



# Enabling Spaces

Supporting older people  
who hoard in Canterbury

### About the photos:

The images that start each chapter are photographs of an exhibition called *Waste Not* by Song Dong, of all the items his mother had accumulated in her house over decades.

His mother, Zhao Xiangyuan, came from a wealthy family that lost everything in the Cultural Revolution. Waste not was a survival tactic that she continued to the extreme. Another contributing factor to her hoarding was the immense loss and void created by the unexpected death of her husband. She refused to throw anything away, or move out and part with her possessions, until Song Dong proposed an art project to meaningfully recycle and preserve them.

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CHRISTCHURCH

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## Contents

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Executive summary	Page - 04
About the project	Page - 05
Understanding the context	Page - 08
Understanding the individual	Page - 14
Understanding the relationship	Page - 27
Understanding the policies	Page - 37
A final word	Page - 44
References	Page - 48
Appendices	Page - 51

## THE CONTEXT OF HOARDING

More than 2 out of every 100 people aged 50+ may hoard.

Older people are more likely to hoard and are more vulnerable to negative impacts.

People who hoard seldom seek treatment themselves.

Moving forward:

- ~ Collate service information
- ~ Explore hoarding in Māori elders



## UNDERSTANDING HOARDING FOR THE INDIVIDUAL

It helps to understand the ways clutter can arise: including from obsessive compulsive hoarding, hoarding disorder, or non-purposeful accumulation.

It helps to understand why it is hard to give up objects: emotional attachments can link to identity, security, or avoiding waste.

It helps to understand the impact for the individual and others: with social, physical, fire, and housing related risks.

Moving forward:

- ~ Provide guidance resources
- ~ Support public and family awareness



# Enabling Spaces

Supporting older people who hoard in Canterbury

THE CONTEXT

THE INDIVIDUAL

THE POLICIES

THE RELATIONSHIP

## RESOURCING AND POLICY

It helps to have resources: that enable long term support and are flexible, and include therapy and stepped care.

It helps to have integration: a coordinated multi-disciplinary approach with clear guidance about sharing information between agencies.

Moving forward:

- ~ Facilitate coordination
- ~ Fund hoarding support as a longer term commitment



## A PERSON-CENTRED APPROACH

It helps to establish trust: by being non judgemental, making a connection, and going at their pace.

It helps to create mutual goals: by respecting autonomy, building motivation, setting small meaningful goals, and focusing on safety.

Moving forward:

- ~ Provide guidance resources
- ~ Support public and family awareness





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## About the project

This project brings together information from a range of perspectives to help understand what great support for people who hoard might look like.

# The enabling spaces project

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People who hoard live with excessive amounts of 'stuff' which they have difficulty discarding. This clutter can render living spaces unusable, create health and safety risks, cause distress for the individual and those that support them, and lead to functional and social impairment.

The purpose of this scoping study was to synthesise information from stakeholders and relevant literature in order to inform effective person-centred practice, planning, and policy to support people who hoard in Canterbury.

This report reviews the key insights from the study, identifies available resources, and outlines potential initiatives that might improve Canterbury's capacity to provide appropriate support for people who hoard.

The report outlines key insights that emerged about

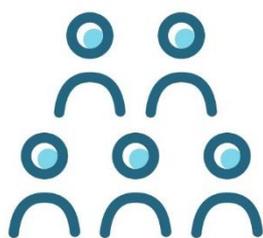
- The context of support for people who live with hoarding in Canterbury
- Understanding the meaning of hoarding for the individual
- Establishing trust and mutual goals
- Supportive policy and resource environment

**The primary focus is the person not the clutter: the goal is to reduce risk and promote the personal and social wellbeing of individuals who hoard.**



This scoping study engaged with stakeholders and the literature to ask:

- What features are important in service provision for people who hoard?
- What is working well currently to support people who hoard?
- What could ideal services for people who hoard look like?



Professional perspectives



Lived experience



Research literature

### Focus groups with representatives of stakeholder agencies

A series of three focus groups were held to build up a picture of the current context and what stakeholders see as important in support for people who hoard.

If a professional was unable to attend one of the focus groups, an individual interview was offered (4 participants). A total of 16 professionals took part in the discussions.

See Appendix A for a summary of the range of professionals and agencies involved.

### Interviews with people with personal or family experience with hoarding

Face to face interviews were utilised to hear from three people who have hoarding behaviours in their own home, and with one family supporter.

