

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



Introduction

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



About this network session

- ***Build knowledge:*** Increase professional knowledge and understanding about the nature and challenges for clients and how to support them
- ***Build a regional network:*** Bring together professionals on a regional basis to encourage case management and partnership working within existing services and raise awareness about what's available locally
- ***Facilitate change:*** Identify gaps and needs on a regional basis that might help inform future development of support services and skills

Outline

9.30	Introduction and housekeeping
Part 1	Building knowledge
9:40	Understanding hoarding and how to support households
10:00	What's happening in Tasmania Panel Questions and discussion
10.40	Comfort break
Part 2	Building a network
10.50	The role of professional networks
11.00	Your regional network Breakout groups Feedback
11.40	Next steps
	Close

Housekeeping

Questions

Please mute when not speaking

Collaborating

Recording

- Technical issues

maryb@anglicare-tas.org.au 0400 524 414.

Or direct message in chat.

- Access issues:

carmelh@anglicare-tas.org.au |

0477 261 615

Part 1: Building knowledge

About hoarding and challenges maintaining a healthy home

Hoarding

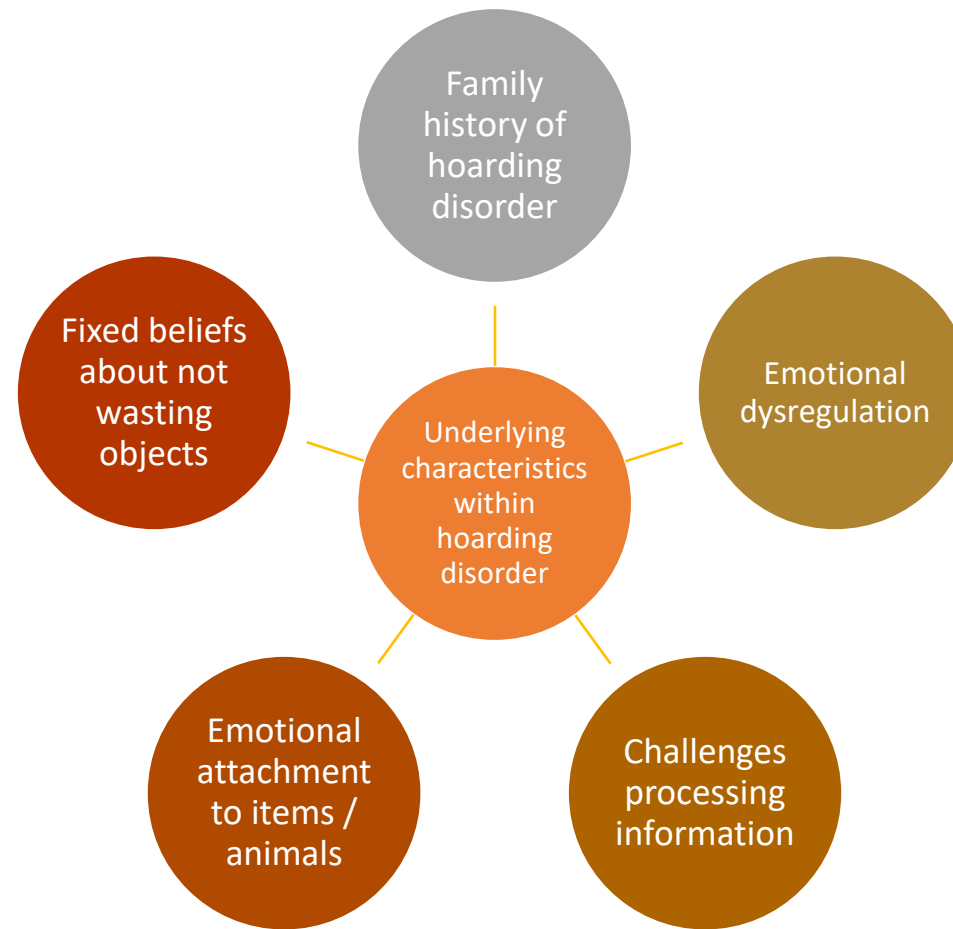
Challenges with (acquiring), sorting or discarding items or animals

Attaching significant meaning to items/animals, which impedes ability to discard

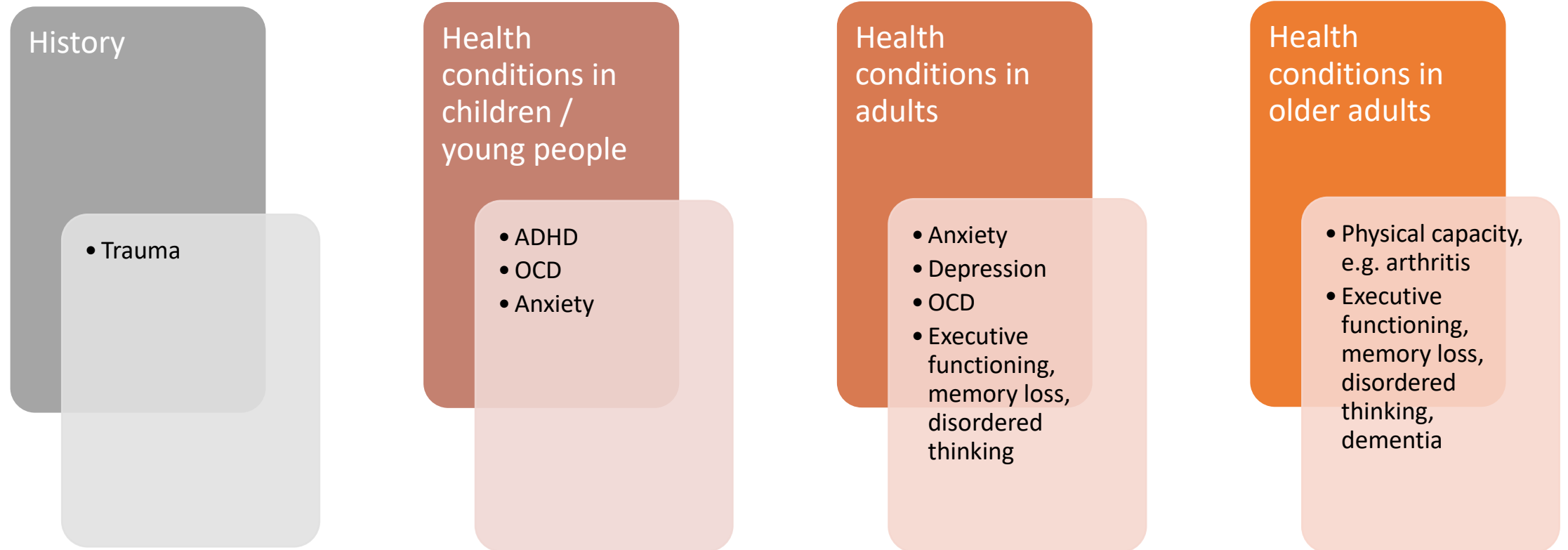
Leading to a cluttered living environment, impeding functioning in living spaces, and impacting on health and safety

