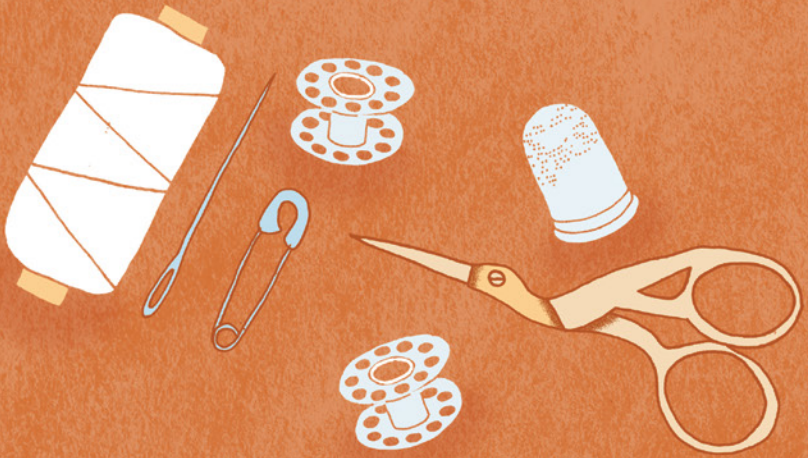
PHASE ONE: FAMILIES AND CARERS

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



LINDSEY FIDLER

AnglicareTAS
Choice, support and hope

SOCIAL ACTION & RESEARCH CENTRE

A catalogue record for this
book is available from the
National Library of Australia

ISBN: 978-1-921267-60-4

Author: Lindsey Fidler
Illustrations: Beth-Emily Gregory
Graphic design: Kelly Eijdenberg and Jamie Roberts
Copy-editing: Selina Claxton

For further information contact:

Social Action and Research Centre
Anglicare Tasmania
GPO Box 1620
Hobart Tasmania 7001

Website: www.anglicare-tas.org.au

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

PHASE 1: FAMILIES AND CARERS

LEAD RESEARCHER:
LINDSEY FIDLER

PROJECT TEAM:
SELINA CLAXTON
ELLEN NICHOLSON

SOCIAL ACTION AND RESEARCH CENTRE,
ANGLICARE TASMANIA

Contents

Tables and figures

Acknowledgements

When we started the Treasured Lives project in early 2020, the world was sliding into something that demanded everyone's attention – COVID-19. And there we were, about to demand the attention of a distinct group of people in Tasmania – those living with hoarding and challenges maintaining a healthy home, their families and carers, those who work with them and the agencies who design and provide policies and programs to support them. It felt like we could be distracting all of these people from the immediate priorities at hand. But we have experienced an incredible generosity from people who can see that the issues Treasured Lives is covering are important to focus on, even amidst a global pandemic.

Whilst undertaking Treasured Lives, I have had the privilege of learning from a lot of people. Most importantly, I have learnt from some of those living in Tasmania with hoarding behaviours and/or challenges maintaining a healthy home and their families and carers. Treasured Lives would not exist without the families and carers who have generously shared their experiences. I feel honoured that they have taken the time to provide us with invaluable insights into what it will take to ensure we can all age well at home in Tasmania.

I'd also like to thank the members of the Treasured Lives Reference Group for their invaluable knowledge, reflections and feedback. Many members have been directly involved in designing, redesigning and delivering COVID-safe policies, programs and services to support Tasmanians' wellbeing during this time, but they still made time to support this project. We're sharing this journey and I feel confident that I'm doing so in excellent company. Reference Group members have been Grant Akesson and Sal Bucksey, Primary Health Tasmania; Louise Beiser, Connie Bruckard and Sharon Scarlett, Anglicare Tasmania; Chris Collins and Brian Wilson, Housing Tasmania; Hannah Cook, Baptcare; Lisa Coppe, Flourish; Douglass Doherty, Family Based Care Tasmania; Matt Fasnacht and Katherine Parsissons, Older Persons Mental Health Services; Maxine Griffiths, Mental Health Families and Friends; Dr Christine Materia, Carers Tas; Erica Heeley, Home and Community Care Reform Team; Soula Houndalas and Sue Leitch, COTA Tas; Ally Hoyle, RSPCA Tasmania; Amigo Huber, Huon Council; Helen Kessler and Ian Roberts, Commonwealth Department of Health (Aged Care Programs Tasmania and Aged Care Royal Commission Taskforce); Lesley King, Tas Fire Service; Darren Turner, Mental Health, Alcohol and Drug Services, Tasmanian Department of Health.

Treasured Lives is a huge and complex project and would not be possible to deliver without the dedication, patience and skills of the research team. Selina Claxton and Ellen Nicholson, thank you for making sense of survey data and distilling good practice from elsewhere. Both have made invaluable contributions to understanding what we need to do to support our Tasmanians to age well at home.

LINDSEY FIDLER

Summary

> *It's not a quick fix. You start hoarding, you stop hoarding and all of a sudden everything's lovely and smooth. No…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.*

RESEARCH PARTICIPANT: FAMILY/CARER

The recently released final report from the Royal Commission into Aged Care Quality and Safety highlights that, 'Older people should be supported to remain in their own homes for as long as possible, because that is where they want to be' (Royal Commission 2021). The report describes how care should, 'Support people living at home to preserve and restore capacity for independent and dignified living, and prevent inappropriate admission into long term residential care.' The Royal Commission has also recognised the crucial roles families and informal carers play in supporting independence and dignity at home for those they care for.

One group of older Australians vulnerable to not being able to age well at home with independence and dignity are those living with hoarding and/or challenges maintaining a healthy home (CMHH). However, there is limited research to inform how to effectively support older Australians and their families and carers when they are dealing with these issues.

What is Treasured Lives about?

Treasured Lives will inform how we can enable older Tasmanians living with these challenges to age well at home, and how to support their families and carers. It is a two-phase investigation: the experiences and needs of families and carers of older people living with hoarding and/or CMHH (Phase 1); older Tasmanians who are living with hoarding and/or CMHH and policy-makers and service providers supporting such older Tasmanians and their families and carers (Phase 2). This report describes the findings from Phase 1: families and carers.

Between August and December 2020, 25 family members and informal carers participated in the Treasured Lives research. Nineteen research participants completed an in-depth online survey, and six more participated in one to one, semi-structured, in-depth interviews. All but one of the interviews were conducted face to face.

What do we mean when we say…?

'Older Tasmanians' within Treasured Lives are those aged 50 and over, or 45 and over if they are of Aboriginal or Torres Strait Islander heritage. This recognises that supporting hoarding and CMHH is a slow and long-term process. The project wanted to consider what supports could help people prepare for 'older age', as well as what is needed once people reach that age.[1]

Hoarding is a recognised psychiatric illness involving challenges with acquiring, sorting and/or discarding items or animals (Buscher et al. 2014). Such collections are likely to compromise living spaces and cause impairment in social and occupational functioning for the person concerned (Guinane et al. 2019). An important element of hoarding disorder is that the person sees meaning or emotional attachment in items that others would not regard as valuable (Danet & Secouet 2018). This attachment leads to significant emotional struggles in thinking about or actually discarding items. People living with hoarding disorder commonly (but do not always) have comorbid mental ill health, particularly depression and/or anxiety (Ayers 2013; Frost et al. 2000; Guinane et al. 2019; Roane et al. 2017), a history of trauma (Brown & Pain 2014; Roane et al. 2017), and issues with executive functioning (working memory, mental control, inhibition and set shifting), especially for those living with late-life hoarding (Ayers et al. 2013; Roane et al. 2017). Amongst older people with hoarding disorder, impairment due to vascular dementia is common, as are arthritis and sleep apnea (Guinane et al. 2019; Roane et al. 2017). Hoarding behaviour occurs irrespective of a person's financial means and their 'standing' in a community, but people living with hoarding are often socially isolated (Roane et al. 2017).

Challenges maintaining a healthy home describes an unsanitary environment that has arisen from extreme or prolonged neglect and poses health and safety risks to the people and/or animals living there, as well as others within the community. It is not a "diagnosis", but 'a description of the appearance and perceptions of a dwelling which reflect a complex mixture of reasons why a person, couple or group are living in such conditions' (DoH [Vic.] 2012). Similar to hoarding, the risks to health, safety and functioning tend to accumulate with a person's age.

There are many people who live with CMHH but do not live in a cluttered environment; likewise, there are many people who live with hoarding but do not have CMHH (Guinane et al. 2019).

---

[1] We are defining 'older age' as 65, or 55 for people of Aboriginal or Torres Strait Islander heritage, in line with the Australian Department of Health's My Age Care programs.

What did we find out?

FAMILIES AND CARERS

> *Recently, I've just been trying to work on getting the house tidied up. Though my brother…is like 'No. It's not going to happen.' He's defeated by it. And I'm like, 'You and I can at least get our stuff out of there.' To which his reply is, fairly legitimately, 'They would just fill the empty spaces with more crap.' And I'm just kind of like, I can't disagree with that. The evidence suggests that this is what will occur.*

RESEARCH PARTICIPANT: FAMILY/CARER

Key roles relational, practical and emotional: Families and carers played a cluster of key roles in the lives of those they cared for. They were often the only person, or one of a small number of people, who visited the person they cared for. Their roles were all encompassing, including:

- relational elements such as navigating stigma, family and community relationships and maintaining trust and privacy for those they cared for;
- practical elements such as negotiating and maintaining a degree of safety in the home of those they cared for, with no or very little input from professional support services. This harm minimisation approach focused on maintaining somewhere for those they cared for to prepare and cook food, some means of washing and toileting, somewhere for them to sleep and a clear exit into and out of the house; and
- emotional factors such as balancing other care responsibilities and maintaining often fragile and fractious relationships with little support for themselves.

For some, particularly adult children and spouses of those with hoarding behaviours, there was a conflict between loyalty and commitment to those they cared for and a strong sense of frustration, hopelessness and lack of agency about how to effectively support their care recipient. They were carrying a significant emotional and practical load.

FIGURE 1: SUMMARY OF FAMILIES' AND CARERS' EXPERIENCES: RELATIONAL, PRACTICAL AND EMOTIONAL

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

- Some 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

OLDER PEOPLE LIVING WITH HOARDING AND/OR CHALLENGES MAINTAIN A HEALTHY HOME

> *She's obviously internalised stigma… For mum professionally, she's convinced that she didn't make it to [the senior role within her job] because people knew how she lived.*

RESEARCH PARTICIPANT: FAMILY/CARER

Perceived social and health pathways to where they are now: As reported by families and carers, the stories of the people they cared for included traumatic experiences and/or a critical incident of grief or loss that may have triggered an attachment to items as a form of comfort. They also described health-related elements such as neurocognitive disorders, including dementia, mental ill health such as depression and anxiety, alcohol use and challenges with physical capabilities.[2]

Main challenges around discarding items: Nearly all of the families and carers who participated reported discarding items was a challenge for those they care for. Acquiring items and sorting items were also reported as challenges. The majority of survey respondents described the level of difficulty with these challenges as 'extremely difficult' or 'severe' based on their last visit. Not all living environments were considered to have challenges with hygiene. Amongst those where there were CMHH, the majority of survey respondents described dirt or grime covering surfaces in the home, and often mouldy or rotten food.

Sentimental, hobby-based and household collections: The items and animals collected could be broadly grouped into three categories – sentimental collections such as family items and memorabilia; household items such as newspapers, books, furniture, containers and tools; and collections revolving around interests and hobbies, such as purposeful collections, craft and DIY items pertaining to activities that were either actively pursued, discontinued, or never begun; and animals.

Perceived positive impacts – comfort and control: Most families and carers recognised that the living environment brought positive impacts for those they cared for. A sense of comfort was the most commonly perceived benefit, followed by control. Holding a sense of permanency, created by attachment and belonging to a place, was also suggested by a couple of family members.

Perceived negative impacts – personal, social and environmental risks and low help seeking: Families and carers shared concerns that those they cared for were living with a high level of personal and social risks to their health and wellbeing, and with a sense of stigma or shame which minimised help-seeking and socially isolated them. Many also described high levels of environmental risks, such as trip hazards, fire risks and clutter preventing clear routes through their house. Some, but not all, reported that it was difficult for those they cared for to use their rooms for their intended purposes, although some families and carers had worked hard to preserve the basics – somewhere to cook, wash and sleep.

---

[2] It is unusual for SARC to consider 'second hand accounts' of those living with the issue we are focused on. But understanding hoarding and CMHH is complex. There is more than one group of stakeholders with lived experience and who are impacted by the issues. For this project, we are building up our understanding of the many layers and issues over two phases. During Phase 1, we asked families and carers to tell us their reflections on the experiences of those they care for. We do not want to build our assumptions about older Tasmanians living with hoarding and/or CMHH solely based on the accounts of families and carers, but it is useful to understand what families and carers perceive about those they care for. We intend to compare their reflections with those provided by service providers and direct accounts from older Tasmanians living with hoarding and/or CMHH.

Perceived poor insight into impacts: Families and carers were more likely to report their care recipients had poor insight into the impacts their hoarding had for them, compared to the impacts of CMHH. They most commonly reported that those they cared for were aware that they were having difficulties keeping their house clean and how this isolated them. Where insight existed, families and carers reported low levels of help-seeking and a sense that the physical clutter and emotional barriers were stopping them from moving forward.

CONVERSATIONS ABOUT AGEING

> *I think the house will get worse, I think that he will eventually find himself being forced into a living situation that he doesn't choose.*
>
> RESEARCH PARTICIPANT: FAMILY/CARER

Desire to age at home: Around half of the survey respondents and two-thirds of interviewees had had at least some discussions with those they cared for about how and where they would like to age. There was an overwhelming desire to age at home.

Concerns about ageing well at home due to environmental risks and personal attachment to place: Families and carers expressed significant concerns about how ageing well at home could happen, given not only their care recipients' attachment to place, but their attachment to the collections within that place. They wondered who would support them, given their reluctance to draw on services, and how services would safely enter the property to provide in-house care. There was a common concern that those they cared for would not be able to stay living in their home unless it was made safer for them. There was a particular concern about trip and fall hazards posed by the living environment, and that such an event would lead to the care recipient having to leave their home and enter residential care.

Concerns care will be emotionally and physically demanding: Most families and carers reported that they would need to accommodate the needs of those they cared for, and that the practical care load would be a physically and emotionally demanding one. They would need to find ways to emotionally support their care recipient to understand the personal, social and environmental risks inherent in their current living environment, and undertake or facilitate a long process of clearing and cleaning and maintaining the living environment so that services would be willing to enter. There were also common concerns raised by families and carers about being left to 'deal with' their care recipient's living environment when they leave, either through having to enter residential care, or through dying in situ.

Concerns current support doesn't address risks: A minority of families and carers reported that those they cared for already received supports to age well at home. Common supports accessed were light domestic cleaning and meals. Where this was the case, they were more optimistic about the person's future ability to age well in place. However, there was often skepticism about whether these supports were effectively addressing the wellness and reablement of the care recipient.

Barriers to accessing supports: The majority of families and carers reported that they thought there were barriers to those they cared for accessing formal supports:

- **Little insights into the impacts:** Due to reportedly low insight into their challenges and their impacts, families and carers described a lack of recognition that supports were needed amongst those they cared for. This is perhaps the most challenging barrier for a model of consumer-directed care such as My Aged Care or NDIS.
- **Stigma:** Stigma and shame were perceived to drive some of the demand for privacy amongst those living with hoarding and/or CMHH, and minimised help-seeking.
- **Wary of intervention:** Some families and carers talked about those they cared for being wary of intervention. This was not only because of low insights into challenges, or shame or judgement, but also, for some, because they were wary of what would happen if support services intervened. This may have been driven by the need to control and protect their current living environment, or because they perceived that services would want different outcomes from support interventions than they did (Chabaud 2020; Neziroglu et al. 2020; Tompkins 2011).
- **Lack of knowledge about what's available:** Families and carers reported that they and those they cared for did not know what services (if any) were available to them regarding hoarding and/or CMHH.

> *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…Then I'll leave it for a month. I might not mention cleaning nothing…I'll go…there and we'll go for a walk… I want her to cherish me as a daughter and enjoy my visits. Not that, 'Oh my God. Here she comes again. What's she going to be on at me about this weekend?' So we do little bit by little bit. Still with me having the fear over her that if someone goes in there and she can't have assistance at home, they might put her away.*

RESEARCH PARTICIPANT: FAMILY/CARER

THE POLICY AND SERVICE ENVIRONMENT FOR FAMILIES AND CARERS

In contrast to other states, such as Victoria, New South Wales and South Australia (DoH [Vic.] 2012, 2013; DoHA [SA] 2013; Stark 2013), Tasmania does not currently have the appropriate social policy, program and practice settings to respond to hoarding and/or CMHH. There are no specialist services that specifically work with Tasmanians or their families and carers who have issues around hoarding and/or maintaining a healthy home to holistically address the underlying causes, the hoarding behaviour itself and its environmental, social and personal impacts (H&SWG 2017).

Families' and carers' perspectives on what those they care for need: There were common themes in what families and carers thought those they cared for might need to age well at home within a framework of wellness and reablement. Core elements were consumer-led design; easily accessible information about what's available; skilled and coordinated case management; and access to specialist support services – clinical, psychosocial and practical on a continuum which included support to plan for ageing and end of life. GPs were flagged as a key contact and trusted relationship, and many families and carers mentioned a desire to be able to work with the case manager and with their care recipient's GP.

Families' and carers' perspectives on what they need themselves: Families and carers mentioned a range of supports that would be useful for them. These were to both support those they cared for to age well at home and provide supports for themselves to manage the relational, practical and emotional load. Most did not name specific supports, but described the type of supports that would be helpful. These included:

- a reduction in stigma to address judgement and increase understanding around those who live with hoarding and/or CMHH;
- a point of information to source supports for themselves and for those they cared for;
- peer and informal supports to ease their sense of social isolation; and
- a range of specialist training, advice and supports for themselves to manage the relational, practical and emotional load.

PATHWAYS TO SUPPORTING REABLEMENT AND WELLNESS

Critical incidents as pathways to positive engagement: It is clear that critical incidents are often where care recipients are forced to engage with services – hospitalisation, fire, risks to tenancies and neighbourhood complaints. Health scares were the most commonly reported. These engagements with services, albeit forced, offer opportunity for contemplation on the safety risks posed by the home environment and the possibility of seeking help. However, given the potentially negative nature of such interactions, often with the threat of sanctions, we need to consider how we can ensure that these points of interaction are *enabling*, rather than negative. We will return to this in Phase 2 of the project.

Conversations as pathways to positive engagement: Families and carers noted a number of conversation topics that had sparked a discussion with those they cared for on what needed to happen to keep them safe at home. At the top of the list was what needed to happen to their living environment so that services could enter and mobility aides could be used. For a couple of families, this had opened conversations about changes to their living environment, mainly focused on creating accessible routes through the home and spaces to cook, wash and sleep.

Other conversations involved:

- discussions about moving, prompted by the desire to ensure those they cared for were closer to their families or carers;
- discussions about making the environment safer and easier, prompted by health concerns; and
- discussions about what they would like to do with some of their treasured possessions, prompted by thoughts about end of life planning.

This all kept control and ownership of the motivation and process in the hands of the care recipients, but slowly tried to prompt some action towards ageing well at home. The stumbling block that all families had was what to do next. In the face of no specialist Tasmanian services to continue those conversations and support those they cared for on the emotional journey of sorting and discarding, and the specialist services to help with the practical work of sorting and removing items, they were stuck and somewhat overwhelmed by the prospect of doing this themselves. In Phase 2 of Treasured Lives, we will return to this topic and examine what would need to be in place so action could be taken.

What works elsewhere?

From the limited evidence (Chabaud 2020; Firsten-Kaufman & Hildebrandt 2016; Neziroglu et al. 2020), the most promising framework of support would combine the following elements:

- **Specialist multi-disciplinary taskforces:** The complexity of addressing the needs of people living with hoarding and/or CMHH requires a range of services to work closely together to support their families and carers. Local specialist taskforces or teams have been developing across Canada, the US, the UK and, more recently, Australia. They are held up as the most efficient and effective way for professions to work together (Bratiotis 2013; Firsten-Kaufman & Hildebrandt 2016; Frost et al. 2000; Koenig et al. 2014; Kysow et al. 2020; McGuire et al. 2013; Steketee et al. 2001), but must include mental health support services at their core (Firsten-Kaufman & Hildebrandt 2016). What makes such taskforces effective is that they are able to respond to cases, including the needs of families and carers, in a holistic, flexible and long-term manner. New South Wales' Pathways through the Maze and its connected industry group provides this framework, along with the information, training, programs and supports needed.[3]

---

[3] https://hsru.com.au/

- **Public/industry awareness campaigns:** There are limited examples of purposeful multimedia campaigns around understanding hoarding and CMHH. Hoarding UK arguably has the most effective campaign in addressing stigma and raising awareness, working alongside TV and radio projects to take an educative approach to understanding challenges and addressing stereotypes.[4] It is also a leading provider of both information and support for families and carers of those living with hoarding, providing online workshops and training for families and carers, as well as online peer support networks. Less high profile, but notable, are the very good information, awareness raising and training campaigns attached to taskforces working in Victoria and New South Wales.
- **Support programs specifically for families and carers:** Specialist one to one therapeutic counselling can help families and carers to work through any emotional and social impacts of growing up with, living with, and/or supporting a family member with hoarding and/or CMHH. This can be crucial to enable families to effectively support the person they care for without presenting anger, frustration or a sense of hopelessness (Neziroglu et al. 2020; Tompkins 2011). To complement this, one-to-one and/or group psychosocial support programs for families and carers are a useful way to reduce the sense of stigma and social isolation, improve family and other relationships, and understand what's happening for those they care for. This can also give insights into the health and safety risks associated with these living environments and support families and carers to understand what they can do to actively address these risks (Neziroglu et al. 2020). Internationally (particularly in the US, Canada and the UK), and in other Australians jurisdictions such as Victoria and New South Wales, a number of family-based support programs are utilised. These include Buried in Treasures (Tolin et al. 2014) and the US-based Family Harm Minimisation Program (Tompkins 2011).
- **Peer support networks:** Peer support networks can provide an additional and informal way for families and carers to enhance their knowledge and support skills and their own wellbeing. In a situation where they are handling a great deal of complexity, peer networks are a powerful way for families and carers to forge social connections within a community that understands their experiences and provides motivation to stay focused on goals (Chabaud 2020). The particular strength of specialist peer support networks for families and carers of those living with hoarding and/or CMHH is the ability to share experiences and service recommendations that address the comorbidities those they care for may be experiencing. Such specialist peer support networks are often part of wider support programs but can also be standalone. Notable examples include Children of Hoarders' various peer support groups for adult children and families of those living with hoarding; volunteer-run peer support through Reddit and Facebook; and ARCVic's Hoarding and Clutter Anxiety Support Group.[5]

---

[4] https://www.hoardinguk.org/

[5] See Appendix 2 for more details.

Recommendations

Recommendations 1 to 6 address the needs of families and carers. They are based on their reflections and shaped by practice elsewhere. These form part of Treasured Lives' final recommendations. Recommendations 7 and 8 relate to the needs of those living with hoarding and/or CMHH. These recommendations will be further developed and added to through Treasured Lives' future conversations with service providers, policy makers and, most importantly, those living with hoarding and/or CMHH.

ADDRESS STIGMA, RAISE AWARENESS, GENERATE RESPECT

1. **Invest in positive community education campaigns:** Like other complex social issues, such as suicide prevention and family violence, that have required public education to highlight the complexities and inherent needs, we need to cultivate a positive professional and community understanding around hoarding behaviour and CMHH. Tasmania needs to foster an environment that breaks down stigma, builds understanding and respect and facilitates help seeking for those living with hoarding and CMHH. Elements should include:
    - raising awareness of why people develop such challenges;
    - cultivating respectful language around how we talk to and about people living with hoarding and/or CMHH; and
    - recognition that families and carers, as well as those they care for, have distinct support needs that require and deserve support and service responses

DEVELOP A COMPREHENSIVE FRAMEWORK OF POLICIES, PRACTICE AND INFORMATION

2. **Establish and invest in specialist regional Tasmanian taskforces that address hoarding and challenges maintaining a healthy home:** These should be collaborative, multidisciplinary professional teams and consumer groups that include all core services, including aged care services, clinical and community mental health services, local government environmental health services, housing providers and support services, emergency services, animal welfare agencies, family and carer support groups, community health and social work teams. The taskforces should aim to develop short- and long-term collaborative case management and support services to support older people living with hoarding and/or challenges maintaining a healthy home to age well at home, and consider support and information services for their families and carers.
3. **Develop a shared practice framework for professionals who work with older people living with hoarding and/or challenges maintaining a healthy home and their families and carers:** This should include common tools for assessing and understanding needs, a shared understanding of appropriate points of intervention, and support and treatment for families and carers as well as those they care for. It should also contain a clear framework for assessing issues of guardianship and ethics, health and safety.

4. **Provide an information portal with resources for families and carers to help them navigate supports for those they care for and for themselves.**

INVEST IN A CONTINUUM OF CARE AND SUPPORT AND SERVICES FOR FAMILIES AND CARERS

5. **Invest in a continuum of locally provided, specialist therapeutic, clinical, psychosocial and practical support services for families and carers:** This will support them to manage their own emotional challenges related to those they care for, reduce their own sense of social isolation and stigma and share knowledge and awareness of effective support for those they care for. This should include:
    - local online and face to face peer support for families and carers;
    - specialist counselling support services; and
    - specialist information, training and programs to enhance families and carers awareness and skills to support those they care for to age well at home. Such programs should include how they can minimise family disruption and maximise help-seeking from those they care for, and support those they care for to access specialist services.

6. **Within existing models of federal and state-based community supports, develop pathways to specialist advice for families and carers to support them in assisting those they care for to age well at home:** This should include consideration of how the reformed model of aged care gateway services, NDIS Local Area Coordinators and assessments for Home and Community Care can incorporate specialist information and advice services for consumers and their families and carers.

BUILD OUR UNDERSTANDING OF THE CONTINUUM OF CARE AND SUPPORTS NEEDED FOR THOSE THEY CARE FOR TO AGE WELL AT HOME

7. **Undertake consumer-led design of the continuum of care and specialist support services for older Tasmanians living with hoarding and/or challenges maintaining a healthy home.**

8. **Consider the opportunities offered by ‘conversation gateways’ to maximise help-seeking amongst older Tasmanians living with hoarding and/or challenges maintaining a healthy home:** This includes planning for ageing and end of life with the support of GPs and other healthcare services.

CHAPTER ONE

About the research

> *Given the large number of family members and friends providing care to people over the age of 65 years, it is clear that the replacement value of these services for the aged care system would be significant, critically affecting its current sustainability.*

ROYAL COMMISSION 2019

> *People's homes I've gone into, you know, in my caring role, … you see them in the first instance, 'Oh it's just the spare room. Shut the door'. Two years later, 'Oh I don't use the living room. Shut the door'. Sitting at the kitchen table. Well, you know, 'Do you want to go in the lounge?' 'Nah, didn't need that, it's too cold in there, brrrr'. And you look in and it's like … it just gradually absorbs …*
>
> *I know of people sleeping on their bed in the kitchen. One, that's all they can afford to heat. But the rest [of the house] is completely absorbed. Commode chair in the corner, bed in the kitchen, kitchen table, that's life. The hoarding, like the mould on the orange, has absorbed [the house].*
>
> *… I don't even know if there is help out there for people. Just people need to be more accepting and be able to do the care in a reasonably safe environment, but not take control of the environment. As long as the person can be cared for safely, let them live their life.*

RESEARCH PARTICIPANT: FAMILY/CARER

1.1 Why should we focus on older people living with hoarding and/or challenges maintaining a healthy home?

The recently released final report from the Royal Commission into Aged Care Quality and Safety ('the Royal Commission') highlights that, 'Older people should be supported to remain in their own homes for as long as possible, because that is where they want to be' (Royal Commission 2021). The report describes that care should, 'Support people living at home to preserve and restore capacity for independent and dignified living, and prevent inappropriate admission into long term residential care' (Royal Commission 2021)

One group of older Australians most vulnerable to not being able to age well at home with independence and dignity are those living with hoarding and/or challenges maintaining a healthy home (CMHH). Hoarding and dementia have been identified as the only two psychiatric disorders that increase in severity and prevalence during the course of a person's life (DoH [Vic.] 2012). But in spite of this, and in the face of analysis highlighting that 'late life hoarding is a serious psychiatric and community problem that warrants considerable attention' (DoH [Vic.] 2012), there is limited research to inform how to effectively support older Australians and their families and carers living with hoarding and/or CMHH.

We are only starting to understand the personal costs of hoarding and CMHH in Australia. International literature, particularly from the UK, US and Canada, suggests these are likely to be broad and wide-ranging – social isolation and poor mental health, health and safety issues (including trip and fall hazards, blocked exits and cluttered environments leading to fire risks, and poor access for emergency services), threatened tenancies, financial vulnerability, self-neglect and disrupted and often broken family relationships (Park et al. 2014; Tompkins 2011; Wilbram et al. 2008).

We also recognise that there are unquantified costs to the economy through increased residential fires, hospital discharge delays due to the home environment being deemed unsuitable, cost of clean ups for local councils and housing providers and premature entry into long-term residential aged care (Bratiotis 2013; Frost et al. 2000; Kysow et al. 2020; Lacombe & Cossette 2018; McGuire et al. 2013). In addition, for those people living with hoarding and/or CMHH who are still in the workforce, there may be lost days of productivity, with one study citing a mean of seven days off work per month for those living with hoarding disorder (Tolin et al. 2010a)

Drawing on international literature, we can understand that supporting older Australians living with such challenges requires a multi-agency response (Bratiotis 2013; Frost et al. 2000; Kysow et al. 2020; Lacombe & Cossette 2018; McGuire et al. 2013). This response has been broadly described in the Royal Commission's recommendations, with aged care supports working alongside primary and allied healthcare to address the underlying causes for older Australians living with hoarding and/or CMHH (trauma, depression, anxiety, possibly OCD-related disorders), the hoarding behaviour itself and its impacts (social isolation, health and safety issues for clients, families, carers and workers, threatened tenancies, financial vulnerability, self-neglect) and potentially any comorbid challenges (dementia, drug and/or alcohol use, physical or other health conditions, family violence).

However, we do not have a clear understanding of what that support model could look like in Australia and how we can ensure it also provides sensitive and effective support for families and carers. Given the evolving models of aged and disability care federally and elements of Home and Community Care and mental health supports within Tasmania, there is a critical moment to explore and inform such a model now.

1.2 Why focus on families and carers?

There are a significant number of Australian families and carers providing informal care for older Australians. Around 420,700 primary carers of older Australians were identified through the last ABS Survey of Disability, Ageing and Caring, with a flag that this is likely to be a significant underestimation (Royal Commission 2019). Whilst there can be some positive benefits for carers, including strengthened family relationships, personal development and new skills, there are often also personal and economic costs associated with this care. Factors that compromise health and wellbeing for carers can include less social connection due to the time needed for care commitments and sometimes strong emotions such as frustration, anger, guilt and distress, caused by conflicts and the stress and strain of the care load. These personal impacts can, of course, also impact on the quality of care for the care recipient, particularly if their care needs are complex.

There may also be financial costs related to out of pocket expenses, as well as forfeiting opportunities to undertake paid work (Royal Commission 2019). It is estimated that forgone earnings for primary and non-primary carers during 2020 was $11.4 billion and $3.8 billion respectively – 10.6% of the estimated value of formal healthcare in Australia (Deloitte Access Economics 2020). It has been estimated that the cost of replacing informal care with services purchased from formal care providers for people with a disability, mental illness, chronic condition, terminal illness and older Australians would be over $1 billion a week (Royal Commission 2019).

The Royal Commission has recognised the crucial roles families and informal carers play in supporting independence and dignity at home for those they care for. However, the ratio of informal carers to need is estimated to decline over the coming years, partly due to Australia's ageing population. Although this can partly be addressed through changes to formal care, such as increases and changes to aged care home-based packages and their connections to wider services such as primary and allied healthcare, there is also a recognition that there will continue to be a demand and a place for informal care. This is particularly the case amongst certain cohorts such as older people from Aboriginal and Torres Strait Islander or other minority ethnic backgrounds, where family care may be preferred (Royal Commission 2019; Deloitte Access Economics 2020), and for those who are less open to help-seeking, such as those living with hoarding and/or CMHH.

The Commission process and the final report have dedicated significant time and space to considering and rethinking the architecture of support needed for carers so that they might more easily be able to fulfil their roles as information seekers, advocates, support organisers and social and health care givers for the older people in their lives who they care for. The final report helpfully recognises that there are likely to be personal, social and financial impacts for families and carers themselves as they fulfil their roles that need understanding and addressing (Royal Commission 2021). However, we understand very little about the experiences and needs of Australian families and informal carers of older people living with hoarding and/or CMHH. The limited literature is clear that they often play key roles as 'team members' and 'support contractors' (Tompkins 2011). We need to understand their specific needs in more depth if we are going to support them in providing independence and dignity at home for those they care for.

1.3 Why is this an important issue for Tasmania?

Tasmania has the highest proportion of the population of any Australian state or territory aged over 65, at 19.4% (nearly 100,000 people). By 2037, it is predicted that a quarter of the state's population will be over 65, and over 40% in some Local Government Areas (COTA Tas 2018).