These discussions focussed on their experiences with hoarding and with support services, and what they value in these services.

See Appendix B for an overview of the lived experience interviews.

### A rapid review of the NZ and international literature

A rapid review of the research and grey literature was conducted to further understand the best practice approaches and tools that are currently available.

Priority was given to New Zealand work to the extent that it was available.



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## Understanding the context

To place hoarding in context generally and in Canterbury it is useful to understand what hoarding is, who hoards, and the effectiveness of forced clean-ups and therapy.

# The context of support for hoarding

*“Sometimes I get referrals...saying ‘they’re a hoarder and it’s really cluttered’ and I’ll go in and see there’s heaps of space...Look it’s not that bad”*

## What is hoarding?

The use of the term “hoarding” has varied across time and context. Throughout this report, hoarding is considered to be when ***a person has difficulties with:***

- 1 Accumulation of and difficulty discarding objects, regardless of their actual value
- 2 which results in excessive clutter in living spaces, restricting their use
- 3 creating significant risk, distress, or impairment of function

### Hoarding may or may not involve active acquisition.

For most people who hoard, belongings accumulate because the individual finds it difficult to discard possessions *and* excessively acquires new objects with a limited amount of storage space. If an individual is actively acquiring, limiting the objects coming into the home can be a good starting point for support (for example, stopping junk mail for someone who collected paper items). In some instances, however, accumulation is driven purely by avoidance of discarding commonly acquired objects.

**Hoarding applies to belongings regardless of their actual value.** While hoarded items are often things that others would see as worthless, any type of object can be accumulated.

*"[There is a woman] in a wealthy part of Christchurch who hoards china and crystal. Now, she's got boxes and boxes of it in her house with little alleyways. There's the bed, you know, but it's got boxes all around it, she climbs over the end of the bed to get into it...It's still a problem. It's still a safety issue."*

**Hoarding may or may not involve squalor.** Not all cases of hoarding involve squalor. Likewise, not all cases of squalor involve hoarding. Squalor refers to a living environment that is unsanitary due to extreme and/or prolonged neglect, and that poses substantial health and safety risks to the individual, the other people or animals living in the property, and/or neighbours<sup>1</sup>.

## How common is hoarding?

The most specific New Zealand study of the prevalence of hoarding estimated that 2.5% of a group of 50 year olds were experiencing pathological hoarding<sup>2</sup>. Another New Zealand study, using a collection of questions from existing InterRAI assessments rather than a specific hoarding measure, estimated that 3.5% of this more frail group may have hoarding issues<sup>3</sup> These figures are consistent with international research<sup>4</sup>. However identification is difficult and studies may underestimate hoarding prevalence as people who hoard may be reclusive, unwilling to self-report their behaviour, or lack insight.

**Who hoards?** Cultural differences in hoarding remain largely undocumented, with the majority of studies carried out in Europe or the USA with mainly Caucasian individuals. While hoarding is assumed to be a universal phenomenon, there is evidence that how people experience hoarding difficulties can vary across cultural contexts<sup>5</sup> and that Caucasians may be over-represented. In Canterbury, there is little evidence of Māori with hoarding difficulties coming to the attention of support services, and the professionals who attended focus groups had not been involved with cases involving Māori individuals. It remains to be seen whether this represents meaningful differences or another example of the disparities in Māori access to healthcare services<sup>6</sup>.

The prevalence of hoarding is probably approximately equal for males and females overall<sup>4</sup>. However, females are more likely to receive clinical services<sup>7</sup>. This could stem from differences in the willingness to ask for help or support.

**"Sometimes I've gone in and actively gagged. I just say: this is not safe for me and it's not safe for you to live like this"**



**" If they go in and do it lock, stock and barrel, six months and it will all be back and probably more so. It's them taking ownership to start with that's the hard bit!! "**



Hoarding behaviours occur across a wide socioeconomic spectrum, although they have been observed to become more common with lower household incomes<sup>8</sup>, meaning those who hoard are often unable to provide personal funding for support services.

**Why a focus on later life?** The data gathering in the present report was weighted towards services for older people, although this was not an exclusive focus. Behaviours that underly hoarding often begin as early as adolescence<sup>9</sup>, although it is often difficult to distinguish problematic behaviour from behaviourally appropriate saving and collecting at young ages<sup>10</sup>. Hoarding difficulties are chronic and progressive<sup>7</sup>, with the severity generally increasing over time and traumatic events later in life often exacerbating the behaviour<sup>11</sup>.

