

# Treasured Lives

Enabling older Tasmanians to age well at home when they are living with challenges related to hoarding and/or maintaining a healthy home



# About hoarding and challenges maintaining a healthy home

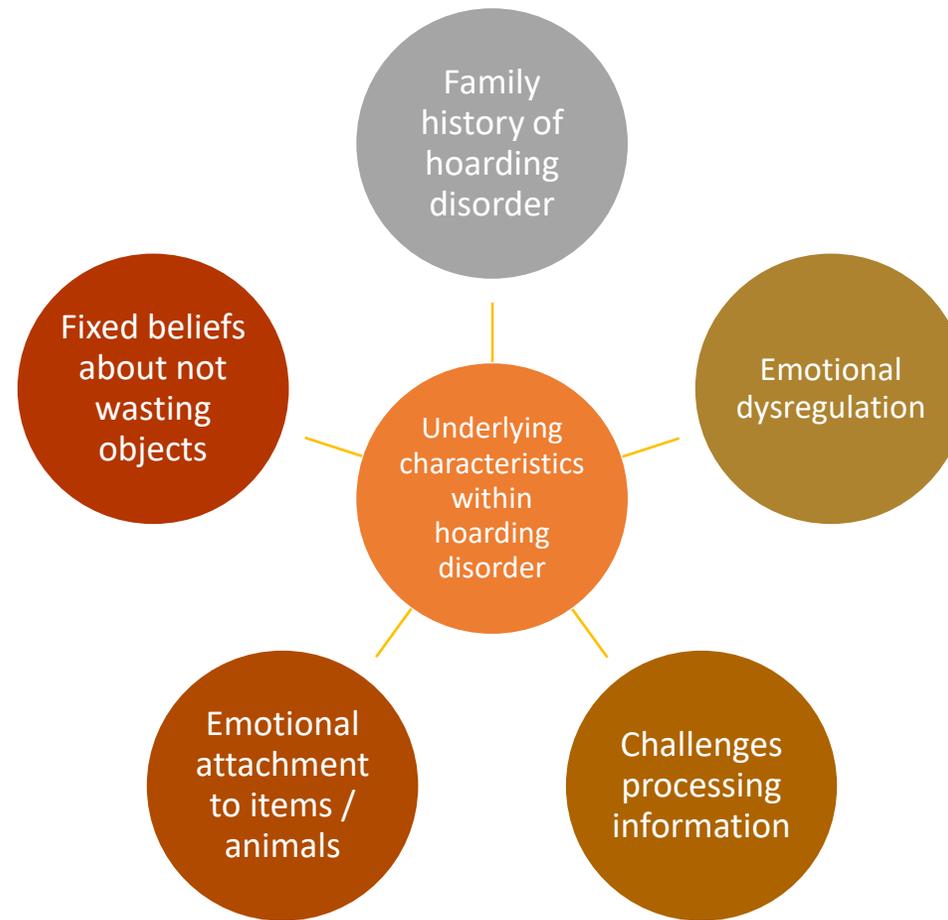
# Hoarding

Challenges with (acquiring), sorting or discarding items or animals

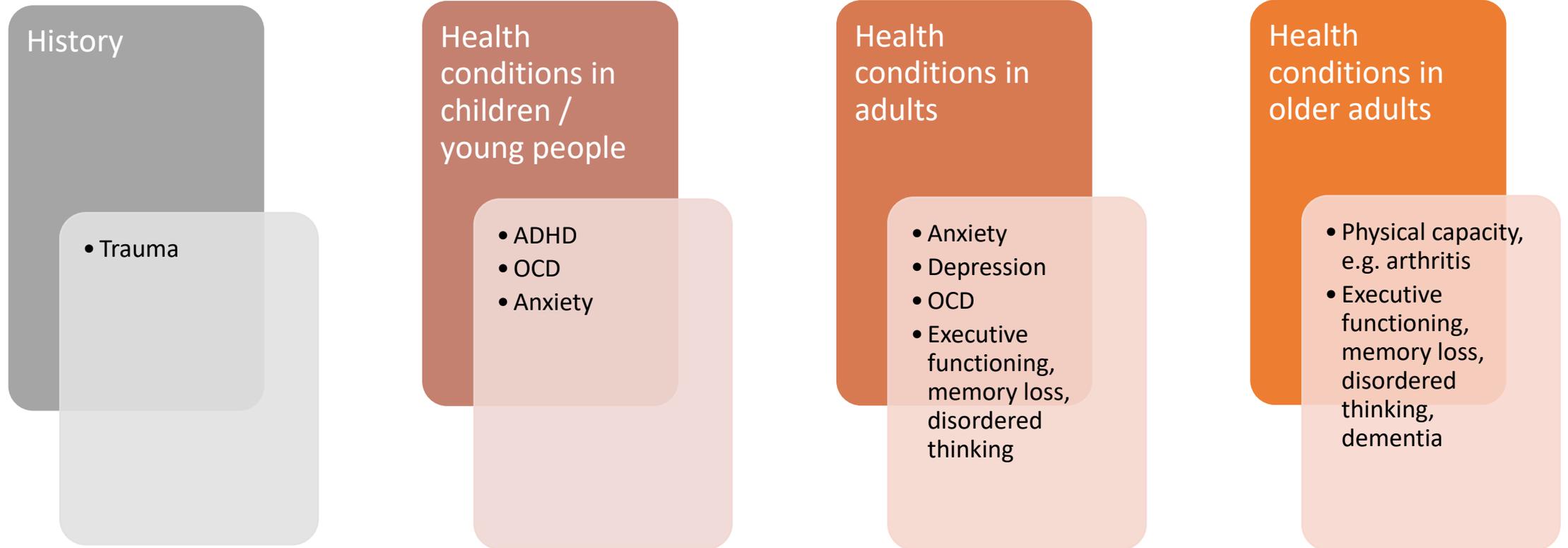
Leading to a cluttered living environment, impeding functioning in living spaces, and impacting on health and safety

May be a diagnosed disorder (DSM5), or co-morbid with mental health or other conditions