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

Hoarding: common characteristics



Hoarding: common co-present challenges



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 co-present challenges

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)

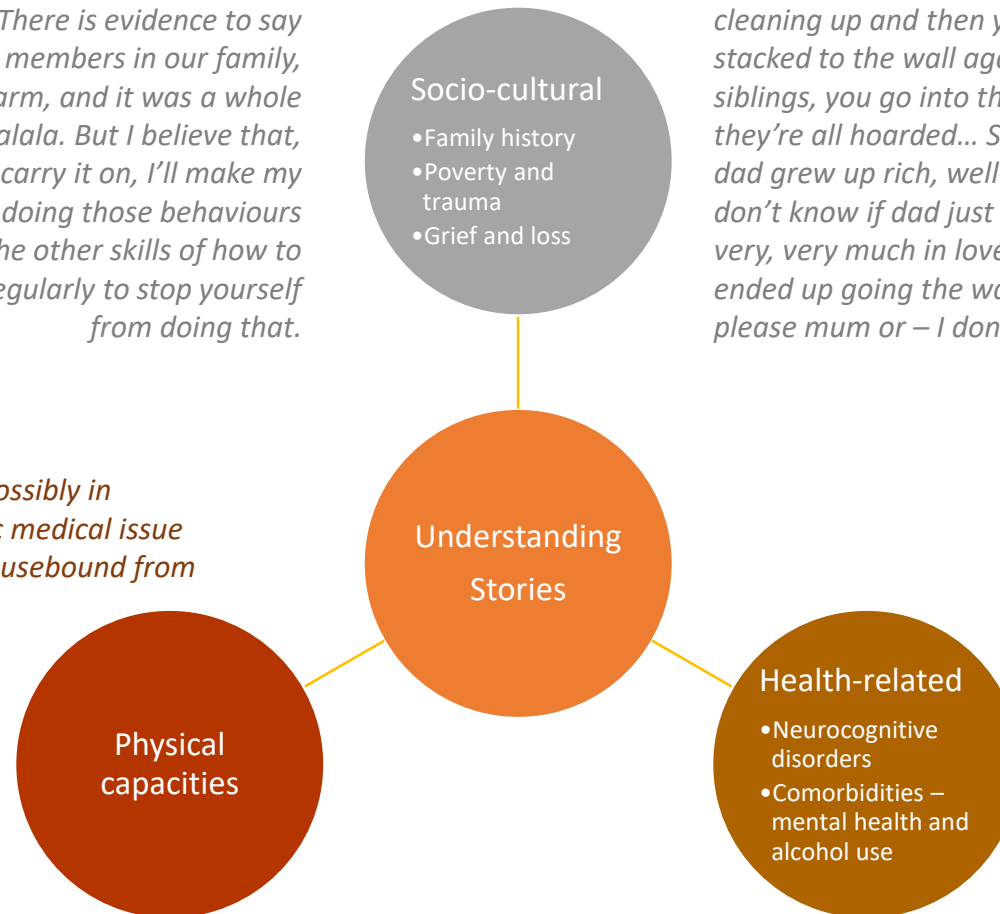
Older Tasmanians: understanding their stories

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'

Why is this important in Tasmania?

Prevalence

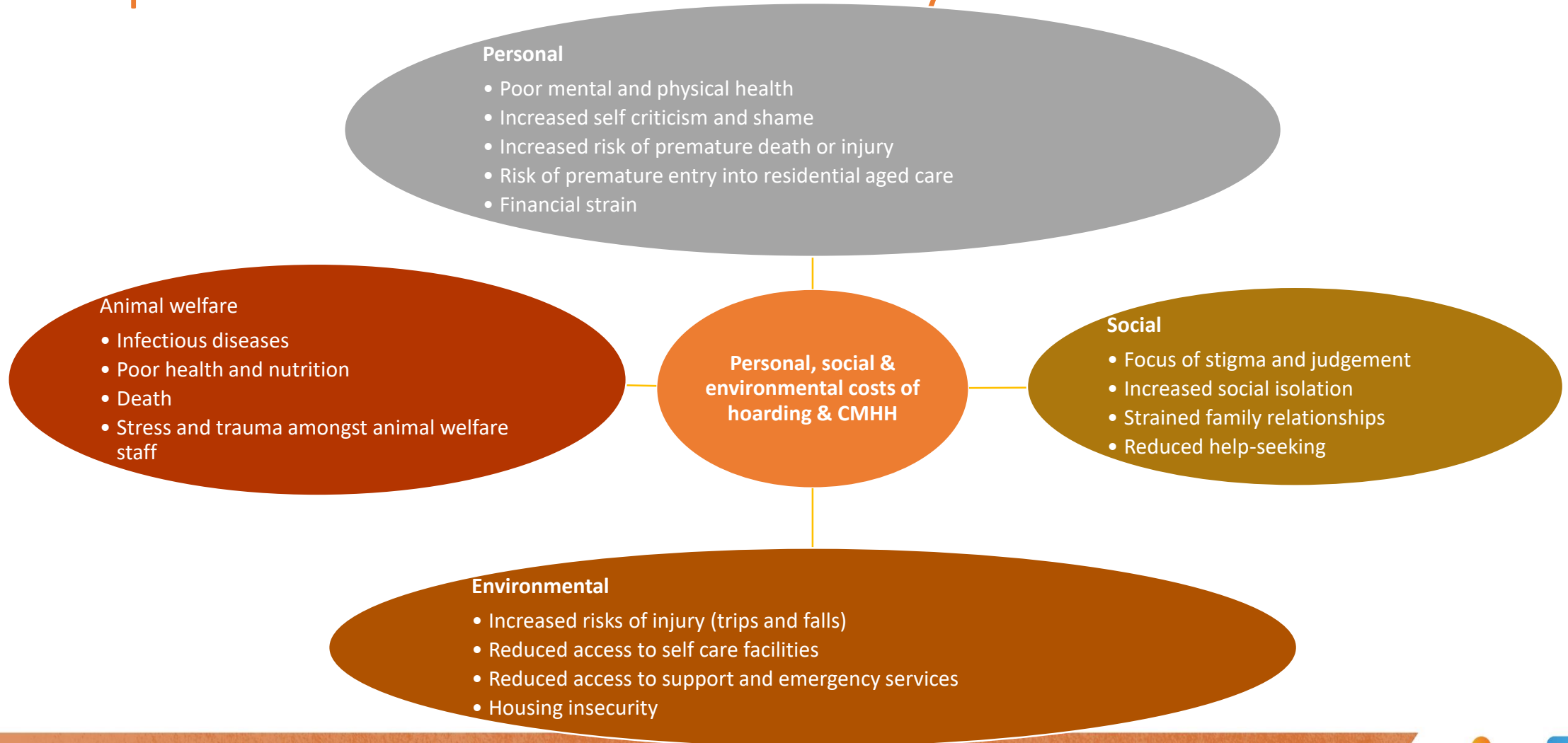
Est. prevalence of hoarding behaviour within Tasmanian adults – @2.5% (range = 1.7% - 3.6%) , (Postlethwaite et al 2019)