Often the presence of a partner or parent (with hoarding in children) can act as a mediator and prevent clutter building up<sup>12</sup>. Loss of this support system (often in older age, with the loss of a partner) or other events such as a decline in mental or physical capabilities, or even inheriting a large number of possessions from a deceased relative can exacerbate behaviours and result in the development of risk, distress, or disability<sup>13</sup>. Along with having more time to accumulate, older people may be particularly vulnerable to the negative impacts of hoarding due to increased risk of frailty, comorbid medical conditions, and cognitive impairment. A sobering indicator of the vulnerability of this group is the finding that elderly people who

hoard have a 5 year mortality rate of approximately 50%<sup>11</sup> compared with 26.7% in the wider population<sup>14</sup>. Given its ageing population, Canterbury will include an increasingly large group of older people who will potentially suffer the most from hoarding difficulties.

## What clinical treatments are effective?

The focus of this scoping study was on general support for older people who hoard and only a small segment of our participants were involved in a clinical treatment role. Furthermore, studies of clinical treatments have consistently high dropout rates<sup>14</sup>, emphasising the importance of considering the totality of support services and the relationship between individuals and support workers. Intervention studies also have relatively poor methodological quality<sup>15</sup>.

The literature is clear on what interventions are unsuccessful. One-time forced clean-ups produce poor outcomes<sup>16</sup>, and are cautioned against almost unanimously in the research and grey literature<sup>17-23</sup>. Although these types of interventions remove the clutter, this is often only a physical manifestation of the underlying problem. This means recurrence of hoarding behaviours is likely, which often makes the distress and costs unjustifiable.

*"Her daughter ordered in a skip. Throwing away her things was like throwing away her memories. She was upset."*

Much of the earlier clinical intervention work was formulated specifically for Obsessive Compulsive Disorder (OCD). This research also used OCD-based outcome measures which had very little analysis of hoarding-related behaviour.

There is some evidence for the efficacy of medications, with one meta-analysis (overview of research) finding that over half of participants with difficulties responded positively to medications used to treat depression<sup>24</sup>. However, again the interpretation of this research is limited as five out of seven studies did not use hoarding-specific measures.

Currently, the most effective treatment seems to be a multi component treatment protocol based on the cognitive behavioral therapy (CBT) model of hoarding developed by Steketee and Frost<sup>25, 26</sup>. This protocol has been shown to be effective at reducing hoarding severity<sup>19, 26, 27</sup>, particularly helping to overcome difficulty in discarding objects<sup>28</sup>. Though initially designed as an individual treatment, this CBT model has been adapted for group therapy<sup>29</sup>, bibliotherapy (in the form of a self-help book)<sup>30</sup> and has had early success as a webcam-based therapy. The individual therapy seems to be the most effective<sup>27</sup>, but other forms are less expensive to

offer. There is potential for a stepped-care model where individuals begin with the more accessible options and only progress to more resource-intensive therapy if needed.

## How do people who hoard enter services?

The unique attributes and needs of people who hoard largely preclude the use of the traditional healthcare identification model, where a concerned individual will request help from their general practitioner and be treated or referred elsewhere. The social isolation, shame and/or lack of insight into the problematic nature of their hoarding often mean that people who hoard will not seek treatment themselves. Hoarding is often not brought to the attention of any support services until the person is referred by others who are concerned about the hoarding, or housing agencies run into problems with the person's hoarding<sup>31</sup>. In the focus groups the accumulation was often identified because the person came into contact with services for another reason, such as other mental health issues, a hospital admission, or following a domestic fire. In Canterbury a number of people who hoard were identified due to housing disruptions in the 2011 and subsequent earthquakes<sup>19, 32</sup>.

**“ And she said ‘there’s a little bit of stuff lying around’. You couldn’t open the door. She had never been in the system, she had no NHI, no nothing. She fell and broke her arm, her humerus, and ended up at public, then ended up at Burwood. It was nothing to do with the hoarding, she fell outside because she had the wrong shoes on. No one knew what was going on until the OT came out here. ”**



# Steps to consider

## to help understand the context of hoarding in Canterbury

### Collating information on service use.

Within the focus groups there were instances when a professional from one sector was surprised by the numbers encountered or mentioned by someone working in a different context. There is very limited data available on the actual numbers of people who hoard to inform service planning. This lack may be particularly salient when attempts are made to justify funding for initiatives.