Tasmania has a clear incentive to lead thinking about how to age well and is well-placed to lead innovations that both prevent people who are nearing retirement age with acute challenges to wellness and reablement from entering aged care and support those already eligible for aged care to age well at home. As the Council on the Ageing (COTA) Tasmania's CEO has highlighted, 'Tasmania could be the experts for age-friendly planning, if it grabs the opportunity with two hands' (COTA Tas 2018).

There is no national framework guiding policy, programs and practice around supporting those living with hoarding and/or CMHH. Different states and territories have a range of responses that fill this void. Tasmania lags behind most other Australian jurisdictions in its strategic response to hoarding and CMHH across household types. In contrast to other states, such as Victoria, New South Wales and South Australia (DoH [Vic.] 2012, 2013; Stark 2013; DoHA [SA] 2013), Tasmania does not currently have the appropriate social policy, program and practice settings to facilitate this challenging work. There are no specialist services who specifically work with Tasmanians or their families and carers who have issues around hoarding/maintaining a healthy home to holistically address the underlying causes, the hoarding behaviour itself and its environmental, social and personal impacts (H&SWG 2017).

This support void became clear whilst undertaking the Treasured Lives project. As has occurred internationally in other research projects focusing on these issues (Garrett 2020), the Researcher has found herself becoming the focus for enquiries from service providers about what supports are available in Tasmania and what tools can be drawn on to assess living environments and their risks, and the focus of concerns from neighbours of those living with hoarding and/or CMHH about risks to neighbourhood health and safety. Additionally, families and carers participating in Treasured Lives interviews regularly commented that they felt the interview was in itself both therapeutic and a useful practical space in which they were able to consider their relationship with the person they care for, what might have led to the current situation, and their own needs. This was, they said, mainly because they had not had the opportunity to discuss these issues with anyone before now.

The incidental and sometimes reluctant pathways to support services has led to difficulties for Tasmanian agencies in understanding the prevalence as well as the nature of hoarding and CMHH (H&SWG 2017). This is problematic for designing appropriate local service responses. We may never understand the full extent of these challenges in Tasmania, but we *can* understand Tasmanians' support needs. Given Tasmania's ageing demographic, the needs of older people living with hoarding and/or CMHH and of their families and carers cannot be ignored or overlooked. Particularly if Tasmania is to proactively achieve wellness and reablement, as outlined in the current model of aged care, or facilitate independence and dignity for our older communities, as outlined by the Royal Commission and echoed in the social outcomes laid out in Tasmania's Strong Liveable Communities Plan for active ageing (DPaC 2017).

Through the Treasured Lives project, we hope to understand these needs and explore a locally designed, innovative framework of support for those living with hoarding and/or CMHH.

1.4 About Treasured Lives

Project aims, phases and approach

Treasured Lives is the first in-depth research project able to inform a Tasmanian-specific framework to address challenges with hoarding and CMHH for older people and their families and carers and how we can enable older Tasmanians living with these challenges to age well at home.

For the purpose of the research, 'older Tasmanians' are defined as those aged 50 and over, or 45 and over if they are of Aboriginal or Torres Strait Islander heritage. These are the ages at which Tasmanians vulnerable to poor life outcomes may become eligible for Home and Community Care (HACC) (DoH [Tas] 2020b) and the Commonwealth Home Support Program (CHSP) (DoH [Au] 2020)[6]. It is the point at which the vulnerabilities of older Tasmanians in relation to income, health and housing are recognised in their preparation for older age. Supporting those living with hoarding and CMHH is a slow and long-term process. So the project wanted to consider what supports could help people prepare for older age, as well as what is needed once people reach that age.[7]

FIGURE 2: TREASURED LIVES' DEFINITION OF 'OLDER PERSON'

'OLDER PEOPLE' …

50+
years of age

45+
years of age if **Aboriginal or Torres Strait Islander** heritage

Either they or their family member/carer **lives in Tasmania**

---

6 The Tasmanian HACC Program focuses on Tasmanians who live in the community and whose capacity for independent living is at risk due to an acute health event, moderate functional impairment or deterioration of an ongoing condition. Priorities include those living with dementia, people who are financially disadvantaged and people who are, or who are at risk of becoming homeless or face housing insecurity challenges. The Commonwealth Home Support Program (CHSP) supports older people (65 or 50+) or prematurely aged people (50+ or 45+) on a low income with a range of potential housing insecurities. Both programs also provide support for carers, if the person they care for has been shown to be eligible for support.

7 We are defining 'older age' as 65, or 55 for older people defining as Aboriginal or Torres Strait Islander, in line with the My Age Care programs (DoH [Au] 2020).

Treasured Lives investigates:

- what information/data exists about the prevalence of these challenges amongst older Tasmanians;
- the experiences of people living with hoarding and/or CMHH and their families and carers;
- the experiences and challenges of clinical and community service providers, emergency services and the local, state and federal government agencies that design policy and programs to support such older Tasmanians and their families and carers; and
- good practice in supporting older people and their families and carers across other Australian jurisdictions and internationally.

Grounded in this analysis, and drawing on the feedback of the project's reference group,[8] the report will provide a set of recommendations on policy, programs and practice to support older Tasmanians living with these challenges to age well in place. The project utilises an inductive approach (Giddens 1982; Sarantakos 1998; Seal 2001) with a focus on understanding participants' experiences, relationships, needs, enablers and challenges, from which a framework for responding will emerge.

Given the complexity and sensitivity of these issues and the breadth of stakeholders with an interest in this area, the project is divided into two phases (see Figure 3). The process for developing recommendations will be both iterative and incremental as the understandings and narratives unfold during each project phase. Each phase will build up a focused understanding of stakeholder needs based on lived experience. This Phase 1 report focuses on families and informal carers. The second phase will focus on understanding the experiences and needs of older people living with hoarding and/or CMHH through their own perspectives. Phase 2 will also focus on the experiences and needs of those working within the policy and service environments relevant to this project. We will do this by engaging with government agencies, statutory agencies and service providers.

The project received research ethics approval from the University of Tasmania's Human Research Ethics Committee.[9]

---

8 The Treasured Lives Reference Group includes members representing consumer voices (older Tasmanians, people living with mental health challenges); peak bodies representing families and carers; key federal and state government agencies with policy portfolios related to adult, disability and aged care, as well as mental health and housing; agencies with statutory responsibility for emergency services and public health (local councils); and key areas of service provision, including clinical and community sector mental health services, aged care services, housing support services and disability services across Tasmania.

9 Project n: 18686.

FIGURE 3: TREASURED LIVES' PROJECT PHASES AND FOCUS

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 the current policy and service landscape for families and carers.
- Explore good practice in other jurisdictions and internationally.

Recommendations:

- Addressing the needs of families and carers.
- Reflections on the gaps in legislation, policy, practice and skills for those working with 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 through interviews.
- 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.
- Outline elements of a good practice framework for legislation, policy, programs and practice in Tasmania.

Phase 1: Families and carers

This phase has focused on exploring the experiences and needs of those caring informally for older Tasmanians living with CMHH. The project asked for participation from those who:

- are related to, provide or try to provide informal care for someone who meets our definition of 'older person' (see Figure 4); and
- live in Tasmania, or those they care for live in Tasmania.

FIGURE 4: TREASURED LIVES' DEFINITION OF 'FAMILIES AND CARERS'

FAMILIES AND CARERS

50+ OR 45+ The person (people) they care for is 50 or over, or 45 or over if Aboriginal or Torres Strait Islander heritage and they are living with hoarding and/or CMHH

They are related to/provide or try to provide informal care

Either they or those they care for **live in Tasmania**

Between August and December 2020, participants either completed an in-depth online survey which contained both fixed response and open questions, or participated in a one to one semi-structured interview with the Lead Researcher. This followed a statewide publicity drive via social media, radio, leafleting and online promotion via family and carer peak bodies, and publicity posters displayed in a range of community service organisations offering mental health services.

The survey and interview explored:

- their relationship with the person or people they cared for;
- their own experiences of supporting the person or people they cared for to age well at home, and what supports they felt they needed to do this effectively in the future;
- the formal and informal supports they drew on for themselves and to support the person/people they cared for; and
- their reflections on what's needed to ensure a respectful support response for those they cared for and for themselves.

The survey also drew on and adapted established measurements for hoarding and CMHH[10] to consider degrees of insight and types of challenges.

During Phase 1, we also wanted to start exploring the lives and needs of older Tasmanians living with hoarding and/or CMHH. Both the survey and the interviews invited families and carers to reflect on the experiences of those they care for and their needs into the future to enable them to age well at home. We are very aware that these are not firsthand accounts of older people's needs and experiences a diversion from the usual phenomenological approach to understanding need. Given the iterative nature of this project, we will be revisiting the experiences of older people through the eyes of service providers and then again through their own eyes in the subsequent phases. Thus it will be valuable to build up a picture of how those perspectives converge or diverge. These participants usually had familiar relationships (often the only relationship) with the person they care for. Their perspectives, as will be evident from the findings, can include valuable and intimate insights into the lives and stories of those who are living with these challenges.

---

[10] The Clutter Image Rating (Steketee & Frost 2007); the Hoarding Rating Scale (adapted from Tolin & Steketee 2010, reproduced in Bratiotis al. 2011), the Home Environment Index (reproduced in Bratiotis et al. 2011) and the risk questions from HOMES© (©Bratiotis 2009, reproduced in Bratiotis et al. 2011).

Phase 1 has also included a literature review. This has focused on:

- what we know about those living with hoarding and/or CMHH from clinical, psychosocial and practical paradigms, and specific literature around older people living with these challenges;
- what we know about the experiences of families and carers; and
- a scan of policy, programs and practice in other Australian jurisdictions and internationally that support families and carers of people living with hoarding and/or CMHH.

Given the tendency for negative stereotyping or sensationalism within this space, we used a set of criteria to guide our search of good practice. They were that the resource/program:

- offers a responsible coverage of the context for hoarding and/or CMHH;
- explains the approaches to support within that context; and/or
- raises awareness and positive engagement about hoarding and/or CMHH.

Maintaining participant choice and control, anonymity and privacy are routine pillars of any research conducted within an ethical framework. Given the often hidden and stigmatised nature of hoarding and CMHH, these elements were at the forefront of many participants' minds. As will be described in the findings, maintaining privacy and respecting control are critical hinges on which many relationships and support provision pivot. Therefore, the Researcher has decided not to feature specific case studies within this report. Rather, the report describes the common elements and range of experiences and scenarios the families and carers recounted.

Phase 2: Older Tasmanians and the policy and service environments

The next phase of Treasured Lives will focus on older people living with hoarding and/or CMHH. The project plans to interview a small sample (3 to 5) of people aged 50 or over (or 45 or over if they are of Aboriginal or Torres Strait Islander heritage) who are living with challenges related to hoarding and/or CMHH.

A phenomenological approach will be utilised to explore and understand the complexities of each context, including experiences, challenges and desired goals for ageing.

We will also explore the current policy and service environment that supports older Tasmanians to age well at home when they are living with hoarding and/or CMHH. This will include an examination of aged care provision, including consumer-led home-based care through the Commonwealth Home Support Program (CHSP) and Home Care Package (HCP) and grant-based Assistance with Care and Housing (ACH) supports through the CHSP sub- program for those at risk of homelessness. It will also explore the landscape of older adult services, including disability supports both in and outside of the NDIS, Home and Community Care, and connected services such as housing and homelessness support, mental health services, GPs and healthcare. It will also explore the roles of statutory agencies, such as the emergency services, local government environmental health, animal welfare and the Guardianship Board.

We will investigate the policy and service environment through a series of semi-structured interviews with staff responsible for delivering services and statutory responsibilities.

The literature review will continue. It will focus on policy, programs and practice in other Australian jurisdictions and internationally that support people living with hoarding and/or CMHH. There will be a particular focus on supports for older people.

Recommendations within Phase 2 will centre around the needs of older Tasmanians living with hoarding and/or CMHH and those who work with them. They will expand upon the recommendations from Phase 1.

CHAPTER TWO

Hoarding and challenges maintaining a healthy home: what are they?

> *That's one of the reasons why I'm here, because it's complicated.*
>
> RESEARCH PARTICIPANT: FAMILY/CARER

> *As an adult and a psychologist, I understand that my father's hoarding is the byproduct of multiple untreated or under-treated mental health conditions – OCD, depression and ADHD – that make the mental and emotional task of sorting, deciding and discarding extremely difficult… As a daughter…my despair at the pervasive toll hoarding has taken on my father's life is jostled together with the hope that he can still dig out of the morass and recover his life. … The question that tugs at our hearts as we imagine the possibilities of tomorrow is this: will he ever embrace the life preservers we have tried in vain to extend, or will he continue to go down with the ship?*
>
> ANONYMOUS 2020

People living with hoarding and/or CMHH and their families are more often judged than understood. The visibility of their condition often defines them in the community and promotes responses of self-criticism, shame and social withdrawal (Chou et al. 2018a; Danet & Secouet 2018; Tompkins 2011). Such stigma and stereotyping can lead to families further retreating from the communities in which they live and tends to result in low help-seeking (Tompkins 2011). Occasionally interventions are forced, for example when a hospitalisation requires the house to be made 'safe' in order for a patient to be discharged, or if there has been a neighbourhood complaint to the local council's environmental health unit. Due to restricted remits or capacities, this can lead to services addressing the presenting issue (i.e. the clutter or unsanitary environment) rather than the underlying causes (i.e. underlying mental health challenges). Often interventions do not (or are unable to) offer appropriate support to the resident's deep anxieties around discarding precious items, ensure that the resident is in control of decisions about what happens to their items, or ensure that the resident's underlying and presenting mental health challenges are supported before, during and after sorting and discarding occurs. Such cleaning without resident support or control usually leads to clutter or domestic hygiene re-escalating in subsequent weeks. It can often lead to a deterioration in the resident's mental health and can further damage their willingness to seek help and support in future (Buscher et al. 2014; Neziroglu et al. 2020; Roane et al. 2017; Koenig et al. 2010).

Shaping appropriate support responses for older Tasmanians living with hoarding and/or CMHH and their families and carers demands that we understand the nature of the challenges, their root causes and their personal, social and environmental impacts. It also requires a shared understanding of when it is appropriate to offer support or intervene in such private matters as how a person chooses to live.

Here, we offer a brief overview of what academic and grey literature tell us on these matters.

2.1 What are 'hoarding' and 'challenges maintaining a healthy home'?

Hoarding is a recognised psychiatric disorder involving challenges with acquiring, sorting and/or discarding items or animals (Frost & Hartl 1996, cited in Buscher et al. 2014). It is defined as, 'The accumulation of a vast amount of possessions which compromises living spaces and causes impairment in social and occupational functioning' (Tolin et al. 2011, cited in Guinane et al. 2019). Excessive collections can consist of anything, but common items include newspapers, food packaging, clothing, electrical appliances and animals (DoH [Vic.] 2012; Stark 2013). An important element of hoarding disorder is holding meaning or emotional attachment to items that others would see as not valuable (Danet & Secouet 2018). This attachment leads to significant emotional struggles in thinking about or actually discarding items. Understanding this rationale is crucial to understanding how to support a person to sort and discard.

Animal hoarding is a specific area of challenge. This is defined as an accumulation of a large number of animals that overwhelms a person's ability to provide a minimum standard of nutrition, sanitation and veterinary care (DoH [Vic.] 2013). Such behaviour requires specialist support (Castrodale et al. 2010; Lockwood 2018). But the underlying principles are the same –understanding a person's reason for collecting animals, any underlying causes and what extent there are risks that need addressing for the human and animal residents.

FIGURE 5: DEFINITION OF HOARDING

DEFINITION OF HOARDING

- Challenges with acquiring, sorting or discarding items or animals
- Attaching significant meaning to items, which impedes ability to discard
- May be a diagnosed disorder (DSM5), or co-morbid with mental health or other conditions
- Leading to a cluttered living environment and impeding the use of rooms for their intended function, the health and safety of residents, and/or leading to an animal welfare concern

Challenges maintaining a healthy home describes an unsanitary environment that has arisen from extreme or prolonged neglect and poses health and safety risks to the people and/or animals living there, as well as others within the community (DoH [Vic.] 2013). This describes an environment, not the people living in it. It is not a "diagnosis", but 'a description of the appearance and perceptions of a dwelling which reflect a complex mixture of reasons why a person, couple or group are living in such conditions' (DoH [Vic.] 2012). Similar to hoarding, the risks to health, safety and functioning tend to accumulate with a person's age. This has been attributed to the neglect of personal hygiene and the living environment due to frontal lobe changes and the increased likelihood of dementia (Snowden et al 2007).

"CMHH" is often referred to as "domestic squalor" by Australian federal and state government agencies, program funders, support professionals such as social workers, support workers and psychologists, and broadly within the international research community. In agreement with the University of Tasmania's Human Research Ethics Committee approval conditions for Treasured Lives, we are referring to "squalor" as "challenges maintaining a healthy home" in all fieldwork and communication with research participants and in our reporting, outside of discussions centred around exploring language. This is in response to many with lived experience finding the term "squalor" as loaded with judgement, offensive and disrespectful.

"CMHH" will be a working term during this project. At this point we are not suggesting that it should be a replacement term. We will be exploring respectful use of language and approaches to support with all research participants. As part of the Phase 2 recommendations we hope to be able to share some reflections on suitable terminology. These reflections will be grounded in what those with lived experience tell us and reflections from professionals on what is appropriate in various peer to peer settings.

FIGURE 6: DEFINITION OF CHALLENGES MAINTAINING A HEALTHY HOME

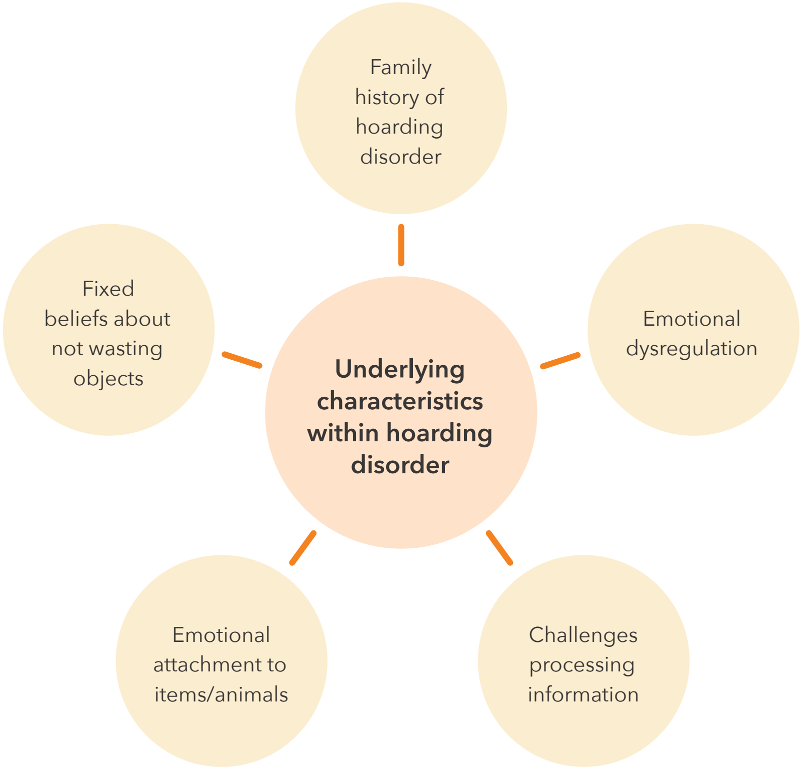
DEFINITION OF CHALLENGES MAINTAINING A HEALTHY HOME

- 'Squalor'/unsanitary environment
- Accumulation of rubbish, decomposing food, excessive grime, dust or mould
- May lead to being unable to use rooms for intended purposes

There are many people who live with CMHH but do not live in a cluttered environment (Lee et al. 2017). Likewise, there are many people who live with hoarding who do not have CMHH (Lee et al. 2017; Roane et al. 2017) This is further explored in Section 2.2.

2.2 Diagnoses and profiles

FIGURE 7: HOARDING DISORDER: COMMON CHARACTERISTICS



Source: Stark 2013

Older Australians with hoarding disorder

Since 2013, hoarding has been classified as a standalone psychiatric disorder in the Diagnostic and Statistical Manual of Mental Disorders V (DSM-5) and was added to the World Health Organisation's (WHO) International Classification of Diseases 10 in 2018 (Whomsley 2020). It is understood to be associated with four underlying characteristics: emotional dysregulation, difficulties processing information, intense emotional attachment, and fixed beliefs about not wanting to waste objects (Stark 2013). Studies also suggest that there may be strong hereditary factors (Mathews et al. 2007, cited in DoH [Vic.] 2013; Grisham & Norberg 2012, cited in Stark 2013). Up to 85% of people with hoarding behaviours can identify another family member who displays similar behaviour (DoH [Vic] 2013). See Figure 7.

People living with hoarding disorder commonly (but do not always) have comorbid mental ill health, particularly depression and/or anxiety (Frost et al. 2011, cited in Ayers 2013; Frost 2000; Guinane et al. 2019; Roane et al. 2017), a history of trauma (Brown & Pain 2014; Chou et al. 2018b; Roane et al. 2017), and/or issues with executive functioning (working memory, mental control, inhibition and set shifting), especially for those living with late-life hoarding (Ayers et al. 2013; Roane et al. 2017). Amongst older people with hoarding disorder, impairment due to vascular dementia is common, as is arthritis and sleep apnea (Guinane et al. 2019; Roane et al. 2017). Hoarding behaviour occurs irrespective of a person's financial means and their 'standing' in a community, but people living with hoarding are often socially isolated (Roane et al. 2017). See Figure 8.

Australia currently has no comprehensive data on the age profile of hoarders nationally. There is a growing literature around hoarding amongst children (see Whomsley 2020 for a comprehensive overview). This suggests that hoarding disorder may be present, although likely to be undiagnosed, amongst children and may develop in early adolescence (see Tolin et al. 2010, Whomsley 2020). However, hoarding tendencies are often suppressed by parents' sorting and discarding efforts and may be escalated either due to a traumatic event (for example a loss or bereavement), or once children gain more independence (Whomsley 2020). So, although studies to date suggest the average age of onset may be 16.5, there is significant speculation that onset is likely to be earlier than this (Hojgaard & Skarphedinsson 2020).[11] The literature also suggests that hoarding behaviour in children is most likely to be comorbid with Attention Deficit and Hyperactivity Disorder (ADHD), and has lesser comorbidities with Obsessive Compulsive Disorder (OCD) and anxiety (Hojgaard & Skarphedinsson 2020; Whomsley 2020).

North American data shows that the mean age of patients diagnosed with hoarding disorder is between 53 and 67 years old (Ayres et al. 2013; Dimauro et al. 2013, cited in Guinane et al. 2019). Further studies suggest onset from 40, which increases in severity after middle age, with others suggesting a bimodal onset, with a second spike after 50 (Roane et al. 2017). Further research confirms that hoarding disorder increases in severity (Dozier et al. 2016, cited in Pittman et al. 2020) and prevalence with age (Cath et al. 2017, cited in Pittman et al. 2020).

Supporting people living with hoarding is a developing area of research and practice in Australia. There are a few local studies and some international work that can help inform diagnosis and shape general approaches to supporting those living with hoarding.

---

[11] The change in diagnosis for hoarding disorder from an element of OCD to a standalone disorder in DSM-5 has led to some questioning of how data around child and adolescent hoarding behaviour has been measured and counted (see Hojgaard & Skarphedinsson 2020).

FIGURE 8: HOARDING DISORDER: COMMON COMORBIDITIES IDENTIFIED IN PEOPLE'S HISTORY AND HEALTH

HISTORY

- Trauma
- Critical incident
- Loss/grief

HEALTH CONDITIONS IN CHILDREN/YOUNG PEOPLE

- ADHD
- OCD
- Anxiety

HEALTH CONDITIONS IN ADULTS

- Anxiety
- Depression
- OCD
- Executive functioning, memory loss, disordered thinking

HEALTH CONDITIONS IN OLDER ADULTS

- Physical capacity, e.g. arthritis
- Executive functioning, memory loss, disordered thinking, dementia

Ayers et al. 2013; Brown & Pain 2014; Chou et al 2018b; Frost et al. 2011, cited in Ayers 2013; Frost 2000; Guinane et al. 2019; Roane et al. 2017

Older Australians living with challenges maintaining a healthy home

CMHH often present as a secondary condition to a range of medical and psychiatric conditions. There is a strong association with impaired frontal executive function (Lee et al. 2017), with 72.3 years as the mean age of diagnosis (Lee et al. 2017, cited in Guinane et al. 2019).

Studies have shown that between 20% and 60% of people who live with CMHH also have challenges with hoarding behaviour (Snowden & Halliday 2011, cited in Lee et al. 2017). For some, prolonged or extreme hoarding may lead to CMHH. Those whose living environment has deteriorated into CMHH tend to present for support at an older age (the mean age being 76), often due to the loss of a domestic partner or onset of frailty or neurocognitive disorders (Lee et al. 2017, cited in Guinane et al. 2019). See Figure 9.

It is important to note, however, that there are many people who live with CMHH but do not hoard (Lee et al. 2017, cited in Guinane et al. 2019). Profile analysis of those living with CMHH has indicated that 'vascular and Alzheimer's type neurodegeneration were significantly more common' in those who also presented with hoarding behaviours, compared with those who only presented with CMHH (Lee et. al. 2017) (See Figure 9). Although these living conditions are often considered together, they do not always go hand in hand. Understanding this distinction is important in shaping appropriate clinical and community-based supports to complement practical supports available for older Australians, as is understanding the relationship and trajectory between these two challenges as people age (Guinane et al. 2019; Lee et al. 2017).

FIGURE 9: CMHH WITH AND WITHOUT HOARDING DISORDER: COMMON COMORBIDITIES IDENTIFIED IN PEOPLE'S HEALTH AND LIFE EVENTS

CMHH WTHOUT HOARDING DISORDER: YOUNGER ADULTS

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

CMHH WTHOUT HOARDING DISORDER: OLDER ADULTS

- Vascular and Alzheimer's neurodegeneration

CMHH WITH HOARDING DISORDER

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

Source: Lee et al. 2017; Guinane et al 2019

2.3 Prevalence

Older Tasmanians living with hoarding and/or CMHH

Given the hidden nature of much hoarding and CMHH, there is no consistent data collection across Australian jurisdictions to currently inform us about prevalence.

US research has estimated that hoarding occurred in 6.2% of those aged between 35 and 94 years (Samuels et al. 2008, cited in Roane et al. 2017). A recent systemic review of international data on hoarding disorder has estimated between 1.5% and 6% (Postlethwaite et al. 2019, cited in Whomsley 2020), and further research has estimated that hoarding occurs for 2% of adolescents (Ivanov et al. 2013, cited in Hojgaard & Skarphedinsson 2020; Whomsley 2020). Estimates also suggest that the prevalence of hoarding disorder in older adults is triple that found in the general population (Cath et al. 2017, cited in Pittman et al. 2020; Roane et al. 2017).

Hoarding and CMHH can occur regardless of socio-economic status (Koenig et al. 2014; Roane et al. 2017). However, its association with early life adversity (Tolin et al. 2010b), work impairment (Tolin et al. 2010a), potential financial burden and comorbid mental health challenges present significant obstacles for sustaining labour force participation and maintaining income (Baldwin et al. 2018).

Due to the mainly opportunistic samples used within studies, there is no consistent evidence around gender and hoarding and/or CMHH (Danet & Secouet 2018; Roane et al. 2017).

The most recent Australian estimates suggest that 2% to 6% of the Australian population is affected by hoarding or CMHH (ANU 2016). Other research has suggested that 1 in 1000 older people live in environments that would be considered as needing intervention (Snowden & Halliday 2009; Snowden et al. 2012, cited in Lee et al. 2017).

TABLE 1: ESTIMATED NUMBER OF OLDER TASMANIANS LIVING WITH HOARDING

	Tasmanian Population*	Estimated number of adults living with hoarding behaviour**	
		@ 2 per cent	@ 6 per cent
Aged 50 to 64	107,694	2154	6,462
Aged 65+	98,753	1975	5,925
Total 50+	**206,447**	**4,129**	**12,387**

**Source: ABS 2016 Census QuickStats*
***Based on ANU estimates on percentage of adults living with hoarding (ANU 2016)*

Based on the ANU estimates, there would be between 4,100 and 12,300 Tasmanians aged 50 and over living with hoarding (see Table 1), noting that this does not include those living with CMHH. However, there is no way to confirm this range at the moment and, as previously stated, we may never know the real extent due to the hidden nature of these challenges and low help-seeking.

There is some information from assessment agencies and service providers about prevalence within their caseloads. Fire service data shows that 25% of deaths from fires in homes occur in the homes of people living with hoarding challenges (ANU 2016). However, prevalence amongst older Australians is difficult to pinpoint. An analysis of patients referred to the Aged Care Assessment Service (ACAS) in Western Melbourne found that only 0.005% of the referral base between 2009 and 2015 had challenges with hoarding and CMHH. The study itself points out that such a small proportion was likely to be a significant under-representation, even amongst those referred to ACAS, due to the hidden nature of many challenges (Guinane et al. 2019). Of those, just over half had challenges with both hoarding and CMHH, just over a quarter needed support with hoarding only and the remaining 18% with maintaining a healthy home only (Guinane et al. 2019). This would indicate that challenges were not widespread. However, it also tells us nothing about the prevalence amongst older Melbournians who had not accessed aged care services. As we explore below, it is typical for this cohort to resist support.

The Hoarding and Squalor Working Group (Northern Tasmania) (H&SWG) provided a snapshot of the extent to which hoarding and CMHH were present for people accessing psychosocial supports in northern Tasmania. Their survey of housing, mental health, disability and family support services working in the north of the state suggested that 80% of Tasmanian Partners In Recovery Support Facilitators were working with at least one person who hoarded and/or lived with CMHH (H&SWG 2017). This survey did not ask for the age of people receiving supports.

Families and carers

Although the ABS Carers Survey can tell us general numbers of informal primary and other carers in Australia (see Chapter 1), there is no data available that tells us the number of families and informal carers who are caring for those living with hoarding or CMHH. The survey does provide broad information about the categories of those receiving care (including older people), but it does not drill down into what the care needs are.

2.4 Impacts on older Australians and their families and carers

Research indicates that challenges with hoarding and/or CMHH may significantly impact older Australians' pathways to wellness and ageing in place. As well as personal risks, there may be environmental, social, safety and public health risks for themselves, their families and carers (Buscher et al. 2014; Chabaud 2020; Davidson et al. 2020; Garrett 2020; Neziroglu et al. 2020; Park et al. 2014; Tolin et al. 2010a, b; Tompkins 2011; Roane et al. 2017; Wilbram et al. 2008).

Older People living with hoarding and/or CMHH

People living with hoarding are often socially isolated and living with mental health challenges and/or executive dysfunction (Ayres et al. 2010; DoH [Vic.] 2013; Roane et al. 2017; Tolin et al. 2010), and hoarding and/or CMHH often progress with age. Older Australians living in such environments are likely to have significant barriers accessing the basic facilities needed for self-care (i.e. washing, sleeping, eating) (Ayres et al. 2010; Steketee et al. 2012; Tolin et al. 2010b).

Older Australians living with hoarding and CMHH may be at higher risk of injury due to falls, trips and/or falling over displaced items (Ayres et al. 2010; Roane et al. 2017; Steketee et al. 2012; Tolin et al. 2010b). Such living environments present enhanced risks to health and safety not only for residents, but also for families and carers, support workers, and emergency services. Hoarded environments are hugely problematic for emergency services (Frost el al. 2000; Tolin et al. 2010b, 2008); there is often limited access to properties in the case of fire or when responding to a critical health incident (Bratiotis 2013; DoH [Vic] 2013; Kysow et al. 2020; McGuire et al. 2013). This means there is an increased risk of premature death for residents and, in the case of fire, for the surrounding community (Clark et al. 1975 cited in Guinane et al. 2019; Visvanathan et al. 2019).

Hoarding in particular is also likely to intensify financial stress for residents (due to the ongoing purchase of items and/or the devaluation of the property) (DoH [Vic] 2013; H&SWG 2017; Tolin et al. 2014).

It is common for people living with hoarding and/or CMHH to have poor insight into the risks their living environment presents for them personally, socially or environmentally. Insight tends to be lower amongst those living with hoarding, compared to those living with CMHH (Tompkins 2011). As previously discussed, the social stigma and judgement faced by many living with hoarding and/or CMHH can intensify social isolation, cause considerable family friction and alienation and can exacerbate poor mental health (Buscher et al. 2014; Chabaud 2020; Davidson et al. 2020; Garrett 2020; Neziroglu et al. 2020; Park et al. 2014; Roane et al. 2017). This often reinforces a person's reluctance to seek help for any personal, social or environmental risks they may face (Chabaud 2020; Neziroglu et al. 2020; Tompkins 2011).