	Tasmanian Population*	Estimated number of adults living with hoarding behaviour**
		@ 2.5 per cent
Aged 20-49	182,239	4556
Aged 50 to 64	107,694	2692
Aged 65+	98,753	2469
Total 50+	206,447	5,161

*Source: ABS 2016 Census QuickStats

**Based on Poselthwaite et al 2019

The personal and community costs



Economic costs of not intervening



About Treasured Lives

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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**.

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

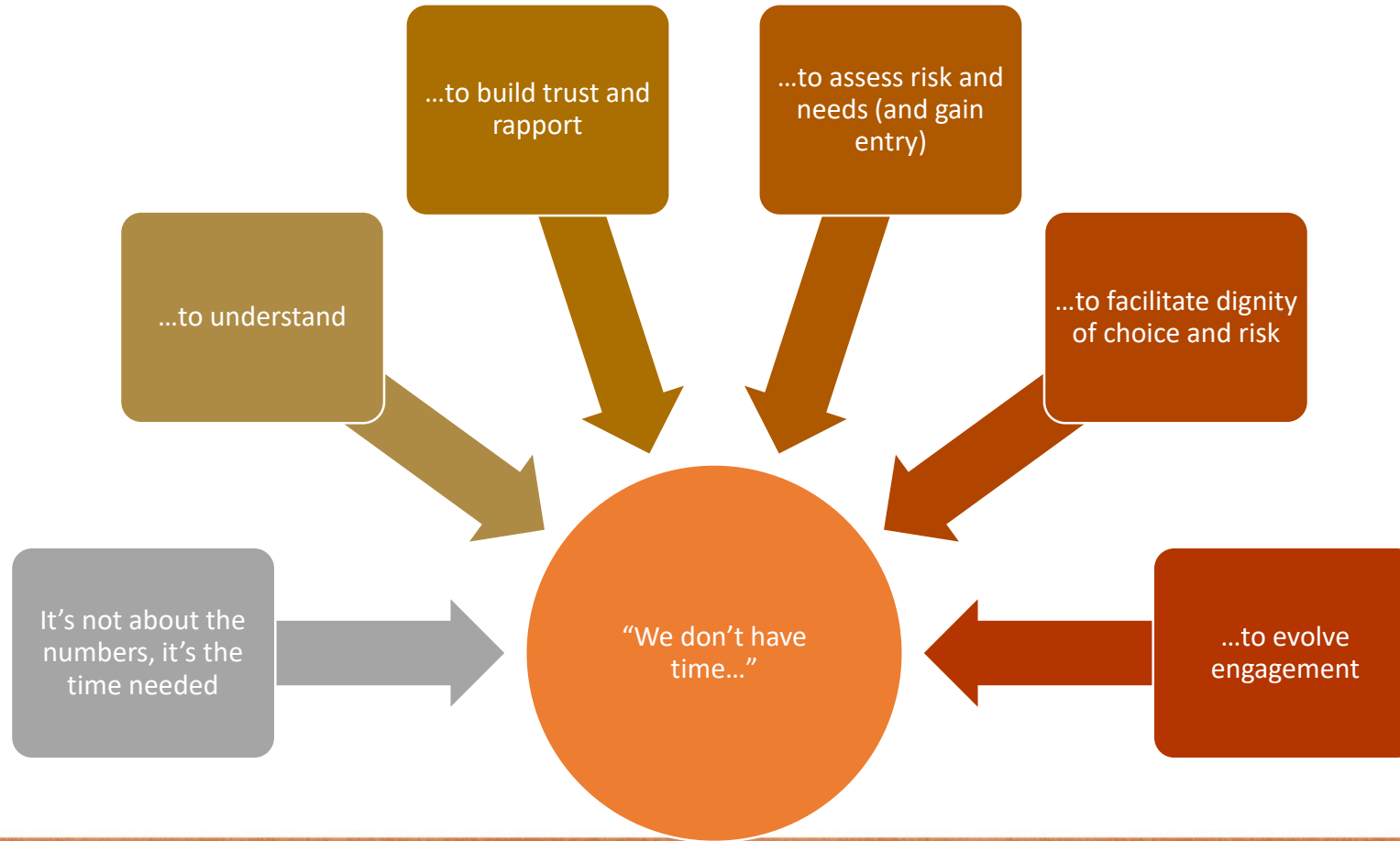
Often 'sandwich' caring

Worried about environmental, personal and social risks

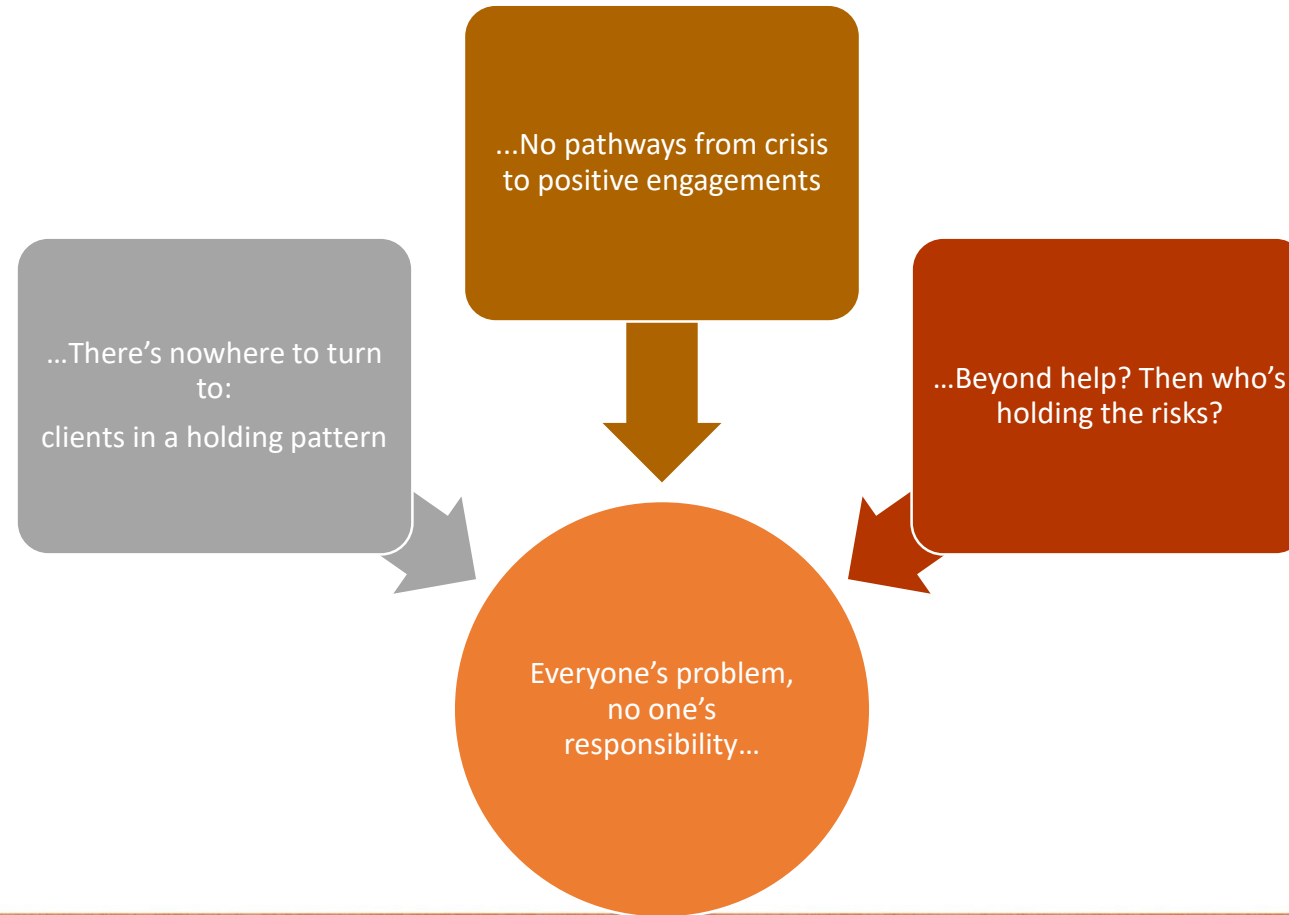
Maintaining fragile relationships

Rarely seek support for themselves

What service providers and agencies said: “We don’t have time”



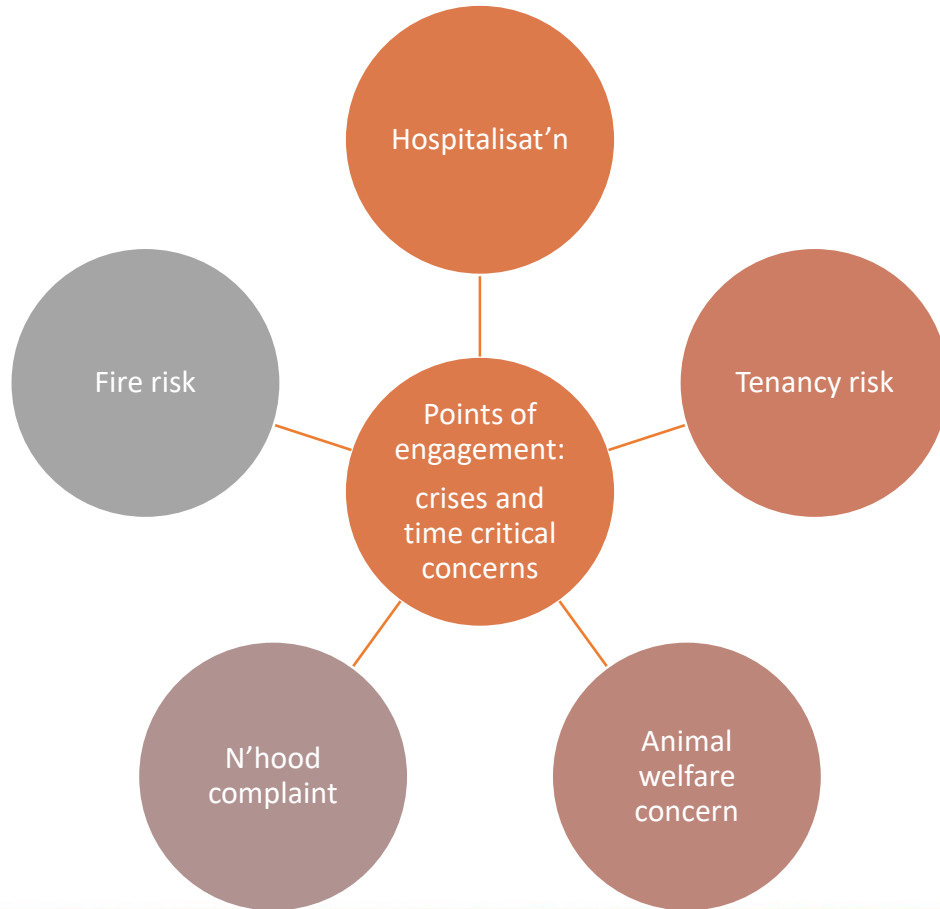
What service providers and agencies said: “Everyone’s problem, no one’s responsibility”



