

Survey Introduction

Thank you for your interest in the *Treasured Lives* Project.

What's the research about?

Anglicare Tasmania's Social Action and Research Centre (SARC) is undertaking this project to help us understand how to support older Tasmanians to stay living in their homes when they have challenges related to hoarding and/or maintaining a healthy home. We also want to understand how to support their families and carers.

Once the research is completed, the project will talk with government agencies about making changes that will improve the lives of these Tasmanians.

The lead researcher is Lindsey Fidler.

Can I take part?

Lindsey would love you to complete the survey if you live in Tasmania and have caring responsibilities for and/or are related to an older person who has (or has had in the past) challenges related to hoarding and/or maintaining a healthy home.

By an 'older person', we mean aged 50 plus, or aged 45 plus if they are of Aboriginal or Torres Strait Islander descent.

What do you 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 meant 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 there is an accumulation of rubbish, or decomposing food, or excessive grime, dust and mould. This may lead to things like cooking, bathing and sleeping being difficult because of the condition of the home.

What would I need to do?

The survey asks about:

- your relationship with the person in your life who has challenges and how that affects you, them and others;
- what you think might happen for you and this person as they grow older;
- the support services you and they use now; and
- how you think services, family and friends could support you and this person to allow them to live the life they want as they age.

The survey asks you to think about one person. If you would like to respond about more than one person, you can complete a new survey for each person you are thinking about. Alternatively, you can contact the Researcher, Lindsey Fidler, to arrange to be interviewed. (Details at the end of this section). If you are interviewed, you can talk about more than one person.

The survey is likely to take between **10 to 40 minutes to complete**, depending on how much you want to say. All questions are optional except for part 1 of the survey, which is where you confirm that you are happy to participate.



More information about the project

How will my survey responses be used?

Taking part in this research is confidential. This means that your name will not be used. 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 state and federal government and other agencies about how to support older Tasmanians and Tasmanian families and carers. The report will be published by Anglicare Tasmania and posted on their website.

The research is due to be completed by March 2021. You can contact Lindsey by email or phone if you would like to receive a copy of the final report and a summary.

How will information about me be stored?

All 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 and then be destroyed.

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 survey. You just need to tell us on the consent form (part 1 of the survey), so that we know what we can do.

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

You might find thinking about your life experiences and future plans upsetting and 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 skip any of the questions, except for part 1.

If you are feeling you need support 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: <u>https://mhfamiliesfriendstas.org.au/carers/</u>
- *Carers Tasmania* provides advice, support and counselling: 1800 242 636.
- If you need immediate support, you can call Lifeline on 13 11 14.

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.

Contact the Research Integrity and Ethics Unit:

- Email: ss.ethics@utas.edu.au
- Phone: (03) 6226 2975



Complaints and further information about *Treasured Lives*

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:

- Email: 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

- Phone: 0444 530 421
- Email: ellenn@anglicare-tas.org.au.

Contacts and more information

For more information about the project please contact:

Lindsey Fidler, Lead Researcher, at the Social Action and Research Centre, Anglicare:

- Phone: 6213 3665
- Mobile: 0417 768 651
- Email: lindseyf@anglicare-tas.org.au

Part 1: Consent

To take part in the survey, you need to confirm you have read and understood the information provided on the previous pages. If you're not sure about any of the information, please contact the Researcher, Lindsey Fidler.

Question 1 asks you to confirm you have understood the information and want to take part. Question 2 asks you whether you're happy for us to use your answers in any future work we do on this topic. You don't have to agree to that. Instead, you can agree to us only using your answers for this study. Either way, your identity will be protected.

These two questions are the only compulsory questions in the survey.



Consent Form

I have read and understood the information provided for this project.

I understand that it will take around 10 to 40 minutes to complete the survey, depending on how much I want to share.

I understand that thinking about my experiences may be upsetting, either while completing the survey or afterwards. To make sure I do not experience any unnecessary distress, I understand that:

- I can choose not to answer a particular question without explanation or penalty.
- I can stop without completing the survey.
- If I feel distress due to the research, I can access support through the organisations listed in the survey information.

I understand that what I share will be used to write a report about supporting older Tasmanians to age at home when they have challenges related to hoarding and/or maintaining a healthy home. I also understand that the report will write about how to better support their families and carers.

I understand that my participation in the research is confidential. My identity will be protected and it will not be revealed at any time.