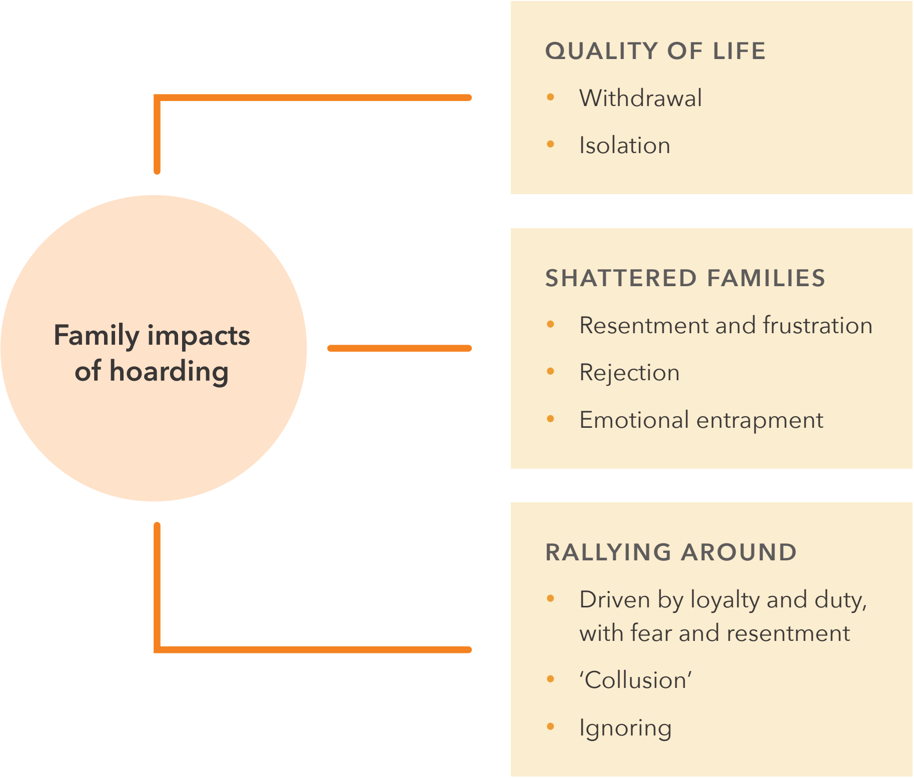
If accommodation, health and personal needs are left unaddressed, this can lead to a deteriorating living environment, increasing self-neglect, deteriorating mental and physical health, disengagement with support services, increased risks of losing tenancies, structurally unsafe dwellings and ultimately eviction due to public health concerns, leading to long term homelessness or premature entry into residential aged care (Visvanathan et al. 2019).

Families and carers

Families and carers of those who live with hoarding and/or CMHH report a number of impacts on their own lives (Wilbram et al. 2008). These include their struggles to effectively support the person they care for to manage their living environment and their health; their difficulties understanding what's happening for the person they care for and how to approach challenges; strains on their relationships and social connectivity; and their own marginalisation due to associated stigma (Buscher et al. 2014; Chabaud 2020; Davidson et al. 2020; Garrett 2020; Neziroglu et al. 2020; Park et al. 2014; Tolin et al. 2008; Tompkins 2011; Wilbram et al. 2008).

Although these impacts on people, their families and carers are generally accepted in the international research literature and are a useful starting point for designing tailored policy and service responses, Australian-specific insights are sparse. In a useful overview of research on adult family members of those who live with hoarding, Buscher et al. (2014) group impacts into three areas (see Figure 10).

FIGURE 10: BUSCHER ET AL.'S META-ANALYSIS OF FAMILY IMPACTS OF HOARDING



Family impacts of hoarding

QUALITY OF LIFE
- Withdrawal
- Isolation

SHATTERED FAMILIES
- Resentment and frustration
- Rejection
- Emotional entrapment

RALLYING AROUND
- Driven by loyalty and duty, with fear and resentment
- 'Collusion'
- Ignoring

Source: Buscher et al, 2014

QUALITY OF LIFE

Quality of life referred to the mental, physical and social wellbeing of families. Impacts for those who had lived with someone who hoarded when they were young included withdrawing from the outside world due to embarrassment about the condition of their home. For those who were living with someone with hoarding behaviour, there were reports of withdrawing within the house into an uncluttered sanctuary. Other family members talked about feeling isolated due to embarrassment about their home, or stigma about how they lived (Chabaud 2020; Davidson et al. 2020; Garrett 2020; Neziroglu et al. 2020; Park et al. 2014; Tolin et al. 2008; Wilbram et al. 2008). Those growing up in cluttered environments talked about growing up without people visiting their home, and shying away from friendships or romantic partners.

SHATTERED FAMILIES

Most family members talked about detrimental impacts on family dynamics. This included heightened conflict and resentment, often around families' frustrations about clutter and their family member's denial that the clutter posed an issue for themselves or anyone else. There were also instances of families rejecting the hoarding members, particularly if they had grown up with them (Chabaud 2020; Neziroglu et al. 2020; Park et al. 2014; Tolin 2008; Tompkins 2011).

There were also feelings of physical and emotional entrapment amongst family members. These were prompted by fears that their relative who has hoarding behaviour would never address their actions and, for adult children of hoarders, a fear that parents would move in with them as they age.

RALLYING AROUND

Rallying around described how families responded to their loved one's behaviour. Tompkins (2011) and Wilbram et al. (2008), amongst others, noted loyalty and duty, tinged with fear and resentment, when adult children became lone carers because their parents would not accept any external support. Other family members – particularly partners – accepted hoarding behaviours as part of their loved one.

Other studies have noted 'collusion', where family members reflected that they are enabling their loved one through 'living with it', or ignoring the behaviours (Tompkins 2011; Wilbram et al. 2008). Tompkins also described family members as 'team members' and 'contractors of help'. This is in recognition of the important role that family members can play in supporting change emotionally and practically.

CHAPTER THREE

Tasmania's policy and service environment

> *The aged care system depends on the contributions of informal carers. It should not take for granted their willingness to contribute. The importance of informal carers to the people they care for and to the aged care system more broadly needs to be better recognised.*
>
> ROYAL COMMISSION 2021

> *While the hoarding family member may already receive a service in response to a comorbid problem such as depression, anxiety or OCD, family members may not be considered by health-care professionals other than in respect of carer support… Family members' care needs to be taken seriously because of the adverse mental health consequences of living with hoarding. Nurses need to understand what compulsive hoarding is and how it affects family members in order to provide adequate and appropriate support…*
>
> *The aim should be to enable families to help each other to live together as they wish, respecting the diversity of personalities within those families. It is important that practitioners do not attempt to produce a kind of social conformity in line with the expectations of the health and social care establishment.*
>
> BUSCHER ET AL. 2014

Both federal and state strategies for older Australians promote a vision of healthy ageing, at home where possible. Federally, this vision is driven by My Aged Care, recently under the spotlight of the Royal Commission into Aged Care and Quality. The Australian Government's Commonwealth Home Support Program (CHSP) and Home Care Packages (HCPs) offer different levels of support for Australians to age well at home once they reach 'older age' at 65 or 55 for Aboriginal and Torres Strait Islander people (DoH [Au] 2020). These consumer-led aged care programs encourage service providers to work within an approach that promotes *wellness* and *reablement* (see Figure 11).

At a state level, the Tasmanian Government's Strong, Liveable Communities Plan outlines the state's vision for active ageing, where our older Tasmanians are valued, engaged and healthy (DPAC 2017).

If we are to achieve those wellness and reablement outcomes, a policy and service environment that directly enables older Tasmanians to age well at home whilst living with hoarding and/or CMHH needs to work together with a policy and service environment that provides for their families and carers (Buscher et al. 2014; Chabaud 2020; Koenig et al. 2010; Neziroglu et al. 2020; Pittman et al. 2020). This imperative has been recognised in the recently released final report from the Royal Commission into Aged Care and Quality (Royal Commission 2021).

To practically achieve wellness and reablement for older Tasmanians, those combined policy and service environments need to achieve three goals. They need to ensure that Tasmanians reach ‘older age’ with minimal risks to wellness and reablement at home; they need to address the inhibiters and facilitate the enablers to wellness and reablement for those who have already reached ‘older age’ (DoH [Vic.] 2012, 2013; Stark 2013; DoHA 2013); and they need to recognise the role that families and carers play in achieving and sustaining wellness and reablement. In achieving this last goal, they must provide specific supports for families and carers that assist them in their caring role, while also providing supports for families and carers in their own right to maintain their wellbeing.

FIGURE 11: WELLNESS AND REABLEMENT: DEFINITIONS FROM THE COMMONWEALTH HOME SUPPORT PROGRAM (CHSP) GOOD PRACTICE GUIDE

MY AGED CARE

Wellness emphasises identifying needs, aspirations and goals. It acknowledges and builds on strengths and has a focus on integrating support services as a path to greater independence and quality of life

Reablement emphasises assisting people to regain functional capacity and improve independence. Similar to rehabilitation, it is goal-oriented and aims at full recovery where possible. It seeks to enable people to live their lives to the fullest.

Figure drawn from that used by Nous Group 2018

In analysing whether the current policy and service environments are fit to deliver these goals, we have considered a number of questions:

- ***Are current policy goals and outcomes appropriate for families and carers supporting older Tasmanians living with hoarding and/or CMHH?*** For example, do outcomes within relevant strategies and policies recognise the roles of this particular cohort of families and carers? And do they consider their wellbeing within the policy goals and outcomes?
- ***Do strategies, action plans and services address the needs of families and carers supporting older Tasmanians living with hoarding and/or CMHH?*** For example, are there clear pathways to support for this cohort of families and carers? Is there an appropriate continuum of supports that addresses their own needs and helps them to support the person they care for? Are services integrated in a way that makes it less complex for these families and carers to navigate the supports they need for themselves and those they care for?
- ***Are families and carers of older Tasmanians living with hoarding and/or CMHH supported in ways that achieve outcomes appropriately and sensitively?*** For example, is there an appropriate practice framework that assists families and carers to understand assessment and review processes around hoarding and CMHH? Is there a framework that helps families and carers and Tasmanian service providers to understand appropriate and sensitive approaches to supporting families and carers and those they care for? Is there an appropriate framework that guides how families and carers and service providers should respect choice and dignity, whilst ensuring health and safety, for older Tasmanians living with hoarding and/or CMHH?

Treasured Lives' Phase 2 report will dive deeper into the legislative, policy and service landscapes as they relate to older Tasmanians living with hoarding and/or CMHH. It will give specific focus to what an appropriate practice framework in Tasmania might look like and delve deeper into issues of choice and dignity, as well as health and safety.

Here, we provide an overview of the federal and Tasmanian policy and service landscapes *as they relate to families and carers* of older Tasmanians living with hoarding and/or CMHH. This includes how the landscape recognises them as families and carers with needs of their own, and how the landscape recognises their roles as trusted advocates (Neziroglu et al. 2020), 'contractors of support and service' (Tompkins 2011) and care givers (Chabaud 2020; Neziroglu et al. 2020). Chapter 8 extends this analysis and provides an overview of what happens elsewhere to support families and carers to meet their own needs and support those they care for.

3.1 The current policy and service environments

Currently, neither federal nor state policy and program settings directly address the inherent challenges faced by older Tasmanians living with hoarding and/or CMHH, or those faced by their families and carers.

FIGURE 12: SUPPORT AND RECOGNITION: DEFINITIONS FROM FEDERAL AND STATE CARERS' POLICIES

DSS CARER GATEWAY, 2019 ONWARDS
TASMANIA'S CARER POLICY 2016 AND ACTION PLAN 2017-2020

Wellbeing and recognition

- Improve wellbeing*
- Recognising the commitments of unpaid carers**

Support, skills and knowledge

- Improve skills and knowledge*
- Supporting them in their caring role*/**
- For themselves and the people they care for**
- Supporting active participation in economic, social and community life**

**Goals from DSS Carers Gateway plan*[12]
***Goals from Tasmania's Carers Policy and Action Plan*[13]

---

[12] For more details, see DSS 2020.

[13] DPAC 2017.

There has been a push federally to recognise the role that informal carers play in supporting vulnerable Australians, including older Australians, through the Australian Government Department of Social Services Integrated Plan for Carer Support Services (DSS 2020). This has led to the development of the Carers Gateway website, recognising the need to provide information, support and services in an integrated manner that meets the broad needs of informal carers. Although it seeks to improve carer wellbeing, skills and knowledge, it does not specifically target specialist areas of need, such as those of informal carers supporting people living with hoarding and/or CMHH. These goals are complemented by those articulated within Tasmania's Carer Policy and Action Plan, which is currently under review (see Figure 12).

Specific recognition of families and carers of those living with hoarding and/or CMHH is also absent from the present My Aged Care policy framework. There is no national or state strategy that specifically picks up the needs of all stakeholders involved with those living with hoarding and/or CMHH and their families and carers. There is a void in recognition of these groups.

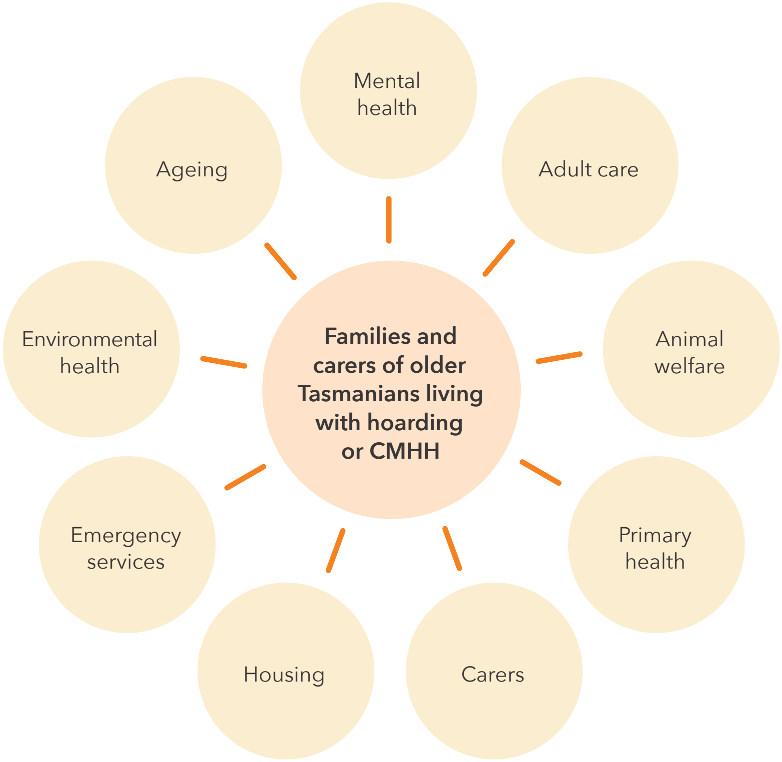
This has led to some Australian jurisdictions filling that void. In contrast to other states, such as Victoria, New South Wales and South Australia[14] (DoH [Vic.] 2012, 2013; Stark 2013; DoHA 2013), Tasmania does not currently have the appropriate social policy, program and practice settings to facilitate this challenging work. The needs of Tasmanians living with hoarding and/or CMHH and their families and carers are invisible within the strategic policy environment and are not purposefully served within the service and program environment in a significant or appropriate manner. Services available to them are either incidental or piecemeal.

Given the wide-ranging personal, social and environmental impacts, outlined in Chapter 2, for older people living with hoarding and/or CHMM and for their families and carers, support demands a multi-agency response. Understanding whether there are any policies and services that meet the needs of families and carers requires a scan across all the major support areas (see Figure 13). Here, we describe the current landscape through the lens of families and carers.

---

[14] See Chapter 8 for a brief overview of what happens in other Australian states.

FIGURE 13: OVERVIEW OF POLICY AND SERVICE AREAS RELEVANT TO FAMILIES AND CARERS OF OLDER TASMANIANS LIVING WITH HOARDING AND/OR CMHH



Pathways to support

Challenges with hoarding and/or CMHH often remain hidden (Guinane et al. 2019). People rarely self-identify as needing support unless they feel there is a significant threat to either their health, their home, or their family (Lee et al. 2017). More often, challenges are "uncovered" by a concern raised by someone else later in a person's life (Roane et al. 2017). For example, a public health intervention may be prompted due to a neighbour raising a concern about "mess"; a home visit from Aged Care, Family, Disability or Mental Health Support Workers may flag a need for clinical and/or community support and practical intervention; or a home visit may be prompted due to a family member or carer contacting services to help "manage" their relative's living conditions. A social or private landlord's tenancy inspection may flag a tenancy risk and prompt practical action; emergency or hospital services may raise a concern about discharging a patient into an environment that continues to pose health and safety risks.

Families can play a crucial role in improving help-seeking for those they care for and being 'contractors of support and services' (Tompkins 2011). Their role in navigating a pathway to support within aged care, disability supports, adult care, mental health and primary healthcare such as GPs can be key. They may be involved in accessing information and supports through NDIS Local Area Coordination services, or through My Aged Care. But there are no clear paths or entry points that recognise their own, specialist needs within these models, unless they too are accessing NDIS or My Aged Care packages and have articulated the need to address psychosocial or practical challenges inherent in their care load.

Outside of NDIS and My Aged Care, again, there are no clear pathways to support for families and carers in Tasmania. Although the Carers Gateway provides a pathway to general information and support for carers, there is no resource nationally or in Tasmania that offers a specialist pathway to information and supports either for those living with hoarding and/or CMHH or their families and carers. Nor are there any means of being guided through a specialist pathway of supports within Tasmania. There is neither a horizontal pathway of information and supports across clinical, psychosocial and practical services, nor a vertical pathway along a continuum of supports as families' and carers' needs ebb and flow.

A continuum of supports

Given the complex nature of addressing hoarding and/or CMHH and how case-specific and long-term such supports need to be, a continuum of support is required for older Australians living with hoarding and/or CMHH and their families and carers – from low level supports that prevent wellness and reablement becoming a concern, or supports that maintain a safe state, through to acute and crisis interventions when personal, social or environmental health and safety concerns escalate (Bratiotis 2013; Brown & Pain 2014; DoH [Vic] 2013; Fleury et al. 2012; Frost et al. 2000; H&SWG 2017; Kysow et al. 2020; McGuire et al. 2013; Moulding et al. 2016; Snowden & Halliday 2009; Tolin et al. 2008; Tompkins 2011).

Care recipients living with hoarding and/or CMHH are likely to retain issues around trust and privacy and have feelings of shame and embarrassment, even when they have already taken the step to seek help. As such, it is likely that family members and carers will remain involved in delivering support and care arrangements, even when professional supports have been engaged. Providing skill development for families and carers to help them support those they care for in an informed manner can be an important tool in maximising wellness and reablement. Evidence indicates that specific supports to help families and carers support those they care for can increase help-seeking amongst people living with hoarding and/or CMHH, improve family relationships and lessen social isolation (Chabaud 2020; Neziroglu et al. 2020; Tompkins 2011).

There is no clear evidence on what mix of supports 'works'. It is *having* a mix to choose from that is important. However, services that help families and carers support their care recipient can include resources and training on the nature of hoarding and CMHH to understand what's happening for the person they care for, training around how to sensitively support the person they care for information on what sorts of services might be useful and how they can access them, and family counselling to encourage more positive family relationships that might lead to addressing risks (Neziroglu et al. 2020; Chabaud 2020).[15]

Targeting services directly at families and carers of those living with hoarding and/or CMHH can help ensure that those families and carers are able to continue their support with minimum impact on their own wellbeing (Chabaud 2020; Neziroglu et al. 2020; Tompkins 2011). A continuum of services for families and carers would both support their care recipient in achieving wellness and reablement at home, and also provide support to maintain their own wellbeing.

It is reported that specialist therapeutic counselling is extremely useful to address the collateral consequences of living with a person who has challenges with hoarding and/or CMHH (either in the past or now), and the challenges that often come with their care load (see Chapters 2 and 8) (Chabaud 2020; Neziroglu et al. 2020 ; Tompkins 2011).

As important are services for families and carers to address their own wellbeing through non-clinical routes. Peer support networks are an invaluable form of such support. Peer networks tend to lessen families and carers' sense of social isolation and stigma. They also provide access to informal supports that enable them to seek advice and emotional strength from those who understand their experiences (Chabaud 2020; Neziroglu et al. 2020). Many families and carers of those living with hoarding and/or CMHH need specific peer supports to manage comorbid mental ill health, the hoarding behaviour itself and any CMHH for those they care for (Chabaud 2020; Neziroglu et al. 2020; Tompkins 2011).

Working within a harm minimisation framework, the alcohol and drug sector has for a long time acknowledged the need to recognise and support comorbidities within mental ill health and substance use (DoH [Tas] 2020a; Tompkins 2011). Targeted support is now commonplace for families and carers supporting those living with mental ill health and challenges with alcohol and other drugs. For example, in Tasmania, Mental Health Families and Friends offer peer support networks for families and carers of those with mental ill health and challenges with alcohol and/or drugs.[16]

---

[15] There are many such courses available online and internationally. They include motivational interviewing to support positive conversations with their care recipient about help-seeking and improving insight around personal and environmental risks, and Cognitive Behavioural Therapy as utilised in courses such as Buried in Treasures. See Chapter 8 and Appendix 2 for examples of such resources.

[16] See https://mhfamiliesfriendstas.org.au/

However, for Tasmanian families and their carers of those living with hoarding or CMHH, not only is there is no consideration of what a pathway into and through support might look like, there is also no continuum of specialist support for them to access.

There are potential elements of supports for families and carers in Tasmania. Families and carers can access the face to face and online peer group support networks offered by Carers Tasmania and Mental Health Families and Friends[17]. There is potential to adapt existing peer support networks that address comorbid mental ill health and challenges with alcohol or other drugs to suit the needs of this specific cohort of families and carers.

Within the clinical pathway, Tasmania's State Adult and Older Persons Mental Health Services can work with older Tasmanians or their families and carers to support their clinical and psychosocial needs through GP, clinical or other referral pathways. However, even if state mental health services are able to support people to address the underlying causes of hoarding behaviour or CMHH, or the collateral consequences of care, there is a lack of specialist support services or programs to work with people to address the specific personal, social and environmental risks associated with hoarding and/or CMHH. There are no specialist counselling services or any specialist training courses or workshops in Tasmania that offer the skills to help people support those living with hoarding and/or CMHH.

Given the low level of insight and help-seeking amongst people living with hoarding and/or CMHH, for most it is unlikely they will seek help under consumer-led models of care, such as NDIS and My Aged Care. Adults under 65 who are eligible for psychosocial support services within NDIS can request supports within their package to address challenges related to hoarding and CMHH, and within that could involve their families and carers in the choices they make. But access is limited in Tasmania by the absence of targeted therapeutic and practical services available in the state. It is not a matter of a thin market. There simply isn't one.

For those 65 and over, My Aged Care does not currently extend to clinical or psychosocial supports, nor does it currently consider the needs of families and carers.

There are a few pockets of emerging specialist service across Tasmania. The Tasmanian Fire Service's Community Safety pilot, currently operating in southern Tasmania, will work alongside any service provider or family member to assess fire risk in homes where there are challenges with hoarding and/or CMHH. This may spark a conversation about how to address other environmental risks, but there are no specialist support services that families and carers can draw on to continue those conversations.

---

[17] See https://mhfamiliesfriendstas.org.au/ and https://www.carerstas.org/how-can-we-help/

For those aged 50 or over, or 45 and over for Aboriginal or Torres Strait Islander people, there are two grant-based funds that recognise the need for supporting those living with hoarding and/or CMHH and their carers. Under My Aged Care, the CHSP's Assistance with Care and Housing (ACH) services recognise the need for targeted support for older Australians at risk of homelessness or living in unstable housing, and for their carers. This includes those living with hoarding and/or CMHH. It offers case management together with a small brokerage fund to address risks related to housing and homelessness.

The Tasmanian Department of Health's Home and Community Care Program (HACC) has been forward-thinking in its provision of support for adults whose tenancy is at risk due to clutter (DoH [Tas] 2020). It is possible for families and carers to be involved with Case Workers in designing and delivering supports for those they care for, and if those they care for have been recognised as eligible for HACC support, their carers can access support as well. Funding has been provided for domestic and psychosocial supports.

This recognition is a welcome oasis in a very barren Tasmanian service landscape. But both programs are hampered by the lack of specialist services that can work with older Tasmanians and their families and carers and by the lack of coordination amongst services. There is a long way to go before we see a continuum of care.

Interagency collaboration and shared practice frameworks

The complexities of hoarding and CMHH require a range of clinical, community and practical services to coordinate support for individuals and their families and carers on a long-term basis (Bratiotis et al. 2011; DoH [Vic] 2013; H&SWG 2017; Moulding et al. 2017; Stark 2013; Steketee et al. 2001). These services need a shared understanding of approaches to assessment, support and decision-making.

Understanding the risks that those living with hoarding and/or CMHH may face helps us to consider when and how interventions might be appropriate (Chou et al. 2018; Lee et al. 2017). Having a shared understanding of these boundaries with residents, families and carers could help to clarify the point at which it's appropriate to call for help. It can also help policy makers and program funders understand where to prioritise program support, i.e. where does "crisis" support start in the continuum of services and what should the supports on either side of that crisis (prevention and long term) look like (Bratiotis 2013; Frost et al. 2000; Koenig et al. 2010, 2014; Kysow et al. 2019; McGuire et al. 2013).

It is not government's or service providers' business to dictate how an individual chooses to run their life or their home, nor is it for families and carers to decide how their care recipients choose to live. Dignity of choice is an important pillar of Australia's aged care and disability support frameworks. This consumer-led approach, at the forefront of models like My Aged Care and NDIS, demands that individuals weigh up their own risks, up to the point at which there are either significant health and safety concerns, or it is deemed that the person involved no longer has capacity to make informed decisions. However, the low levels of help-seeking and low insight among people living with hoarding and/or CMHH test these consumer-driven models ethically, as well as practically (DoH [Vic] 2013).

Where people living with hoarding and/or CMHH enter services through incidental pathways, such as housing support services due to a tenancy risk, or local government due to a public health complaint, the challenges of how to appropriately support families, carers and those they care for multiply. Often issues need to be addressed within a set period or sanctions (often homelessness) will be imposed. Families and carers and professional support workers are often working to support people who may not be ready or do not want to consent to addressing challenges. They often refuse support (Frost et al. 2000; Kim et al. unpublished, cited in Frost et al. 2000; Lee et al. 2017, cited in Guinane et al. 2019; Snowden 2012). Furthermore, therapeutic services are likely to be outside of these services' remit and are unlikely to be available in Tasmania (DoH [Vic] 2013; Frost et al. 2000; Lauster et al. 2016). This can often lead to the care and coordination burden falling to the family member or carer.

Some Australian and international jurisdictions have sought to tackle the challenge of case coordination in such a complex and specialist space and address the dilemmas inherent in addressing personal and environmental risks through establishing specialist state practice frameworks and local case coordination groups (Bratiotis 2013; Frost et al. 2000; Koenig et al. 2010; Koenig et al. 2014; Kysow et al. 2019; McGuire et al. 2013). We will expand on these in Chapter 8 and in Phase 2 of Treasured Lives. There are currently no such specialist case coordination services in Tasmania for families and carers of those living with hoarding and/or CMHH; nor is there a Tasmanian practice framework guiding such ethical and practice dilemmas. Again, this leaves space for inconsistent decisions and practice across professions and professionals. It also means that families and carers have no frame of reference around what to expect in terms of supports and no sense of when intervention should be sought. Further, there are no case coordination services specifically for families and carers that could support them to navigate services for themselves and for those they care for in Tasmania. As such, the burden of care and support stays with families and carers.

3.2 Opportunities in future policy environments

There are a number of current reforms that provide opportunities for more targeted responses to evolve.

Families and carers have received considerable attention in the recommendations from the Royal Commission into Aged Care and Quality (Royal Commission 2021). At the time of writing, the Royal Commission had only just released its report, so deeper analysis of its framework and recommendations will come in Phase 2 of Treasured Lives. But from a brief overview, it is promising to see that the Commissioners have recognised the many roles families and carers play in the lives of the older people they care for – trusted companion, information and support seeker, advocate, transport provider, carer. The report has also recognised some of the positive experiences and challenges faced by carers highlighted in Chapter 2, from it being extremely rewarding to frustrating, stressful and exhausting (Royal Commission 2021).

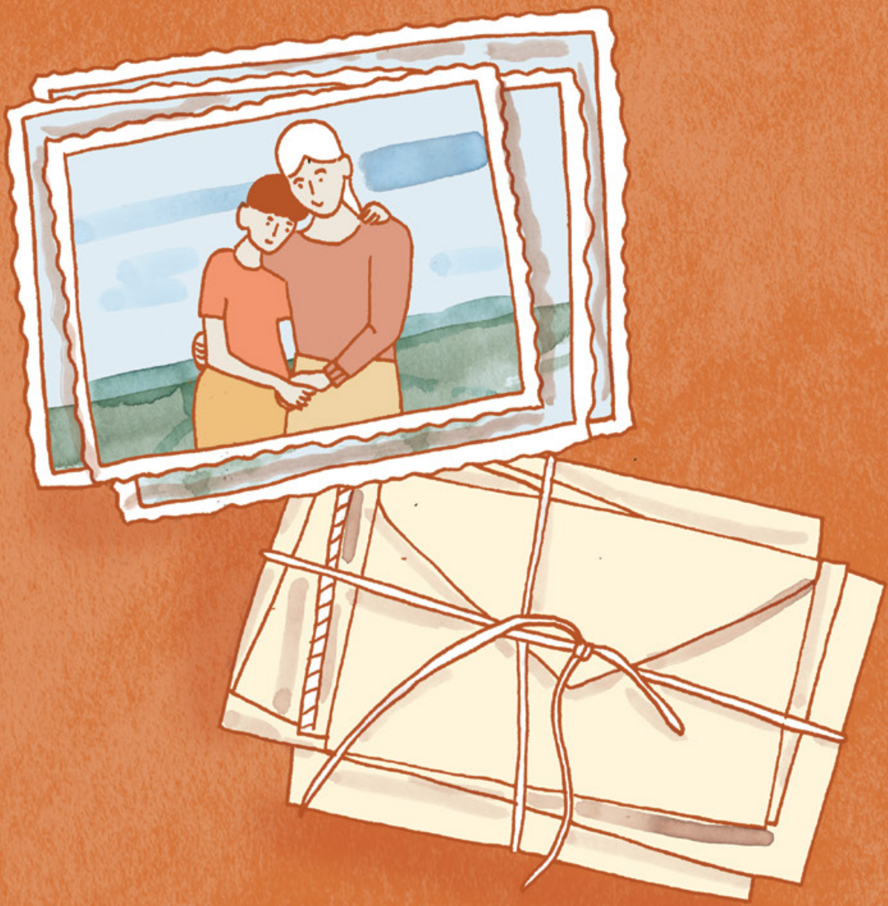
Consideration of how the Carers Gateway and Aged Care Gateway can work together has been another element of the Royal Commission recommendations, as has specific mention of supports for hoarding and CMHH. These are all promising steps towards serving the needs of families and carers supporting older Tasmanians living with hoarding and/or CMHH.

It is also promising to see recommendations in the Royal Commission's final report aimed at sharing information about aged care package supports with families and carers, in liaison with the care recipient and new Care Finders, and including families' and carers' needs in care package assessments and design. Further to this, there is a huge drive to widen current age care package supports, so that practical and psychosocial supports can be coordinated with primary and allied healthcare and other services such as housing (Royal Commission 2021). This in itself opens up opportunities for families and carers to have their own needs met, as well as help ensure those they care for do too.

Within the Tasmanian government, there are a number of relevant policy reviews occurring. The Carers Policy and Action Plan (DPAC 2017) is due for release shortly after this report is written. The Tasmanian Department of Health is working with Primary Health Tasmania to review the state's mental health strategy, *Rethink* (DoH [Tas] 2015), along with the future for the Southern Tasmanian Mental Health Integration plans (DoH [Tas] 2019). These mental health reforms have a focus on exploring integrated care models and providing a continuum of supports for Tasmanians living with mental health challenges. Both are promising approaches for framing support available to families, carers and care recipients who are living with hoarding and/or CMHH. However, we do not know at this point whether this cohort will be recognised in the reforms.

CHAPTER FOUR

Our families, carers and those they care for



4.1 How families and carers participated

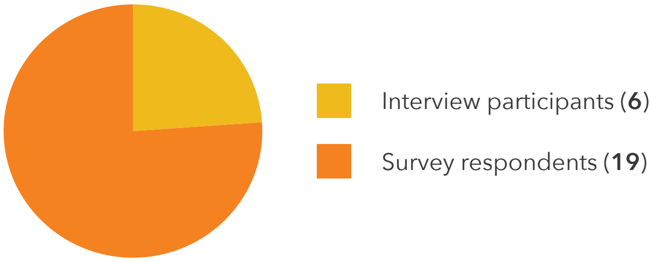
Between August and December 2020, 25 family members and informal carers participated in the Treasured Lives research. Nineteen research participants completed an in-depth online survey, and six more participated in one to one, semi-structured, in-depth interviews (see Figure 14). All but one of the interviews were conducted face to face. This followed a statewide publicity drive via social media, radio, leafleting and online promotion via family and carer peak bodies, and publicity posters displayed in a range of community service organisations offering mental health services.

This was an opportunity sample. We did not strive for our sample to be representative of carer profiles in general, or representative of the limited knowledge that exists around families and carers of those living with hoarding and/or CMHH.

The survey and interview explored:

- their relationship with the person or people they cared for;
- their experiences of supporting the person or people they cared for to age well at home, and what supports they felt they need to do this effectively in future;
- the formal and informal supports they draw on for themselves and to support the person/people they cared for;
- their reflections on the experiences of those they cared for and their needs into the future to support them to age well at home; and
- their reflections on what's needed to ensure a respectful support response for those they cared for and for themselves.