As noted, there are considerable difficulties involved in attempting to research the prevalence of hoarding. One potential step to consider is to explore the feasibility of a systematic collation of the numbers of individuals who hoard that are known across agencies. While this would only provide a lower limit for estimating the size of the issues, it would provide initial hard data that is currently lacking. Another potential step to consider is to more formally document and analyse the anecdotal stories of cases of hoarding uncovered subsequent to the Canterbury earthquakes, to identify any lessons around the types of cases that were previously unidentified and if there were particular aspects of response in that situation that were effective.

### Exploring hoarding in the Māori community and service responsiveness.

Anecdotally, none of the professionals who attended focus groups had been involved in support for hoarding for an individual who identified as Māori. It was speculated that the differences in cultural values could mean that there is less emotional attachment to personal possessions, possibly reducing the prevalence of hoarding amongst Māori elders compared to the non-Māori population. Alternately there is the concern that there are underlying issues of accessibility and appropriateness that are limiting service use among older Māori who hoard. A potential step to consider is to consult with service providers who work with older Maori to gather information about whether there are any known cases, whether their needs are being met outside mainstream services, and how accessible culturally responsive support could be provided.



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## Understanding the individual

A cluttered living environment may come about in a range of ways, and have a range of meanings. Good support for people in challenging living environments needs to be based on an understanding of hoarding for that individual.

# It helps to understand the ways clutter can arise

*“First of all, I want to get to know the person. It’s not all related to obsessive acquiring, it can be related to trauma, it can be about keeping safe, it can be because they just don’t have organisational skills. I think it’s really important that you’re building that trust, you’re getting to know the person. And try, through your conversations, to define what’s driving the hoarding. Then you can look at how you’re going to approach it”.*

## A diagnosis of hoarding

Hoarding has come to be recognized as a distinct mental health issue, albeit one that is very often accompanied by other mental health issues. In some cases, there may be a specific diagnosis of hoarding. In other cases, a formal diagnosis is not available as the individual may not have had access or co-operated with a health professional. Arguably, hoarding is best viewed as a “disorder” in terms of being a maladaptive ‘way of being’, although an illness may underlie it.

A formal diagnosis of hoarding was seen as positive in some situations by the professionals. A diagnosis may provide a key to unlocking services. The diagnosis may help those around the individual to better understand the hoarding, rather than seeing it as a ‘lifestyle choice’<sup>19</sup> or ‘laziness’<sup>33</sup>.

It was also recognised however that a diagnosis or label of hoarding may be seen as stigmatising and people may reject services associated with it.

*“I know it’s a mental health issue and I’m pleased that people can be diagnosed now. But hoarding or hoarder... it just sounds so horrible I guess”*

## Compulsive hoarding

For some people the need to acquire or to avoid discarding certain things is caused by obsessions or compulsions. In the past, all hoarding was thought to be a symptom of obsessive compulsive disorder (OCD)<sup>15</sup>. It is now thought that OCD plays a role in around 20% of cases<sup>34</sup>.

*“I had to buy a wee pair of slip on slippers just for her place (her insistence). As I said, the place was absolutely filthy, it was dirty, it was smelly and she didn’t like you touching things because you would ‘contaminate things’. It didn’t make any sense but you’ve got to be respectful”*

## Hoarding disorder

Since 2013, hoarding has been considered a distinct mental disorder within the current edition of the DSM-5, the diagnostic handbook for mental disorders most commonly used in NZ. The DSM-5 classifies hoarding as persistent difficulty and distress associated with discarding items due to perceived need, resulting in the accumulation of possessions leading to significant impairment that is not attributable to a medical condition or better explained by the symptoms of another mental disorder<sup>35</sup>.

**Insight.** It has been estimated that around half of people who hoard do not view the issues associated with their hoarding as problematic<sup>20</sup>. Without this insight the person doesn’t “want to change” and this motivation to change was repeatedly seen as key by many of the professionals. For family members this lack of insight can be distressing and may increase the likelihood of family conflict<sup>27</sup>. For those seeking to provide support, a lack of insight can be one of the biggest challenges and necessitates a different starting point for beginning to work together.