# Hoarding: common characteristics



# Hoarding: common comorbidities



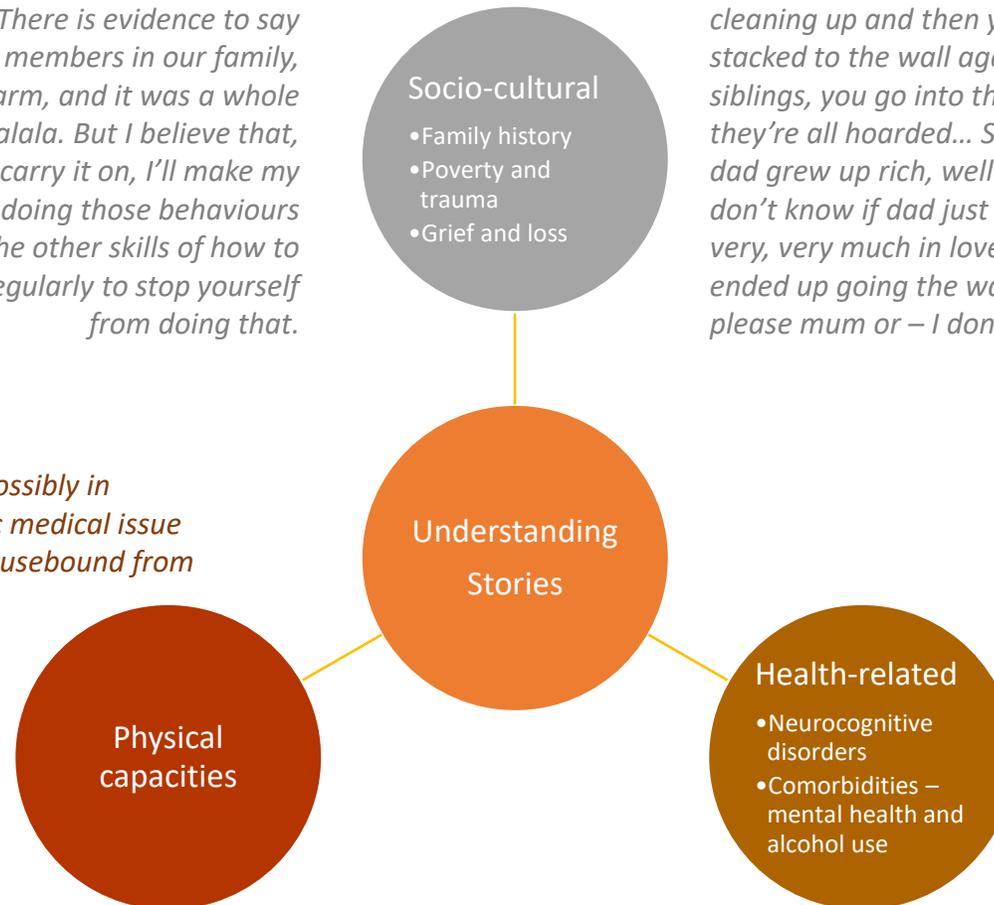
# Older Tasmanians: understanding their stories

*I would say that hers is in response to dad. And I would say my hoarding is in response to them. I would say it's environmental. A nurture thing... There is evidence to say it's genetic, because there's other members in our family, especially where they did have a farm, and it was a whole double shed up to the ceiling and lalala. But I believe that, because I also believe that if I just carry it on, I'll make my kids that way. And they could be doing those behaviours anyway. But it's about learning the other skills of how to manage your life and do those regularly to stop yourself from doing that.*

*Mum's whole family hoards. My memories as a grandchild was we'd spend all Christmas holidays cleaning up and then you go back up and it was stacked to the wall again. Yeah. And Mum's – all her siblings, you go into their houses and they're all hoarded... She grew up hoarding, whereas dad grew up rich, well-off, not a speck of dust. So I don't know if dad just succumbed to mum. They were very, very much in love... So I don't know why dad ended up going the way he did, whether it was to please mum or – I don't know.*

*Developed in adult possibly in response to a chronic medical issue which keeps them housebound from time to time.*

*She got postnatal depression. And the place...it actually got from the time [the child was] a baby til [they] were at kindergarten age, it gradually built up and up... Was that the thing that triggered her?*



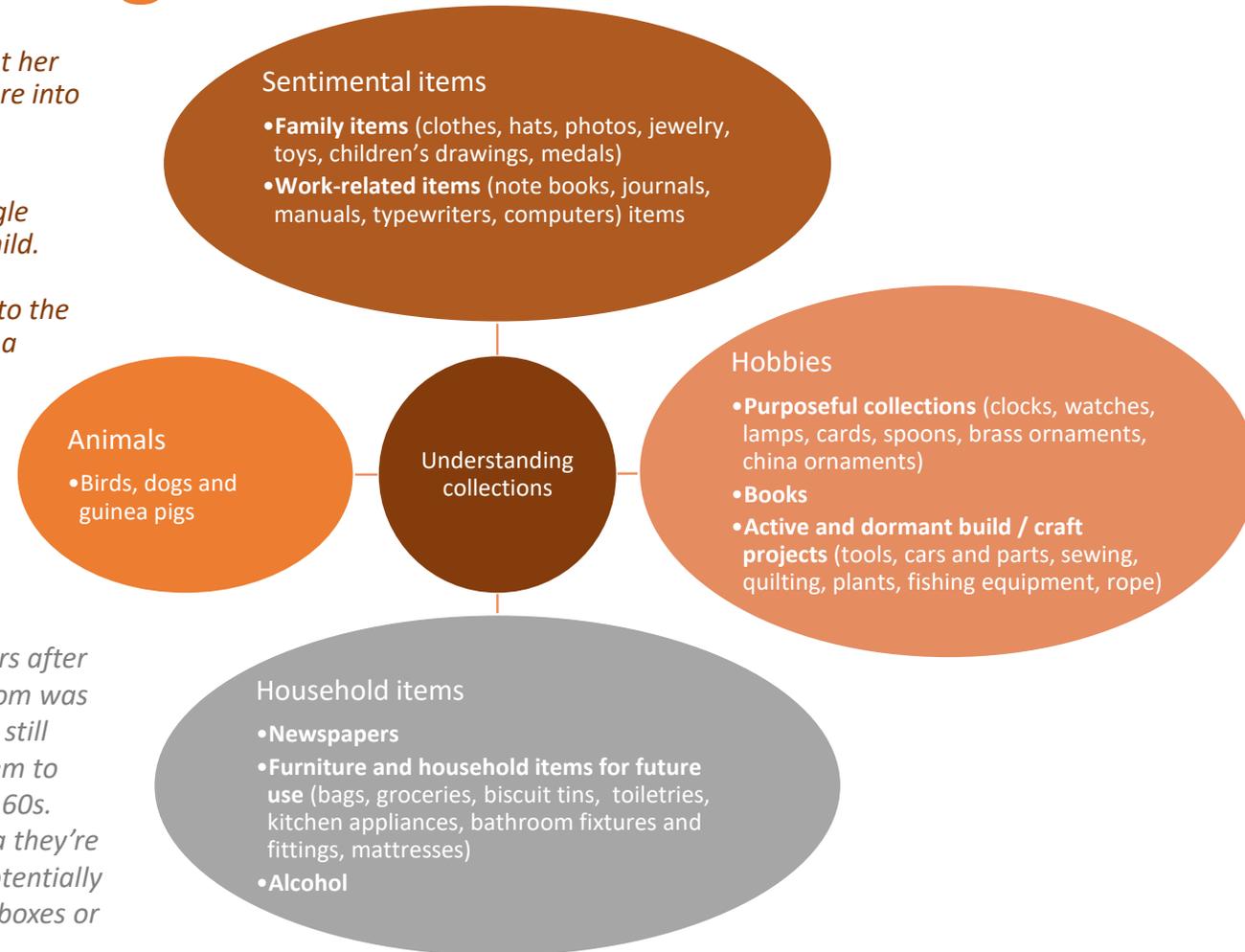
*She grew up very poor and was taught to never throw anything away, because it could be useful someday. She got worse after her divorce when her husband denied her access to her special belongings and told her he had burned them. She has always torn out cuttings from newspapers or magazines 'in case she wants to refer to them in the future'*