FIGURE 14: NUMBER OF FAMILIES AND CARERS WHO PARTICIPATED: SURVEY AND INTERVIEWS



N=25

4.2 Relationships

The 25 research participants were, or had been, caring for 28 older people living with hoarding and/or CMHH. Three participants offered their reflections on caring for two different people. Two had cared for parents and the third had cared within an extended family unit.

Two-thirds of the families and carers who participated were children of the people they were caring for. The remaining third were a combination of siblings, partners, friends and carers (informal and paid) (Table 2).

Two-thirds of the families and carers had lived with the person they were caring for at some point during their lives. Of those 16, most had lived with the person they cared for for 11 years or more. Only two participants were currently living with the person they were caring for.

TABLE 2: ALL FAMILIES AND CARERS: RELATIONSHIP WITH CARE RECIPIENTS

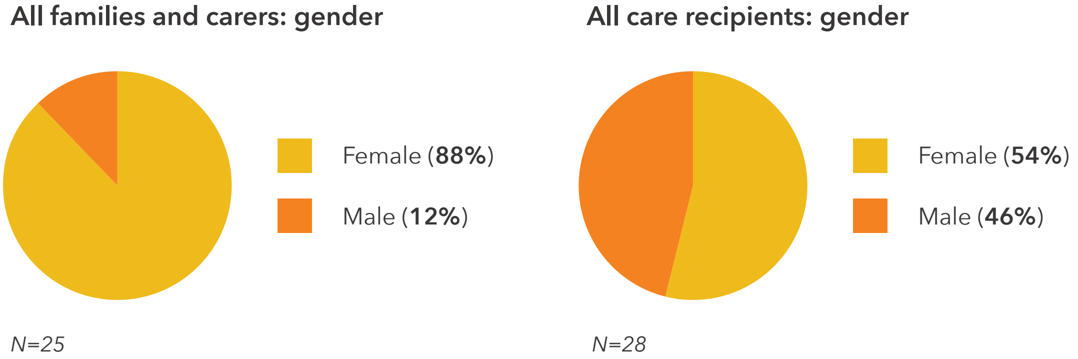
Participants relationship with older person	Survey	Interview	Total	%
I am their child or step-child	7	5	12	46
I am their sibling or step-sibling (brother or sister)	3	2	5	19
I am another family member	3		3	11
I am their partner	2		2	8
Other	2		2	8
I am their informal carer	1		1	4
I am their paid carer	1		1	4
Grand Total	**19**	**7***	**26***	

**Total number of responses equals more than the number of research participants. This is because some participants were caring for more than one person. Their different relationships with each person are counted separately.*

4.3 Personal characteristics

The majority of families and carers were female. In contrast, those they cared for were more evenly distributed across gender (see Figure 15).

FIGURE 15: GENDER: FAMILIES AND CARERS AND CARE RECIPIENTS



Families and carers were spread across the age ranges 54 and under, over 55 and the most common age range for families and carers was between 55 and 64 (see Figure 16).

Just over half of those they cared for were 65 or over. A third were 64 or younger (Figure 17), with the remainder being deceased. Thus, families and carers were reflecting both on those they care for who are 'preparing' for old age and those already potentially eligible for aged care services.

FIGURE 16: AGE RANGE: ALL FAMILIES AND CARERS

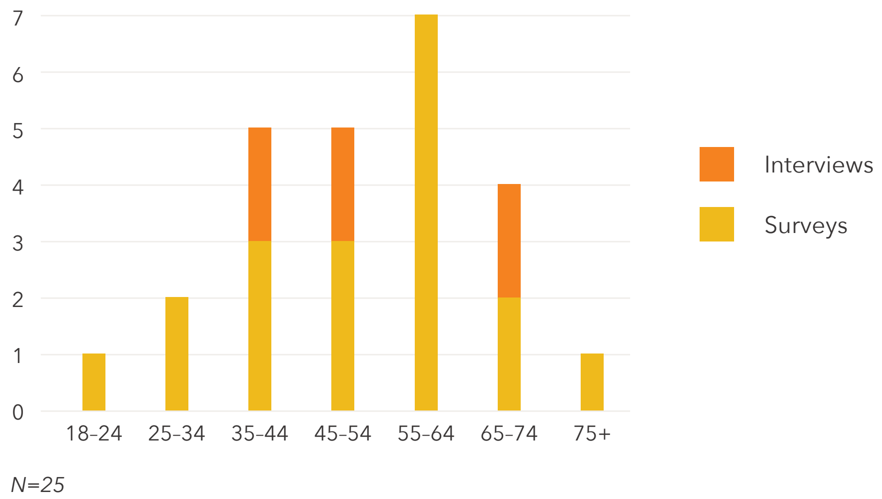
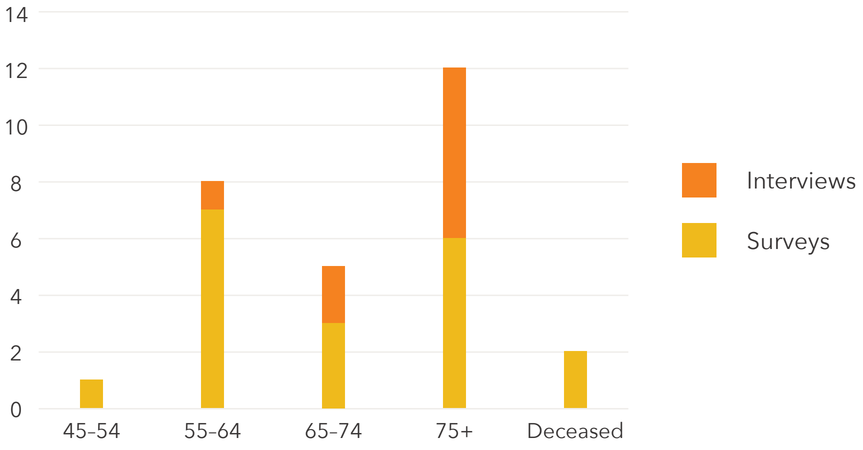


FIGURE 17: AGE RANGE: ALL CARE RECIPIENTS



N=28

No respondents identified as of Aboriginal or Torres Strait Islander heritage, or thought that anyone they cared for did. Only a very small number of participants identified with any other ethnic or cultural groups (see Table 3).

TABLE 3: ALL FAMILIES AND CARERS: CULTURAL AND ETHNIC IDENTITIES OTHER THAN ABORIGINAL OR TORRES STRAIT ISLANDER – FAMILIES, CARERS AND CARE RECIPIENTS

Identify with ethnic or cultural group other Aboriginal or Torres Strait Islander*	Ethnic/cultural identity	No. families and carers	No. of older people
No		21	25
Yes	English South African	1	
	British		1
	Irish	1	
	South Africa	1	1
	Vietnamese	1	1
Total		**25**	**28**

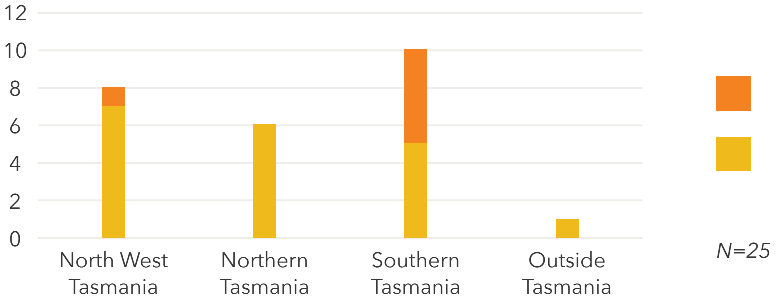
**This question was deliberately 'open'. There were no categories offered, so that respondents could articulate their cultural affinities in the broadest sense however they wished.*

4.4 Where they live

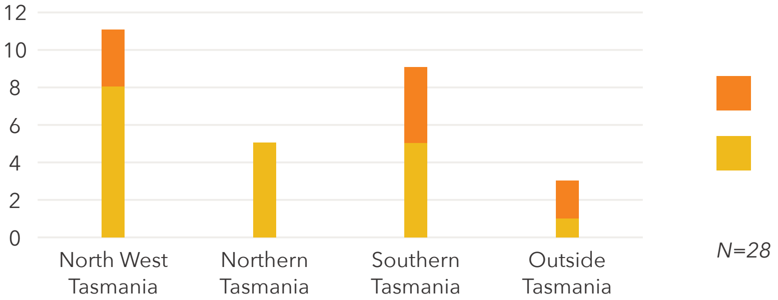
Families and carers who responded were fairly evenly spread across the state of Tasmania, as were those they cared for (Figure 18). Of particular significance here is whether they were living close to those they cared for.

FIGURE 18: WHERE THEY LIVED: FAMILIES AND CARERS AND CARE RECIPIENTS

All families and carers: where they live



All care recipients: where they live



As Figure 19 shows, the majority were living within the same region as those they care for, but a quarter did not. For those living either in a different region to the person they care for, or in a different Australian state, any care challenges are likely to be exacerbated. This is also an important issue to consider around the design of services across regions and state boundaries.

FIGURE 19: WHERE FAMILIES AND CARERS LIVED COMPARED TO THEIR CARE RECIPIENTS

N=25

CHAPTER FIVE

Families' and carers' reflections on their own experiences

> *As a naturally tidy person – a sorter, a filer and junk chucker – to be living with a partner who is the dead opposite is a continual challenge. I do not suffer from any mental illness, depression, anxiety, psychosis or dementia. But I know my husband can't help it. Hoarding disorder is a mental illness from which he did not choose to suffer.*

RESEARCH PARTICIPANT: FAMILY/CARER

> *I got a book at home. It's about a little girl and her father starts to hoard… That was a happy ending. But mine hasn't ever ended. It's a happy ending in the fact that I've still got my mum… but it's not like in the book. 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.*

RESEARCH PARTICIPANT: FAMILY/CARER

Not all older Tasmanians living with hoarding and/or CMHH will have family members or informal carers, such as friends or neighbours, with whom they have a connection. It is clear that many of those living with hoarding and/or CMHH are socially isolated (Roane et al. 2017), often with strained or no connections to family (Neziroglu et al. 2020), and have a low levels of help-seeking (Chou et al. 2018; Tompkins 2011). Phase 2 of Treasured Lives will explore in more depth the experiences and needs of older Tasmanians who have no such connections, through the perspectives of those with lived experience and a range of service providers who work with them.

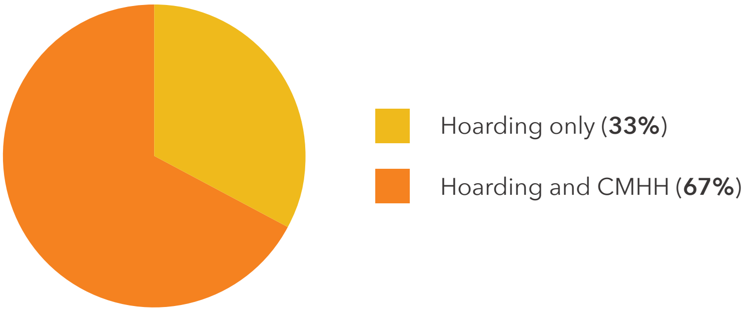
For those who do have a connection to family or informal care, no matter how strong or fractious that relationship is, it is crucial to consider the value it brings to those concerned, along with the challenges and impacts.

In Chapter 3, we highlighted some of the important roles carers can play in promoting wellness and reablement for those they care for who are living with hoarding and/or CMHH, and the roles that positive supports can have in minimising family disruption, improving insight into risks and maximising help-seeking amongst those living with hoarding and/or CMHH. We also highlighted the value that providing supports to families and carers can bring in maximising not just care recipients' wellbeing, but that of families and carers themselves (Chabaud 2020).

Chapter 2 explored what the limited existing literature tells us about families' and carers' experiences. Here, we add to that body of knowledge through reflections from families and carers who participated in the survey and interviews. It is evident that their experiences echo those of their international peers, but are compounded by their invisibility within the Tasmanian policy and service landscapes.

The sample of families and carers who completed the survey and participated in interviews all reported that their care recipients were living with challenges related to hoarding, or hoarding with CMHH (see Figure 20). There were no households reported to be solely living with CMHH. We have no way of knowing whether this is "representative" of households in Tasmania, or of families and carers connected to such households. Initial project conversations with Tasmanian service providers and previous work around Tasmanian hoarding and CMHH (H&SWG 2017) have indicated that there are many households who live with CMHH without hoarding. We aim to explore the full range of living environments and their support needs in future project phases. Please note that the experiences reported here, and therefore the focus of commentary, are dominated by the impacts of hoarding, along with any coexisting CMHH.

FIGURE 20: FAMILIES' AND CARERS' DESCRIPTIONS OF CARE RECIPIENTS' LIVING ENVIRONMENTS



N=25

Families and carers participating in the Treasured Lives research played a cluster of key roles in the lives of those they care for. These roles were all encompassing, embodying relational, practical and emotional dimensions (see Figure 21). For some, particularly adult children and spouses of those with hoarding behaviours, there was an conflict between loyalty and commitment towards those they cared for and a strong sense of frustration, hopelessness and lack of agency about how to effectively support their care recipient. These themes are reflected in much of the limited literature on this cohort (Buscher et al. 2014; Chabaud 2020; Davidson et al. 2020; Garrett 2020; Neziroglu et al. 2020; Park et al. 2014; Tolin et al. 2008; Tompkins 2011; Wilbram et al. 2008).

FIGURE 21: SUMMARY OF FAMILIES' AND CARERS' EXPERIENCES: RELATIONAL, PRACTICAL AND EMOTIONAL

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

- Some 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

5.1 Relational: a window on the world

Many families and carers reported being either one of a few, or the only regular visitor inside the house of the person they cared for. This experience was typified by comments such as, '*She doesn't have friends to visit, and won't let anybody but family through the door*'. They commonly described this as being due a combination of the person they cared for having trust issues, poor mental health and a need to both control and protect their living environment from intervention, whilst also being embarrassed about the condition of the house. This is a state that Chabaud describes as 'living in a world of contradictions and paradoxes' (Chabaud 2020), which families and carers need to manage and navigate if they wish to retain a relationship with the person they care for and try to keep them safe.

It is common for families to swing between accommodating and antagonistic styles of relating to those in their family living with hoarding (Neziroglu et al. 2020). Family disruptions, or inability to "accommodate" what was happening, and dramatic changes in the nature of their relationships were abundantly reported, but were not consistently the case. This is an issue we will return to in Section 5.3.

Many of the families and carers had deliberately chosen to keep open their communication with the person they cared for and purposefully maintain their relationship, however challenging that could be:

> ***Lindsey:*** *Are there…other people in your family who helped support him?*
>
> ***Respondent:*** *No, not really. So my sister lives [in another state] and my brother lives [close to the care recipient]… But…he doesn't go around there very much. He used to, but he sort of stopped… He isn't a proactive contributor… But…I don't want to be too hard on him, because I kind of understand…some of the things that he's battling with as well… Even though Dad's alive, it's like we've lost him… It's a reminder every time you see him of what you don't have any more. Yeah. So I think for my brother that might be harder for him. Even though he might not admit that. But I've certainly come to accept that. That's one of my struggles.*

Many described how their role as a carer had incidentally developed. This was due to there either being no one else to care for that person, or no one else who would care for them. Many who had become carers incidentally did not necessarily identify as "carers", but recognised their role in looking out for the person concerned:

> *I suppose I'm not his carer, but I am his go to person. And really, I am his only go to person.*

For this specific group, broad literature about informal carers suggests that the lack of agency they often feel and a perceived lack of improvement in their loved one's wellbeing is likely to exacerbate their reluctance to take on such an identity and the responsibilities and care load that come with it (Neziroglu et al. 2020; Tompkins 2011). However, all of the families and carers who participated in Treasured Lives had voluntarily come forward to share their experiences. It is probable that our cohort would consist of those who, at least while participating in the research, recognised that there were responsibilities significant enough to reflect on.

Many family members and carers talked about the need to navigate stigma surrounding the hoarding behaviour and/or CMHH, both on behalf of the person they cared for and, sometimes, for themselves. This could include 'defending' or advocating for the person they cared in the face of family or neighbourhood hostility, or being their care recipient's 'window on the world' as they advocated with family, communities and services.

> *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.*

The sense of shame and embarrassment, along with judgement by others in the community – and often within their own family – was a real and present companion guiding much of families' and carers' understanding of what was happening and driving their support for them:

> *Mental health, stigma, shame… Mum says this thing about, 'Well I'm the one who had to go to the doctor and get the referral for being crazy and he just gets to sit there.' You know? And she's obviously internalised stigma… To me, I'm like, 'There's no stigma to that. Be proud of yourself. You went to therapy. You went, "I'm worth working on. I'm worth, you know, unpacking and…making as…best you can be." And you did that. Pat on the back. It's not shameful.' If that's what she thinks me going to therapy for 10 years was, I'm like, 'I'm sorry. You did six months. Get in there.'*
>
> *For mum professionally, she's convinced that she didn't make it to [the senior role within her job] because people knew how she lived… She felt very professionally stymied by a certain point… She felt that was one of the reasons. It's possible.*

> *That's where I find it really hard. Like I hear comments and I've had the comments made. No one knows what I have lived. If you meet my mum in church, you would have no idea. And yet there's people around saying… 'Have you seen Mrs such and such? Filthy house, filthy this.' And my mum's standing there listening to it. You think, no wonder they've built these blocks and…not*

> *letting anyone in. Because they think that of her, are they are going to think that of me?*

Others described explaining their own or their care recipient's "behaviour" to others, understanding that there were times when they needed to explain why their family's behaviour or "norms" might be different to others who had developed '*common sense by common doing*', as one participant described.

Chabaud (2020), Neziroglu et al. (2020) and Park et al. (2014) describe the 'manipulation of family behaviour' that those living with hoarding may exhibit in order to ensure that living environments remain private and protected from intervention. Many families and carers participating in Treasured Lives mentioned the importance of maintaining trust between them and the person they cared for in order to retain their relationship. This required them to "accommodate" aspects of their care recipient's behaviour that demanded control of the living environment, and privacy on their terms. This protection of privacy was typified by comments such as, '*No one has any idea about the dementia or hoarding and I respect his privacy. I am quite alone with the difficulties I face every day.*'

But maintaining that sense of trust and privacy meant that relationships were often fragile and at the behest of the care recipient's demands or emotions. There was often reported to be a quiet, or not so quiet, tension or treading on eggshells required to maintain the relationship:

> *He can be aggressive/belligerent if appropriate social/respectful boundaries are not followed.*

> *She…doesn't want people to know. There are many secrets with my mum. That's a choice that she's made about living her life. It is exasperating to deal with because there are so many secrets. Secrets and lies… I feel gnarly saying that about mum. But she does this… So she wouldn't seek help.*

Beyond the adherence to privacy and control – and often the motivation to accommodate it – came a commonly reported intimacy and understanding. Many families and carers – particularly the adult children and spouses – demonstrated excellent insights into the "story" of how and why those they cared for got to where they are today. This is further explored in Chapters 6 and 7. Many had observed and emotionally recounted the history of trauma or critical incidents that had triggered those they care for to develop attachments to items or animals rather than with people. They recounted the waves of mental ill health that often progressively isolated those they cared for and exacerbated their attachment to items, and they described how collections and clutter had slowly 'absorbed' those they care for:

> *My husband has a high IQ, is often great company but sadly about 8 years ago he dropped all his many lifelong friends and family like hot bricks. He has lost approx. 50% of his vocabulary. But he is fabulous with our animals … My husband now only relates to animals.*

> *When my grandfather passed away, my dad didn't go through his stuff or remove it. He took all of it back to their house. Furniture, books, everything.*

Some had observed – and often lived with – a developing collection of treasured items that overtook the house. Others observed how this clutter and/or declining order within the house had developed after they had left, or following a critical emotional incident in their life. Observations around this from interviewees were evocative and provided a compelling backstory and rationale for these visible manifestations of the trauma and mental ill health their care recipient had experienced:

> *More and more stuff slowly filling up. And as we moved out, mum'd sort of go into rooms and start filling them up. And there's a couple of rooms that are entirely filled that you can't get into. Like we had this room called the 'good room'… You know – nice tables and chairs. We'd sit around this big table for our Christmas dinners… That table that we used to sit around is completely covered…I actually conceivably recall the stack on it over the years just getting higher. So…that room became dysfunctional. There was what was one of my little brothers' rooms. That became filled with stuff. There was my other brother's room. My mum sleeps in that, but there's stuff all around her. And the last time I saw it…there was stuff stored on the bed that I think she slept in… And I can remember looking at that and being really disturbed by it. And there was stuff… in Dad's room. Heaps of shit.*

> *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?*

Families and carers developed a range of emotional responses to the need for control and privacy those they cared for demanded. This in itself had a range of positive and negative impacts on them personally. But there was a clear dedication amongst many respondents to understand and translate their care recipient's challenges and to make sense of them in a way that would enable them to keep their loved ones safe.

> *For many years, I was resentful [that] I didn't know how to do things and I couldn't bake, which…is a super femme ideal or quality… And then, when I put two and two together, that [Dad] removed the gas oven from his…home with his history of trauma. Maybe not consciously. And maybe it doesn't make sense in a linear way…and maybe that's not the only reason, you know? There was actually a safety thing. But that just helps me recontextualise it in the narrative of his life and have some compassion for what otherwise was an excruciating, embarrassing and frustrating situation, you know?*

5.2 Practical focus: lone carers, minimising risks

All of the interviewees and half of the survey respondents had actively tried to support their care recipient with their challenges with hoarding or CMHH. On a basic level, these supports were usually a combination of practical and emotional supports, simply articulated by one respondent as, '*Assist with talking, cleaning, understanding*.' But all participants reported that the intricacies of this care were far from simple or straightforward (see Table 4).

Safety first

Many described how they balanced the care recipient's imperative to retain control of their collections and living environment whilst attempting to create changes that improved safety, as one participant described, '*Encouragement to clear specific areas of the house, to provide basic housekeeping, finding people to buy items that he has spare.*'

TABLE 4: SURVEY RESPONDENTS: CHALLENGES THEY FACE IN SUPPORTING THOSE THEY CARE FOR

What challenges do you face in trying to support this person?	Total no.	%
I struggle to talk about their challenges in a way that's okay for them	11	58%
I struggle to balance my own needs with their needs	9	47%
I can't find support services that can help me	8	42%
I struggle to understand how I can support them	7	37%
I struggle to understand what's going on for them	5	26%
I have no one to talk to about this	5	26%
Other	3	16%

N=19

This harm minimisation approach to support is the point at which choice and dignity meet concerns about wellbeing (Koenig et al. 2010, 2014). This priority was echoed by many of the families and carers. They sought to create safety paths or routes through the house, so that those they cared for could enter and exit the house unimpeded and there were clear paths to the priority areas of function – somewhere to cook, somewhere to wash and toilet and somewhere to sleep, even if they weren't in the rooms intended for those functions. Certainly for interviewees, the safety issue was at the forefront of their thinking:

> *Mum was walking to the computer when we were on Skype and dad put his hand out so that she could step across the room. And I thought, 'Isn't that romantic? He's putting his hand out.'…And then I went, 'Why does she need a hand to walk across her lounge room when she can walk? She doesn't need a mobility aid.' And I said, 'Dad, what is on the floor that mum needs to step over? And maybe, if there isn't a path there, can we have what's called a red route, so she can just walk in front of your chair to get to the computer?' So even that, even in the spaces that they do use, it's unsafe.*

For a few families and carers, their understanding of their care recipient's behavioural and control boundaries meant that they had created small but effective ways to support their care recipient to chip away at clutter beyond the basic safety issues. However, they stressed it was a very slow, iterative process:

> ***Lindsey:*** *So you said that she has developed insights into the clutter?*
>
> ***Respondent:*** *Yes. 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.*

Those who reported making some progress with clearing items from the house had learnt that discussions around 'clearing clutter' should not be the dominant theme in their care relationship, to both avoid heightened anxiety for their care recipient and to minimise conflict:

> *Then I'll leave it for a month. I might not mention cleaning nothing…I'll go… there and we'll go for a walk…I won't go…there every week and go on about that because I want her to cherish me as a daughter and enjoy my visits. Not that, 'Oh my God. Here she comes again. What's she going to be on at me about this weekend?' So we do little bit by little bit. Still with me having the fear over her that if someone goes in there and she can't have assistance at home, they might put her away.*

Those who felt they had a positive, supportive relationship with the person they cared for described that prioritising safety and chipping away at sorting and discarding clutter needed to be part of the practical and psychosocial supports they provided, in order to improve their loved one's sense of wellness and reablement and help them to build their skills at not acquiring excessively, sorting and discarding:

> *I didn't have Buried in Treasures[18] or anything. But I was trying to help her. And so we were grouping or categorising things. This is a…Konmari rule: keep the same type of things in one place. Which is difficult in any home, but more difficult in a hoarded environment. But we had already tried to group all her fabric and remnants into plastic tubs, so she could see what there was in there by colour. And by the time we got it all out of the cupboards and various places it was like 10 stacked tubs and she was like, 'Okay. So I can never buy fabric again. That's it…This is my fabric collection for life.' So…just this last year she has been making skirts for the girls and sending them down.*

The toll on family relationships

However, such a negotiated sorting and discarding progress was not commonly reported. It was explored more by interviewees than survey respondents, over half of whom were struggling to broach the subject of their care recipient's living environment, and a third struggling to understand how to support them (see Table 4). Care recipients' lack of insight into the challenges that their living environment posed was reported as a significant barrier for families and carers being able to broach the issue without fear of disrupting their relationship. One respondent reflected, '*It is such a delicate subject, and hard to discuss given they don't think there is a problem*.' Comments such as this were commonplace:

> *I have tried to help her to be more organised, or have a tidy up, or to have a garage sale to make some money. I offer to help her sort/clean up, but she won't let even me touch anything. She gets quite anxious if I mention it too much.*

Others reported vacillating between moments when sorting and discarding were possible and others when they were completely alienated from their care recipient. Disruptions in relationships are common following attempts to 'clear up' the homes of those living with hoarding (Davidson et al. 2020; Firsten-Kaufman & Hildebrandt 2016; Neziroglu et al. 2020; Park et al. 2014; Tompkins 2011). Many families and carers reported that they had learnt this firsthand: '*Have tried to help them understand and provided rubbish skip to assist them in cleaning out some clutter. This was difficult as it was visibly obvious the stress it was causing the afflicted*.'

---

[18] See Chapter 8 for a description of the Buried in Treasures Program.

One respondent's experience typified what this anxiety looked and felt like:

> *[They] said I could help. [I] went there and we sort of started sorting things. And it was all fairly slow and painful, because you had to show [them] every single thing you picked up. I'm not a very patient person, so it nearly drove me mad. Anyway, I stepped outside and when I came back in… I said, 'Oh, let me finish this. You can go and do something else.' And [they] said, 'There's nothing else I want to do or need to do.' I think it was 'want to do'. And I thought, 'Oh, you're kidding me.' So I just sort of stayed the rest of the time that I was going to stay and fiddled around and did a bit of stuff. But I didn't go back after that.*

Literature tells us the feelings of frustration and hopelessness are often intensified if those they care for refuse help (Neziroglu et al. 2020; Park et al. 2014; Wilbram et al. 2008). Our families and carers shared a number of frustrations around this:

> *It is hard being friends with someone who is so in denial. Also we feel very angry about the detrimental impact her hoarding has had on her sons. They tried to talk to her about it...but it's always their problem...after all, it's just a bit of clutter!*

Feeling unable to address the living environments of those they care for, or frustration about there being no action, or needing to address urgent situations such as tenancy risks, house evictions or animal welfare concerns, are all common scenarios faced by families and carers. If this leads to 'forced' attempts to 'clean up', families and carers can face anger and hostility by those they are caring for.

> *Taking over, threats, blinding rows, insistence… Try all the time to help with sorting, clearing and organising stuff. Help always rejected until I take over and INSIST! It's really difficult…I'm often at the end of my tether. Can't stand the rubbish, dirt and clutter. So bloody hard.*

Most families and carers who were interviewed reported periods of having no contact with their care recipient, often due to an upset during 'negotiated' or 'forced' sorting and discarding. Incidents like the following were typical and evocative of how families and carers are navigating Chabaud's world of contradictions and paradoxes:

> ***Respondent:*** *Their hot water cylinder started to not work… So they needed to get it repaired. So they got a plumber and the plumber got in under the house and…saw stuff and they were mortified. And there was all this stuff in the way that had been leaked on and had to be chucked out. So a complex procedure is required and they would need access through this [space] that's filled with crap. So what do we have to do? There's these two people and they're old and they need to move all this stuff so that they can have hot water again… I'm like, 'I can help. I will do this.'*

I got dad to get hold of a truck, a ute, and I was like, 'Let's just put stuff into the back of it. Come on, let's do it.' I was putting stuff into the back of it and it was going okay, and then mum just went. And she started screaming. 'It's precious. It's precious' ... And I was just like, 'we have to do this. You know, you need hot water. We just got to move it.' 'No, you can't throw it out.' She's standing on the street screaming and crying… Dad's like, 'You can sell that.' I said, 'No, you can't… It has no value. I'm sorry.'

I was pretty brutal, but I also perceived the task is needing to be done. And it just kept escalating and escalating and escalating and I was trying to remain calm. And, you know, I just went crack and I turned around and I said to both of them, 'You both need to fucking shut up and fucking lift some fucking boxes and put that shit in there, or I will do something to both of you and believe me I can.' And it was nasty. But the task got done.

Lindsey: *It got done, did it?*

Respondent: *Yeah, yeah, yeah. And that's the thing. We cleared the room out. We moved all the shit and they were both really quiet for a long time. And mum'd start saying something and I'd be like 'shut up'. And I made them not talk and I made them lift boxes and I got to the end of it. Covered in dust. And I was like, phew, and it got done. And their hot water cylinder got changed over and it was okay. And later on, I apologised to both of them... And Dad was like, 'How dare you speak' and I was like, 'No. Don't put me in that position. I was trying to help you. And you didn't even have hot water.' …And then I didn't see them for a while. We didn't talk… I needed a break from them after that…*

Lindsey: *So going back to that incident, how was your mum with you after that?*

Respondent: *Took her a while to calm down. And she's really angry with me. 'It's precious. You threw out a lot of precious stuff. I hated going to the tip. I hated going to the tip shop. I hated that.' And she was really vehement about 'I hated this'. So, you know, I did things like take her out for lunch. Take her and look at art. Just like worked on trying to repair that. It's pretty good. It's fine now…but the incident itself is not brought up. I don't know that there's anything much to be gained there. It was pretty rude though. I pulled a voice from the pits of hell at that point, and I'm absolutely certain that I frightened both of them, which I do not like.*

Lindsey: *How did you feel after that happened?*

Respondent: *How did it get here? Why am I doing this? Why was this the option? Where is this anger? Because that was this unadulterated monstrosity. But it was also functional.*

This is where the burden of guilt, anger and frustration often crystalised. Most of those who participated in the survey and interviews were lone carers who were carrying that intense care burden, described by Buscher et al. (2014), Neziroglu et al. (2020) and Park et al. (2014) and articulated so clearly by our families and carers. They were very aware that if they walked away, the wellness and reablement for those they cared for was likely to decline. They carried a burden of responsibility with nowhere and often no one to call on (see Table 4).

Three-quarters of the survey respondents and most of the interviewees had not received help to support the person they care for. For nearly half of the survey respondents (see Table 4) and most of the interviewees, this was reported to be due to a lack of, or lack of knowledge about, specialist services available, as one respondent described: '*I was not aware of any support services that could assist/advise me*.' This extended to the My Aged Care process: '*When I took him through the geriatric assessment process, there was probably information available about services on offer. I was still not aware of it*.' This was often compounded by a 'Reluctance to seek help for [them] in case [they are] offended' and that overarching need to retain and respect their care recipient's privacy.

Reflecting families' tendencies to be along a spectrum of accommodation to antagonism, there were also reports of unsuccessful attempts at trying to draw in other family members to help address safety concerns:

> *Recently, I've just been trying to work on getting the house tidied up. Though my brother…is like 'No. It's not going to happen.' He's defeated by it. And I'm like, 'You and I can at least get our stuff out of there.' To which his reply is, fairly legitimately, 'They would just fill the empty spaces with more crap.' And I'm just kind of like, I can't disagree with that. The evidence suggests that this is what will occur.*

Such expressions of resignation are common amongst family members (Neziroglu et al. 2020; Tompkins 2011) and intensify the burden of responsibility and care that the 'accommodating' carer has chosen to take.

5.3 Emotional journey: a private long-term care load

The social and emotional impacts of caring for those living with hoarding have been found to be as high as the impacts for those who are actually living with hoarding disorder (Drury et al. 2014, cited in Neziroglu et al. 2020). The caregiver burden for those caring for someone with hoarding disorder is reported as similar to caring for someone with dementia, and this burden increases with age (Drury et al. 2014, cited in Neziroglu et al. 2020). Given that hoarding and dementia are both progressive conditions which can co-exist, and that CMHH can add further progressive risks, it is likely that the care burden for those supporting older people living with hoarding and/or CMHH will become increasingly amplified if the care recipient and the caregiver remain unsupported. Our families and carers described this toll well.