### Non purposeful accumulation

Sometimes, excessive clutter can occur in the absence of intentional accumulation or resistance to discarding. This may be due to a lack of motivation or an inability to clean up effectively, for example because of depression or physical illness. Sometimes the clutter may develop due to the loss of organisational capabilities or awareness of what to keep due to cognitive impairment<sup>36</sup>. For these people it may be most effective to manage the underlying issue, provide support for a clean-up, and then provide appropriate on-going home-based support.

*“There was a couple who the gentleman was very compromised. He was on dialysis... just exhaustion on everyone’s part.”*

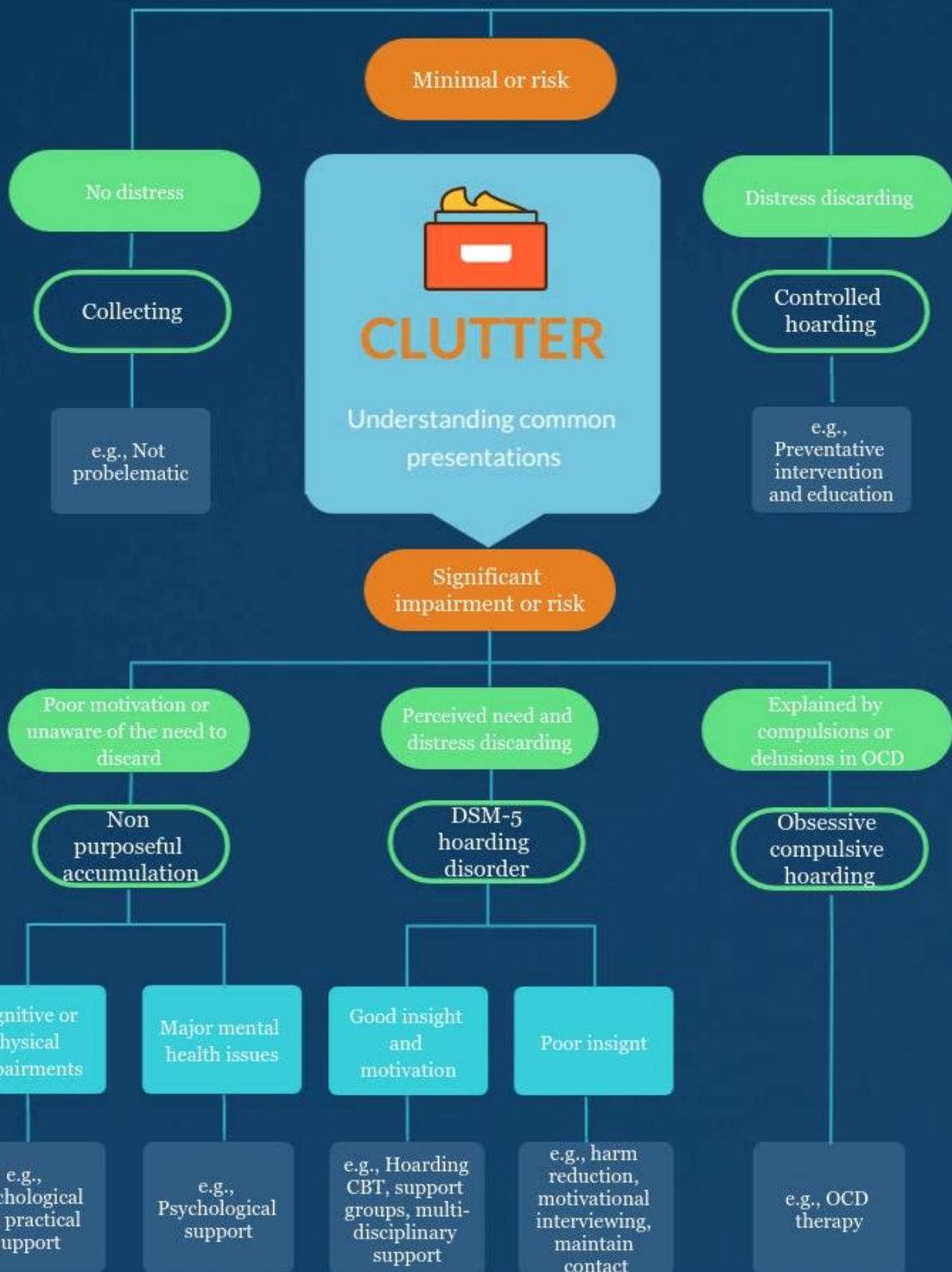
Understanding common presentations of clutter can be one of the factors that help professionals decide the best approach to support each individual. The figure on the page 15 provides a model for some underlying conditions that can manifest as a cluttered home. It also gives examples of how interventions may differ based on the circumstances.

