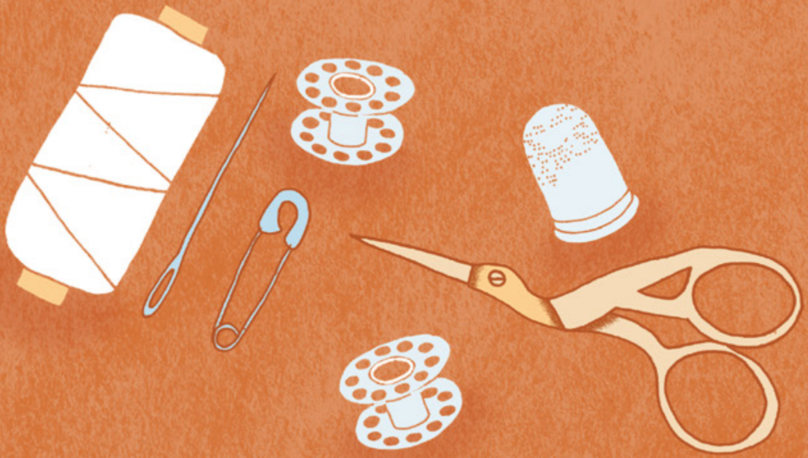
PHASE ONE: FAMILIES AND CARERS
RESEARCH BRIEF

# 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

# Contents

> *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**

**Author:**
Lindsey Fidler

**Project team:**
Selina Claxton and Ellen Nicholson

**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

AnglicareTAS
Choice, support and hope

SOCIAL ACTION & RESEARCH CENTRE

**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]

---

[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.

**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).

## 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… To me, I'm like, 'There's no stigma to [seeking help]. Be proud of yourself'…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.

---

[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 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.

**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 both to support 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.

## 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 full report, 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 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 CMHH 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 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 CMHH**.
8. **Consider the opportunities offered by ‘conversation pathways’ 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.

## References

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.

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.

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

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.

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 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.

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.

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.

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.

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.

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.

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

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 & 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 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.


190
50
7