# Understanding their collections

*When my grandmother passed away and she got her share of the furniture, she crammed that furniture into an already packed house.*

*My mother has every single drawing I ever did as a child. Every toy. This is all to be hoarded – handed down to the grandchildren. So there's a purpose.*

*We moved into their old house 12 years after they vacated it and the biggest bedroom was full of (clean) rubbish. The pantry also still contained medicines (use by dates seem to have been invented in 1984) from the 60s. Everyone put it down to 'that's the era they're from', they never chucked anything potentially useful (like 150 ice-cream containers, boxes or bags of any kind) out*



*I would very easily just write 'crap' on this list. But it is actually items pertaining to home and home renovation which they just haven't done and may never do. So every iteration of an ex-fridge that has ever lived there. ...Ex-barbecues still in the backyard, and then whatever possible replacement, but they haven't done it. So toilet, sink, cooktop tucked into places and things. It could just be in your lounge room. Because it's important, you've got to keep it*

*[Their collections started] 30 years ago. Started with collecting magazines of interest and electronics. He turned his attention to collecting spoons... Then he started collecting brass... What he used to enjoy is he'd sit and he'd polish his brass... And then he'd put it all on display... Every part of his house would be covered*

*What may seem like a piece of paper to you, that might be a note from their dead husband, their child. The phone number to the friend they've lost. You can't just walk in and take over.*

# Challenges maintaining a healthy home (CMHH)

‘Squalor’ / unsanitary environment

Accumulation of rubbish, decomposing food, excessive grime, dust or mould

May lead to being unable to use rooms for intended purpose

# CMHH: common comorbidities

## CMHH without hoarding disorder: younger adults

- Range of medical and psychiatric conditions
- Executive functioning, memory loss, disordered thinking
- Use of alcohol and other drugs

## CMHH without hoarding disorder: older adults

- Vascular and Alzheimer's neurodegeneration

## CMHH with hoarding disorder

- Loss of domestic partner
- Onset of frailty
- Neurocognitive disorders

# Hoarding and CMHH: interaction

Many people living with CMHH do not live with hoarding (Guinane et al 2019)

20%-60% of those living with CMHH also have challenges with hoarding behaviour (Lee et al 2017)

Those living with hoarding may develop CMHH. For these, older age of presentation (av = 76) (Guinane et al 2019)

# Why is this important in Tasmania?

Hoarding and Squalor Working Group (Northern Tas) snapshot survey (2017)

80% of Tasmanian Partners in Recovery Support Facilitators were working with at least one client who had challenges with hoarding and/or CMHH

# Why is this important in Tasmania?

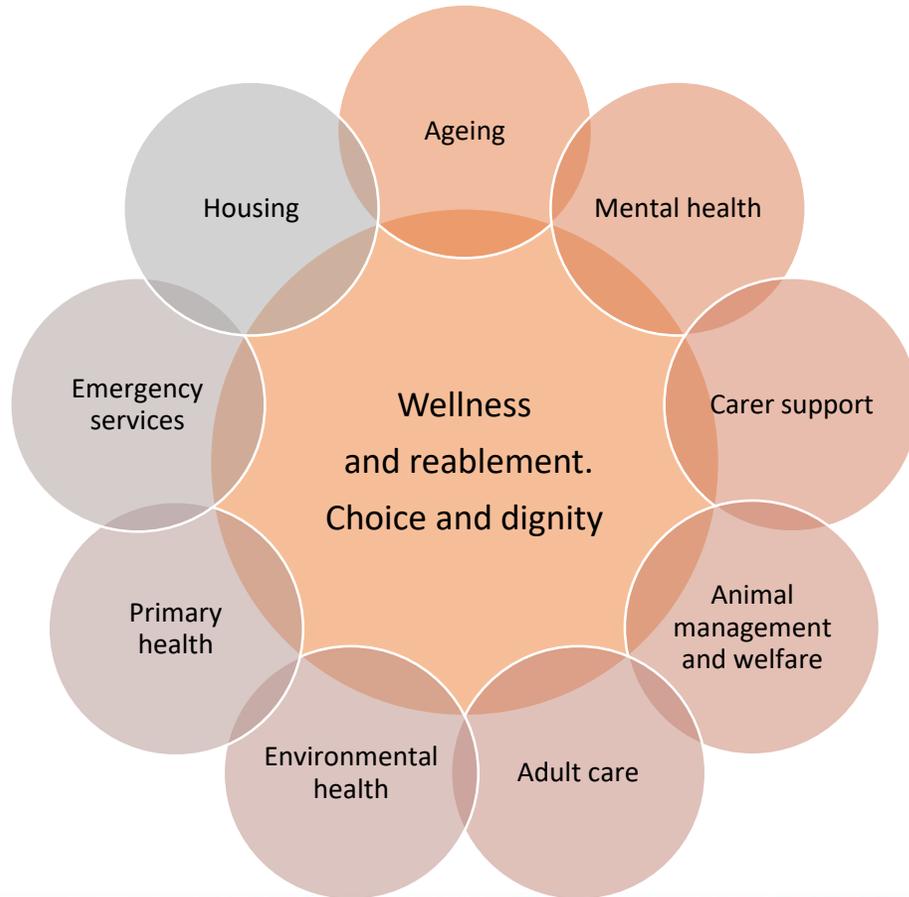
Est. prevalence within Aus adults – 2-6% (ANU 2016)