I understand that the research information will be 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, unless I give permission for Anglicare Tasmania to use the data for any future related projects. I agree to participate in this project.

Any questions that I have asked have been answered to my satisfaction.

QUESTION 1

Do you consent to participate in the survey? *Please choose one box.*

Yes, I consent to participate

No, I do not consent to participate

If you answered no, please do not complete this survey.

QUESTION 2

Thank you. We might decide to do more research about this topic in the future. If we do more research, we'd like to know if we can reuse the responses you give us in this survey. Your identity will not be revealed in this research or in any future research.

Please let us know here whether you would prefer we only use your responses in this project, or whether you're happy for us to use them in future projects related to this topic. *Please tick one box.*

I agree that my de-identified study data can be shared and used for future research projects in the same general topic area.

I agree that my de-identified study data can be used only for this specific project.



Part 2: About you

QUESTION 3

Which of the following describes your gender? Please choose one box

Male

Female

Transgender

Other (please specify)

QUESTION 6

Do you identify with any other ethnic or cultural groups? Please choose one box

Yes

No

If yes, please tell us here:

QUESTION 4

Which age group are you in? Please choose one box



QUESTION 5

Do you identify as Aboriginal or of Torres Strait Islander descent? Please choose one box

Yes,	Aboriginal
 /	

Yes, Torres Strait Islander

- Yes, both
- No

QUESTION 7

Where do you normally live?
Please choose one box
Southern Tasmania
Tasmanian Midlands
Northern Tasmania
North West Tasmania
ACT
New South Wales
Northern Territory
Queensland
South Australia
Western Australia
Victoria
Other (please specify)



Part 3: About the person you are related to/care for

Understanding a bit about the person in your life who has challenges related to hoarding and/or maintaining a healthy home.

QUESTION 8

Which of the following describes Do they identify with any other ethnic or their gender? cultural groups? Please choose one box Please choose one box Male No Yes Female Unsure Transgender If yes, please tell us here: Other (please specify) **QUESTION 9 QUESTION 12** Which age group are you in? Where do you normally live? Please choose one box Please choose one box E. _

QUESTION 11

45-54	75+	Southern Tasmania
	They are	Tasmanian Midlands
65-74	deceased	Northern Tasmania
QUESTION 10		North West Tasmania
Do they identify as Aborigina	al or of	ACT
Torres Strait Islander descent		New South Wales
 Please choose one box Yes, Aboriginal Yes, Torres Strait Islander Yes, both 		Northern Territory
		Queensland
		South Australia
		Western Australia
No		
Unsure		Victoria
Onsure		Other (please specify)



Part 4: About you and them

What is your relationship with the person in

QUESTION 14

QUESTION 13

Who else lives in their household (including you, if you live there)? Please choose as many as apply

No one	your life who has challenges with hoarding and/or maintaining a healthy home?
Their parent(s)	Please choose as many boxes as you need to
Their child(ren)/step-child(ren)	I am their parent/guardian
Their partner/spouse	I am their partner
Their siblings/step-siblings	I am their former partner
Other family member(s)	I am their child or step child
Other people	I am their sibling or step sibling
Animals	(brother or sister)
Please tell us more here:	I am another family member
	I am their informal carer
	I am their paid carer
	Other
	Please tell us more here:

QUESTION 15

Have you ever lived with this person? Please choose one box

Yes

No

If you answered no, please skip to Part 5, Question 19.



Part 4: About you and them

Understanding your relationship with the person you're thinking of

QUESTION 16

How old were you when you started living with this person?

Please choose one box



11-20

21+

QUESTION 17

Do you live with this person now? *Please choose one box*

Yes

No

QUESTION 18

How long did you live, or have you lived, with this person?

Please choose one box

- Less than 1 year
- Around 1-5 years
- Around 6-10 years
 - Around 11 years or more

Part 5: About their challenges related to hoarding

Understanding the nature and severity of the challenges this person has in relation to hoarding. Your perception of what insight they have into their challenges.

QUESTION 19

	What sort of challenges related to hoarding would you say they have?		
	Please choose as many boxes as you need to		
	They do not have challenges related to hoarding		
	Please go to Part 6, Question 25.		
	They acquire a lot of items (for example, they keep buying or getting more things)		
	They have challenges with sorting items (for example, things in their home are not organised in a way which makes them easy them use)		
ved,	They have challenges with discarding items (for example, they find in difficult to throw things away, even if they are not using them, or if they seem of little value to others)		
	Other challenges related to clutter or collecting		
	Please tell us more here:		
	For example, do you want to tell us anything about what they collect? How are things in their home stored?		