Many of the families and carers were "sandwich" caring. They talked about either having dependent children or a partner, in addition to the caring responsibilities for the person living with hoarding and/or CMHH. This led to expressions of guilt about not being able to spend more time with the person they cared for and exhaustion.

> ***Lindsey:*** *This is clearly a big…practical load on you… Is there an emotional load coming with that?*
>
> ***Respondent:*** *Yes and no… Well I guess it depends how much you think about it really… Like, I could spend all day thinking about how neglectful I am in some ways… That I'm not as proactive and that I'm not as present as I should be with him. But equally, I try to balance that with the fact that we've made sure that he's got all the supports that he needs around him… And then I've got a family… So I don't really think about it too much. There are times when I think, 'Jeeze, I should be doing more.'*

> *Exhausting a lot of the time, without sounding cruel to [care recipient]. Like some days, I'd like to just have a mum where we could go and sit in a nice clean house, have a cup of tea and a nice chat. It's race in the door, scull a cup of tea, race outside, brush cut and [animal management tasks], cleaning up paths, digging out the septic tank. Doing all the jobs that normally you would ring a tradie and they'd come and do. But because we can't have people there, I've become the plumber. It's amazing what I can do.*

> *I'm often at the end of my tether… It's so bloody hard.*

It is important to note that not all perceived impacts were negative. Nearly half of survey respondents and interviewees articulated positive elements to their relationship with the people they cared for, and for most respondents there was a clear underlying love, affection and commitment:

> *I've found some really old cards that must have been given to them…It's nice to have those things to keep, you know.*

> ***Lindsey:*** *She sounds amazing, your mum.*
>
> ***Respondent:*** *She's awesome. She's awesome. She's great, and I think that's part of the problem of my work ... She doesn't like me talking to her about my hoarder work you know? She just doesn't like the word hoarder and the stigmatising of it. But it's like, that's why I'm doing it, because I don't like someone as awesome as her being stigmatised.*

> *Now I really, really struggle and I get angry. And then I get angry at myself and upset with myself that I could be angry at my dear mum, because she's a beautiful person. Like, I could not say nothing nasty against my mum. You know, she's always been there for me. She's always been there for my kids. She's just a beautiful person… And she's going to lose that independence. I hope she never has to go to a home. Every year that goes by I'm thankful for, one, that she's with me. And two, that my kids are growing too, so if something happens with mum tomorrow, I'll nearly be in a position where I can become a full time carer.*

> *I would love nothing more than to see her tidy her house up because she'd just feel like a different person… I've even dreamt that she's tidied the house up.*

Worried about environmental, personal and social risks

There was clearly an underlying concern for families and carers about the immediate environmental risks posed by their care recipient's living environment. These included concerns about trip hazards (What if they fall? How would the ambulance reach them?) and fire hazards (What if there was a fire? How would emergency services get to them inside the home?) (See Table 5):

> *Prior to the death of this person's partner 3 years ago, ambulance officers advised that they did not have appropriate access to the house for patient transfer.*

> *I'm concerned that if he collapses or something, he may not be found for days as I am the only one who checks on him.*

> *Well she's probably going to trip over something and break her neck. Yeah, I mean you can get up and down the stairs I suppose. They've shoved things to the side so you can get up and down the stairs. But it's really not a suitable house…like trip hazard stuff everywhere. And…if the toaster got some paper near it could catch fire. I don't know. Doesn't bear thinking about, does it?*

> *…the thing I keep being amazed when they do the flash inspection, because it really must be getting close to a fire hazard. I don't know. And he's actually quite concerned about fires because he doesn't want his books, his own writing material burnt.*

TABLE 5: SURVEY RESPONDENTS: PERCEIVED NEGATIVE IMPACTS OF CARE RECIPIENTS' LIVING ENVIRONMENT

What negative impacts do you think their living environment has for them?	Total no.
They are unable to use their living spaces for their intended purpose, due to clutter	15
They are at risk of tripping and falling due to their living environment	13
It has isolated them, or further isolated them	11
It has had negative impacts for their physical health	11
It has had negative impacts for their mental health	9
They are under the threat of eviction from their home	2
I don't think their living environment has any negative impacts for them	1
Other negative impacts	1

N=19

Another common question was whether the house was structurally safe and whether hot water, gas and electricity systems were safe and working. If repairs were needed, there were frequent concerns about allowing repair workers into the property and ability to access fixtures and fittings. There were also concerns about whether their housing situation was stable, especially in rental properties:

> *He's lucky in his landlord…I mean, he's probably quite a good tenant, actually, because he would be paying his rent. Yeah. He's quiet. Well, actually he could be an annoying tenant in some ways in that he…doesn't like noise around, but I mean, I think probably he's quite a good tenant. The owner hasn't put up the rent much… But I suppose that's one thing that does worry me, and it worries [him] periodically, is if he has to move.*

At least half of the survey respondents and all of the interviewees flagged concerns over the care recipient's wellbeing (see Table 5). These concerns covered areas such as mental health, whether they were taking medications that had been prescribed, quality of nutrition and whether the kitchen area functioned sufficiently for cooking, psychosocial wellbeing, and the wellbeing of other family members who lived with them:

> *I don't know how well they eat. I don't know about that. There's a lot of old food. Mum doesn't throw food out, the cupboards are just layers of old jars and things like that. There are bench tops that are slowly being covered with things like that… She likes bread. Loves fresh bread…But I perceive her as being largely by herself. I don't know, is the real answer to that. I don't know. She seems to be generally tired, stressed, impatient and unhappy, and she complains about Dad's behaviour a lot.*

> *I think my concern is always isolation for him more than anything. I think there is, you know, that constant struggle, and that's where I guess my guilt probably comes in occasionally, which is that I could be more proactive in arranging for him to come down here or going to get him or whatever.*

> *Mum has lived in her unit for 27 years. In that time we (as a family of 5) have never been able to visit her all at the same time, or have a meal with her, as there just isn't room to move or sit down.*

> *He can't get past initial stages of new relationships because he can't take anyone home.*

Other concerns were around how they were doing financially:

> *The hoarding's got worse...I suppose I find it very hard now to go and visit him because I can't cope with the hoarding… And he wouldn't see it as hoarding at all. But this room, I'd come in here and he'd have one chair he could sit on and the other chair that's there would be covered with stuff. And so he will move it for me… So what he does, he buys books and, A, he can't really afford it. And B…his money is going to come to an end pretty soon. And really when it comes to an end, it's not going to be good because obviously his money allows him luxuries like buying the books.*

> *All the email was… directed to me. And part of the reason for that was because he was [buying a lot of] stuff. When I took over looking after his finances. He had like six grand in debts to places… , where he'd just get something and they'd continually market to him. And I told them probably five times to stop sending stuff to him because of his condition, and they just kept doing it. So I ended up getting everything redirected.*

This cacophony of concerns could be summarised by a general worry about their care recipient's quality of life and how that might diminish as they continued to age:

> ***Lindsey:*** *So if nothing changes for them, what's life going to be like for them as they age?*
>
> ***Respondent:*** *Not very comfortable. There's an oven that needs repairing…and it's like, is there electricity in there and the electricity hasn't been fixed or things like that. So there's a part of me that's slightly worried, that's to some extent worried about fires. And the house, it would go up like a frigging tinderbox. Good way of getting rid of all the stuff. Yeah, I'm worried about them getting stuck in it or trapped in it.*
>
> *There's a lot of stairs in there, but I think they're actually using less and less of the place. There have been some repairs and things done, but basically there's been no work or maintenance done on it the entire time. So there's a lot of stuff which may not work. But once again, hard to say, not allowed in the house.*

> *I think their quality of life is pretty diminished by just neglect to living standards.*

Disrupted family relationships and feelings of hopelessness

It is common for parents living with hoarding disorder to have poor relationships with their families (Neziroglu et al. 2020; Park et al. 2014; Tompkins 2011). They have been reported to be 'less emotionally available' and tend to use objects or animals to regulate their emotions (Rees et al. 2017, cited in Neziroglu et al. 2020). Some of our families observed this:

> *Because mum perceives…a mess, but I don't know that she perceives it as as much of a mess as it is. And she sees value in history and stories in itself. And it's weird because you know, she doesn't spend much time with her grandkids, and has all this stuff and these memories that seem to stand in the way of that ever occurring.*

> *They can't be social or have friends over, and they can't have our family or their grandchildren over.*

> *No one enters the home apart from myself and my daughter and my son and my husband's allowed in now. For a long time, it was a cup of tea out in the backyard. But he's allowed to come in now. There's grandkids to my marriage. They're allowed in but only to the kitchen and bathroom. Mum loves having them there, and would do anything with them, but she's always unsure of things in case they tell their parents how she lives. Mum's really embarrassed about that. But kids are accepting.*

In response to this, adult children of those living with hoarding tend to have heightened responses to their parents' behaviour – from frustration and anger to rejection (Neziroglu et al. 2020; Tomkins 2011). Such emotions were present amongst the families and carers participating in the Treasured Lives project, as described above. Most expressed a sense of hopelessness that nothing had helped the person they cared for to address their challenges with hoarding and/or CMHH, emotionally or practically.

Families commonly reported that they'd tried many different approaches, but in vain:

> *For so long in so many different ways! Always encouraging, educational & supportive, but rarely effective.*

> *On an emotional level, he has felt heard and understood (he has said this). On a physical, practical level, not much [has changed]!*

Families and carers were prone to reporting that they felt the wellness and reablement of those they cared for was in decline due to increasing age and decreasing physical and mental capacities, causing more risk for them within their living environment. They were trying to hold back a tidal wave of challenges:

> *They're…worse off than they were 20 years ago… 20 years ago I was worried that that was going to stop me from having a partner and children. I thought I was just going to have to stay there my whole life trying to fix them and pushing shit uphill forever… And in my own therapy, she encouraged me to get out and have my own life. And we have that now. And a lot of their quality of life comes from interacting with my life and interacting with their grandchildren.*

A number of studies have described families and carers' feelings of hopelessness and frustration. Those who participated in our project commonly offered feelings like '*I feel like I'm drowning*'. Many talked about the unlikelihood of there ever being a resolution to the living conditions of those they cared for. This tended to be for a couple of reasons, one of which was gendered. Firstly, and most prominently, families and carers reflected on the entrenched nature of the care recipient's mental health, attachment to items, control of their environment and own feelings of hopelessness to do anything about it:

> *She doesn't think there is anything that can't be solved with a bit of a clean out/a bit of time. She doesn't realise/or can't do anything about the problem. It seems part denial, part an anxious/mental issue.*
>
> *She used to say, 'Oh, I've got to sort through things … So she must have been aware at some point that you didn't need to have all this stuff … She'd go off and sit on the end of the bed … She'd keep letter I'd written … years ago, greetings cards from years ago. And she'd pull them out and go through them and then put them back somewhere else.*

Secondly, there were observations about there being a generational culture for older men not having the capacity to sort and to do housework:

> *One of the things with mum is like … there is some shame there. There is some shame with Dad as well. 'We can't have…anyone in the house.' To which I've gone, 'Well tidy up. Then you'll be able to have people over at the house.' But he can't actually do that. Because he's never done it. Never done a damn thing. As I look back with the position where I am now. He never changed my nappy … He just didn't do that. He was gob-smacked when he found out I changed both my kids.*
>
> *My mum was like, 'Oh, you're so good taking part.' And I'm like, 'Well it needs doing … I think it's more of a function of that. But thanks. That's nice of you to say that.'*
>
> *It's like [my partner's] studying and we got to share the housework or it doesn't get done. Housework's about, like holy crap, it's not about whose turn it is. It's just friggin' come and do it … But she's left to do absolutely everything and he retired and he does fucking nothing and it fucking shits me.*

Supports

Our families and carers were holding a significant number of risks and responsibilities concerning those they cared for, others they cared for and for themselves. As Neziroglu et al. (2020) state, '*It is important that the adult child of people with hoarding disorder to view themselves with empathy.*' However, two-thirds of survey respondents and half of interviewees had not sought support for themselves to manage their relationship with the person they cared for, or the impacts:

> *I haven't received any help as I haven't needed any carer support. Mum receives all the help she needs. I am confident to navigate services as I work in the sector.*

This was often because supports were not available:

> *Clinical reports relating to his 'cognitive decline'…have been supported by documents that outline ways to manage the decline in him... All very practical and necessary, but not supportive of the emotional challenges faced by myself. My own expectations that I manage everything perfectly…*

Of those who had accessed support, one to one counselling and therapy was the most common form of formal support, and a few family members and carers had sought out specialist training on hoarding and/or CMHH.

> *I have had professional counselling about the impact her hoarding has on me. But they have made me realise there is nothing physical I can do. Only mentally (how I react to hoarding)…*

There is a body of literature that describes how adult children of hoarders often wrestle with their own tendencies to acquire, and challenges with sorting and discarding and their impacts (Chabaud 2020; Davidson et al. 2020; Garrett 2020; Neziroglu et al. 2020). There was a small cluster of family members participating in Treasured Lives who had deliberately undertaken some significant personal work through a combination of therapy and self-reflection about their own relationship with attachment to items, and behaviours that they perceived could inhibit their abilities to positively address challenges in themselves and those they cared for. They drew on different frameworks and perspectives for their self-development, but their resolve to engage in this work was strikingly similar.

> *I sound glib, but one of the reasons I'm here today is because I've been to therapists and stuff like that. And this one keeps coming up. It's a thing. It's not just something I've got to nut out and have a realisation of and my life will be better. It's physical work that needs to be done. I realised it was one of the motivations for me to look after my health and go through a bunch of things. So I'm physically able to do it. Cause I remember, I go back to this day that I told you about, and how mentally and physically exhausted I was. And that was one section of the house.*

> *If I just carry it [hoarding behaviours] 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.*

Literature tells us that families' and carers' frustration can often trigger a desire to understand more about the reasons for their care recipient's behaviour in order to develop an effective way to support them (Neziroglu et al. 2020; Wilbram et al. 2008). Ultimately, this may be to gain some sense of control or agency (Neziroglu et al. 2020; Tompkins 2011). A small number of families and carers had sought out specialist training around understanding hoarding and CMHH and had found this useful for providing context for their support. It is worth pointing out that none of these training courses were based in Tasmania.

Informally, partners, other family members and friends were most often mentioned as sources of support. Common responses were, '*My friends give me the support and let me vent*'. A smaller number chose art-based forms of expression to work through elements of their experiences. But it was clear that this support often came with concern, which was left unaddressed or unresolved by the frontline carer or those they turned to for their support:

> *My family worry about how visiting her affects me.*
>
> *I sometimes talk to our family interstate but they either empathise but are not helpful or they increase the stress levels for both of us.*

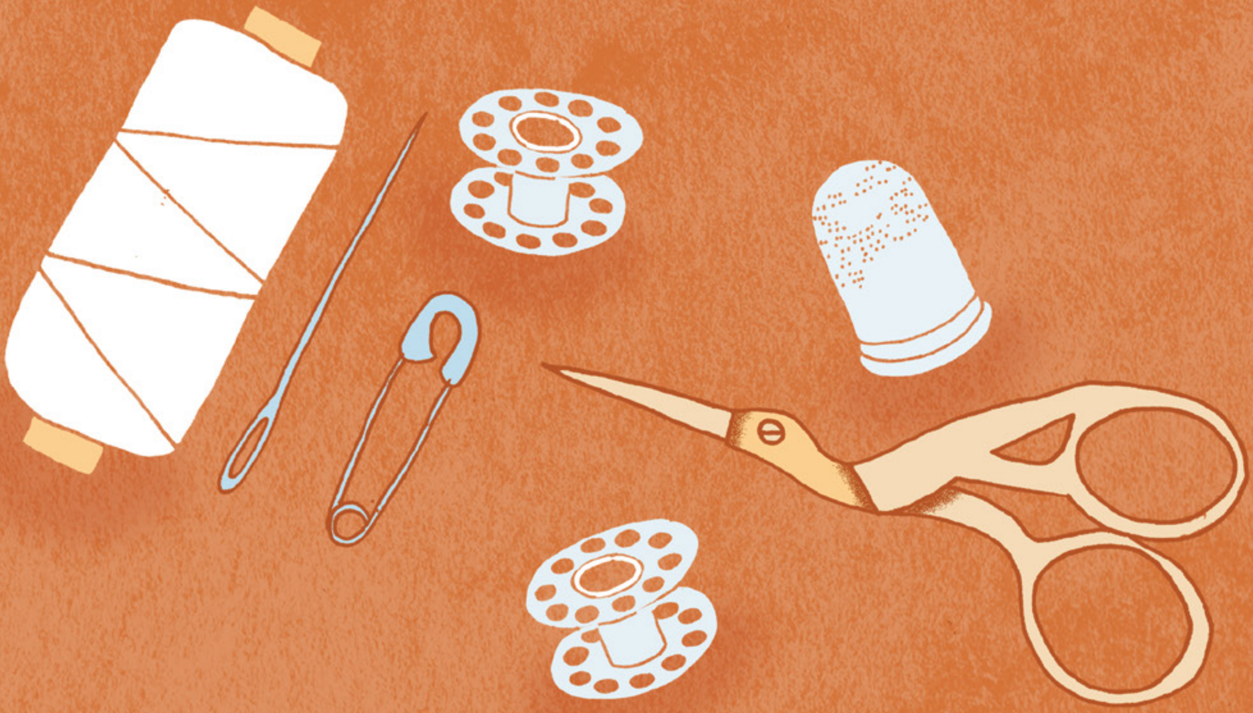
Families and carers reported that what had helped when they'd sought support was knowing that '*Other people feel the same way*' and acceptance of the situation and their sense of agency (or lack of) within that:

> *Counsellors have made me realise that it is not my problem (at least until I have to get rid of it all), therefore there isn't much I can do about it except try to not let it "get to me!"*

It was clear that families and carers of older Tasmanians living with hoarding and/or CMHH were holding a significant body of relational, practical and emotional responsibilities, mostly unsupported and mainly invisible from the service landscape.

CHAPTER SIX

Families' and carers' reflections on the experiences of those they care for



> *As a child, the space that held my father's accumulation was like an island of lost treasure to discover. But now, in adulthood, I have come to think of it as a sinking pirate ship, drawn under water by the weight of its own precious cargo. And what has become even more clear: my father is going under with it, clinging to his loot…The task of managing his things exhausts him mentally, emotionally and physically and takes him away from engaging with his family and enjoying life. Sorting and deciding what to do with each item is painful for him.*

ANONYMOUS 2020

> ***Lindsey:*** *Is there any other advice you'd give about being respectful when supporting or working with someone who's living with hoarding?*
>
> ***Respondent:*** *Don't take over. What may seem like a piece of paper to you, that might be 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. Go through stuff with them, slowly. And ongoing. It's not a quick fix. It will never be a quick fix…I don't know if you can retrain the brain or anything like that, or you've just got to live with it and try to keep the environment safe.*

In Anglicare Tasmania's Social Action and Research Centre (SARC), we believe in taking a phenomenological perspective to developing social policy. We foreground understanding issues from the perspectives of those who live with and through the structural disadvantage and vulnerabilities we are examining and we ground our analysis and recommendations to address those structural barriers based on their experiences. Two central perspectives are of families and carers and, of course, of those living with hoarding and/or CMHH.[19]

It is unusual for SARC to consider 'second hand accounts' of those living with the issue we are focused on. But, understanding hoarding and CMHH is complex. There is more than one group of stakeholders with lived experience and who are impacted by the issues. For this project, we are building up our understanding of the many layers and issues over phases. During Phase 1, we asked families and carers to tell us their reflections on the experiences of those they care for. We do not want to build our assumptions about older Tasmanians living with hoarding and/or CMHH solely based on the accounts of families and carers, but it is useful to understand what families and carers perceive about those they care for (Tolin et al. 2010). Later we will compare their reflections with others – those provided by service providers and direct accounts from older Tasmanians living with hoarding and/or CMHH.

Here we offer some of the reflections provided by families and carers about those they care for.

---

[19] We are aware of the important perspective of neighbours and communities in matters relating to hoarding and/or CMHH, particularly in addressing stigma and responses to neighbourhood safety. We will begin to explore some of these issues in Phase 2 of Treasured Lives.

6.1 Perceptions about the 'stories' of those they care for

The profiles of care recipients as understood by families and carers were typical of those reported internationally for older people living with hoarding and/or CMHH (Lee et al. 2017; Guinane et al. 2019; Roane et al. 2017) (Also see Figures 7 to 9). This included socio-cultural reports of family histories embodying hoarding behaviour and CMHH, traumatic experiences and/or a critical incident of grief or loss that may have triggered an attachment to items as a form of comfort. They also described health-related elements to their care recipients' stories – neurocognitive disorders, including dementia, mental ill health such as depression and anxiety, alcohol use and challenges with physical capabilities.

To fit with the complex nature of hoarding and/or CMHH, there was rarely *one* element to the reported stories – families usually speculated that there was a mixture of socio-cultural and health-related experiences that had led to the person they cared for having challenges with hoarding and/or CMHH. And, although there were common elements across many of those stories, no two stories were the same.

These are speculated 'rationales'. We had no way to check or validate these stories. Nor did we want to. As we have stated, for us there is a validity to the stories as the means by which families and carers understand what is happening for the person they care for. These interpretations drive the relational, practical and emotional experiences described in Chapter 5.

Also important to flag here is that, although many of these stories included elements of health challenges, there were no families and carers who cared for an older person who had been officially diagnosed as having hoarding disorder. Furthermore, very few mentioned a formal diagnosis for neuro-cognitive disorders and mental health challenges.

Socio-cultural stories

THEIR FAMILY HISTORIES

A few families and carers described family histories involving intergenerational hoarding behaviour. Amongst these stories, there was a sense of it being either a "genetic" trait in the family, or having been learnt as the behavioural norm:

> *Genetics, same as his mother and dementia, cognitive impairment.*

> *Just been going on for so long, it was totally normal for them. Even after they'd filled the house, the shed, a shipping container and another large shed.*

> *In his early 20s … he was living independently…but…he was starting that thing with the newspapers, piling the newspapers up. Which wasn't a problem because he didn't own much. He was in quite a spacious thing.*

> *But you'd go there and there'd be these piles of newspapers on the floor. And I mean, in some ways, you know…we lived in a house with lots of books, lots of newspapers when we were a kid. It was a good way to grow up. And, you know, my father would have piles of newspapers…I suppose probably when he was younger he'd go through them more. But now they just continue to stack up…*

> *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.*

POVERTY AND TRAUMA

There were many accounts of a cultural logic for collecting, keeping and saving items – mainly referencing poverty and a post-World War II mentality of "make do and mend" and "waste not, want not"; what we might now refer to as a culture of recycling and repair. But this socio-economic and cultural grounding was usually coupled with another backstory, of trauma or a critical incident that had triggered an intensity in this behaviour:

> *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'.*

> *For dad, he had a very traumatic childhood and he lost his mother to suicide... So, I feel like that is – if you're looking for the core, you know, trauma thing. Which might not be for everyone, but in our family I guess, there's a – my grandfather was a very violent alcoholic, from what I understand… But then, that sounds incredibly common. You talk to people, and that's generational. That was happening for the men who came back from the war and had nowhere to put their aggression... I'm not excusing it, but that's not a unique story, from what I understand.*

> *She was brought up in a very poor family environment with an abusive father. Now she suffers extreme night horrors and I'll go in to her and she will tell me stuff that just destroys you. I never knew a human being could do that to another human being. But it was accepted when mum was a child as discipline.*
>
> *So um, I think that's where a lot of it is just control. And I think that's why dad might have just let her go. Because like I said their love of each other.*

> *There is a vague kind of awareness of some sort of intergenerational trauma or something like that, that comes, you know. Like my grandfather…was involved in combat… He came back. He married my grandmother. She left him. I'm not entirely sure of the mechanics of this. Never been told. But…she brought dad up on her own, worked full time. He's on his own a lot. Grandfather was still around. Used to sort of like, you know, was always harassing him for being fat and unhealthy… Dad'd tell me about this quite jokingly. And I was like, wow, that's fucking horrible.*

GRIEF/LOSS

Many families and carers speculated that a critical incident may have triggered a change in the behaviour of the person they cared for, such as unemployment and/or low income, or losing a child or other loved one such as a partner or sibling. For others, it resulted in a ramping up of existing behaviour. All were perceived as life events that changed the way they referenced the world around them and how they might draw comfort from it"

> *Needs things to replace the people who are not around anymore.*

> *20 years ago, unemployment*

> *They began around 30 years ago...they had a difficult time financially. It has become worse since the death of their son.*

> *I think in my mum's case, hoarding is her way of protecting herself against the future. E.g., she has plenty of food stored, newspapers to read, personal mementos, items of significance (to her) surrounding her, and familiar and sentimental items close by. She has had a lot of "losses" in her life, and I think this is her way of compensating for that.*

> *[She] had a baby who lived a few days or a week and then she died… If it's triggered by something traumatic, could have been that.*
>
> *As communication with his wife faltered, the only power he had was to accumulate goods. However, after she left the marital home there was no one to keep him in check and the collecting and hoarding became much worse.*
>
> *She was sent down here quite young and lived with her grandmother and grandfather that she loved very much… So she wasn't actually brought up by her parents… My parents were married quite young. I was an accident… Classic.*
>
> *She got postnatal depression… I'm 90 percent sure everything was pretty tidy until that... By the time that child got to kindergarten age it must have been pretty bad, because she said, 'Oh, when he starts school all day, I'll clean the house up.' I remember those words, word for word. It's got worse.*

Health-related experiences

NEURO-COGNITIVE DISORDERS

Conditions that lead to disordered thinking were mentioned as a contributing factor by a few families, who speculated that such disorders were likely to have contributed to hoarding behaviours and/or CMHH. Specific disorders included schizophrenia and dementia.

A couple of family members described how the transition to residential aged care when those they cared for had developed dementia either triggered or amplified hoarding behaviours. This is an issue we will further explore in Phase 2 of Treasured Lives:

> *I feel it is a combination of something she has always liked to do and a component of her schizophrenia. Doctors are currently changing her medication as it could also be a side effect of her medication but I don't feel this will be the case, only time will tell.*

> *He was diagnosed when he was in his early 20s with schizophrenia, but probably, oh I don't know really. I suspect he's bipolar. He hasn't been diagnosed as being bipolar yet. And obviously…[you] can get a different diagnosis every five minutes, can't you, depending on who you see and stuff like that. But to me, I'd say he's probably is bipolar… Of course, he thinks he doesn't have a problem, which is classic. He doesn't take any medication… He has very disordered thinking, right. I mean, that's terrible because he's a very intelligent person.*

> *[They have shown hoarding tendencies] since adolescence. Developed in adult possibly in response to a chronic medical issue which keeps them housebound from time to time*

> *Approx. 20 years ago age 57-ish, predated vascular dementia by around 5 years. Same trajectory as his mother.*

> *Mum being court ordered into supported accommodation 10 years ago had the biggest positive impact of all. As this was the day she finally started to receive the treatment and care she needs. She was a risk to others and herself in the community so being court ordered into care truly was a blessing. The hoarding commenced after that possibly because she was now in an environment where her food and shelter was being provided, bills paid and finances managed. Which then allowed her to go out, shop and hoard things. But in the big scheme of things, I feel this was still the best outcome.*

COMORBIDITIES: MENTAL HEALTH AND ALCOHOL USE

There were frequent mentions of comorbid mental ill health, particularly depression. These families and carers also flagged alcohol use by their care recipients:

> ***Respondent:*** *And Dad got some form of depression.*
>
> ***Lindsey:*** *Do you know when that happened, when he became depressed?*
>
> ***Respondent:*** *Mid 40s and he retired…and never did another thing. And he's been basically drunk since then. Yeah.*
>
> ***Lindsey:*** *And…has his living environment become more cluttered since he was depressed?*
>
> ***Respondent:*** *Yeah. Yeah. He's also a man of his generation and would do no housework at all. Like none. You know, mum had to do everything.*

> *He got quite sick about three years ago. Yeah. And it was to do with his alcoholism. And he went to hospital for a period of time. And at that stage we weren't even. Well, the doctors said that they never thought that he would recover or wouldn't come home and that they thought he was going to go into an aged care facility. So…I went…there at that stage, because he'd sort of distanced himself for about two years. He just wasn't really engaging with anyone in the family very much… And that was probably to do with some of his drinking. I don't know. He has early onset dementia, which is probably from the alcohol as well, although that is hereditary in our family. We've got a history of dementia. But when I went up at the time, when he went into hospital and then it became apparent that it had just gone out of control.*

Physical capacities

And, lastly, given we were focused on an older demographic, a number of families raised concerns around how physical capacities and declining mobility interacted with hoarding and CMHH:

> ***Lindsey:*** *Is she storing [items] or accessing them?*
>
> ***Respondent:*** *Storing. The rooms are inaccessible now by mum, who's elderly. We climb over the top of things to pull stuff out occasionally. But I got rid of a lot of stuff.*

This will be explored further in Chapter 7.

6.2 Perceptions about their challenges with hoarding behaviours and maintaining a healthy home

Challenges with hoarding behaviours

Nearly all (95%) of the families and carers who participated in the survey and all of those who were interviewed reported discarding items was a challenge for those they care for (See Table 6), typified by comments like, '*He is paralysed and cannot throw anything away*'. The vast majority (84%) of survey respondents described the level of difficulty with discarding experienced by those they care for as 'extremely difficult' or 'severe' based on their last visit (see Figure 22).

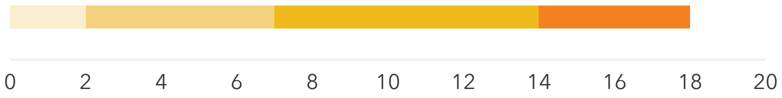
TABLE 6: SURVEY RESPONDENTS: REFLECTIONS ON THE TYPES OF CHALLENGES RELATED TO HOARDING CARE RECIPIENTS HAD

What sort of challenges related to hoarding would you say they have?	Total no.	% of survey respondents
They have challenges with discarding items (for example, they find it difficult to throw things away, even if they are not using them, or if they seem of little value to others)	18	95
They acquire a lot of items (for example, they keep buying or getting more things)	14	74
They have challenges with sorting items (for example, things in their home are not organised in a way which makes them easy them use)	13	68
Other challenges related to clutter or collecting	9	47
They do not have challenges related to hoarding	0	0

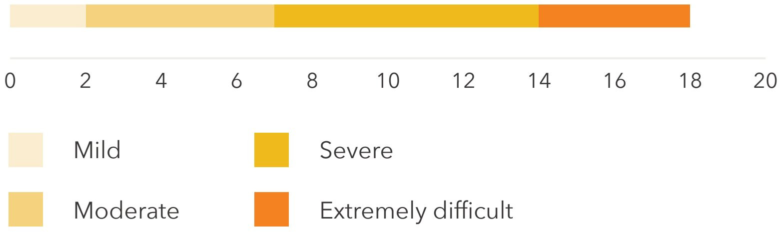
N=19

FIGURE 22: SURVEY RESPONDENTS' OBSERVATIONS ON THEIR LAST VISIT ABOUT THE CHALLENGES FACED BY CARE RECIPIENTS

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?



To what extent do they have difficulty discarding (or recycling, selling, giving away) ordinary things that other people would get rid of?



Acquiring items and sorting items were also reported as challenges for the care recipients of the survey respondents and interviewees (see Figure 22). Around half of the survey respondents describing these challenges as 'extremely difficult' or 'severe' based on their last visit (see Figure 22):

> *Buys stuff off eBay that he doesn't even unpack.*

> *When he was in hospital, he'd get like a jelly cup…He'd eat the jelly and then he'd wash out the cup and put it in his cupboard next to the bed. And when he was ready to go, he had this massive stack of goodies, like, is it lyrebirds that collect…? ...And I'd say, 'Mate, what are you doing with all of that shit?' And he goes, 'Oh, you never know when it could come in handy.' And I'm like, 'It's never going to come in handy. Just throw it out.' 'No, no, I've got to take that…It's good stuff.' …But, you know, you win if you pick your battles.*

Challenges with maintaining a healthy home

The majority of survey respondents explained that there was often dirt or grime covering surfaces in the home, and there was often mouldy or rotten food. A high proportion of survey respondents also described there often being insects and/or insect droppings visible in the home, cobwebs, dirty clothes lying around and/or the person was wearing dirty clothes, and a strong odour in parts of / all of the home (see Table 7).