Age group	Tasmanian Population 2016*	Estimated range of Tasmanian adults living with hoarding behaviour**	
		@ 2 per cent	@ 6 per cent
Younger Adults			
<b>20-49</b>	182,239	3,645	10,934
Older Adults			
<b>50 to 64</b>	107,694	2154	6,462
<b>65+</b>	98,753	1975	5,925
<b>Total older adults</b>	<b>206,447</b>	<b>4,129</b>	<b>12,387</b>

\*Source: ABS 2016 Census QuickStats

\*\*Based on ANU estimates on percentage of adults (ANU 2016)

# The Tasmanian service and support environment



- Ageing population
- Low level of help seeking in a consumer-led service environment.
- Dilemmas:
  - Dignity and choice
  - Health and safety
- Everybody's problem, no-one's responsibility

# The Tasmanian void

No specific policy / strategic lead at federal or state level

No way to understand prevalence and consumer challenges.

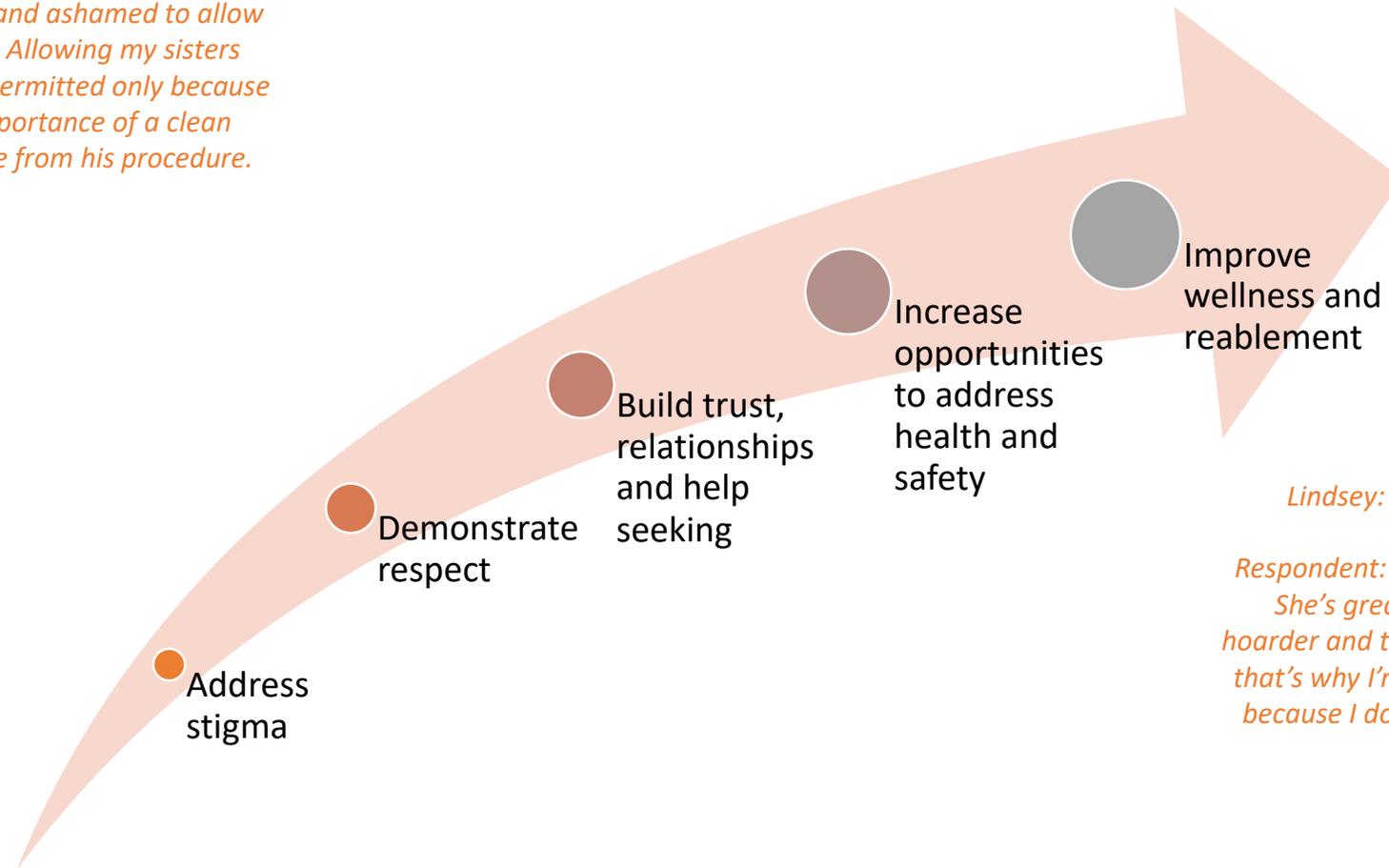
No collaborative infrastructure.

Very little specialist supports, or workforce for those with challenges, or their families and carers.

No practice framework

# Addressing stigma and building trust

*My father was too proud and ashamed to allow strangers inside his home. Allowing my sisters inside was a disgrace he permitted only because he understood the dire importance of a clean environment to convalesce from his procedure.*  
ANONYMOUS 2020



*Lindsey: She sounds amazing, your mum.*

*Respondent: She's awesome. She's awesome. She's great...She just doesn't like the word hoarder and the stigmatising of it. But it's like, that's why I'm doing [work around hoarding], because I don't like someone as awesome as her being stigmatised.*

# About Treasured Lives

**Treasured Lives**

Enabling older Tasmanians to age well at home  
when they are living with challenges related to  
hoarding and/or maintaining a healthy home



# Treasured Lives: goals

*Treasured Lives* examines how older Tasmanians with challenges related to hoarding and/or maintaining a healthy home can **age well at home**.

- Understanding what we know about the **prevalence** of these challenges amongst Tasmanians aged 50+, or 45+ for Tasmanians of Aboriginal and Torres Strait Islander heritage.
- Understanding the **experiences, challenges and needs** of older Tasmanians living with these issues, their families and carers and the services that seek to support them.
- Exploring the **social policies and investment in programs** that serve older Tasmanians and their families and carers in this area.
- Examining how similar households are supported in **other Australian jurisdictions and internationally**.