### Controlled hoarding

In some cases, the psychology and behaviours underlying hoarding are present and the individual experiences distress and difficulty associated with discarding, but, for any of a multitude reasons, the clutter has not yet accumulated to a level that causes significant impairment or risk. An example may be a person whose spouse limits the accumulation of clutter within the house.

**“ sometimes people... they’ll rate it as something quite minor ‘oh, it’s not bad dear’. But I can’t open the door, and I have to climb. So that’s another interesting measure of insight. ”**





# It helps to understand why it is hard to give up objects

*“She took stuff to the Riccarton market to sell and her husband and daughter said what was left over is going to the op-shop. And she said, ‘I’m standing in front of the van’, [she was] crying and screaming that they were taking the stuff away”.*

When supporting people who hoard it can be tempting to see the clutter as innately problematic and to structure interventions around the goal of ‘cleaning up’. This is complicated by the fact that people have different standards of living and one person can live happily in an environment that would distress another. Accumulated possessions often provide a source of positive emotions<sup>15</sup> even in the face of overwhelmingly negative consequences.

## Attachment

We all value some objects in our life for different reasons. We may see them as having an essential functional role, conferring status, holding sentimental value, or possessing desirable aesthetic qualities. It can be useful to conceptualise hoarding as an extension of this as there is evidence that emotional attachment to objects plays an important role in hoarding behaviours<sup>37</sup>. People who hoard may form attachments to a wider range of objects than what is typical. Whatever the reasons, people who hoard value their possessions just as anyone else does and understanding this can help support people to better empathise with the distress involved in discarding them.

The level of attachment that an individual has to their belongings may influence whether an assisted cleanup is appropriate. For example, an individual who non-purposefully accumulates may benefit from a large-scale clean up and development of skills to maintain the change, whereas this is unlikely to be acceptable or helpful for a person with DSM-5 Hoarding Disorder.

*“For most of them, the bits they have are really precious. A lot of my clients are or were war children or*

*babies, so you don’t throw anything away because you might need it”*

## Vulnerabilities

There is often a family history of hoarding, for example with one study found that 85% of people who hoarded could identify another family member who also hoarded<sup>1</sup>. Hoarding behaviours are also associated with elevated risk of certain mental health disorders. Just under a quarter of people who hoard are estimated to have social phobia and approximately half to have major depressive disorder<sup>34</sup>.

*“One appointment we said ‘Okay, we are going to work this afternoon on how we are going to sort it and you can carry on that process’. But interestingly, the Aunty turned up as well because she hoards, mum hoards, grandma hoarded so they’re all wanting to learn”*

## Attention

Attention deficit problems<sup>38</sup> and information processing deficits<sup>27</sup> have also been associated with hoarding difficulties, and it has been theorised that categorisation and organisational deficits can play a role in the development of hoarding behavior and hinder progress with decluttering. This can have implications for those providing support, for example one professional talked about how she employed explicit strategies to help her clients focus.

*“They’re very distractible...they flit”*

Everyone places value on objects for different reasons. This can help cultivate empathy for the distress people experience in discarding hoarded objects. As one person said: *“You want to know my why?”*



Identity

Objects can hold value for the person through an association with positive memories, as a way to express how they see themselves, or through the potential to allow engagement in meaningful activities. Examples were given of an engineer who hoarded machinery, a woodworker who hoarded wood, a crafter who hoarded crafting materials, and a ‘giver’ who hoarded cookbooks. While for an outside observer the person may not ‘actually’ be engaged in these roles, it may be hard to give up the potential of leading the life they want to live.



Security

Social phobia, depression, and anxiety disorder are very common amongst people who hoard<sup>34</sup>. People who have more severe hoarding are more likely to have experienced traumatic life events. For example, one individual who was interviewed saw a link between her own accumulation and a period of intense emotional and financial insecurity as a young mother due to her partner’s alcoholism. People who hoard may find particular comfort from having their possessions<sup>38</sup>.



Avoiding waste

For some people it is hard to throw things away because this is seen as a waste. Some may believe that they are being ecologically friendly and helping the environment by not discarding the objects. Many anecdotes were shared about people who were entirely unwilling to relinquish belongings unless they were sure that they would be put to good use and not thrown out.