Typical observations included:

> *The place was an absolute mess. Like, apart from all of the pets and all the stuff…He'd asked…one of my uncles…whether…he could provide him with like some wallaby meat to feed the dogs, I guess. But it was just left…like hanging in his laundry and there were maggots. The smell was atrocious. So I'll never forget having to go in there when all that happened, because it was just so far gone…Like he always maintained his garden…But he's let all that go at that time because he got quite sick because of his alcoholism, I think. And maybe because of his dementia was getting worse…But yeah, we just had to be quite ruthless.*

> *Because of the piles of newspapers, magazines and craft items everywhere, it is impossible to dust or vacuum properly. Windows cannot be reached to be opened. Cobwebs are everywhere. The rubbish bin always smells.*

> *The house was oddly clean, a surprising lack of vermin. They hoarded mostly clean rubbish and bought multiples of non-perishable food (14 jars of honey). However, after Pa died and we started cleaning the house, I found incontinence pads in the bed. Nana had gone into aged care some months before and they'd been left there all that time. I also found faeces behind the sofa cushion. Pa was clearly not coping with Nana's dementia. We found a small amount of rotten food, but it was mostly canned or sealed food they hoarded. Some cans were so old, they'd nearly rusted through.*

TABLE 7: SURVEY RESPONDENTS: PERCEPTIONS OF THE TYPE OF CHALLENGES CARE RECIPIENTS HAD WITH MAINTAINING A HEALTHY HOME

What sort of challenges related to maintaining a healthy home would you say they have?	Total no.
There is often dirt or grime covering surfaces in the home	12
There is often mouldy or rotten food in the home	11
There are often insects and/or insect droppings visible in the home, or cobwebs	8
There are often dirty clothes lying around and/or the person is wearing dirty clothes	8
There is often strong odour in parts of / all of the home	8
There are often unwashed dishes	7
There are often dirty bed coverings	6
There is structural damage to the home (for example, walls, ceilings, floors, beams, surfaces)	5
There is often water left standing in places (for example, the bathroom, kitchen, on floors)	4
Human or animal waste or vomit is present in the home	3
There is considerable, noticeable mildew/mould in the home	3
There are often contaminated objects over the floors or surfaces in the home (such as tissues, hair, sanitary products)	2
Other challenges related to maintaining a healthy home	2
They do not have challenges related to maintaining a healthy home	2

N=19

It is important to note here that not all living environments were considered to have sanitary challenges. There were a number of reports of hoarding behaviour that, in the view of families and carers, did not lead to CMHH. This was usually reported to be because the clutter was contained within certain areas of the house, or ensuring that sanitation was maintained within key areas:

> *As we both have Home Care Packages, my husband level 2 and me level 4, our home is kept quite clean and tidy by our handyman. Except for the hoarding room which is disgusting.*

> *I don't class it as squalor. Like the washing up is done. The toilet's clean. You don't check a cup before you drink out of it. There's no vermin. There's no filth on the floor… It's very dusty. But to me, I don't class her as squalor. It's not dirty.*

> *Mum had always kept a boundary. Bins out. Toilets, laundries, all that stuff of self-care – we never had squalor… And people probably look at the front and they're like, 'Oh God. Are they keeping their poos and wees in there?' You know? You don't know…*

6.3 Nature of collections

Every environment and collection of items or animals will be unique, with its own features and its own logic. Understanding this logic can help understand the attachments people have to their collections (Chou et al. 2018; Danet & Secouet 2018). We asked families to describe to us the types of items or animals the person they cared for collected.

There was a great deal of diversity in the items and animals collected. They could be broadly grouped into four categories (see Figure 23) – sentimental collections such as family items and memorabilia; household items such as newspapers, books, furniture, containers and tools; collections revolving around interests and hobbies, such as purposeful collections, and craft and DIY items pertaining to activities that were either actively pursued, discontinued, or never begun; and animals. Below we describe these through the lens of families and carers. They clearly show the need to understand the context and 'rationale' for each person's challenges and collections, in order to design a sensitive and multi-layered support response.

FIGURE 23: TYPES OF COLLECTIONS REPORTED BY FAMILIES AND CARERS

TYPES OF COLLECTIONS

Animals

- Birds
- Dogs
- Guinea pigs

Hobbies

- Purposeful collections (*clocks, watches, lamps, cards, spoons, brass ornaments, china ornaments*)
- Books
- Active and dormant building/craft projects (*tools, cars and parts, sewing, quilting, plants, fishing equipment, rope*)

Sentimental items

- Family items (*clothes, hats, photos, jewelry, toys, children's drawings, medals*)
- Work-related items (*notebooks, journals, manuals, typewriters, computers*)

Household items

- Newspapers
- Furniture and household items for future use (*bags, groceries, biscuit tins, toiletries, kitchen appliances, bathroom fixtures and fittings, mattresses*)
- Alcohol

Sentimental collections

A significant amount of items that were described as being stored related to deceased relatives. Families and carers described that these items had either been inherited or gathered by the care recipient. This ranged from clothes and books to pieces of family furniture. On the theme of preserving family memories, photos, cards, children's drawings and toys were also regularly mentioned:

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

> *A lot is related to childhood memories or activities. The house is full to the ceiling including books, magazines piles against walls and on tables and other surfaces. The yard is also full.*

> *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.*

Given the lament amongst some families and carers about an inability to relate to the present family (see Chapter 5), this was reflected on as a point of sadness and for some frustration, particularly where there was perceived to be no clear order to how such precious items were being stored:

> *Every cupboard, wardrobe drawer etc. is chockers… Nothing is catalogued, itemised or ever even looked at. We live in a tiny cottage with very limited storage space. Collections of coins, bank notes, medals, work papers from 30 years ago, 120 year old piano music from his mother.*

> *He has all of my grandmother's clothing… None of this is stored particularly well. Silverfish, moths.*

However, most families and carers could empathise with why their care recipient would want to preserve family memories, and reflected on why such items could be difficult for their care recipients to part with:

> *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.*

Interestingly, there were a couple of reports that collecting sentimental items continued into aged care facilities. But with comorbid dementia, it was not clear whether such continued collecting was due to sentimental reasons or simply 'habit':

> *At the [aged care] home, she'll acquire items from up in the communal lounge room – packs of cards or a photo of someone we've never seen in our life.*

Hobbies

These hobby-based collections tended to be gendered. Masculine collections were reported as items such as tools, cars and trucks, mechanical and electronic items. Feminine collections were reported to be items such as sewing and craft equipment. Books were an exception to this, and a very common part of people's collections.

Specific collections such as medals, ornaments and clocks were reported, some ordered and displayed, others not so ordered:

> *[Their collections started] 30 years ago. Started with collecting magazines of interest and electronics.*
>
> *He turned his attention to collecting spoons. Yeah. And then…he started making like spoon decoration boards and then putting them all over his walls and everything. 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. But it was to the extreme. Where he would literally like every part of his house would be covered.*

There was also observations about aspirations for craft and DIY projects that were not implemented. These varied from kitchen renovations through to sewing projects. The theme with all of them was the collection of excess equipment (kitchen sinks, tools, pieces of rope or wood) that was not used:

> *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.*

One participant reflected on how seeing similar items to those her father collects in a different context had prompted her to consider the importance of challenges with sorting and the impacts that had had for her family:

> *[This farmer] looked after a property for 20 years and he's got…this stuff that he knows he might need, and he's the kind of guy who's actually out there doing it. Ten minutes later, I saw him. He had his work pants on. He's in his 60s or 70s or something. He's up and down the [land] doing a burn, doing this, and he's got all the different types of wood. Big woods over there…all the little wood that you might do a little detail on a window or something is all there. I'm like, 'Where have I seen this before?' And I'm like, 'But this is his men's shed.' We had this stuff in our bathroom or all over our house, in our house. My dad is making my mum live in a men's shed. I would look at all that stuff in our house and go, 'This is crap.' When you see it in the men's shed, you go, 'Okay. It's not my things. It's not my personal interest. It's not my, you know, magazine materials or glue or glitter or whatever I like doing, because I like femme things.' His masc. things that he likes doing I label crap, but if it was in the context of the garage it would be a valid thing to keep, if not a bit excessive or whatever.*

One of the crucial issues reflected on by families and carers about these collections was the sense of unfulfilled aspirations. Items were acquired with an intention of doing something, but the goal was never achieved. This was often compounded by feeling overwhelmed by the volume of items with which they were surrounded. Families and carers commented that their care recipients had a sense that they could not spare time for the hobbies because there was so much other "work" to do. This concept that those they cared for had a 'busy mind' was common – saying they were 'too busy' or 'had so much to do', while families observed that the tasks they said they were busy doing were not getting done.

However, there were other perspectives in households where more than one person had challenges. This could lead to a 'dynamic stopping energy' as adeptly described here:

> *I would say that there's a thing that they can't agree on what to do in terms of the next, 'Okay. So what should the cooktop look like?' Or, 'Okay. What's the next renovation move?' And then they can't agree on what to do, so they're…[at] stalemate and so they just don't do anything. And then if they ever try and make progress on something, my mum knows that if she moves ahead, dad just will wash his hands of it and wouldn't help. Wouldn't have an opinion. Might not ever use the thing that got put in. That kind of thing. So, there's that kind of dynamic stopping energy moving on or tasks getting done.*

Household collections

Functional collections were a regular part of the collections that families and carers described, particularly those who perceived their care recipients as having a history of poverty and trauma. These collections were wide ranging. Newspapers were a very common item, as were groceries and alcohol, toiletries, kitchen appliances, bags, and household furniture:

> *Collecting multiples of the same 'useful' item. Using every available space to store things, including the toilet and bathroom and the other side of the double bed that he sleeps in. The kitchen table is stacked about a metre high with items, the only clear space is enough room for a cup next to the kettle.*

> *The house is a disaster. There is no space to sit. There are tins of food everywhere. There is no clear bench space. There is a small space between the bedroom door and the bed… When cleaning the kitchen after [a family incident], we found 17 cheese graters, 12 potato mashers and many other items in large numbers.*

> *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.*

> *Newspapers in the lounge room she's probably got 300 newspapers stacked up…Just in case there's something in it.*

Animals

There were a couple of families and carers who described their carer recipients as having excess animals over the years, including birds, dogs and guinea pigs. Other families and carers reported that their care recipients had animals that were well managed and in a manageable number. We are aware from initial conversations with the animal welfare sector in Tasmania that this is an area of concern and will return to this issue in Phase 2 of Treasured Lives.

6.4 Perceptions about their levels of insight into challenges

Challenges with hoarding

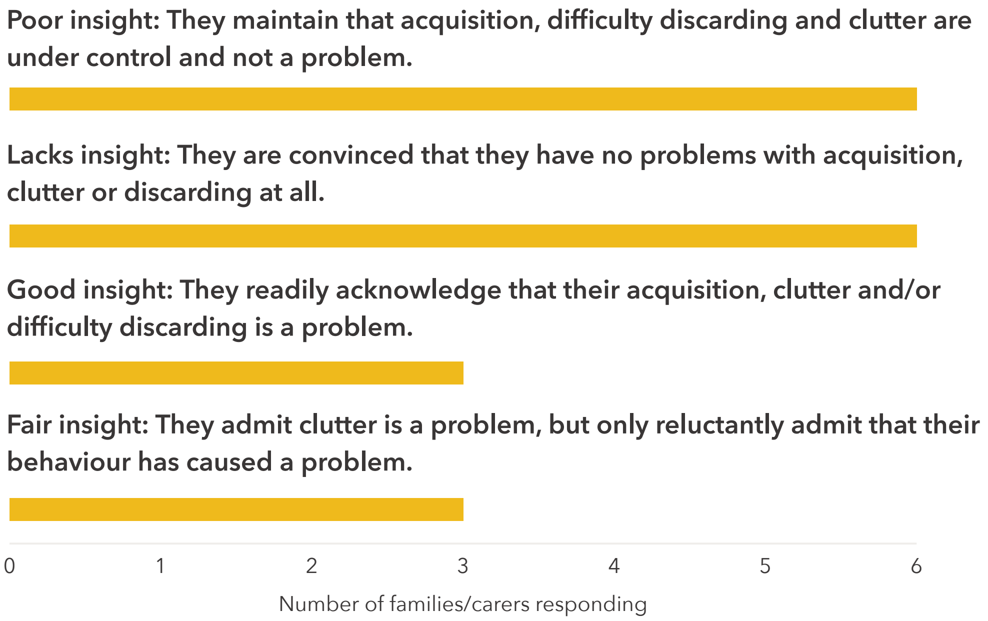
It is common for reported insight around the impacts of hoarding to be lower than insight around the impacts of CMHH. This was reflected in our families' and carers' assessments. Two-thirds of the families and carers who completed the survey described those they cared for as having no or poor insight into the impacts their hoarding had for them (see Figure 24). This perception was supported by all of those families and carers participating in interviews. Comments such as the following were common:

> *They have nil awareness or insight whatsoever. Neither do they have any empathy about how this issue affects me. Blinding rows all the time about junk and clutter. Will not accept any help because 'there is no problem'.*

> *They are unable to see the impact their hoarding had on their son (who died) and also their surviving son. They are isolated, but in denial. My friend calls it clutter. But every living soul in that house has some kind of anxiety – even the dog!*

When asked what insights they thought care recipients had into their challenges related to hoarding and its impacts on them now and into the future, the most common response was that they were aware that their home was cluttered (see Table 8). However, there was a perception that few acknowledged the impacts and consequences of living in a cluttered environment.

FIGURE 24: SURVEY RESPONDENTS: PERCEPTIONS OF THE LEVEL OF INSIGHT INTO HOARDING BEHAVIOUR CARE RECIPIENTS HAD



N=18

Amongst survey respondents, very few families and carers perceived that those they cared for were aware that their home may impact on their physical or mental health, or that the way they lived might make it difficult for them to age at home:

> *They are aware that parts of their home is cluttered but don't believe that is their fault or that they have any power over it or that it's a problem.*

Other perceived insights families and carers mentioned were that social interaction was compromised and that there were trip hazards (see Table 8). Accompanying insight was usually a sense of being overwhelmed about how to tackle the impacts:

> *[She's] aware of it. Like every Christmas she gets upset, 'Oh, I'm useless. We can't have Christmas here.' You know. She's aware of it. But she just doesn't seem to know how to deal with it. How to fix it.*

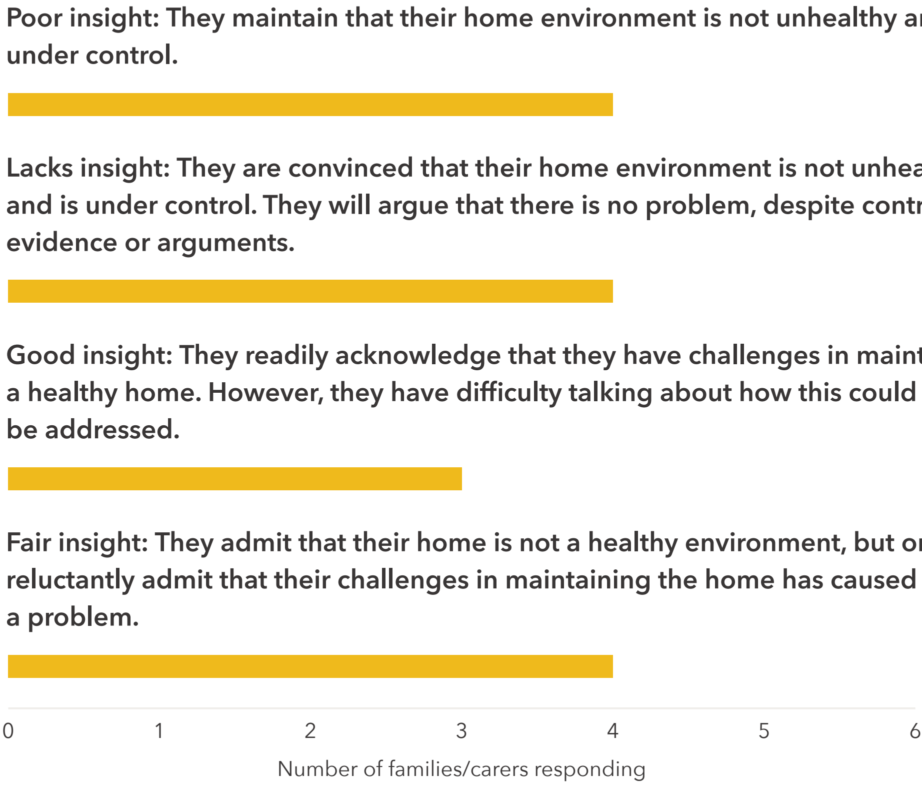
TABLE 8: SURVEY RESPONDENTS: PERCEPTIONS OF THE INSIGHTS CARE RECIPIENTS HAD INTO HOARDING AND ITS IMPACTS

What insights do you think they have into their challenges related to hoarding and its impacts on them now and into the future?	Total
They are aware that their home is cluttered	10
They are aware that their living environment has isolated them, or further isolated them	5
They are aware that their living environment poses risks to them tripping and falling	5
They are aware that they have challenges with acquiring, sorting and/or discarding items around their home	4
They are aware that their living environment impacts negatively on their mental health	3
They are aware that the way the live might mean it's difficult for them to age well at home	3
Other	3
They are aware that their living environment impacts negatively on the physical health	1
They are aware that they have or have had financial problems due to acquiring a lot of items	1
They are aware that their home is at risk of being taken from them	1

N=18

CMHH

FIGURE 25: SURVEY RESPONDENTS: PERCEPTIONS OF THE LEVEL OF INSIGHT INTO MAINTAINING A HEALTHY HOME CARE RECIPIENTS HAD



N=15

Families and carers who participated in the survey were more likely to report that their care recipients had 'fair' insight into CMHH (see Figure 25). Again, this was supported by interviewees. They most commonly reported that those they cared for were aware that they were having difficulties keeping their house clean and how this isolated them (see Table 9):

> *General awareness that the home creates a barrier for meeting new people*

> *They are aware that people don't like to visit due to the state of their home. But blame others for feeling that way. They don't see the state of their home as a problem.*

]

TABLE 9: SURVEY RESPONDENTS: PERCEPTIONS OF THE INSIGHTS CARE RECIPIENTS HAD INTO THE IMPACTS OF CMHH

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?	Total no.
They are aware that they are having difficulties keeping their home clean	8
They are aware that their living environment has isolated them, or further isolated them	5
Other	4
They are aware that they are having difficulties repairing their home so that it's structurally sound	3
They are aware that their living environment poses a risk to their mental health	3
They are aware that their living environment poses a risk to their physical health	1
They are aware that their home is at risk of being taken from them	1
They are aware that their living environment could make it difficult for them to age at home	1

N=18

CHAPTER SEVEN

Conversations about ageing well

> *It'd be nice to have somewhere, have someone that is just – I mean, if you've got an alcoholic husband there's Holyoake, if you're an alcoholic yourself. If you need Lifeline you can ring them up. I don't know, maybe there is. I can ring up… [a] hoarding hotline and say, 'Look, I'm really not coping, I've gone down to mum's and this has happened. What do I do?' And someone who has either lived it, experienced it, or trained in it, can say, 'Okay, this is how we can deal with this today'.*

RESEARCH PARTICIPANT: FAMILY/CARER

> *Prior to the complex gastrointestinal surgery that saved him from pancreatic cancer, he allowed my three sisters (who still live in close proximity to him) to help him prepare his home for his return from surgery. Although I encouraged them to employ the service of professionals, there was no time for the slow, therapy-guided process that would promote lasting change. Besides, 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

In Chapter 5, we explored some of the general concerns families and carers shared about the wellbeing of those they cared for. As a recap, they reported their concerns that those living with hoarding and/or CMHH:

- lived with a high level of personal and social risks to their health and wellbeing, with a sense of stigma/shame which minimised help-seeking. They were often socially isolated, with very few people visiting their home;
- lived with high levels of environmental risks, such as trip hazards, fire risks and clutter preventing clear routes through their house; and
- had low levels of insight into their challenges. Where insight existed, there were low levels of help-seeking and a sense that the physical clutter and emotional barriers were stopping activity from moving forward.

We know that both challenges with hoarding and/or CMHH and those related to ageing – a decline in physical capacities and/or neurological decline through dementia – are likely to intensify with age (Guinane et al. 2019; Pittman et al. 2020; Roane et al. 2017; Steketee et al. 2001). Meanwhile if the physical environment is unsupported, it may pose increasing risks to wellness and reablement (Guinane et al. 2019; Pittman et al. 2020; Roane et al. 2017; Steketee et al. 2001). It may become harder for them to move about in their house; difficult to use mobility aides due to floor space restrictions; difficult to access and use functional areas such as bathrooms and kitchens, impacting on personal hygiene and nutrition; and more difficult to maintain a place to comfortably sleep. The impacts of prolonged social isolation may increasingly take a toll on mental health and cause cognitive decline. If clutter continues to increase, their living environment may continue to pose risks to their own and wider health and safety, including fire hazards. This is all happening whilst a person's physical ability to manage their living environment may be declining exponentially.

We explored with families and carers their perceptions of how those they cared for would be able to age within a framework of wellness and reablement, and what supports were needed to facilitate that, if any. We also explored what supports families and carers felt they themselves needed to maintain their own wellbeing as carers, in order to support their care recipient to age with dignity.

7.1 Families and carers: concerns about those they care for as they age

Perceived impacts for their those they care for

POSITIVE IMPACTS

Just over half of the families and carers who completed the survey (see Table 10) and most of interviewees recognised that the living environment brought positive impacts for those they cared for. A sense of comfort was the most commonly perceived benefit, followed by control:

> *Maybe being able to keep your possessions close. I don't know. There might be a feeling of safety…that's just me speculating.*

> *It's almost like a security blanket for him having all of those things around him, which is strange to me.*

> *It gave him something to do with his hands. Which, being an ex-builder, he probably enjoyed being able to feel like he was doing something that was making something better.*

Holding a sense of permanency was also suggested by a couple of family members. This was created by attachment and belonging to a place, rather than, as used in child welfare, attachment to people:

> *He feels safe & secure to have everything he knows around him. After FOUR migrations & having to continually 'start again', he finds comfort in having his history around him.*

> *Yeah. She owns [the house]…She never owned anything growing up. She comes from a big family, a very poor family, and now she owns it.*

TABLE 10: SURVEY RESPONDENTS: PERCEIVED POSITIVE IMPACTS OF THEIR CARE RECIPIENTS' LIVING ENVIRONMENT

What positive impact do you think their living environment has for them?	Total no.
It provides them with a space they are comfortable in	11
It provides them with a space they can control	8
I don't think their living environment has any positive impacts for them	6
It has had positive impacts for their mental health	2
It has had positive impacts for their physical health	0
Other positive impacts	0

N=19

NEGATIVE IMPACTS

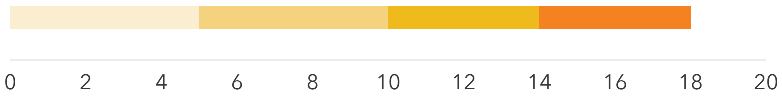
Families and carers perceived these impacts to be significant. Over half of the survey respondents observed on their last visit that it was difficult for those they cared for to use their rooms for their intended purpose and nearly half felt their care recipient's daily life was impeded by the clutter they lived in (see Figure 26). These concerns were supported by interviewees:

> *Everything that you know. Read it straight out of the book. Health concerns. Dust, mould, risk of falls, things falling on them, fire risk. Lack of quality of life. Lack of ability to ask for help. And even if they ask for help, there's a major transition that has to happen for either me to go help them, or for someone else to be able to get into the house to help them. It's not just like, 'bing!', you've got a cleaner, you know!*

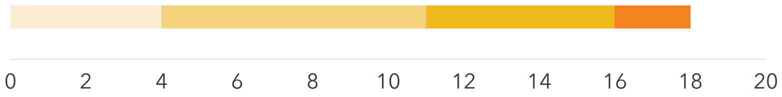
As we explored in Chapter 5, this had led to a significant relational, practical and emotional load for families and carers to manage. This load usually included managing fragmented or disrupted family relationships and a sense of hopelessness and frustration about being able to support those they cared for to effectively address any challenges to their wellbeing.

FIGURE 26: SURVEY RESPONDENTS: OBSERVATIONS ON LAST VISIT ABOUT IMPACTS OF LIVING ENVIRONMENT

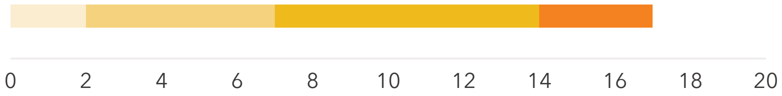
To what extent do they experience imparment in their life (daily routine, job/school, social activities, family activities and financial difficulties) because of the clutter, difficulty discarding or problems with buying or acquiring things?



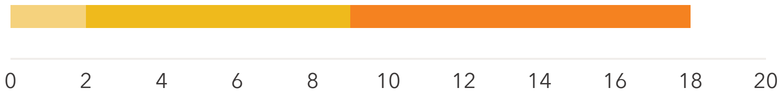
To what extent do they experience emotional distress because of clutter, difficulty discarding or problems with buying or acquiring things?



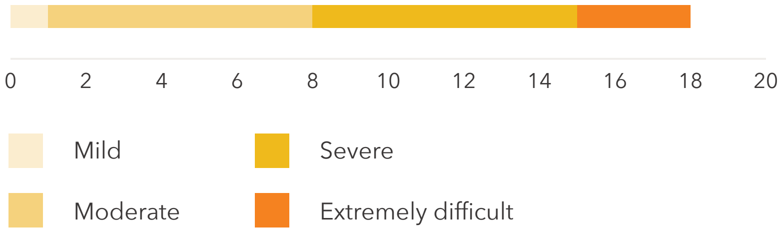
To what extent do they currently have a problem with collecting free things or buying more things than they need or can use or afford?



To what extent do they have difficulty discarding (or recycling, selling, giving away) ordinary things that other people would get rid of?



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



Concerns about ageing

This carer load was compounded by concerns about how those they cared for might age, and how they as families and carers were going to be able to support them.

There was broad consensus that life was going to get harder both for those they cared for and for themselves as carers. They perceived that challenges would intensify for those they cared for and for themselves due to a combination of the living environment not being addressed to make mobility easier and the reluctance to accept informal or formal supports. These concerns were typified by comments such as:

> *I think a point will come where they are unable to maintain an appropriate living standard due to their clutter and mess.*

There were also common concerns raised by families and carers about being left to 'deal with' their care recipient's living environment when they leave, either through having to enter residential care, or through dying in situ:

> *When I visit her I feel very anxious and depressed, as I know that I will be stuck with the huge task of cleaning out her junk when the time comes.*

> *I suppose what worries me is if he has to move from that flat…Well I would help him move. And the thought of having to move all those bloody books and newspapers does not instill me with joy.*

> *My brother is like, 'We're just gonna have to wait until they're dead. His anger with them is much larger than mine…If I'm actually going to tackle this…It's gonna hurt. And I've got to do it in stages...And it's not me…[My brother's] gonna fucking help. I'm gonna have that negotiation with him too…You're doing this work as well…Cause this is work. And it needs to be seen as work.*

7.2 Conversations about ageing

Around half of the survey respondents and two-thirds of interviewees had had at least some discussions with those they cared for about how and where they would like to age (see Table 11).

As reflected in the Royal Commission's recommendations, there was an overwhelming desire to age at home, typified by comments such as:

> *I get the impression that she would not like to be in a home. She didn't want her mum to be in a home and she would not like to be in one. And I don't want her to be in one. There's a time for her to be with our grandkids and having time to use all her skills and everything with them now. And that time is passing. But dad just probably doesn't even realise that…you know?*

> *He wants to stay home until they 'take him out in a box'.*

> *We have discussed a retirement community several times but he always changes the subject if we start talking about specifics.*

TABLE 11: SURVEY RESPONDENTS: NUMBER OF CARE RECIPIENTS WHO HAD DISCUSSED HOW THEY WOULD LIKE TO AGE

Have they talked to you about how they would like to age?	Total No.
Other	1
Unsure	1
(blank)	2
No	5
Yes	10
Total	**19**

However, families and carers expressed significant concerns about how ageing well at home could happen, given not only their care recipients' attachment to place, but their attachment to the collections within that place. These concerns spanned who would support them, given their reluctance to draw on services, and how services would safely enter the property to provide in-home care. When prompted to reflect what life will be like for those they care for if nothing changes in the current supports they receive, families' and carers' responses did not describe a scenario of wellness and reablement. In fact, for most, it was the opposite:

> *It will be terrible, unmanageable. I suspect no home help would want to enter.*
>
> *Extremely difficult and unsafe.*
>
> *Her mental and physical health will deteriorate. Her social/family life will be non-existent.*
>
> *Think they will not be able to live independently.*
>
> *So, ideally, I would like to have them here [in Tasmania]… And mum asked dad. And dad didn't respond for a couple of days. And then said, 'Oh, I don't think I want to move.' Or something… But mum was like, 'Drop of a hat. If it was just me, the house would be on the market…I'd be down here doing my thing.' So, her choice is different from his choice. But they're implicated together… He seems to think he can stay there forever… If I'm in Tasmania... If you needed help – someone to come in and do little things – cleaning, laundry, food, whatever – How are they going to get round that house? So this brings up my fear… If mum goes first…that he will descend into full hoarding and squalor, and through isolation of not picking up the phone, I would not know… So that's where the distance is significant.*

There was a resolution amongst most families and carers that they would need to accommodate the needs of those they cared for, and that the practical care load would be a physically and emotionally demanding one. They would need to find ways to emotionally support their care recipient to understand the personal, social and environmental risks inherent in their current living environment, and undertake or facilitate a long process of clearing and cleaning and maintaining the living environment so that services would be willing to enter:

> *She said things like, 'I'm going to have to clean this up.' Once when I was fairly grumpy with her… And I said, 'Bullshit. Me and my brother will.' She went really quiet…I was like, 'Maybe I shouldn't have said that.' But…there's always this stonewalling, or, 'We'll do it another day.', or 'I'm stressed right now. Can we do it later?' I've said to her really actively…'You are getting older. You are not getting more physically… Like the physical demands of this task are getting away from you. If you ever want to do anything about it, you need to start…You are stonewalling.' …I've said to her, 'You can help. It doesn't have to be a huge thing. We can do little bits.' I've kind of stopped over the last year and a half, because I spent about eight or nine years really trying to get into that.*

There was a common concern that those they cared for would not be able to stay living in their home unless it was made safer for them. There was a particular concern about trip and fall hazards posed by the living environment, and that such an event would lead to the care recipient having to leave their home and enter residential care. These concerns were typified by comments such as:

> *I think the house will get worse, I think that he will eventually find himself being forced into a living situation that he doesn't choose.*

They were more inclined to feel that the inevitable path for those they cared for was that they would either be forced to move into residential care or to move in with their family/carer. This inevitability, expressed by some, goes against the Royal Commission's aspiration for older Tasmanians to age well in place, independently, with choice and dignity.

Families and carers expressed concerns that those they cared for would not cope with residential care because of their attachment to places and items. The prospect of those they cared for moving in with them was viewed as a challenging option for families and carers, due to fractious relationships and their care recipients' need to control their environment and the items within it:

> *I suppose all he wants is a quiet space. Yeah. To be allowed to do what he wants to do. Yeah. …That's actually not a lot to ask.*

> *I can't live with mum now. I can live with mum in my home. My rules.*

There were some concerns expressed about whether the devaluation of property caused by years of neglect may have a financial toll on their care recipient's future choices about where and how they age: '*The value of the house has been greatly degraded due to its condition. This will have an impact if he decides he wants to sell.*' Another financial concern was over the cost of clearing and cleaning the living environment, either to make it safer as those they cared for aged, or after the home was vacated. And there was a common concern voiced amongst families and carers that clearing the house will inevitably be left to them, as discussed in Section 7.1.

These concerns heightened the anxieties and emotional load many families and carers felt. Comments such as '*I do feel stressed about how he lives and what will happen to him?*' were common.

7.3 Supports currently accessed by care recipients to address challenges

To understand how we can create a policy and service landscape that can enable older Tasmanians living with hoarding and/or CMHH, we need to understand more about what supports our older Tasmanians draw on now, and what the barriers to accessing support are. Furthermore, we need to understand what supports are needed to facilitate ageing in place within the framework that emerges from the Royal Commission – one of choice, dignity and independence.

There were a minority of families and carers who reported that those they cared for already received supports to age well at home (see Table 12). Where this was the case, they were more optimistic about the person's future ability to age well in place:

> *I think he'll continue to live in the unit, he'll continue to get support. I am concerned that more kind-hearted people will keep giving him shit. Yes. And he will continue to take it into his unit and we'll continue to have to try to argue with him about whether or not he needs a... But I'm not sure that a huge amount will really change in his routine now. He gets Meals on Wheels. He doesn't cook substantial meals himself. Yeah. I don't think a huge amount will change.*

TABLE 12: SURVEY RESPONDENTS: PERCEPTIONS OF CARE RECIPIENTS' ACCESS TO SUPPORTS TO ADDRESS THEIR CHALLENGES

Have they accessed support to address their challenges either in the past or right now?	Total	%
No	9	47
Yes	5	26
Unsure	3	16
(blank)	2	11
Total	19	

However, most families and carers reported that those they cared for did not currently access any formal supports to help them to address challenges with their living environment or health, or if they did, families and carers were unaware of them (see Table 12). Reasons given for no support varied. They included the care recipient having no insight into their potential support needs, from the families' and carers' perspectives, reportedly not needing or wanting supports, or a reluctance for support services to enter their home:

> *No external supports at all. Even when my dad was dying, I gave up work and went home and became a nurse… Because we didn't have no one in the house.*

Only a quarter of the survey respondents and one interviewee reported any current supports. Common supports accessed were light domestic cleaning and meals:

> *Home help for cleaning one hour per week, meals delivered. And one person to do errands.*

> *He has an hour a fortnight. A lady comes in and does some of the floors and the bathroom for him.*

> *Pre-COVID he went to…a day support program…four days a week….since COVID he hasn't been out at all.*

Amongst the families and carers of those who did access supports, there was often skepticism about whether those supports were effectively addressing the wellness and reablement of those they cared for to a point that they could be considered 'safe':

> *He has an aged care package or a disability care package where people come in and will just touch base with you. Do medication problems, that kind of stuff. And might encourage him to go on a bit of a walk occasionally. But…even though it's quite an intensive package as far as the time they spend there, it's quite low level, as far as what they're doing to assist you.*
>
> *I do wonder how much she has really said to [her counsellor] about [hoarding behaviours].*

Families and carers commonly mentioned that previous supports had been cancelled by those they cared for:

> *Supports were put in place for him for cleaning, food prep, shopping and assistance with managing bills and finance. Over 3 months he cancelled them all.*
>
> *The carers tried to gently address the clutter issue but I'm not sure what the result was. I don't think they pushed very hard.*
>
> *Doctor, cleaner, friends. Only makes a difference for a little while and then they go backward.*

7.4 Barriers to accessing support

The vast majority of families and carers reported that they thought there were barriers to those they cared for accessing formal supports. This was the case for survey respondents (Table 13) and interviewees. All of these barriers reflect those reported in previous literature about families and carers (Buscher et al. 2014; Anonymous 2020; Neziroglu et al. 2020; Tolin et al. 2010; Tompkins 2011).