Part 5: About their challenges related to hoarding

Understanding the nature and severity of the challenges this person has in relation to hoarding. Your perception of what insight they have into their challenges.

QUESTION 20

For each statement below, please choose the description that most closely reflects your observations the last time you visited this person. Please ignore the statement if it is not applicable or you don't know.

Because of the clutter or number of possessions, how difficult is it for them to use the rooms in their home?

Mild Moderate Severe Extremely difficult			
To what extent do they have difficulty discarding (or recycling, selling, giving away) ordinary things that other people would get rid of?			
Mild Moderate Severe Extremely difficult			
To what extent do they currently have a problem with collecting free things or buying more things than they need or can use or afford?			
Mild Moderate Severe Extremely difficult			
To what extent do they experience emotional distress because of clutter, difficulty discarding or problems with buying or acquiring things?			
Mild Moderate Severe Extremely difficult			
To what extent do they experience impairment in their life (daily routine, job/school social activities, family activities and financial difficulties) because of the clutter, difficulty discarding or problems with buying or acquiring things?			
Mild Moderate Severe Extremely difficult			



QUESTION 21

Please select the description below that <u>most</u> <u>closely</u> describes the level of insight that they have into their challenges related to hoarding

Excellent insight. Their hoarding	11005
behaviours may be bad, but they fully recognise that they have a problem.	T 🗌
Good insight . They readily acknowledge	it
that their acquisition clutter and/or	— –

that their acquisition, clutter and/or difficulty discarding is a problem. When at home or out shopping / acquiring, they have difficulty seeing that they have a problem with acquiring or not discarding things.

Fair insight. They admit clutter is a problem, but only reluctantly admit that their behaviour (such as acquiring too many things, or failing to discard things) has caused a problem. When at home or out shopping / acquiring, they have difficulty seeing that they have a problem with acquiring or not discarding things.

Poor insight. They maintain that acquisition, difficulty discarding and clutter are under control or not a problem. When someone discusses the problem with them, they acknowledge that they might have a problem, but still underestimate the severity of the problem.

Lacks insight. They are convinced that they have no problems with acquisition, clutter or difficulty discarding at all. They will argue that there is no problem, despite contrary evidence or arguments.

QUESTION 22

What insights do you think they have into their challenges related to hoarding and its impacts on them now and into the future?

Please choose as many boxes as you need to

	They are aware that they have challenges with acquiring, sorting and/or discarding items around their home	
	They are aware that their living environment impacts negatively on their mental health	
	They are aware that their living environment impacts negatively on the physical health	
	They are aware that their home is cluttered	
	They are aware that their living environment has isolated them, or further isolated them	
	They are aware that they have or have had financial problems due to acquiring a lot of items	
	They are aware that their living environment poses risks to them tripping and falling	
	They are aware that their home is at risk of being taken from them	
	They are aware that the way the live might mean it's difficult for them to age well at home	
	Other	
Please tell us more here:		





QUESTION 23

When did their challenges related to hoarding begin? And how did they develop?

QUESTION 24

Why do you think they have challenges related to hoarding?



Part 6: About their challenges related to maintaining a healthy home

Understanding more about the nature and severity of their challenges. Your perception of what insights they have into those challenges.

QUESTION 25

What sort of challenges related to maintaining a healthy home would you say they have? Please choose as many boxes as you need to

They do not have challenges related to There is often dirt or grime covering surfaces in the home maintaining a healthy home Please go to Part 7, Question 30. There are often contaminated objects over the floors or surfaces in the home (such as There is structural damage to the home tissues, hair, sanitary products) (for example, walls, ceilings, floors, beams, surfaces) There are often insects and/or insect There is often mouldy or rotten food in droppings visible in the home, or cobwebs the home There are often dirty clothes lying around and/or the person is wearing dirty clothes There is often water left standing in places (for example, the bathroom, There are often dirty bed coverings kitchen, on floors) There is often strong odour in parts of / all Human or animal waste or vomit is present of the home in the home Their home is not connected to a power There are often unwashed dishes source, like electricity or gas There is considerable, noticeable mildew/ Other challenges related to maintaining a mould in the home healthy home

Please tell us more here:



QUESTION 26

Please select the description below that <u>most closely</u> describes the level of insight that they have into their challenges related to maintaining a healthy home

Е	xcellent insight. Their challenges in
m	naintaining a healthy home may be bad,
b	ut they fully recognise that it is a risk to
tł	neir health.

