to take part and any information we have about you and what you said will be destroyed. You can change your mind about taking part until three weeks after you have been given a copy of what you said during your interview.

What are the risks and benefits for me in taking part?

You might find that thinking or talking about your life experiences and your plans upsetting. It may stir up emotions. It can also feel really rewarding to know that sharing your experiences and thoughts will be valuable for other people in your circumstances.

If you do not want to answer any particular questions you do not have to. You can say that you don't want to continue the interview at any point. In the survey, you can skip any of the questions.

If you are feeling distressed during the interview and do not want to continue, we will stop the interview. If you feel like you need immediate support, or if you are feeling you need support following the interview or after completing the survey, there are a number of places you can go:

- Mental Health Families and Friends Tasmania provides a list of organisations and resources you can access: <https://mhfamiliesfriendstas.org.au/carers/>.
- Carers Tasmania provides advice, support and counselling: 1800 242 636.
- If you need immediate support, you can call Lifeline on 13 11 14.

The researcher has a duty to keep you and others safe. She is required to report disclosures about safety concerns for people receiving support through the National Disability Insurance Scheme, about the safety of children and about criminal activity. She is also required to seek advice from Anglicare on what to do if you share concerns about others things affecting the safety of yourself or another adult, such as elder abuse. If you disclose anything like this to Lindsey, she will discuss with you the steps she is going to take.

How do I get involved?

You can complete the survey here: <https://www.surveymonkey.com/r/TreasuredLivesFC>, or by contacting Lindsey for a paper survey.

If you're interested in participating in an interview, or would like more information, please contact Lindsey. Her details are at the end of this information sheet. She will answer any questions you have and arrange for the interview to happen in a way that works for you.

If you would like more information, or are not sure whether to complete the survey to participate in an interview, let Lindsey know. She'll explain a bit more about the research and help you to make a decision.

Does this project have formal ethics approval?

The project has been approved the University of Tasmania's Social Sciences Human Research Ethics Committee. Project ID 18686. Research Integrity and Ethics Unit: ss.ethics@utas.edu.au | Phone: (03) 6226 2975.

What if I have a complaint?

If you have a complaint to make about how this research is being conducted, please contact:

Research Integrity and Ethics Unit: ss.ethics@utas.edu.au | Phone: (03) 6226 2975.

If you have a complaint to make about any other matter relating to the project, please contact:

Ellen Nicholson, SARC Coordinator, on 0444 530 421 or email ellenn@anglicare-tas.org.au.

Contacts

For more information about the project please contact Lindsey Fidler at the Social Action and Research Centre, Anglicare on:

T: 6213 3665 | M: 0417 768 651 | Email: lindseyf@anglicare-tas.org.au