*" One of my daughters ... was quite vicious about what she was throwing out. Some of it she went through with me but then some of it she didn't and we ended up having a great row about it because I don't like to just throw things out if I can see that they can be used or reused or given to someone. I've always been mindful of recycling, composting and reusing. So I know I keep things that I'd probably be better just to dispose of. But also, I got really keen on quilting. I'd always been a sewer and used to knit. I like doing crafty things and so that part of me is really important. "*

*- lived experience of hoarding*

# It helps to understand the impact for the individual and others

*“One of my clients, she’s just so complex, she was referred for PTSD, depression, anxiety, all sorts of other stuff and hoarding just wasn’t seen as the main problem, but it was impacting on her a lot”.*

## Significant impact

Hoarding becomes a focus for intervention when there is risk, distress, and/or disability as a result of hoarding behaviours.

- **Risk** refers to the likelihood and imminence of future health and safety issues or diminished quality of life for the individual or for others as a result of the hoarding.
- **Disability**, also referred to as **functional impairment**, refers in this context to an inability to perform important activities. It is important that impairment is considered relative to societal norms *and* relative to the individual’s own values (i.e. whether the individual is able to perform the activities that matter to them).
- **Distress** refers to substantial negative emotions for the individual or for others associated with the hoarding, both distress acknowledged by the people themselves and that observed by others.

**Focus** A clear focus on whether or not the impact of hoarding has become truly significant can help to keep the person and their well-being central and to separate the personal values of support workers from the goals of successful support. This can help shift the focus from ‘cleaning up’ and aiming for social conformity to ensuring the safety and boosting the quality of life for someone experiencing hoarding difficulties.

*“It’s the safety goal. So, what is going to make it safe? Because, I personally believe that my house is my castle, I live the way I want to live in my house and what right do people have to tell me to do what I want to do in my own home. As long as it’s safe”*

**Measurement.** One of the most commonly used tools for assessing hoarding severity is the Clutter Image Rating Scale<sup>39</sup>, a set of visual examples which allows key functional rooms to be rated on a scale of one to nine. This score can be averaged to give an indication of the level of clutter in the home, along with an idea of the corresponding functional impairment. This tool can be used without any expertise and gives an easily understood rating, making it ideal for interagency communication based on the level of clutter. However, it does not gauge how the hoarding influences the individual’s wellbeing and is not sufficient in isolation as an assessment or outcome measure. There are a number of other measurement tools that assess the degree of distress and the impact of hoarding, probably the most used and well-validated being the Savings Inventory Revised (SI-R)<sup>26, 40</sup>.

# Risks of hoarding

Hoarding is associated with significant impairment across various aspects of functioning, as well lower quality of life<sup>41</sup>. The myriad of impacts that hoarding can have on an individual can be devastating, not only from their direct effects but also in how they accrue and influence an individual's wellbeing.



## Social

Social isolation and loneliness were identified as common for older adults who hoard both within the focus groups and the literature<sup>11,42</sup>. This may be a two-way interplay with hoarding placing a strain on relationships and loneliness exacerbating hoarding. Regardless of which comes first, hoarding or social isolation, hoarding often has a negative impact on social well-being. The presence of clutter or squalor may make an individual less likely to invite others to visit due to the fear of judgement and it may make others less likely to engage due to disgust. It can lead to frustration, confusion, and rejection amongst family members<sup>43</sup>. Well-intended attempts to help by colluding or by organising forced cleanups can further damage relationships<sup>13</sup>.

*“she said ‘no one has ever had a coffee with me in my house before. People don’t do it, If I offer they say no’.”*



## Physical

Clutter can increase the risk of falling, and of ‘clutter avalanches’ when a large pile of clutter falls on top of the occupant. Obstruction of spaces can make self-care difficult by limiting access to the bathroom or kitchen facilities<sup>45</sup> and significantly limit activities<sup>44</sup>. Major health concerns can arise if the hoarding behavior creates squalid or unhygienic conditions. This can include infestations, mould, rotting food, and even accumulation of excrement. These conditions can also endanger service providers and make it difficult to provide support

*“we’ve got disposable overalls, hand sanitizer, face masks and gloves. Big deal... I had one chap who said, ‘don’t put your hand anywhere but where I put mine’. He had live wires”.*



## Fire

Hoarded items such as clothes, papers, and books can create large fire loads and flammable surface areas. This represents a danger not only for the person who hoards but also for pets, dependents, emergency responders and occupants of surrounding properties. Severe clutter makes it extremely difficult for emergency services to enter and locate occupants. A study in Melbourne found that although hoarding fires made up only 0.25% of all residential fires, they accounted for a tragic 24% of all preventable domestic fatalities<sup>46</sup>.