Good insight. They readily acknowledge that they have challenges in maintaining a healthy home. However, they have difficulty talking about how this could be addressed.

Fair insight. They admit that their home is not a healthy environment, but only reluctantly admit that their challenges in maintaining the home has caused a problem. They have difficulty talking about how this could be addressed.

Poor insight. They maintain that their home environment is not unhealthy and is under control. When someone discusses the problem with them, they acknowledge that they might have challenges in maintaining their home sometimes, but still underestimate the severity of the problem.

Lacks insight. They are convinced that their home environment is not unhealthy and is under control. They will argue that there is no problem, despite contrary evidence or arguments.

QUESTION 27

What insights do you think they have into their challenges related to maintaining a healthy home and its impacts on them now and in the future?

Please choose as many boxes as you need to

	They are aware that their living environment has isolated them, or further isolated them
	They are aware that they are having difficulties keeping their home clean
	They are aware that they are having difficulties repairing their home so that it's structurally sound
	They are aware that their living environment poses a risk to their physical health
	They are aware that their living environment poses a risk to their mental health
	They are aware that their home is at risk of being taken from them
	They are aware that their living environment could make it difficult for them to age at home
	Other
Ple	ase tell us more here:





QUESTION 28

When did their challenges related to maintaining a healthy home begin? And how did they develop?

QUESTION 29

Why do you think they have challenges related to maintaining a healthy home?

Treasured Lives: Family and Carers' Survey



Part 7: Impacts on them

Understanding your views on the positive and negative impacts on the person you have in mind

QUESTION 30

QUESTION 31

What <i>positive</i> impact do you think their living environment has for them?	What <i>negative</i> impact do you think their living environment has for them?		
Please choose as many boxes as you need to	Please choose as many boxes as you need to		
I don't think their living environment has any positive impacts for them	I don't think their living environment has any negative impacts for them		
It has had positive impacts for their mental health	It has isolated them, or further isolated them		
It has had positive impacts for their physical health	It has had negative impacts for their mental health		
It provides them with a space they are comfortable in	It has had negative impacts for their physical health		
It provides them with a space they can control	They are at risk of tripping and falling due to their living environment		
Other positive impacts	They are unable to use their living spaces for their intended purpose, due to clutter		
Please tell us more here:	They are under the threat of eviction from their home		
	They are under the threat of their home being condemmed		
	It has led to them having problems with money		
	Other negative impacts		
	Please tell us more here:		



Part 8: Ageing at home

Understanding what they plan to do as they age

QUESTION 32		QUESTION 33	
Have they talked to you			
where they would like to age?		If nothing changes in the supports they currently get, what do you think life will be	
Please choose one box		like for them as they get older?	
Yes	Unsure		
No	Other		
Please tell us more here	:		



Part 9: Supports they have used

Understanding about any supports this person has used in the past, or is using now, to help them address challenges they have with hoarding and/or maintaining a healthy home

QUESTION 34

Have they accessed support to address their challenges either in the past or right now?

QUESTION 36

What supports have they accessed in the past? What difference have these made?

Please choose one box

Yes	
No	Unsure

If you answered 'No' or 'Unsure', please go to Part 9, Question 37.

QUESTION 35

What supports do they access now? What difference have these made?

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Do you think there are barriers to them accessing or accepting support to address their challenges?

Please choose one box
 Yes No Unsure
 Please tell us more here:



Part 10: Supports they will need as they age

Understanding what supports this person might need to age well in their home

QUESTION 38

What supports do you think this person will need to age well at home?

QUESTION 39

How could those supports best be provided for them?



Part 11: You supporting them

Understanding the supports you provide for them and the challenges this presents for you

QUESTION 40

Have you tried to actively support this person with their challenges around hoarding and/ or maintaining a healthy home? This could be support you provide at the moment or have provided sometime in the past.

Please choose one box

Yes

No

Unsure

If you answered 'No' or 'Unsure', please go to Part 11, Question 43.

QUESTION 42

What has worked in the support you have provided?

OLIESTION 13

QUESTION 43
What challenges do you face in trying to support this person?
Please choose as many boxes as you need to
I struggle to understand what's going on for them
I struggle to talk about their challenges in a way that's okay for them
I struggle to understand how I can support them
I struggle to balance my own needs with their needs
I have no one to talk to about this
I can't find support services that can help me
Other
Please tell us more here:

please go to Part 12, Question 48.