# Project phases

## Phase 1: Families and carers

### Research activities:

- Explore families and carers' experiences and needs.
- Explore families and carers' reflections on older people's experiences and what they need to age well at home.
- Map current policies and programs for families and carers.

### Recommendations:

- Addressing the needs of families and carers.

## Phase 2: Older people and the policy and service environment

### Research activities:

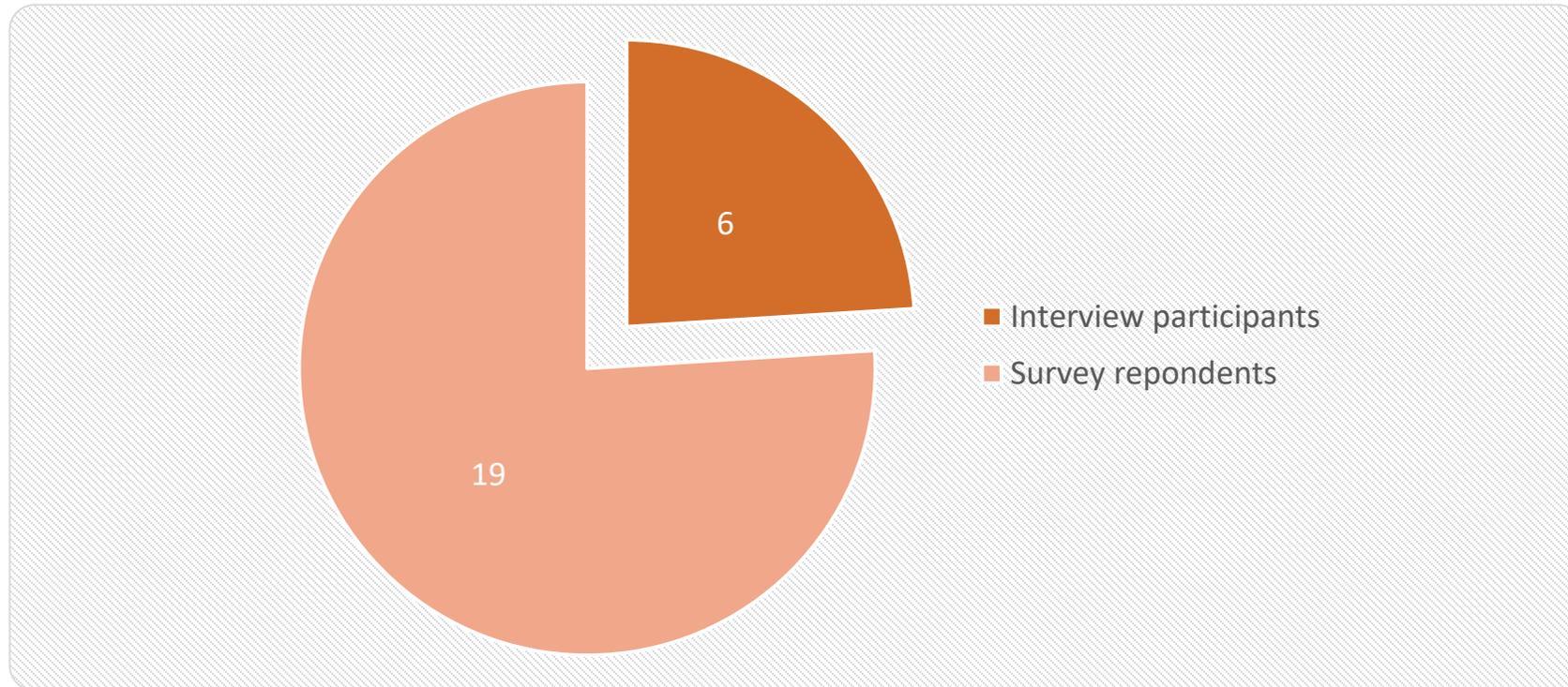
- Explore the experiences of those living with hoarding and/or challenges related to maintaining a healthy home through a set of case studies (3-5)
- Explore the needs of service providers, statutory agencies and government agencies.
- Map current policies and programs
- Explore good practice in other jurisdictions and internationally.

### Recommendations:

- Addressing the needs of older Tasmanians living with hoarding and/or challenges related to maintaining a healthy home.
- Addressing the needs of government agencies, statutory agencies and service providers working with older Tasmanians.

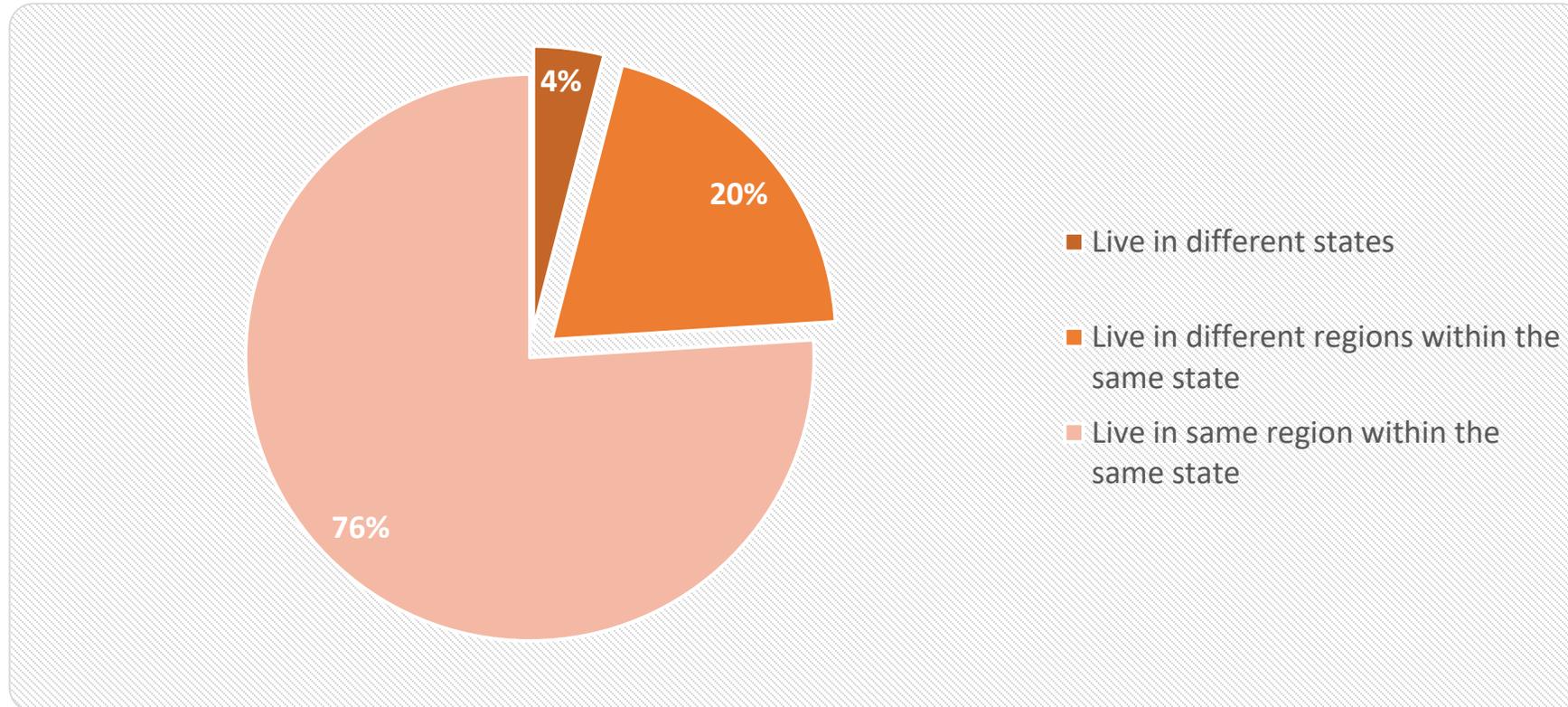
# Treasured Lives phase 1: families and carers