TABLE 13: SURVEY RESPONDENTS: PERCEPTIONS OF WHETHER THERE ARE BARRIERS FOR THEIR CARE RECIPIENTS ACCESSING SUPPORTS

Do you think there are barriers to them accessing or accepting support to address their challenges?	Total
Yes	12
No	4
(blank)	3
Total	**19**

Little insights into the impacts

As discussed in Chapter 3, this is perhaps the most challenging barrier for a model of consumer-directed care, such as My Aged Care or NDIS. Families and carers reported that many of those they cared for either lacked or had low insight into their challenges and their impacts (see Chapter 6). Therefore they reported a widespread lack of recognition that supports were needed amongst older people living with hoarding and/or CMHH cared for by our families and carers:

> *He believes that everything belongs to him and it is his right to keep his home the way he wants to. If it bothers anyone else, then they don't need to visit him is his attitude to his way of life.*

> *He thinks he is right and everyone else is wrong.*

> *The only barrier is her acknowledging that there is a problem.*

> *I think their lack of acknowledging the mental and physical health aspects of the issue is preventing them from seeking additional help.*

> *He needs to be willing to accept help. Achieving this state of mind will be the biggest hurdle.*

> *His beliefs about what was necessary versus what others thought he needed to live healthfully.*

Families and carers reported that some of those they cared for did access supports, including Home Care Packages, but that these supports did not address issues concerning hoarding and/or CMHH. This was reported to be the care recipient's choice:

> *They see counsellors about other issues. I do not think they are aware of the hoarding however.*

> *We do have home care packages but my husband will never talk about any mental health or hoarding issues. Point blank refuses.*

Consumers' right to live life as they choose needs to be at the forefront of how aged care supports are designed. Later in this project we will explore the balance between choice and dignity and health and safety for those living with hoarding and/or CMHH, and how this can be realised within a consumer-driven support framework.

Stigma

As discussed in Chapters 5 and 6, stigma and shame are perceived to drive some of the demand for privacy amongst those living with hoarding and/or CMHH. This was reflected in comments from families and carers about the reluctance of those they cared for to allow people in the house:

> *[One of] the toilet's been not working for years. And [their partner] wouldn't get a plumber in because [they'd] have to… The…room is just stuff everywhere and you've got to step over things. When [domestic appliances] go kaput, [their partner] hates getting the person up to look at [them] because you can hardly get in the [room], because there's piles of [items].*

> *I'm hoping that one day I can care for her. I do not think professional carers would be an option. One, she wouldn't feel comfortable enough having someone else come into her home. And two, they would class it as a safety risk, I think. And wouldn't let someone come into her home without more changes… And more changes would upset mum even more. Mum's always suffered, in my non-trained eye, depression… Mum's dream…is to live in a nice cottage with no clutter and you take your shoes off at the door. She said, 'I dreamed of it as a kid and I dream of it now. But it's never going to happen, is it?'*

Wary of intervention

Literature tells us that those living with hoarding and/or CMHH are often wary of intervention. This is not only because of low insights into challenges, or shame or judgement, but also, for some, because they are wary of what will happen if support services intervene (Tompkins 2011). This may be driven by the need to control and protect their current living environment (Chabaud 2020; Danet & Secouet 2018; Neziroglu et al. 2020) or because they perceive that services will want different outcomes from support interventions compared to them, as discussed in Chapter 2.

This wariness was reported by some families and carers to be compounding the reluctance to let services engage. For some it was a source of conflict, and an issue to be avoided in order to maintain the relationship:

> *I think they will actively resist the perceived intrusion.*

> *She needs help from a cleaner, but won't let anyone into the house in case they 'touch her things'.*

> *She is eligible for home care, but refuses to allow anyone in the unit. So that isn't any use.*

> *He doesn't want to access help. And I suffer abuse from him when I do.*

> *[I] try to liaise with the carers. He tries to stop me.*

This creates a tension between support needs as perceived by families and carers and as perceived by those they are caring for. This is, of course, a common source of tension in families as people age, but may be heightened when there are challenges with hoarding and/or CMHH, due to heightened environmental risks and the implications for accessing any home-based services. This is where clarity on the goals for support or intervention can be helpful.

Lack of knowledge about what's available

Lastly, families reported that they and those they cared for did not know what services (if any) were available to them regarding hoarding and/or CMHH. Again, we have explored this in Chapter 3:

> *Mostly pride, and an inflexibility. Also a lack of understanding of what services he can access.*
>
> *Knowledge of types of support available for this illness is not known. Reluctance to seek support.*

7.5 Supports needed: families' and carers' perspectives on what those they care for need

There were common themes in what families and carers thought those they cared for might need to age well at home within a framework of wellness and reablement. They suggested a combination of information resources, case coordination and support services. Core elements were consumer-led design; easily accessible information about what's available for those they cared for; coordinated and skilled case management (working with the older person and with their family member / carer, with their GP mentioned as a key contact and trusted relationship); and access to specialist support services – clinical, psychosocial and practical on a continuum which included support to plan for ageing and end of life.

Consumer-led design

Families and carers were clear that any supports must be led by those they cared for. This appeared to be driven by a combination of factors. First, there was the ethical principal, as seen in My Aged Care, NDIS and the Royal Commission, that it's not our business to make decisions on their behalf. The care recipient needs to lead and control decisions about their care and wellbeing:

> *Perhaps suggested by his GP. Being able to discuss what's available with no expectation or obligation. To be able to have some control over the process.*

> *To be able to live the last phase of…life not being ashamed to have people visit.*

> *It's his story… It took me a long time to see Hoarding Disorder as a disability. As a mental illness and just a disability like any other that needs different forms of care and services… And it's completely personal…It's not going to be, 'Oh, okay.' And then we know that that person has that knee problem, because they've got a problem with the ligament. And it's going to be the same in every single person…It's going to be completely unique in every person.*

And, pragmatically, they perceived that those they cared for would not cooperate with any intervention or support that they hadn't bought into:

> *I'd like to see him choose what supports he will need or where he wants to live. I don't think he's going to be proactive though.*

However given the perceived reluctance of those they cared for to seek help, there was a tension between honouring consumer-led approaches to support and acknowledging their anxieties around addressing key health and safety concerns, particularly with an eye on 'future-proofing' the living environment so that it would be an appropriate place to age well:

> ***Lindsey:*** *If nothing else changes in terms of the supports she has, what do you think life will be like for her as she gets older?*
>
> ***Respondent:*** *She's gonna lose her independence rapidly, because I will just have to take over. That sounds awful. But…she's a beautiful person…. I hope she never has to go to a home… Now as I get older and my life gets easier and mum gets older and her life gets harder, I'm hoping that one day I can care for her.*

Coordinated and skilled case management

Many families and carers expressed a desire for there to be one point of case coordination for those they cared for, and for them as carers to have a way of working with those case coordinators. They believed that they needed to be involved as advocates, as points of reference to help provide context in the design of appropriate supports and to enable them to work alongside formal supports where appropriate:

> *Flow of information between services about circumstances so there is a continuance of support without stressing the person.*

They also suggested a need for case managers to understand the nature of hoarding and/or CMHH.

Most did not have a suggestion for who should provide this role. Of those that did, the aged care assessment process was mentioned. They also saw a role for GPs, given that they were often one of the few points of service engagement for those they cared for:

> *Make it as easy as possible for families to access what's available and as pressure-free as possible, to look at them, so their loved one doesn't feel like they are being forced into anything.*

> *If they take notice of family members that the person needs help to clean up. And to make him think about who will have to clean up if they don't.*

> *Support from his doctors to encourage him to accept help or make changes in his life.*

There was a concern raised about the transition from NDIS supports to aged care, due to the lack of integrated healthcare supports within My Aged Care packages. The Royal Commission's final report acknowledges this issue and has made extensive recommendations around the future interaction of such supports. We will explore this further in Phase 2 of Treasured Lives.

Access to specialist support services – clinical, psychosocial and practical

There were many comments about the need for specialist professional supports in Tasmania to address the range of clinical, psychosocial and practical needs experienced by those they cared for:

> *Specific psychiatric help specialising in this area of mental health.*

> *Assistance in psychological support to assist dealing with the situation and creating a plan to address key issues, which would help for growing older in the home, or alternatives available.*

Coupled with specialist supports, families and carers frequently mentioned appropriate supports. Given that those they cared for often did not welcome intervention and supports, the approach to engaging and working with them was frequently raised as important for trust-building, the sustainability of the support relationship and gaining effective outcomes. This approach was articulated in a number of ways, offered here with our emphases:

> ***Respectful** visits from trained counsellors, if they could gain trust.*

> ***Patience** to go through years of stuff.*

> *Initial help to de-clutter, then continued support to **motivate** them to continue their positive actions.*

> *My mental health training, expertise, patience and **assertiveness** plus cleaning and gardening etc.*

Also … not sure …

It is also important to add here that some families and carers were unsure about what to suggest, or resigned to no supports being available:

> *I am actually unsure to be honest.*

> *Since I am an educated professional in the field I really don't know how anyone could offer help. I think I've read almost every word written about dementia and hoarding disorder.*

> *I don't see how anything can change until she goes into aged care. And then we have a massive cleanup/throw out (i.e. skip bin, or maybe two)!*

7.6 Supports needed: families' and carers' perspectives on what they need to support the person they care for as they age

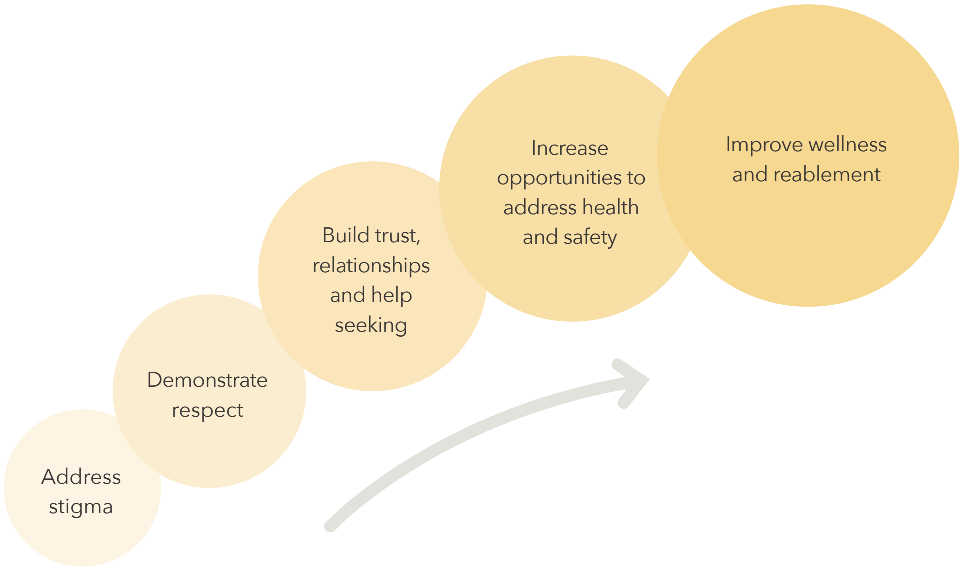
Families and carers across the survey and interviews mentioned a range of supports that would be useful for them. This was both in supporting those they cared for to age well at home and supports for themselves to manage the relational, practical and emotional load. Most did not name specific supports, but described the type of supports that would be helpful. These included:

- a reduction in stigma to address judgement and increase understanding around those who live with hoarding and/or CMHH;
- a point of information to source supports for themselves and for those they cared for;
- peer and informal supports to ease their sense of social isolation; and
- a range of specialist training, advice and supports for themselves to manage the relational, practical and emotional load.

Essentially, they were describing having access to an enabling structure of information, knowledge and a continuum of supports that would help them to prevent challenges from becoming 'risks' and prevent personal, social or environmental risks from escalating so that those they cared for could age well at home. They also recognised that their care load had emotional consequences that they needed to address and manage.

Reduction in stigma/stereotyping – not being 'judged'

FIGURE 27: IMPORTANCE OF ADDRESSING STIGMA



Existing literature and our families and carers frequently mentioned the crucial role that stigma plays in preventing wellness and reablement for those living with hoarding and/or CMHH and those who support them. As we've explored, it amplifies shame for families and carers and those they care for, minimises help-seeking and entrenches conflict amongst those living with challenges, their families and carers, and the communities they live within (Chou et al. 2018; Anonymous 2020; Neziroglu et al. 2020; Tompkins 2011).

Addressing perceptions and judgements within the community and within service industries will go a long way towards initiating a path to building respect, wellness and reablement (see Figure 27). As Chabaud describes, '*Building trust starts safety as the goal. Opening the door to a hoarded house by first emphasising safety could allow the eventual transformation of the meaning of objects in that person's life*' (Chabaud 2020).

Evidence suggests that addressing stigma can minimise family disruption and conflict and support their own social connection and wellbeing (Neziroglu et al. 2020; Tompkins 2011). Our families and carers clearly recognised the barriers to help-seeking and increased social isolation that negative judgements created for those they cared for and for themselves. So there were a number of suggestions around the need for hoarding and/or CMHH to be destigmatized:

> *Advertising and more front of mind to acknowledge the hoarding problem (maybe like the gambling ads).*

> *She just doesn't like the word hoarder and the stigmatising of it…That's why I'm doing it…because I don't like someone as awesome as her being stigmatised.*

> *Sympathise with the person. Ask what they need to assist them.*

> *You can't just go in and take things. Mum knows where everything is, there's no dementia. She might forget where she left her keys three minutes ago with short term memory loss. But it's their life and it's her – she's still got dad with her and that's how she copes with it. It might not be your dad, it might be your child. They may just be your friends, all your books and your pieces of paper and your collection of tins, it's all memories. And as people get older, they don't want to lose their memories.*

Somewhere to turn to find supports for themselves and for those they care for

Navigating the complex landscape of supports and services needed for those they cared for to age well at home was frequently mentioned as being overwhelming by families and carers. Many described how difficult it was to understand what supports were needed or available, and how time consuming it all was.

In the absence of a specialised point of information in Tasmania, they were not sure whether they were missing supports that they could access for themselves, or whether there simply weren't any. This drove a cluster of suggestions around the need for a go-to information point:

> *More information on the services available.*

> *Information provided by one source, so I don't have to spend more time pursuing it.*

Peer and informal supports

The most common form of support families and carers mentioned drawing on were informal supports – from partners, other family members and friends. They were the confidants and the comforters (Chapter 5). When asked what supports they needed, families and carers flagged these informal supports again:

> *Alcohol?! (Just joking) When I get home from visiting her I need a cup of tea made for me, and someone for me to 'vent' to. Then I am alright till the next time.*

> *I have good support networks.*

> *I will continue to have support from my husband and one of her other friends who I can talk to.*

Being able to talk with those in a similar situation to themselves was mentioned by a number of families and carers. This really spoke to the sense of isolation many families and carers had expressed in carrying their responsibilities:

> *I find all those peer support groups really useful… I mean, obviously, I understand that people are different…but you know, for me, I find that peer support stuff is really good. Really helpful… Well…you go into a room with people and they know exactly what…their story may be different, yeah, but they understand what it's like. And…that's really powerful.*

> *People to talk to who aren't judging me, or of the circumstances that mum lives in.*

Specialist family and carer supports

Families and carers mentioned a range of supports that they felt would help them help the person they cared for and support them emotionally and practically. These included therapeutic counselling services for themselves, information and awareness about hoarding and CMHH so that they could understand what was happening for those they cared for, and training, skills and specialist support workers to provide some practical strategies and ongoing support to work with those they cared for:

> *Access to resources that I can share with the person, advice on how to assist them to maintain good habits.*

> *To have someone who could act as intermediary would be awesome!*

> *A quick-response team who could respond with practical advice as well as emotional support. Mostly, emotional support!*

> *It'd be nice to have somewhere, have someone that is just…I mean, if you need Lifeline, you can just ring them up. I don't know, maybe there is…I can ring up the…hoarding hotline and say, 'Look, I'm really not coping. I've gone down to mum's and this has happened. What do I do?' And someone who has either lived it, or trained in it, can say, 'Okay, this is how we can deal with this today.' Because I know growing up, when I was at my wit's end, I would have loved that.*

Their role as advocates recognised

Along with the suggestion for a point of case coordination, came a plea for themselves as carers to be more included in the conversations about the person they care for and their care needs. This is in line with the Royal Commission's recognition of carers' roles and the need to liaise more closely with primary healthcare, mental health services and allied health services. We will return to this issue in Phase 2:

> *I don't think I will need a real lot apart from my voice being heard when I need to be mum's voice. I am her legal Guardian and most of my caring role involves advocating for her with professionals and NDIS.*

> *I need to know that he's being cared for as he is not easy to care for.*

> *I will just need her professionals to listen to both of us about her needs.*

> *Ability to talk to his doctors about what he needs.*

> *I would like to discuss some needs with his GP. He seems to be having some health issues that don't seem to be resolved, I think it's going to get worse but I'm not sure how bad or soon.*

7.7 Pathways to supporting wellness and enablement

In conversations with families and carers and through survey responses, families and carers mentioned that triggers for insight and engagement with services often involved either health scares or complaints. Given that help-seeking is low amongst those living with hoarding and/or CMHH, these points of engagement are critical and provide opportunities for continued and sustained support. Treasured Lives, is mapping these points of service engagement, whether they be through incidents or conversations, and will consider how these potential 'gateways' could be developed as opportunities for positive engagement with appropriate services. This will be covered in more detail in Phase 2. Here we note the critical incidents have led to service engagement – albeit usually briefly – as reported by families and carers, and the conversations that were mentioned as offering opportunities for service engagement.

Critical incidents

It is clear that critical incidents are often where care recipients are forced to engage with services – hospitalisation, fire, and risks to tenancies, neighbourhood complaints and animal welfare concerns (see Figure 28).

Health scares were the most common. The following example was typical:

> *He got quite sick about three years ago. And it was to do with his alcoholism. And he went to hospital for a period of time. And at that stage we weren't even…the doctors said that they thought that he wouldn't recover or wouldn't come home and that they thought he was going to go into an aged care facility. So…I went…there at that stage, because he'd sort of distanced himself for about two years. He just wasn't really engaging with anyone in the family very much… And that was probably to do with some of his drinking. I don't know. He has early onset dementia, which is probably from the alcohol as well, although that is hereditary in our family… But I went up at the time, when he went into hospital, and then it became apparent that it had just gone out of control.*

These interactions are points of opportunity that potentially open a moment of contemplation on the safety risks posed by their home environment and the possibility of seeking help. However, given the nature of these issues, they are potentially negative interactions, often with the threat of a sanction – the loss of a tenancy, property or beloved animals if clutter and CMHH are not addressed. We need to consider how we can ensure that these points of interaction are *enabling*, rather than negative. We will return to this in Phase 2.

FIGURE 28: OLDER TASMANIANS LIVING WITH HOARDING AND/OR CMHH: CRITICAL INCIDENTS AS POINTS OF ENGAGEMENT WITH SERVICES

Conversations about ageing

Our families and carers noted a number of conversation topics that had sparked a discussion with those they cared for on what needed to happen to keep them safe at home. At the top of the list was conversations on what needed to happen to their living environment as they aged so that services could enter and mobility aides could be used. For a couple of families, this had opened conversations about changes to their living environment, mainly focused on creating accessible routes through the home, somewhere to cook, somewhere to wash and somewhere to sleep (see Chapter 5):

> *I've seen in aged care people go into hospital and they don't come back out and stuff like that. Doctors come in [to the home]. They say they're unfit to go home. They can't do this and they end up in a nursing home. Mum's biggest fear is to ever be put in a nursing home. So I've used that as a bit of a pull. You have got to be able to get your wheelie walker up the hallway, or you cannot come home. So we've got a path wide enough now for you to walk. You can't have your bathroom cluttered, so now it's clear with the bath removed and shower in… So it's sort of been this ongoing threat that I put towards her… It doesn't matter how much I fight. If they think you're unfit to come home, you can't come home.*

Other conversations involved:

- discussions about moving, prompted by the desire to ensure those they cared for were closer to their families or carers;
- discussions about making the environment safer and easier, prompted by health concerns; and
- discussions about what they would like to do with some of their treasured possessions, prompted by thoughts of end of life planning.

This all kept control and ownership of the motivation and process in the hands of the care recipients, but slowly tried to prompt some action towards ageing well at home. The stumbling block that all families had was what to do next. In the face of no specialist support services to continue those conversations and to support those they cared for on the emotional journey of sorting and discarding, nor the specialist services to help with the practical work of sorting and removing items, they were stuck, and somewhat overwhelmed by the prospect of doing this themselves.

There are services that are 'natural fits' for some of these conversations. However, to follow through on these conversations would require Tasmania to have a landscape of suitable and specialist support services. In Phase 2 of Treasured Lives, we will return to this topic and examine what would need to be in place so action could be taken.

CHAPTER EIGHT

What happens elsewhere?

> *Hoarding [adults] fear discovery because it threatens freedom to self-manage relationships with objects and to protect what these relationships are felt to supply, such as comfort, satisfaction and relief from deep emotions associated with unspoken traumatic experiences, and psychological ownership. Trust building is the foundation of any successful intervention. Rapid clean-outs are often threatening, worsen the disorder.*
>
> CHABAUD 2020

> *I work in aged care and there are people out there in the community that I see and I hear others talk about them, and it just tears my heart out, because I think you've really got no idea. Because most hoarders are just seen as dirty. Dirty old bag ladies that should get their act together. Dirty old men. They're not dirty people, you know. It's a condition that people need to understand.*
>
> RESEARCH PARTICIPANT: FAMILY/CARER

There is limited evidence on the most effective supports and practices in working with those living with hoarding and/or CMHH (Firsten-Kaufman & Hildebrandt 2016), and even less about effective supports for their families and carers (Chabaud 2020; Neziroglu et al. 2020). Based on what program evaluations and academic literature tell us, together with more informal consumer and professional feedback, the most promising framework of support would combine the following elements for those living with hoarding and/or CMHH and for their families and carers (see Figure 29).

FIGURE 29: ELEMENTS OF SUPPORT USED ELSEWHERE FOR FAMILIES AND CARERS IN RESPONSE TO HOARDING AND/OR CMHH

MULTI-DISCIPLINARY TASKFORCE

- Information and referral
- Case coordination, goal setting, planning, review
- Workforce development

Clinical supports

- **Examples:** medication, mental health planning, one to one therapuetic counselling
- **Goals:** To support comorbid mental health challenges. To address relational and emotional impacts of caring / growing up with people with hoarding behaviour / CMHH. Create an emotional space to maximise positive family relationships

Psychsocial supports

- **Examples:** Motivational interviewing, family-based training and therapy
- **Goals:** To maximise positive family relationships. Reduce isolation. Decrease hopelessness.

Practical supports

- **Examples:** Harm minimisation support, health and safety planning, specialist cleaning and sorting, animal welfare services
- **Goals:** To support the person they care for to address the risks in their living enviroment and to their social and psychological safety

Peer supports

- **Examples:** Face to face and online informal support.
- **Goals:** To reduce social isolation. Minimise stigma. Reduce hopelessness. Learn about useful approaches and services.

Information and advice

- **Examples:** Psychosocial education. Awareness/training programs. Information portals. Specialist advice. Public awareness campaigns
- **Goals:** To understand what's happening and approaches to support. To source supports and services

On the next few pages, we explore some of the key elements of good practice in more detail.

8.1 Specialist multi-disciplinary taskforces

Given the complexity of addressing the needs of people living with hoarding and/or CMHH, it requires a range of services to work closely together to support them and their families and carers. Local specialist taskforces or teams have been developing across Canada, the US, the UK and, more recently, Australia. They are held up as the most efficient and effective way for professions to work together (Bratiotis 2013; Firsten-Kaufman & Hildebrandt 2016; Frost et al. 2000; Koenig et al. 2013;Kysow et al. 2019; McGuire et al. 2013; Steketee et al 2001).

What makes such taskforces effective is that they are able to respond to cases, including the needs of families and carers, in a holistic, flexible and long-term manner. When focused on addressing the unique – and often complex – circumstances for each case, they are '*showing particularly promising results*' (Bratiotis 2013; Whitfield et al. 2012; Koenig et al. 2014; Brown & Pain 2014; Firsten-Kaufman & Hildebrandt, 2016). They must include mental health support services at their core (Whitfield et al. 2012).

These multi-disciplinary taskforces work well as the hub for case coordination, professional training and development. This can have the benefit of reducing service and development costs (Chabaud 2020) and create a welcoming hub of information, liaison and development for families and carers who wish to support those they care for. Having a local multi-disciplinary taskforce makes the goal for families and carers of being able to '*better manage self, family and interpersonal relationships*' (Chabaud 2020) a lot easier.

We will explore these taskforces further in Phases 2 and 3 of Treasured Lives. Here we provide some of the useful elements of a coordinated approach as they relate to families and carers support.

8.2 Public/industry awareness campaigns

We are familiar with general mental health awareness campaigns in Australia and, more recently, some around suicide awareness. There are limited examples of purposeful multimedia campaigns around understanding hoarding and CMHH. Hoarding UK has arguably had the most effective campaign in addressing stigma and raising awareness. They have worked alongside TV and radio projects to take an educative approach to understanding challenges and addressing stereotypes. Less high profile, but still impressively, there are very good information, awareness raising and training campaigns attached to taskforces working in Victoria and New South Wales (see Section 8.5).

8.3 Support programs specifically for families and carers

It is common for family members who grew up in or have lived within these challenging environments to experience anxiety, depression and possibly be addressing their own tendencies towards hoarding and/or CMHH (Chabaud 2020; Garrett 2020; Neziroglu et al. 2020; Whomsley 2020). Specialist one to one therapeutic counselling focused on supporting individuals to understand and work through the root causes of behaviour, as well as the impacts, is a crucial element of support. Such a therapeutic environment helps to work through any emotional and social impacts of growing up with / living with / supporting a family member. This can be crucial to enable families to effectively support the person they care for without presenting in anger, frustration or a sense of hopelessness (Neziroglu et al. 2020; Tompkins 2011).

To complement this, one-to-one and/or group psychosocial support programs for families and carers are a useful way to reduce the sense of stigma and social isolation, improve family and other relationships, and understand what's happening for those they care for. This can also give insights into the health and safety risks associated with these living environments and support families and carers to understand what they can do to actively address these risks (Neziroglu et al. 2020). Another benefit of these programs, as Neziroglu et al. (2020) highlight, is to provide a space for 'emotional validation' for families and carers.

There is very little research on how to clinically intervene to support families and carers of those living with hoarding. Neziroglu et al. (2020) provide a useful review of methods being utilised to address families' and carers' own challenges and improve their wellbeing. Briefly, these include:

- **Psycho-education:** This is a common component of support programs for families and carers. It seeks to explain the nature of the disorder experienced by those they care for. By doing so, it aims to help families and carers understand their care recipients beyond the visible clutter. It also aims to reduce stigma and shame through enhancing understanding. It is also designed to prepare families and carers for further training on strategies that might help them to minimise feelings of anger and frustration that they may hold. Such training is aimed at reducing relationship disruption and improving help-seeking amongst those they care for. For examples, see the therapies and strategies below.
- **Group family therapy:** Family group therapy, introduced by Van Noppen and colleagues to support families living with OCD (Neziroglu et al. 2020), is flagged as useful for supporting families and carers living with hoarding disorder. This model provides group treatment for all members and is aimed at training members how to positively participate in supports, through understanding the disorder, managing symptoms, learning coping strategies and improving quality of life (Neziroglu et al. 2020). It is essentially the basis for many family programs offered in this space.

- **Acceptance and commitment therapy strategies:** This is focused on supporting families and carers to address their frustrations and anger with those they care for and within the wider family (ACT and Hayes et al. 1999, cited in Neziroglu et al. 2020). It can be used to either prepare for supporting those they care for to act, or to prepare to accept no action. In either scenario, it again promotes a minimisation of family disruption, anger, stigma and shame.
- **Motivational interviewing:** Aimed at enhancing motivation, preparation and engagement, some family support programs will train family members and carers in this communication style. This is seen as a gradual and non-confrontational way of supporting those they care for to realise the impacts of their behaviour in their environment, relationships and health. It also seeks to open up conversations about addressing safety risks and seeking support.
- **Assertion training skills:** Where families and carers find themselves accommodating the behaviours of those they care for, assertive training skills may be offered. This would be geared towards providing families and carers with a more assertive way to express their needs – firmly, but without high emotion, so that family disruptions might be minimised rather than escalated.
- **Exposure and response prevention:** For those families and carers who have strong negative feelings and experiences around the person they care for, or their living environment, this approach can be used to reconfigure those responses. By controlled exposure and discussion, it can minimise negative emotions and promote a more positive engagement between families and carers and those they care for.
- **Intervention strategy:** Similar to the intervention approach used in substance use treatment, this strategy is designed to convince a person living with hoarding behaviours to agree to an initial consultation with a hoarding treatment expert. Often used alongside other methods of harm minimisation, such as motivational interviewing, this may be part of a broader family support approach which might repair and strengthen family relationship bonds.

Internationally (particularly in the US, Canada and the UK), and in other Australians jurisdictions such as Victoria and New South Wales, a number of family-based support programs have drawn on these approaches.

Buried in Treasures is an internationally known program that uses a combination of information and awareness raising (psycho-education) and practical approaches with families and carers, as well as those living with challenges and service providers. The program draws on Cognitive Behavioural Therapy to help those living with hoarding behaviour to learn the skills for behavioural change and the decision-making needed to address challenges with acquiring, sorting and discarding items (Neziroglu et al. 2020). There is also a book *Buried in Treasures* that can be used as a workbook for those who cannot access this course (Tolin et al. 2014).

The US-based Family Harm Minimisation Program recognises the key role that families can play as motivators. It draws on harm minimisation approaches that focus on safety first and can help reduce family distress and increase help-seeking for families and for those living with hoarding. It uses motivational interviewing training as a way to coach families in how to support those they care for towards insight and action to address environmental, social and personal risks in a compassionate manner, and uses family therapy to help heal anger and promote forgiveness across the family (Neziroglu et al. 2020; Tompkins 2011).

The Group Treatment for Hoarding Disorder resource uses a combination of these approaches in book form (Muroff et al. 2014).

Services in other Australian jurisdictions have drawn on such programs to provide holistic support to families and carers who are supporting those living with hoarding and/or CMHH. See Section 8.5 and Appendix 2 for examples.

To give a flavour of such approaches, here is an example of how one of our respondents used such techniques to support her parents:

> *I pushed for [a focus on the backyard] more recently, because she was opened through the Buried in Treasures program. And even if it doesn't seem like a first priority, it was a big problem. And I needed to get her to see how to prioritise getting help with it. One of the things I was thinking about doing…is a Wish list/Repair/Replace Discard List. So, you've got acquire and discard. And all your various ways of discarding – selling or just bin or whatever. But if it's not absolutely necessary, it needs to go on a wish list. 'I want bright pink roller skates.' Not totally essential. So, it's a wish list item…*
>
> *"Now I don't get to buy anything. I don't get to get my jollies off getting anything." Yes, you do. You are out of toothpaste. 'Repair and replace'. Get yourself down there. Buy that toothpaste … I get to go and buy that at the shop. I can acquire it and then tick it off my list.*
>
> *Your window is broken. We need to repair and replace the broken window. We've got stuff to do. We've got things we're doing. We're busy. We're acquiring. We're fabulous. But we're focusing on the priority of 'repair, replace' when we acquire. These are the priorities. And this [wish list item]…has to sit there for a good six months until you find the perfect pair. You find them on sale, you save up for them. And then, as your reward, you can get your bright pink roller skates. But it's prioritising.*
>
> *So, I think, through that process she eventually came to see that the garden was irritating neighbours. Totally unmanageable. No way that she could manage it herself. Pest weeds. It wasn't even like "The rosebush needs pruning." … They had killed the mango trees... I feel like, through this process of prioritising, we identified the garden. She couldn't possibly do it herself so she needed help to do that. And she didn't have to worry. It wasn't like the workers were into the house …*

> *So, coming into the house this past year, they have had a new bed delivered. I had to go up to get the old out and the new one in, but that's fine. Kitchen tap fixed because I accidentally bumped the kitchen tap, which was not to be touched, and it just went permanently on… And I'm like, "Guys, you can't – is this why you're not using the cold tap in your kitchen sink?"*
>
> *Anyway, new washing machine delivered. Old one taken away. And a man came to fix the antenna. TV check. So, small things. Small things. People have come and attended to things. But just small amount of access and a small amount of allowing, and a little bit of the prioritising.*

8.4 Peer support networks

As discussed in Chapters 3 and 7, peer support networks can provide an additional and informal way for families and carers to enhance their knowledge and support skills and their own wellbeing. In a situation where they are handling a great deal of complexity, peer networks are powerful ways for families and carers to forge social connections within a community that understands their experiences, reduce stigma and isolation and provide motivation to stay focused on goals (Chabaud 2020;). The particular strength of specialist peer support networks for families and carers of those living with hoarding and/or CMHH is in the ability share experiences and service recommendations that address the comorbidities those they care for may be experiencing.