What service providers and agencies said: “We’re not prepared for this”



What families, service providers and agencies said: critical incidents as opportunities for engagement

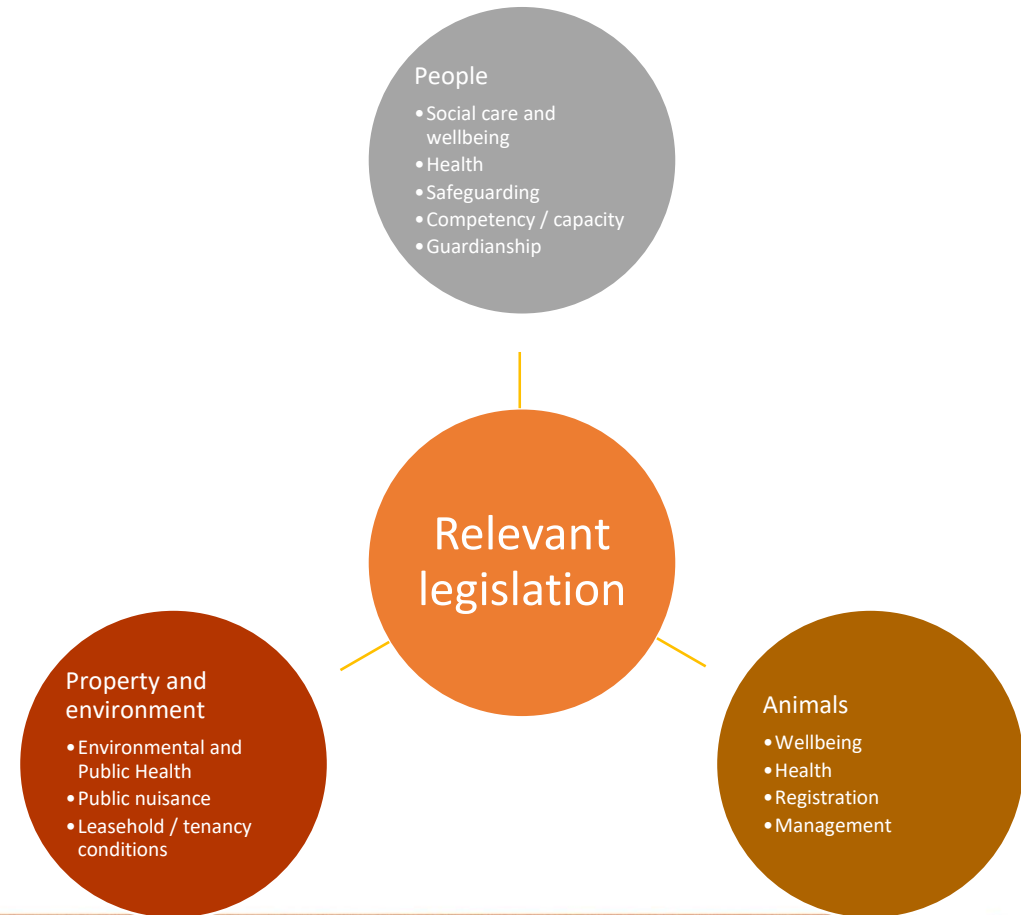


- Moments of contemplation / trigger for actions through critical incidents
- These incidents are mainly negative or forced engagements with services
- Need ways to turn these into positive engagements:
 - Crisis response specialist supports
 - Leading to ongoing specialist supports

What works in supporting families

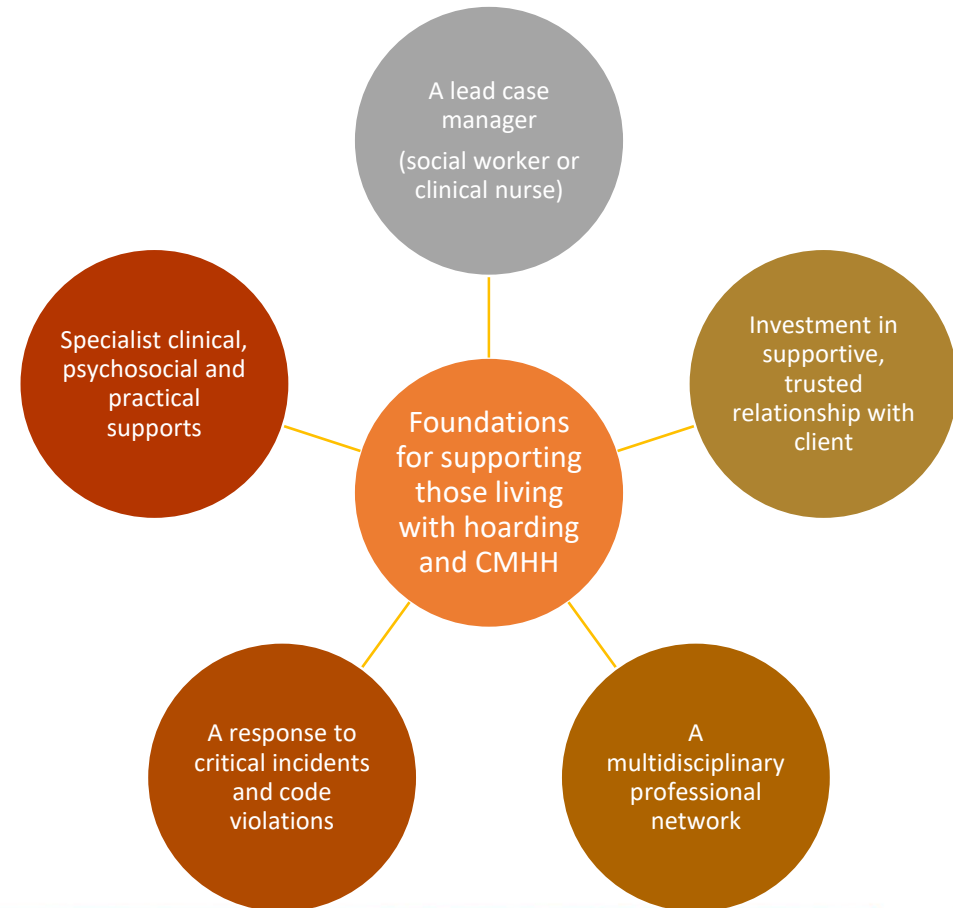
What works? Policy and legislation

- Federal or state government leadership needs to see and prioritise hoarding and CMHH as **a complex community policy issue**, which impacts on personal wellbeing and community safety.
- North America, England and some Australian jurisdictions bring together social policies and approaches related to **people, animals and property** into a consolidated and focused directive;
- Need a **lead government agency to convene a collective approach to addressing supports for those living with hoarding and CMHH**