# Research participants: families and carers



N=25

# Where the family member or carer lived in comparison to those they care for



N = 25

# Families and carers: gateways to trust and support

## Relational: Window on the world

May be only / one of a few home visitors

Navigating stigma, family and community relationships

Excellent insights into health and history

Maintaining trust and privacy is critical

## Practical: Lone carers, minimising risks

Excellent insights into behaviour and boundaries

Focused on safety first

The toll on family relationships

Nowhere to turn for support

## Emotional: a private and long-term load

Often 'sandwich' caring

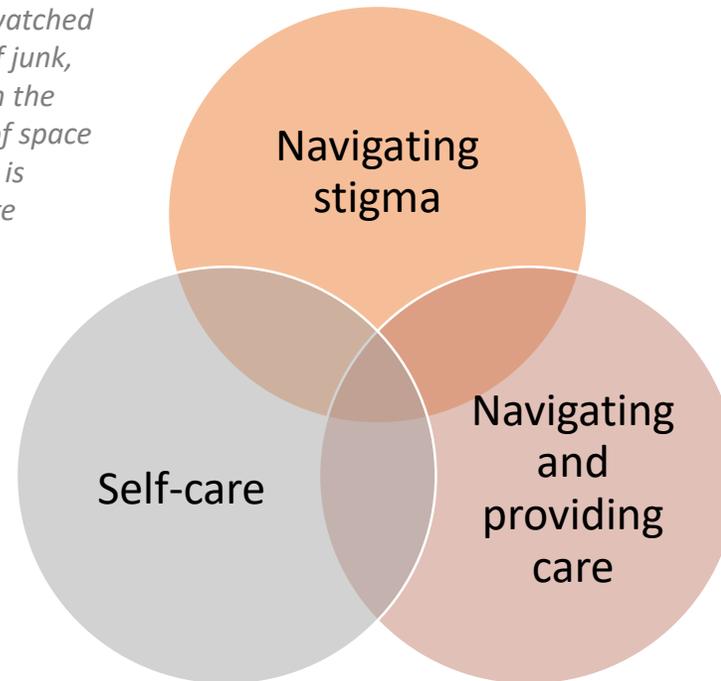
Worried about environmental, personal and social risks

Maintaining fragile relationships

Rarely seek support for themselves

# Families and carers: multiple roles and challenges

*It's not a quick fix. You start hoarding, you stop hoarding and all of a sudden everything's lovely and smooth. No. Normally once they start, and I watched it progress from – we had a spare room full of junk, and then the lounge room was half full... Then the lounge room is completely absorbed... the roof space is completely absorbed. Mum's bedroom now is completely absorbed. It's like a disease. It's like watching mould on a piece of fruit.*



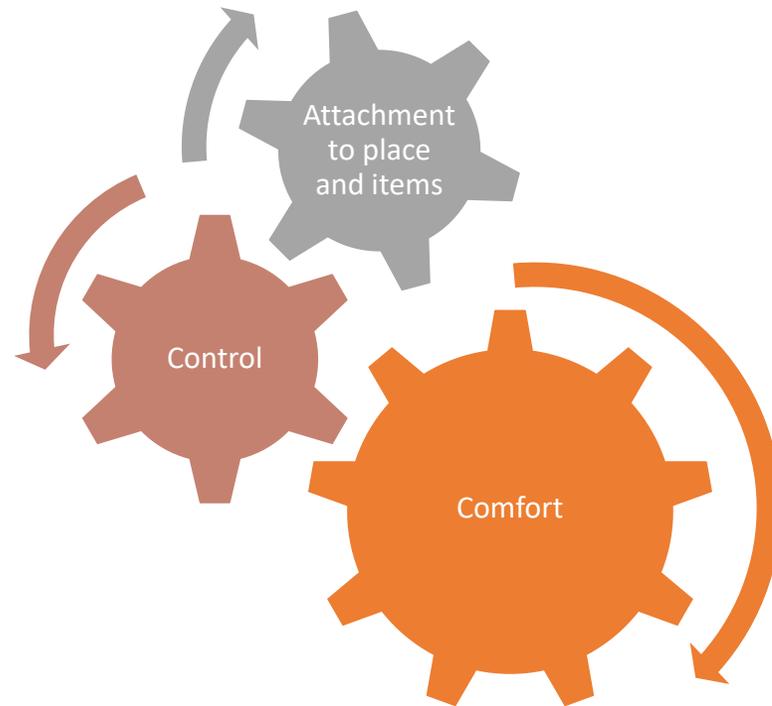
*We never had visitors. She's of religious faith... But because the closest thing to God is cleanliness, she's extremely embarrassed by how it was, how it is... The gate's not locked now but no one will ever visit, they know their boundaries. If you're going to pick mum up... then you pick her up at the gate. No one enters the home apart from myself and my daughter and my son, and my husband's allowed in now.*