Such specialist peer support networks are often part of wider support programs that address challenges related to hoarding and/or CMHH, but can be standalone forms of support. Either way, they provide a crucial means of empowering and affirming families and carers (Chabaud 2020; Neziroglu et al. 2020; Tompkins 2011).

Online peer support networks provide an ongoing and more informal way for families and carers to access these supports. Notable examples include (see Appendix 2):

- Children of Hoarders' various peer support groups for adult children and families of those living with hoarding
- Volunteer-run peer support through Reddit and Facebook
- ARCVic's Hoarding and Clutter Anxiety Support Group

8.5 Notable examples

In Appendix 2, we have provided a summary of some key family and carer supports provided across Australia and internationally. This is a **selected** list of resources that may be useful for families and carers of those living with hoarding and/or CMHH. It has been curated by this project based on the following criteria.

That the resource/program:

- offers a responsible coverage of the context for hoarding and/or CMHH;
- explains the approaches to support within that context; and/or
- raises awareness and positive engagement about hoarding and/or CMHH.

This resource list includes books, websites, training, peer support and multimedia forms of support either directed towards families and carers, or relevant to help them build the body of knowledge they are likely to need to support their care recipients to age well at home.

Below, we have also highlighted some of the notable collaborative support hubs that families and carers can access elsewhere in Australia and the UK.

Pathways through the Maze, New South Wales

A cluster of cross-sector agencies (Catholic Healthcare, Homelessness NSW and RSPCA) host New South Wales's Pathways through the Maze.[20] This offers an impressive range of targeted information for families and carers, together with training and support groups for families and carers, as well as for those living with these challenges and the service providers who work with them.

Behind this is the New South Wales Hoarding and Squalor Taskforce or Industry Group. This was convened by Catholic Care in recognition that hoarding and challenges maintaining a healthy home were estimated to be a $1.8 billion issue. [21] The industry group brings together partners across state and federal government, primary and mental health, aged care, community sector, emergency response, environmental health and housing, animal welfare and the research community.

---

[20] https://hsru.com.au/

[21] https://hsru.com.au/industry-working-group/about/

Victorian Hoarding and Squalor Practice Guidelines and Community

The Victorian State Department of Health and Human Services offers a leading edge range of information sheets and resources for the public and service industries.[22] This is supported through a multidisciplinary community of practice, training programs and support courses for families and carers around the state.[23]

Hoarding UK

This UK-wide charity[24] is a leading provider of both information and support for families and carers of those living with hoarding. They work closely with the UK media on public awareness programs, and provide online workshops and training for families and carers, as well as online peer support networks.

---

[22] https://www2.health.vic.gov.au/ageing-and-aged-care/wellbeing-and-participation/hoarding-and-squalor

[23] See for example, https://crm.chiavic.com.au/event/hoarding-and-living-in-squalor/

[24] https://www.hoardinguk.org/

CHAPTER NINE

Recommendations

Recommendations 1 to 6 address the needs of families and carers. They are based on their reflections and shaped by practice elsewhere. These form part of Treasured Lives' final recommendations. Recommendations 7 and 8 relate to the needs of those living with hoarding and/or CMHH. These recommendations will be further developed and added to through Treasured Lives' future conversations with service providers, policy makers and, most importantly, those living with hoarding and/or CMHH.

Address stigma, raise awareness, generate respect

1. **Invest in positive community education campaigns:** Like other complex social issues, such as suicide prevention and family violence, that have required public education to highlight the complexities and inherent needs, we need to cultivate a positive professional and community understanding around hoarding behaviour and CMHH. Tasmania needs to foster an environment that breaks down stigma, builds understanding and respect and facilitates help seeking for those living with hoarding and CMHH. Elements should include:
   - raising awareness of why people develop such challenges;
   - cultivating respectful language around how we talk to and about people living with hoarding and/or challenges maintain a healthy home; and
   - recognition that families and carers, as well as those they care for, have distinct support needs that require and deserve support and service responses

Develop a comprehensive framework of policies, practice and information

2. **Establish and invest in specialist regional Tasmanian taskforces that address hoarding and CMHH**. These should be collaborative, multidisciplinary professional teams and consumer groups that include all core services, including aged care services, clinical and community mental health services, local government environmental health services, housing providers and support services, emergency services, animal welfare agencies, family and carer support groups, community health and social work teams. The taskforces should aim to develop short- and long-term collaborative case management and support services to support older people living with hoarding and/or challenges maintaining a healthy home to age well at home, and consider support and information services for their families and carers.
3. **Develop a shared practice framework for professionals who work with older people living with hoarding and/or CMHH and their families and carers**. This should include common tools for assessing and understanding needs, a shared understanding of appropriate points of intervention, and support and treatment for families and carers as well as those they care for. It should also contain a clear framework for assessing issues of guardianship and ethics, health and safety.
4. **Provide an information portal with resources for families and carers to help them navigate supports for those they care for and for themselves**.

Invest in a continuum of care and support and services for families and carers

5. **Invest in a continuum of locally provided, specialist therapeutic, clinical, psychosocial and practical support services for families and carers.** This will support them to manage their own emotional challenges related to those they care for, reduce their own sense of social isolation and stigma and share knowledge and awareness of effective support for those they care for. This should include:
   - local online and face to face peer support for families and carers;
   - specialist counselling support services; and
   - specialist information, training and programs to enhance families and carers awareness and skills to support those they care for to age well at home. Such programs should include how they can minimise family disruption and maximise help-seeking from those they care for, and support those they care for to access specialist services.

6. **Within existing models of federal and state-based community supports, develop pathways to specialist advice for families and carers to support them in assisting those they care for to age well at home.** This should include consideration of how the reformed model of aged care gateway services, NDIS Local Area Coordinators and assessments for Home and Community Care can incorporate specialist information and advice services for consumers and their families.

Build our understanding of the continuum of care and supports needed for those they care for to age well at home

7. **Undertake consumer-led design of the continuum of care and specialist support services for older Tasmanians living with hoarding and/or CMHH.**

8. **Consider the opportunities offered by ‘conversation gateways’ to maximise help-seeking amongst older Tasmanians living with hoarding and/or CMHH.** This includes planning for ageing and end of life with the support of GPs and other healthcare services.

References

Anonymous 2020, 'Going down with the ship: a daughter's observations on hoarding', in *Children Australia*, vol. 45, pp. 167-169.

Australian Bureau of Statistics (ABS) 2016, *Census Quick Stats*.

Australian National University (ANU) 2016, *Australian hoarders falling between the gaps*, viewed March 2021, https://www.anu.edu.au/news/all-news/australian-hoarders-falling-between-the-gaps.

Ayers, C, Loebach Wetherell, J, Schiehser, D, Almklov, E, Golshan, S & Saxena, S 2013, 'Executive functioning in older adults with hoarding disorder', in International Journal of Geriatric Psychiatry, vol. 28, no. 11, pp. 1175–1181.

Bratiotis, C 2013, 'Community hoarding task forces: a comparative case study of five task forces in the United States', in *Health and Social Care in the Community*, vol. 21, no. 3, pp. 245-253.

Bratiotis, C, Sorrentino Schmalisch, C & Steketee, G 2011, *The Hoarding Handbook: A guide for human service professionals*, Oxford University Press.

Brown, F & Pain, A 2014, 'Developing an approach to working with hoarding: space for social work practice', in *Social Work in Action*, vol. 26, no. 4. pp. 211-224.

Buscher, TP, Dyson, J & Cowdell, F 2014, 'The effects of hoarding disorder on families: An integrative review', in *Journal of Psychiatric and Mental Health Nursing*, vol. 21, pp. 491-498.

Castrodale, L, Bellay, Y, Brown, C, Cantor, F, Gibbins, J, Headrick, M, Leslie, M, MacMahon, K, O'Quin, J, Patronek, G, Silva, R, Wright, J & Yu, D 2010, 'General public health considerations for responding to animal hoarding cases', in *Journal of Environmental Health*, vol. 72, no. 7, pp. 14-18.

Chabaud, S 2020, 'Children in hoarded homes: a call for protection, prevention, intervention and compassionate care', in *Children Australia*, vol. 45, pp. 186-192.

Chou, CY, Tsoh, J, Vigil, O, Bain, D, Uhm, S, Howell, G, Chan, J, Eckfield, M, Plumadore, J, Chan, E, Komaiko, K, Smith, L, Franklin, J, Vega, E, Delucchi, K & Mathews, C 2018a, 'Contributions of self-criticism and shame to hoarding', in *Psychiatry Research*, vol. 262, pp. 488-493.

Chou, CY, Mackin, R, Delucchi, K & Mathews, C 2018b, Detail-oriented visual processing style: Its role in the relationships between early life adversity and hoarding-related dysfunctions, in *Psychiatry Research*, vol. 267, pp. 30-36.

Council on the Ageing Tasmania (COTA Tas) 2018, *Embracing the Future: Tasmania's ageing profile Part 1*, COTA Tasmania, Hobart.

Danet, M & Secouet, D 2018, 'Insecure attachment as a factor in hoarding behaviours in a non-clinical sample of women', in *Psychiatry Research*, vol. 270, pp. 286-292.

Davidson, E, Dozier, M, Mayes, T, Baer, K & Ayers, C 2020, 'Family and social functioning in adults with hoarding disorder', in *Children Australia*, vol. 45, pp. 159-163.

Deloitte Access Economics 2020, *The Value of Informal Care in 2020*, Carers Australia.

Department of Health Australia (DoH [Au]) 2020, *Commonwealth Home Support Programme: Program Manual 2020-2022*, Commonwealth Government.

Department of Health & Ageing South Australia (DoHA) 2013, *A foot in the door: Stepping towards solutions to resolve incidents of severe domestic squalor in South Australia*, Government of South Australia, Adelaide.

Department of Health Victoria (DOH [Vic.]) 2012, *Discussion Paper: Hoarding and Squalor*, State Government Victoria.

- 2013, *Hoarding and squalor: a practical resource for service providers*, State Government Victoria.

Department of Health Tasmania (DoH [Tas]) 2015, *Rethink Mental Health: better mental health and wellbeing – a long term plan for mental health in Tasmania 2015-2025*, Tasmanian Government, Hobart.

- 2019, *Mental Health Integration Taskforce Report and Recommendations*, Tasmanian Government, Hobart.

2020a, *Reform agenda for the alcohol and other drugs sector in Tasmania*, Tasmanian Government, Hobart.

2020b, *Tasmanian Home and Community Care (HACC) Program Manual Update 2020*, Tasmanian Government, Hobart.

Department of Premier and Cabinet Tasmania (DPaC) 2017, *Strong Liveable Communities: Tasmania's active ageing plan 2017-2022*, Tasmanian Government, Hobart.

Department of Social Services Australia (DSS [Au]) 2020, *Integrated Carer Support Service Model*, viewed March 2021, https://www.dss.gov.au/disability-and-carers-carers/integrated-carer-support-service-model.

Firsten-Kaufman, E & Hildebrandt, C 2016, *What are effective interventions for hoarding? Rapid Review, Evidence Exchange Network for Mental Health and Addictions*.

Fleury, G, Gaudette, R & Moran, P 2012, 'Compulsive hoarding: overview and implications for community health nurses', in *Journal of Community Health Nursing*, vol. 29: no.3, pp. 154-162.

Frost, R, Steketee, G & Williams, L 2000, 'Hoarding: a community health problem', in *Health and Social Care in the Community*, vol. 8, no. 4, pp. 229-234.

Garrett, C 2020, 'The perspective of children of hoarding parents (COHP)', in *Children Australia*, vol. 45, pp. 164-166.

Giddens, A 1982, *Sociology: A brief but critical introduction*, Macmillan Publishers.

Guinane, J, Bailey, D, Fuge, F & Sook, M 2019, 'Analysis of patients referred for aged care assessment with concerns related to hoarding or squalor', in *Internal Medicine Journal*, vol.49, pp. 1313-1316.

Hoarding and Squalor Working Group Northern Tasmania (H&SWG) 2017, *Hoarding and Squalor in Tasmania Policy Paper*, unpublished.

Hojgaard, D & Skarphedinsson, G 2020, 'Assessment, treatment and the importance of early intervention of childhood hoarding', in *Children Australia*, vol. 45, pp. 145-152.

Kim, H-J, Steketee, G & Frost, R 2001, 'Hoarding by elderly people', in *Health and Social Work*, vol. 26, no. 3, pp. 176-184.

Koenig, T, Chapin, R & Spano, R 2010, 'Using multidisciplinary teams to address ethical dilemmas with older adults who hoard', in *Journal of Gerontological Social Work*, vol. 53, no. 2, pp. 137-147.

Koenig, T, Spano, R, Leiste, M, Holmes, R & Macmillan, K 2014, 'Multidisciplinary teams' practice strategies with older adult clients who hoard', in *Social Work in Mental Health*, vol. 12, no. 1, pp. 81-97.

Kysow, K, Bratiotis, C & Lauster, N 2020, 'How can cities tackle hoarding? Examining an intervention program bringing together fire and health authorities in Vancouver', in *Health, Social and Community Care*, vol. 28, pp. 1160-1169.

Lancombe, M & Cossette, B 2018, 'The role of public health in the development of a collaborative agreement with rural and semi-urban partners in cases of severe domestic squalor and hoarding', in *Community Mental Health Journal*, vol. 54, pp. 766-772.

Lee, S, Lewis, M, Leighton, D, Harris, B, Long ,B & Macfarlane, S 2017, 'A comparison of the neuropsychological profiles of people living in squalor without hoarding to those living in squalor associated with hoarding', in *International Journal of Geriatric Psychiatry*, vol. 32, pp. 1433-1439.

Lockwood, R 2018, 'Animal hoarding: the challenge for mental health, law enforcement, and animal welfare professionals', in *Behavioural Science Law*, vol. 36, pp. 698-716.

McGuire, J, Kaercher, L, Park, J & Storch, E 2013, 'Hoarding in the community: a code enforcement and social service perspective', in *Journal of Social Service Research*, vol. 39, pp. 335-344.

Moulding, R, Nedeljkovic, M, Kyrios, M, Osborne, D & Morgan, C 2017, 'Short-term cognitive-behavioural group treatment for hoarding disorder: A naturalistic treatment outcome study', in *Clinical Psychology and Psychotherapy*, vol. 24, no. 1, pp. 235-244.

Muroff, J, Underwood, P & Steketee, G 2014, *Group Treatment for Hoarding Disorder: Therapist Guide*, Oxford University Press.

Neziroglu, F, Upston, M & Khemlani-Patel, S 2020, 'The psychological, relational and social impact in adult offspring of parents with hoarding disorder', in *Children Australia*, vol. 45, pp. 153-158.

Nous Group 2018, *Wellness and reablement: Summary of consultations in the home care sector*, report commissioned by the Department of Health (Australia).

Park, J, Lewin, A & Storch, E 2014, 'Adult offspring perspectives on parental hoarding behaviour', in *Psychiatry Research*, vol. 220, pp. 328-334.

Pittman, J, Davidson, E, Dozier, M, Blanco, H, Baer, K, Twamley, E, Mayes, T, Somerfield, D, Lagre, T & Ayers, C 2020, 'Implementation and evaluation of a community based treatment for late-life hoarding', in *International Psychogeriatrics*, pp. 1-34.

Roane, D, Landers, A, Sherratt, J & Wilson, G 2017, 'Hoarding in the elderly: a critical review of the recent literature', in *International Psychogeriatrics*, vol. 29, no. 7, pp. 1077-1084.

Royal Commission into Aged Care Quality and Safety (Royal Commission) 2019, *Carers of Older Australians: Background Paper 6*, The Office of the Royal Commission.

- 2021, *Final Report: Care, Dignity and Respect*, The Office of the Royal Commission.

Sarantakos, S 1998, *Social Research*, Macmillan Press.

Seale, C (ed.) 2001, *Researching Society and Culture*, Sage Publications.

Snowden, J & Halliday, G 2009, 'How and when to intervene in cases of severe domestic squalor', in *International Psychogeriatrics*, vol. 21, no. 6, pp. 996-1002.

Snowden, J, Shah, A & Halliday, G 2007, *Severe Domestic Squalor: A Review*, published online by Cambridge University Press (Sept 2006). International Psychogeriatrics. 19:37-51. Copyright International Psychogeriatric Association. Printed UK.

Stark, D 2013, *Beyond Overwhelmed: identifying pathways to deliver more effective services for people and their pets affected by hoarding and squalor across NSW*, NSW Hoarding and Squalor Issues Paper, commissioned by the NSW Hoarding and Squalor Taskforce.

Steketee, G & Frost, R 2007, *Compulsive Hoarding and Acquiring: therapist guide*, Oxford University Press.

Steketee, G, Frost, R & Kim, H-J 2001, 'Hoarding by elderly people', in *Health and Social Work*, vol. 26, no. 3, pp. 176-184.

Tolin, D, Frost, R, Steketee, G, Gray, K & Fitch, K 2008 'The economic and social burden of compulsive hoarding', in *Psychiatry Research*, vol. 160, no. 2, pp. 200-211.

Tolin, D, Fitch, K, Frost, R & Steketee ,G 2010a, 'Family informants' perceptions of insight in compulsive hoarding', in *Cognitive Therapy and Research*, vol. 34, pp. 69-81.

Tolin, D, Meunier, S, Frost, R & Steketee, G 2010b, 'Course of compulsive hoarding and its relationship to life events', in *Depression and Anxiety*, vol. 27, pp. 829-838.

Tolin, D, Frost, R & Steketee, G 2014, *Buried in Treasures: Help for compulsive acquiring, saving and hoarding*, Oxford University Press.

Tompkins, M 2011, 'Working with families of people who hoard: a harm reduction approach', in *Journal of Clinical Psychology*, vol. 67, no. 5, pp. 497-506.

Visvanathan, R, Amare, A, Wesselingh, S, Hearn, R, McKechnie, S, Mussared, J & Inacio, M 2019, 'Prolonged wait time prior to entry to home care packages increases the risk of mortality and transition to permanent residential aged care services: finding from the registry of older south Australians (ROSA)', in *Journal of Nutrition, Health and Ageing*, vol. 23, no. 3, pp. 271-280.

Whomsley, S 2020, 'An overview of hoarding difficulties in children and adolescents', in *Children Australia*, vol. 45, pp. 182-185.

Wilbram, M, Kellett, S & Beail, N 2008, 'Compulsive hoarding: A qualitative investigation of partner and carer perspectives', in *British Journal of Clinical Psychology*, vol. 47, pp. 59-73.

Appendix 1: Treasured Lives acronyms and definitions

ACAT

Aged Care Assessment Team. These are teams of medical, nursing and allied health professionals who assess the physical, psychological, medical, restorative, cultural and social needs of older Australians to help them and their carers to access appropriate levels of support for aged care.

CHSP

Commonwealth Home Support Program. This program helps older Australians with entry-level supports to live independently and stay at home. Supports my include those to keep people 'well and healthy', such as meals, personal care, nursing and allied health and respite care; supports to ensure their home is safe, such as domestic assistance, home maintenance and modifications equipment; supports to stay connected with community, such as transport and social support; and homelessness services for those who need it.

CMHH

Challenges maintaining a healthy home. The term used in Treasured Lives documents, fieldwork and reporting for domestic "squalor".

COTA Tas

Council on the Ageing Tasmania. Peak body representing older Tasmanians.

DoC

Department of Communities Tasmania. This State Government department aims to create strong, active and inclusive communities. It oversees a range of strategies and services to deliver this, including housing and homelessness, disability and community support.

DoH Aus

Department of Health (federal). It is the federal Government department that oversees aged care support.

DoH Tas

Department of Health (state). This State Government department manages government health services for the wellbeing of all Tasmanian. This includes the delivery of Ambulance Tasmanian and public health services, and the planning, purchasing and performance management of key physical and mental health services, delivered by other agencies, such as the THS.

DPAC

Department of Premier and Cabinet. This is the central agency for the State Government. Its services include delivering programs that improve the wellbeing of Tasmanians and leading and coordinating whole of government policies and strategies.

DSM-5

Diagnostic and Statistical Manual of Mental Disorders Five. This manual is used as a guideline to support the classification and diagnosis of mental health issues in Australia and internationally.

HACC

Home and Community Care. This program provides grant-based maintenance, support and care services for adults whose independence is at risk due to acute health events, moderate functional impairment or deterioration of an ongoing condition. The program will also support their carers. Adults are defined as people aged less than 65, or less than 50 if of Aboriginal or Torres Strait Islander heritage. It is funded through the Tasmanian Department of Health.

HCP

Home Care Package. This program helps older Australians to live independently home. It is for those who have more complex needs than those accessing CHSP. The range of supports is similar to those described for CHSP.

Hoarding

'*The accumulation of a vast amount of possessions which compromises living spaces and causes impairment in social and occupational functioning*' (Tolin et al. 2011, cited in Guinane et al. 2019).

Housing Connect

This service helps low income Tasmanians to find or maintain appropriate and affordable homes either in the emergency, private, public or social housing sectors. The service also offers information, advice and referral to other agencies and financial support. They do not directly house people.

LGAT

Local Government Association of Tasmania. The peak body representing the interests of Local Councils in Tasmania.

My Aged Care

This federal Government service is the information service to help older Australians find the right aged care support for them.

PHT

Primary Health Tasmania is one of 31 similar organisations under the Australian Government's Primary Health Networks Program. Primary Health Tasmania (Tasmania PHN) is a non-government, not-for-profit organisation working to fund initiatives that connect care and keep Tasmanians well and out of hospital.

Reablement

Reablement is one of the goals for home-based aged care. It emphasises assisting people to regain functional capacity and improve independence. Similar to rehabilitation, it is goal-oriented and aims at full recovery where possible. It seeks to enable people to live their lives to the fullest.

SARC

Social Action and Research Centre. This centre is fully funded by Anglicare Tasmania. It exists to undertake research, policy and advocacy towards achieving a just Tasmania.

Service provider

An organisation or agency providing community or health related service for children, adults and older people. They may be universal services (for example My Aged Care), or targeted services based on a specific need, such as mental health, disability or aged care services. The organisation may be a contracted agency of Government service delivery (such as the Tasmanian Health Service, providing statewide mental health services), a not for profit organisation from the community sector contracted to provide services to the community, such as Anglicare Tasmania or the Salvation Army providing housing and homelessness services or Aged Care Home Care Packages, or a for profit company contracted to provide services in the community and health sector, such as Oak Possability providing disability support services.

SHS

Specialist Homelessness Services provide more intensive help than Housing Connect for those who need it to find housing and other accommodation. They can also provide advice, advocacy and financial supports. SHS can only be accessed via Housing Connect.

Squalor

Domestic squalor is specifically describing an environment, not the people living in it. So it is not a "diagnosis", but, 'a description of the appearance and perceptions of a dwelling which reflect a complex mixture of reasons why a person, couple or group are living in such conditions' (DoH [Vic.] 2012). Within Treasured Lives documents, fieldwork and reporting, this will be referred to as 'challenges related to maintaining a healthy home'.

Support services

Community or health related services for children, adults and older people. These include pre- and post-natal services, family support, disability services, housing and homelessness support, aged care, clinical and community-based mental health services.

THS

Tasmanian Health Service. The agency commissioned by the state Government Department of Health (DoHs) to deliver physical and mental health services.

Wellness

Wellness is one of the goals for home based aged care. It emphasises identifying needs, aspirations and goals. It acknowledges and builds on strengths and has a focus on integrating support services as a path to greater independence and quality of life.

Appendix 2: Resources for families and carers

This is a selected list of resources that may be useful for families and carers of those living with hoarding and/or maintaining a healthy home.

It is not a comprehensive list. It has been curated by this project based on the following criteria:

The resource/program:

- offers a responsible coverage of the context for hoarding and/or CMHH;
- explains the approaches to support within that context; and/or
- raises awareness and positive engagement about hoarding and/or CMHH.

The resource list includes:

- Books
- Websites
- Multimedia
- Training
- Peer support

Books

Buried in Treasures

Date: (2nd ed. 2013).

Author: David Tolin, Randy Frost and Gail Steketee.

Target group: People who have a problem with hoarding, with asides for families and friends and professionals.

Description: Self-help treatment program.

Digging Out: Helping your loved one manage clutter, hoarding and compulsive acquiring

Date: 2009.

Author: Michael Tompkins and Tamara Hartl.

Target group: Families and friends of people who have a problem with hoarding.

Description: Practical advice focusing on harm reduction and salvaging relationships.

Children of Hoarders: How to minimize conflict, reduce the clutter, and improve your relationship

Date: 2013.

Author: Fugen Neziroglu and Katharine Donnelly.

Target group: Adult children of people who have a problem with hoarding.

Description: Aimed at helping CoH manage their own emotions. Uses Cognitive Behavioural Therapy, mindfulness etc.

Stuff: Compulsive hoarding and the meaning of things

Date: 2010.

Author: Randy Frost and Gail Steketee.

Target group: General audience.

Description: Case studies and exploration of the psychology of hoarding.

Dirty Secret: A daughter comes clean about her mother's compulsive hoarding

Date: 2011.

Author: Jessie Scholl.

Target group: General audience.

Description: Memoir of the daughter of a hoarder.

Coming Clean

Date: 2014.

Author: Kimberley Rae Miller.

Target group: General audience.

Description: Memoir of the daughter of a hoarder.

White Walls: A memoir about motherhood, daughterhood and the mess in between

Date: 2016.

Author: Judy Batalion.

Target group: General audience.

Description: Memoir of the daughter of a hoarder.

Websites

Children of Hoarders

Date: 2006–

Run by: Volunteer grassroots non-profit.

Target group: Children of hoarders.

Description: Biggest and best known online support for family members of hoarders. Resources, information and support.

r/hoarding

Date: 2011–

Run by: Hosted by large social media platform Reddit, run by volunteer moderators. Reddit has 52 million daily active users; r/hoarding has 34000 registered members.

Target group: 'For those affected by hoarders, hoarders themselves or people interested in it'.

Description: Public discussion forum offering advice and support. People post questions, share their feelings and experiences, and personal progress. Has a wiki with comprehensive info and resources.

International OCD Foundation

Run by: Non-profit promoting awareness and providing resources and support for people affected by OCD.

Target group: For people affected by hoarding, including families, mental health professionals and community responders.

Description: Website with information and resource directory.

Maroondah Hoarding and Squalor Network

Run by: Forum for agencies and community groups in City of Maroondah, Victoria.

Target group: General community, including hoarders and their families, and the community sector.

Description: Excellent introductory articles. Comprehensive resource guide for Maroondah locals and others.

Pathways through the maze

Run by: Catholic Community Services.

Target group: Hoarders, families, and service providers.

Description: Basic information, resources and training.

Hoarding Home Solutions

Run by: For-profit training and coaching provider.

Target group: Hoarding clients, their families and professional service providers.

Description: Good resources page, blog and free newsletter.

Multimedia

Hoarding Home Solutions

Author: International OCD Foundation.

Medium: YouTube.

Description: A playlist of short (2-3 minute) videos explaining hoarding disorder and giving tips for family members.

Clutter Chronicles

Date: 2017-2020.

Author: Lori Koppelman.

Medium: Podcast.

Description: Described as, 'An ongoing conversation with Mary, who calls herself a recovering hoarder. She is willing to share her up-til-now very private life in an effort to be helpful to others, may they be packrats, someone who loves a hoarder or those who just want to understand something that's mystifying to them.'

The Hoarding Solution Podcast

Date: 2020-

Author: Tammi Moses.

Medium: Podcast.

Description: Described as, 'Join us on a DEEP Dive into Hoarding Issues & HOW we as a community can approach this issue with compassion, kindness & awareness!'.

The Hoarding Solution Podcast

Date: 2015.

Author: ABC Radio.

Medium: Archived radio broadcast.

Description: An interview with Jessica Grisham, a clinical and research psychologist at the University of New South Wales.

The psychology of hoarding

Date: 2016.

Author: ABC Radio.

Medium: Archived radio broadcast.

Description: Interviews with Professor Randy Frost (co-author of *Buried in Treasures*), a support worker, and two people who have hoarding behaviours.

Training

Hoarding Home Solutions Family & Friends

Cost: Fee to be paid.

Run by: Hoarding Home Solutions.

Target group: 'Anyone concerned about a loved one's hoarding'.

Description: Online. Workbooks, video lessons, real life stories and resources and tools. 12 x 1-hour sessions (recommended).

Understanding and treating hoarding disorder

Cost: Fee to be paid.

Run by: University of Sydney.

Target group: Open to everyone, but mainly targeted at professionals.

Description: Online; one 8-hour session. Covers aetiology, assessment and therapy (Cognitive Behavioural Therapy).

Virtual Hoarding Awareness Training

Cost: Fee to be paid.

Run by: Hoarding Disorders UK.

Target group: Practitioners and staff, family and friends.

Description: Online. 4.5 hours over one day. Covers understanding hoarding, how to help and further knowledge. An advanced course is also available.

Helping People who Hoard: Alternatives to nagging, pleading, and threatening

Cost: Free.

Run by: Michael Tompkins via IOCDF.

Target group: Family members.

Description: 44-minute Youtube video. Covers dealing with people who refuse help and repairing damaged relationships.

Family as Motivators

Cost: Free via GP referral.

Run by: Lifeline Harbour to Hawkesbury.

Target group: Family members and carers.

Description: One 2-hour session per week for 10 weeks. 'How to encourage a person with hoarding disorder to seek help and look after your own wellbeing.' In person in Sydney.

Hoarding and squalor training in effective service responses

Cost: Not given.

Run by: Catholic Community Services.

Target group: Service providers, relatives and anyone with an interest.

Description: Full day workshop. Unclear whether online or in person. Half day introductory workshop also available.

Understanding animal hoarding

Cost: Fee to be paid.

Run by: Animal Courses Direct.

Target group: Staff working in animal rescue and social services.

Description: Online. Study time 10 hours.

How to help someone who hoards

Cost: Free.

Run by: Hoarding Home Solutions.

Target group: Anyone dealing with a hoarding situation.

Description: Online. 40 minute video.

Peer support

Adult Children of Hoarders

Platform: Facebook.

Run by: Children of Hoarders.

Aimed at: Adult children of hoarders.

Description: 'A place to get support, share experiences and feelings, and sometimes laugh at the absurdity of it all – without judgment'.

Family and Friends of Hoarders Support Group

Platform: Facebook.

Run by: Children of Hoarders.

Aimed at: Family and friends of hoarders.

Description: 'A safe place to be able to let out the frustration of living with a hoarder.'

MYCOHP

Platform: Groups.io

Run by: Children of Hoarders.

Aimed at: Minor children of hoarding parents.

Description: 'A safe, understanding, peer support group for minors and youth living in hoards.'

Children of Hoarders

Platform: Groups.io

Run by: Children of Hoarders.

Aimed at: Adult children of hoarders.

Description: 'Join us for support, information sharing, and understanding… a community of people who grew up the same way or have similar adult experiences and can relate'.

r/hoarding

Platform: Reddit.

Run by: Volunteer moderators .

Aimed at: 'For those affected by hoarders, hoarders themselves or people interested in it'.

Description: Public discussion forum offering advice and support. People post questions, rants/venting, and personal progress.

r/ChildofHoarder

Platform: Reddit.

Run by: Volunteer moderators.

Aimed at: 'For the children, friends, loved ones of hoarders'.

Description: Public discussion forum offering advice and support. People share stories, ask questions and vent their frustration.

Hoarding/Cluttering Support Group

Platform: Facebook.

Run by: Unknown.

Aimed at: 'A support group for Hoarders and those with Clutter problems – and for those impacted by Hoarding'.

Description: 'What we're trying to do in this group is to provide tools, education and information - in addition to support for everyone impacted by Hoarding – and that includes loved ones, social workers, therapists, organizers, and clean-up crews … not on any formal basis – but as a grass-roots effort. We're learning from each other.'

Hoarding and clutter anxiety support group

Platform: Zoom.

Run by: ARCVic.

Aimed at: Unknown whether this is for families or for hoarders themselves.

Description: Peer online support group facilitated by ARCVic volunteers.

Arafmi Carer Support Group

Platform: Zoom.

Run by: Arafmi.

Aimed at: 'Parents, partners, relatives and friends caring for/about a loved one with mental illness'.

Description: 'A supportive environment where people have the opportunity to talk about their feelings, help explore alternative ways of coping, offer support to other group members, or to simply listen and observe'.

Safe Spaces

Platform: Face-to-face and Zoom.

Run by: Mental Health Families and Friends Tasmania.

Aimed at: 'Families and friends who support a person with mental ill health'.

Description: 'An opportunity to share experiences with others who understand the ups and downs'.


190
50
10
7