What works? Collaboration and programs

- Successful models manage to bring together policy remits concerning people, animals and property under two approaches: addressing hoarding disorder as ***a chronic illness management model***, which addresses client self-care, care coordination and consistent follow-up; and/or under ***a harm minimisation model***, which focuses on, ‘*managing and mitigating the negative impact rather than eradicating the hoarding behaviour entirely*’.



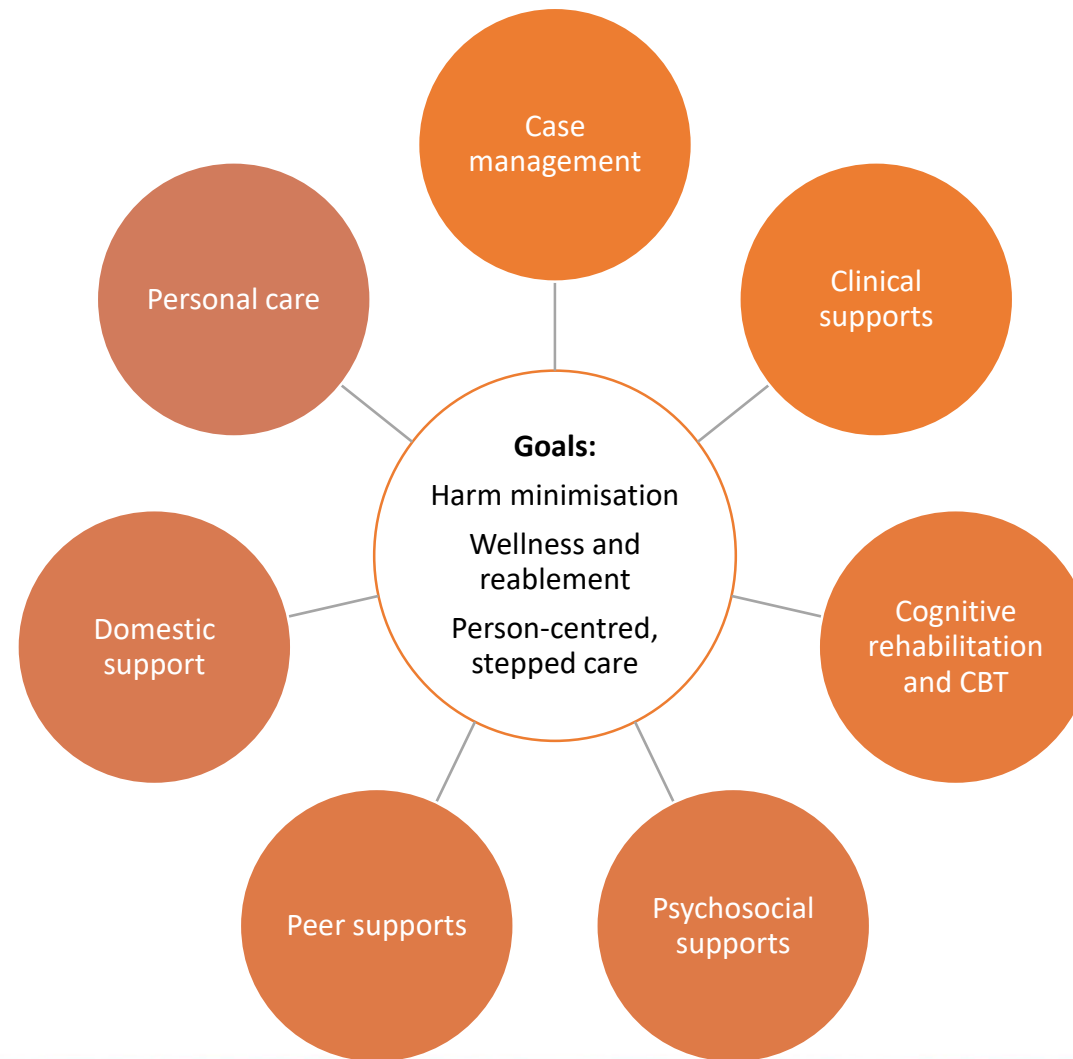
What works? Practice framework

Purposes:

- Creating a **shared understanding** of hoarding behaviour, CMHH and the approaches needed to support people living with these challenges.
- Providing a **shared structure for collaborative working**
- Placing the person, human dependents and animals first in a planned response, ensuring they are **safe and risk is minimised**.
- Confirming **a common language, systems and tools** that can be utilised by services
- Presenting **information about services**, what they do and how to contact them.



What do 'supports' look like for those living with hoarding?



Recommendations

Tasmanian Government and Primary Health Tasmania invest in:

- a policy and a practice framework, developed and implemented by a designated lead state government agency
- a positive community education campaign
- regional Tasmanian collaboration and services which include:
 - multidisciplinary professional networks for local case management and support
 - specialist case management
 - specialist clinical, psychosocial, practical and peer supports for older people
 - specialist clinical, psychosocial, practical and peer supports for families and carers
 - a partnership response to critical incidents that leads to positive supports
 - services of last resort that can minimise client and environmental harm to levels within the risk tolerances of mainstream services
- a workforce development plan
- a digital hoarding and CMHH information hub.
- testing the service design with older Tasmanians living with hoarding or CMHH.

What's happening in Tasmania?

Families and carers

Existing services

What's happening in Tasmania?