*It might take all day to fill two garbage bags, but she will fill two garbage bags. I take them directly to the car and directly to the tip. If you leave anything that we've gone through, it will then be re-sorted and your two garbage bags will come down to one Woolworths' bag that you can take to the tip. I've made a pact with her over the years. We never touch anything if she is not home. We do clean off her kitchen table. That gets put in a box that gets put in her bedroom and then she can sort through it at her leisure... Because that's mum's biggest fear – that she'll go away and we'll get in and we will destroy her stuff. So we don't touch anything.*

# Conversations on ageing

- Some discussions about ageing in place
- Overwhelming desire to age at home...
- ... But huge obstacles

# Ageing in place: positive impacts



# Ageing in place: concerns

## Practical concerns

Functioning in the home

Personal risks

Environmental risks

Ability of services to enter the home

## Maintaining control and dignity

Low insights into risks

Low motivation to address risks

Low help seeking

Wary of intervention

Lack of appropriate services

## Trajectory

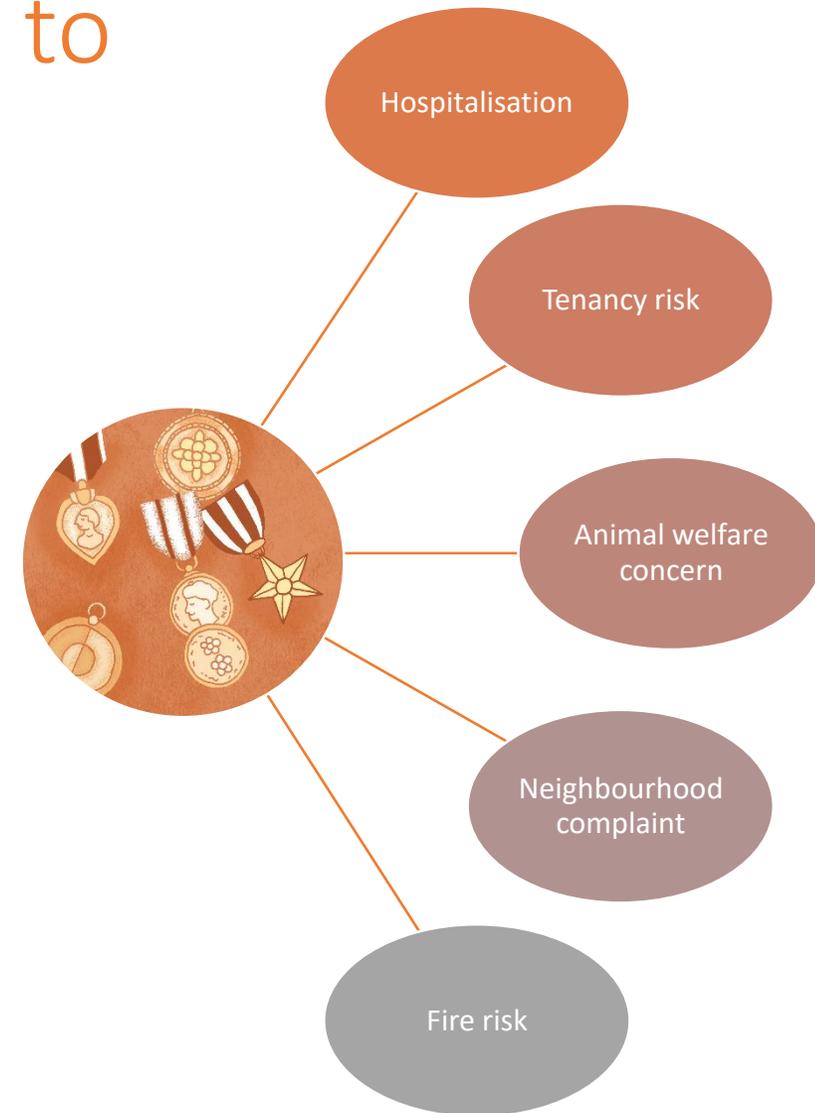
Ultimately, will not have a choice

Critical incident will trigger move.

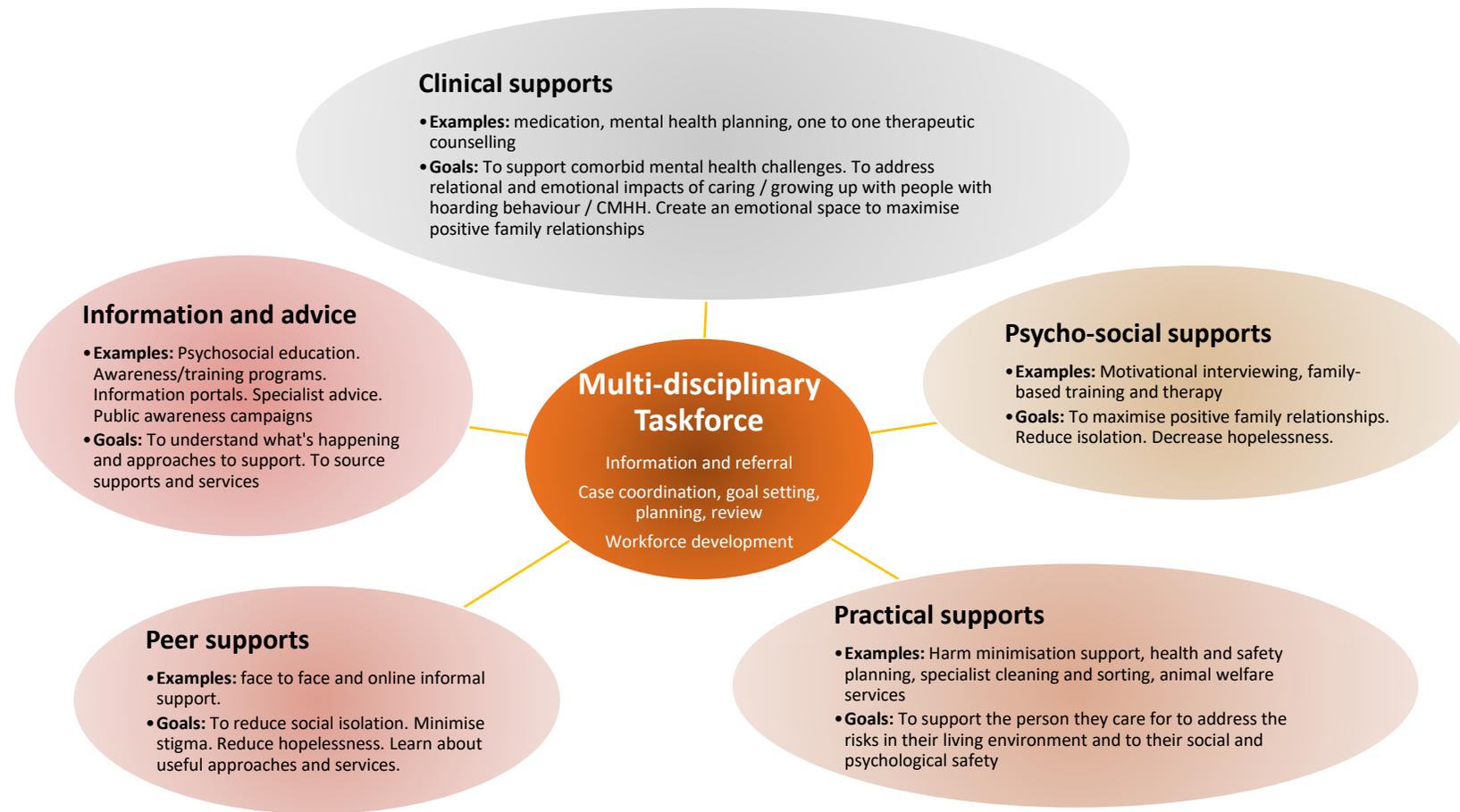
Or will die in place.