If yes, please tell us more here:



Part 12: Helping you to support them

Understanding what help you have received or feel you need in the future to support this person to age well at home.

QUESTION 44

Have you received help to support this person with their challenges?	What <i>hasn't</i> you've recei
Please choose as many boxes as you need to	
Yes, professional assistance	
Yes, from people in a similar situation	
Yes, from friends or family	
Yes, other assistance	
No	
Unsure	
Other	QUESTION
lf you answered 'No' or 'Unsure',	What has we

QUESTION 45

worked well for you about help ived to support them?

46

What has worked well for you about help you've received to support them?

QUESTION 47

What difference has this help made for you, your family and/or the person you care for?





QUESTION 48

Thinking again about how and where this person wants to age, what sort of help do you think you need to support them in the future?

QUESTION 49

How would this help best be provided?



Part 13: Impacts on you and on others

Understanding your views on the positive and negative impacts for you and others of caring or being a family member of someone who lives with these challenges

OUESTION 50

QUESTION 50	QUESTION 52
Do you think your relationship with this person brings positive impacts for you and/or your family? Please choose one box	Do you think there are <i>positive impacts for</i> <i>others</i> in living with or near this person? (For example, for those who live with them, community members, their friends)
	Please choose one box
Yes Unsure No Please tell us more here	 Yes Unsure No Please tell us more here
OUESTION 51 Do you think your relationship with this person brings negative impacts for you and/or your family? Please choose one box Yes Yes No Please tell us more here	OUESTION 53 Do you think there are <i>negative impacts</i> for others in living with or near this person? (For example, others they live with, friends, neighbours, the community they live in) Please choose one box



Part 14: Personal support for you

Understanding what you have used, or may need, to support you to deal with the impact on you of supporting this person

QUESTION 55

QUESTION 54

Have you received personal support to What hasn't worked well for you in the help you to manage your relationship with support you've received to manage your this person, or to manage the impacts this relationship with this person, or its impacts? relationship has for you? Please tick as many boxes as you need to Yes, professional support Yes, support from people in a similar situation Yes, support from friends or family Yes, other support No If you answered 'No' or 'Unsure', Unsure please go to Part 14, Question 58. Other Please tell us more here:

QUESTION 56

What has worked well for you in the support you've received to manage your relationship with this person, or its impacts?



QUESTION 57

What difference has the support you received made for you, your family and/or for the person you care for?

QUESTION 59

How would those supports best be provided for you?

QUESTION 58

Thinking again about how and where this person wants to age, what do you think *you* will need to support *you personally* into the future?



Part 15: How we talk to each other

Understanding about the language they use to describe their living environment and challenges. How you talk about it and what we need to consider to be respectful in our language

QUESTION 60

How do they describe their living environment?

QUESTION 61

How would you describe their living environment?



QUESTION 62

Is there any language they *don't* like you to use to describe their living environment, or their challenges related to hoarding and/or maintaining a healthy home? Why is that?

QUESTION 63

What advice would you give to ensure we are respectful in how we talk to and about people living with these challenges?

Your advice can be to the general public, to professional workers, to government agencies, or anyone else.

QUESTION 64

What advice would you give to ensure we are respectful in how we talk to and about *families and carers* of people living with these challenges?

Your advice can be to the general public, to professional workers, to government agencies, or anyone else.



Part 16: And finally ...

QUESTION 65

Is there anything else you think would improve how Tasmania could support older people living with challenges related to hoarding and/or maintaining a healthy home? Anything else that could support you as their family or carer?

Thank you for completing this survey.

Your thoughts will be part of the Treasured Lives final report, which is due for release in March 2021. It will be available from the Anglicare Tasmania's Social Action and Research Centre website: <u>www.anglicare-tas.</u> <u>org.au/social-action-research-centre</u>

If you would like to be notified about the launch, please contact:

Lindsey Fidler, Lead Researcher, at the Social Action and Research Centre, Anglicare:

- Phone: 6213 3665
- Mobile: 0417 768 651
- Email: lindseyf@anglicare-tas.org.au

Please return the survey to Lindsey Fidler, using the pre-paid envelope supplied. Please contact Lindsey of you did not receive an envelope to return your survey in, or return the survey to:

Lindsey Fidler, Social Action and Research Centre, Anglicare Tasmania, 18 Watchorn Street, Hobart, Tasmania 7000.