- Siobhan Marriott, artist and family member
- Lesley King, Project Manager, Tas Fire Service
- Rick Fulton, Statewide Manager, Housing Tasmania

Precious Excess

PRECIOUS EXCESS

AN EXPLORATION OF COMPULSIVE ACQUISITION

CURATED BY SIOBHAN MARRIOTT



EXHIBITING ARTISTS

Eleanor Murrell
Christie Torrington
Tammy Law
D. Stewart-Lookin
Siobhan Marriott

MAC

MOONAH ARTS CENTRE

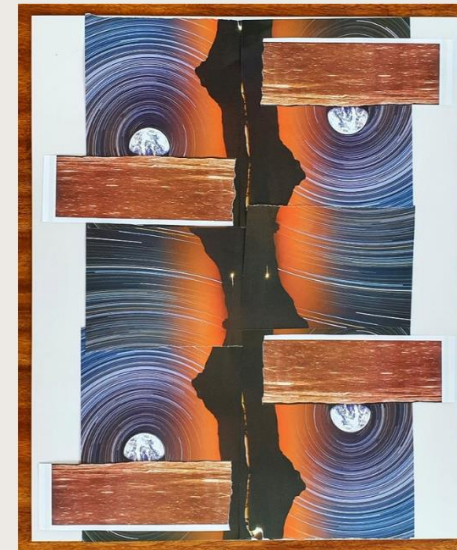
11-26 Feb 2022

moonahartscentre.org.au

PRECIOUS EXCESS

AN EXPLORATION OF COMPULSIVE ACQUISITION

CURATED BY SIOBHAN MARRIOTT



Siobhan Marriott, moonscape (2020)

Moonah Arts Centre : 11-26 Feb 2022

moonahartscentre.org.au

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Precious Excess

PRECIOUS EXCESS

AN EXPLORATION OF COMPULSIVE ACQUISITION

CURATED BY SIOBHAN MARRIOTT



Tammy Law, Last hook on the wall (2016/2017)

Moonah Arts Centre : 11-26 Feb 2022

moonahartscentre.org.au

PRECIOUS EXCESS

AN EXPLORATION OF COMPULSIVE ACQUISITION

CURATED BY SIOBHAN MARRIOTT



Christie Tarrington, homeland/wasteland (2018)

Moonah Arts Centre : 11-26 Feb 2022

moonahartscentre.org.au


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Precious Excess

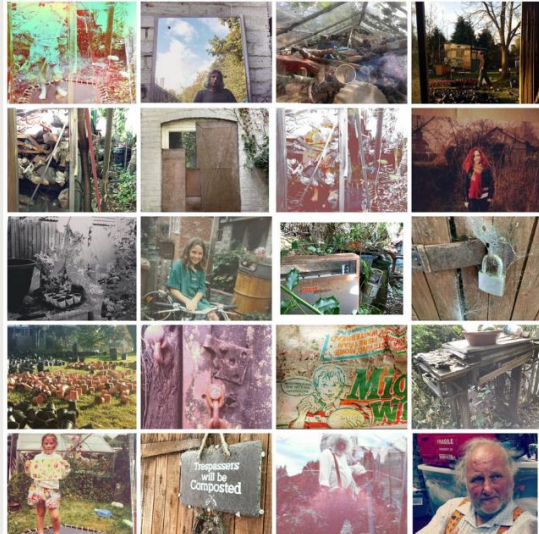
P R E C I O U S E X C E S S
AN EXPLORATION OF COMPULSIVE ACQUISITION
CURATED BY SIOBHAN MARRIOTT



D. Stewart-Lookkin, *Acquisition Addiction* (2021)

Moonah Arts Centre : 11-26 Feb 2022
moonahartscentre.org.au

P R E C I O U S E X C E S S
AN EXPLORATION OF COMPULSIVE ACQUISITION
CURATED BY SIOBHAN MARRIOTT



Eleanor Murrell, *Ghostly garden whispers, gone but never forgotten*

Moonah Arts Centre : 11-26 Feb 2022
moonahartscentre.org.au



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Precious Excess

- [International artists' show](#)
- Moonah Arts Centre
- 11th to 26th February
- Instagram @precious.excess
- Online discussion with artists
- 9am, Saturday 26th February
- Register via [Eventbrite](#)

Hoarding hazards increase fire risk of the occupant because:

- Accumulation of possessions results in an abnormally high fuel load, meaning bigger and more toxic fire.
- Greater opportunity for ignition especially near cooking and heating equipment.
- Blocked exits and narrow internal pathways impede escape for the occupant.
- Lack of smoke alarms or inability to hear existing smoke alarms because of excess clutter hinder early detection of a fire.
- Non-functional gas or electricity may result in unsafe practices for cooking and heating.



Workplace health and safety risks to fire fighters



Tasmania Fire Service



TFS Residential Hazard Notification System

A discreet firefighter dispatch alert of residential fire hazards to increase firefighter preparedness and community safety.

Who can notify?

- ✓ Department Police, Fire and Emergency Management volunteers and employees
- ✓ Home and community care agency staff and volunteers
- ✓ Aged care and community care assessors
- ✓ Medical and allied health practitioners (including Community Nurses, General Practitioners, Psychologists/ Psychiatrists)
- ✓ Housing Tasmania and social housing agency staff and
- ✓ Local Government Environmental Health Officers.

Important links:

- [Hazard Notification Online Form](#) QR code
- fire.tas.gov.au/hazardnotifications
- [Residential Hazard Notification System Information Pack](#)



Fire hazards may include high level of clutter due to hoarding and other hazards such as LPG gas used inside for cooking, charging of mobility scooters or wheelchairs unsafely inside the home.

The collection of names and personal details about the occupant/s of a residence is not within the scope of the Residential Hazard Notification System. It has been designed to improve safety outcomes using minimal amount of personal information. Security of information is in accordance with the DPfEM Personal Information Management Guidelines and the DPfEM Information Security Policy.