# Critical incidents as pathways to support

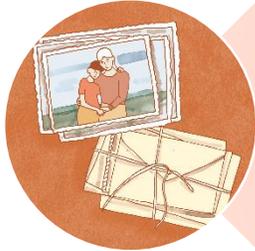
- Moments of contemplation / trigger for actions through critical incidents
- These incidents are mainly negative or forced engagements with services
- Need ways to turn these into positive engagements:
  - Immediate specialist supports
  - Leading to ongoing specialist supports



# What works in supporting families and carers elsewhere



# What Tasmanian families and carers need



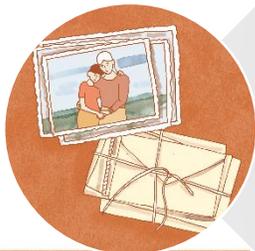
## Address stigma, raise awareness, generate respect

- Positive community education campaigns



## Develop a framework of specialist policies, practice, and programs

- Regional Tasmanian 'taskforces'
- Shared practice framework and case management for services
- Specialist information services
- Specialist clinical, psychosocial and practical support services for those living with hoarding and CMHH



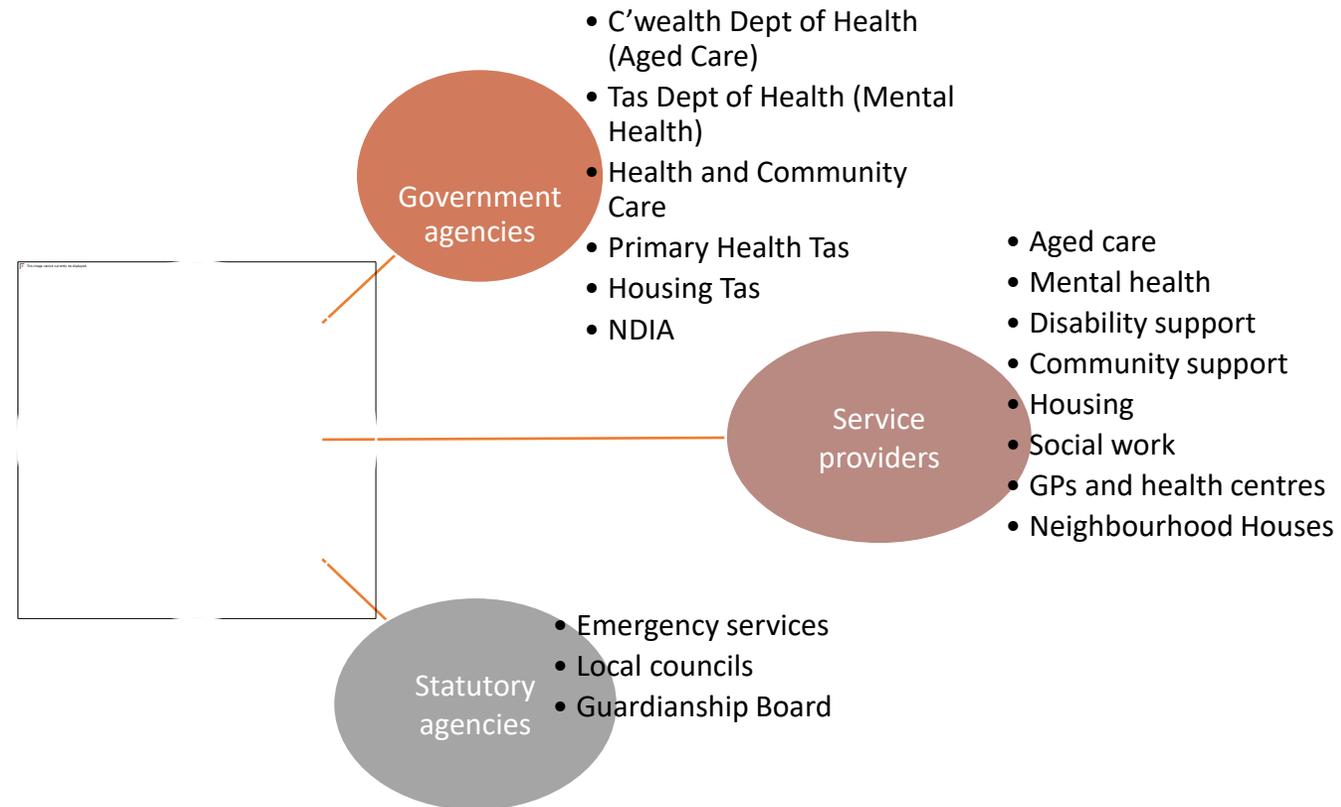
## Invest in continuum of care for families and carers

- Specialist personal counselling
- Training programs around hoarding and CMHH
- Online and face to face peer support
- Family support programs

# Taking part in Treasured Lives phase 2

April to October 2021

# Who are we talking with?



# Can you take part?

Directly or incidentally work with older people living with challenges related to hoarding and/or maintaining a healthy home

And/or work with their families/carers

# Ways you can participate

Take part in an interview / focus group

Complete an [online survey](#)

Complete a case study form

# More information

Contact Lindsey Fidler, lead researcher: E:  
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See the [Treasured Lives website](#)