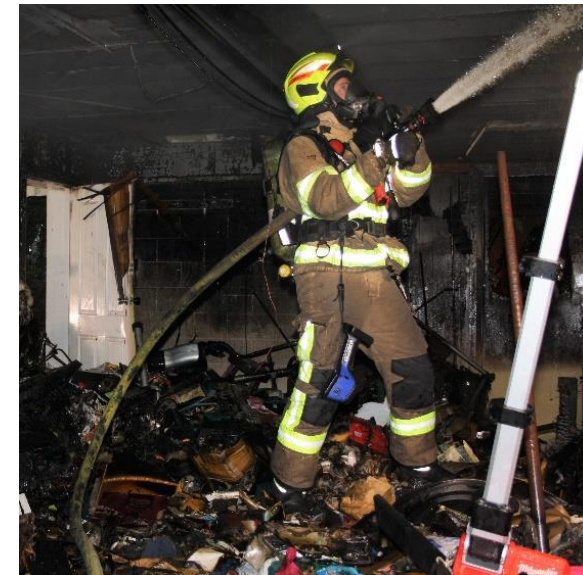
For more information about the TFS Residential Hazard Notification System contact the program manager on 1800 000 699 or email communityed@fire.tas.gov.au



Tasmania Fire Service



Tasmania Fire Service



Hoarding fire risk reduction

- Interconnected smoke alarms should be installed in living areas and rooms where people sleep
- Unblock exits
- Widen internal pathways
- Check utilities are connected
- Prioritise removing clutter from around cooking area, heaters and electrical items
- Discourage the use of open flame.



Assessment tools: personal wellbeing, environmental risks

Client wellbeing in the home

Self-report:

- [Activities of Daily Living in Hoarding Scale](#) (ADL-H) (Frost et al. 2013)
- [The Hoarding Rating Scale](#) (HRS-I) (Tolin, Frost et al. 2010)
- [Compulsive Acquisition Scale](#) (CAS) (Frost et al. 2002)
- [Savings Cognition Inventory](#) (SCI) (Steketee et al. 2003)
- [Saving Inventory Revised](#) (SIR) © (Frost et al. 2004)

Self-report and clinical assessment:

- [Hoarding Rating Scale Interview](#) (HRS-I) (Tolin, Frost et al. 2010)
- [UCLA Hoarding Severity Scale](#) (HSS) (Saxena et al. 2015)
- [Montreal Cognitive Assessment Basic](#) © (MOCA-B) (Julayanont et al. 2015)
- [Structured Interview for Hoarding Disorder](#) (SIHD) (Nordsletten et al. 2013)
- [Depression Anxiety Stress Scales](#) (DASS) (Lovibond & Lovibond 1995)
- [Personal Wellbeing Index - Intellectual Disability](#) (PWI-ID) (Cummins & Lau 2005)
- [Mini International Neuropsychiatric Interview](#) (Sheehan et al. 1998) for psychiatric co-morbidities

Service provider assessment:

- [Health, Obstacles, Mental Health, Endangerment, Structure and Safety](#) (HOMES)© (Bratiotis et al. 2011)
- [Hoarding and Squalor Program Screening Tool](#) (CCS 2021)
- Homelessness risk assessment as required

Animal welfare

- [Tufts Animal Care and Condition \(TACC\)](#) (Patronek 1997)

Environmental assessments

- [Environmental Cleanliness and Clutter Scale](#) (ECCS) (Halliday & Snowdon 2009)
- [Clutter Image Rating Scale](#) (CIR) (Frost et al. 2008)

Environmental assessments: clutter image rating scale

Clutter Image Rating Scale (CIRS)*

The purpose of this tool is to gauge the impact of hoarding on the person with the hoarding behaviour.

Clutter Image Rating Scale: Part 1 of 3 – Kitchen

Please select the photo below that most accurately reflects the amount of clutter in your room.



* Source: Frost RO, Steketee G 2006a, *Compulsive Hoarding and Acquiring: Therapist Guide*. New York: Oxford University Press. The Clutter Image Rating (CIR) Tool, p. 188. Used with permission of Oxford University Press, USA.

Environmental assessments: environmental cleanliness and clutter scale

Environmental Cleanliness and Clutter Scale (ECCS)*

This form has been designed for service providers to respond to situations involving squalor. The form assists with rating the cleanliness of a person's accommodation.

This first page may be removed if it is desirable to de-identify the person when communicating with other agencies.

Demographic details					
Name of person	Surname	Other names			
Date of birth and/or approximate age of person					
Gender (please circle)	Male		Female		
Marital status (please circle)	Single	Married/ de facto	Widowed	Divorced	Separated Not sure?
Address					
Does he/she live alone? (please circle)	Yes		No		
If not, who with?					
Number and type of pets					
Home ownership	Owner	Tenant – private	Tenant – DOH	Other – non-owner (e.g. lodger)	
Accommodation type	House	Unit	Bedsit	Other (specify)	
How long has he/she been living like this? (please circle)	Less than 1 year	1–3 years	4–10 years	Over 10 years	
Known medical illnesses and/or disabilities					
Mental disorders now or in the past					

* Source: Halliday G, Snowden J, 2006 Environmental Cleanliness and Clutter Scale (ECCS) based on the version devised by Snowden (1986), which mostly used items listed by Macmillan & Shaw (1966). Some descriptions used by Samios (1996) in her adaptation of the scale have been included.

Part 2: Building a network

Why build a regional network?

- Reaching more families
- Shift responses from negative engagements or holding clients to positively supporting clients
- Case management
- Holistic support – for people, animals and property
- Knowledge and skill development
- Collective impacts

Your regional network

- What would you like to achieve?
- How can you work together **now**?
- What would make working together easier? (Partnerships? Knowledge? Skills? Services?)

Part 3: Feedback and next steps

Feedback

- How useful has this session been for you in doing your job?
(1=extremely useful, 5=not at all useful)

- Please tell us more...

A regional network: expressions of interest

- Are you interested in being part of a regional hoarding support network?
- If yes:
 - please provide your email address
 - which regional network do you want to join?
 - what would you like further network sessions to cover?
- Would you be interested in leading / coordinating your regional network?

Next Steps: advocacy

Engaging decision makers

- December: Budget priority statement with costed recommendations
- Now to March 2022: Ministerial and departmental staff briefings
- July/Aug 2022: Senior bureaucrat round table – codesigning a system
- Ongoing: informing state and federal policy reforms:
 - Aged care
 - HACC
 - Mental health, including reform of OPMHS
 - Healthy Ageing Strategy
 - Carers Strategy

Next Steps: addressing stigma

- Feb and April 2022: Public awareness raising / destigmatizing via art exhibitions:
 - [Precious Excess](#), Moonah Arts Centre (10th to 26th Feb 2022)
 - Salamanca Arts Centre (1st to 24th April 2022)
- Ongoing: Targeted media stories to show hoarding as a complex community concern

More information

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See the [Treasured Lives website](#)