*“When she turned around she saw the flames coming up the back of the couch.... She did manage to get out but the worst thing for her was that her cat didn’t. She couldn’t get in to the cat because of the clutter”*



## Housing

Hoarding in rental properties can pose serious challenges to housing agencies or other landlords, potentially damaging the home and causing complaints of neighbouring properties. This can eventually culminate in threats of eviction<sup>AD</sup>.

Anecdotally, two of the people with lived experience of accumulating mentioned the daunting nature of the accumulation as a reason for considering entering aged residential care.

## Statutory powers

When there is a reasonably imminent risk of serious harm to a person who is hoarding or to others, and the context prevents less restrictive approaches from being undertaken, there are legal avenues that can provide for compulsory interventions in certain limited circumstances. There are three main legal processes that may be relevant.

The Protection of Personal and Property Rights Act 1998 allows for citizens to appoint their own 'proxy agents' to act in their stead in respect of their property and their health and welfare: "Enduring Powers of Attorney". If a person is declared to have lost their capacity to manage their own affairs by a suitably qualified health practitioner, usually a doctor, their proxy decision-makers can make any decision required in the person's best interests, with the caveat that they should act in accordance with the person's prior competent wishes. The Family Court is also able to appoint proxy guardians for people who lack capacity to do so but did not set up EPOAs previously, or to make specific orders for the benefit of the subject person. This law is widely misunderstood and should not be viewed as a *carte blanche* for well-meaning proxy decision-makers to move a person out of their house or clear their hoard, however in some situations this may be warranted. Clinical and/or legal advice is recommended.

The City Council can, under the Health Act 1956 and section 131 of the Building Act 2004, issue a warning notice for an unsafe or unsanitary building, and if the issue is not addressed, it can prevent access to the building. The council can also apply for a court order to have the necessary work done. The Christchurch City Council released an updated Dangerous and Insanitary Buildings Policy in 2018.

Under section 126 of The Health Act 1956 (infirm and neglected persons), a Medical Officer of Health may apply to a court to have an "aged, infirm, incurable or destitute person" found to be living in insanitary conditions, committed to an appropriate hospital or institution. The person can be detained there under the order of committal. The Mental Health (Compulsory Assessment and Treatment) Act 1992 allows for compulsory assessment in a psychiatric hospital but only when there is reasonable suspicion (or definite diagnosis) of a psychiatric illness causing the hoarding-related risks and it is considered possible that psychiatric treatment might be helpful. These avenues cannot be used to enable state agencies to clear a house of material or to remove a person from their home for this purpose.

Across the focus groups and interviews, professionals from a range of roles consistently emphasised that these avenues are rarely employed. This reflected practical considerations of the high threshold for compulsory treatment applications, care models that supported a person's autonomy as much as possible, and a recognition that forced clean-ups are traumatic and seldom deal with the underlying issues. A key impetus for compulsion was when there was a risk to others.

*"In my mind, people have the right to make their own decisions about anything in life...Provided they recognise the risks and understand the risks that they are taking. So, it's like a 21-year-old going out and hand gliding or doing other risky things. There's a risk involved, they're aware of the risk involved and are prepared to take it. Where it becomes difficult and where you do have to intervene, is when there is a risk to others."*

# Steps to consider

## to help understand hoarding for each individual

### Provide guidance

A shared set of assessment tools could help keep the goals of minimising risk, disability, and distress at the forefront of support service planning and aid interagency integration. While a full suite of suggestions is beyond the scope of this report, the following hoarding specific measures may be of particular interest:

- Christchurch City Council uses a Hoarding Assessment tool which assesses living conditions and safety issues (see Appendix C). A version of this could potentially be used by other agencies with guidance about when and how a referral for council support would be recommended.
- Clutter Image Rating Scale (CIRS) (see Appendix D) provides photo cues to rate clutter which, as discussed earlier, can be a useful, but not a standalone, assessment and outcome measure. An innovative person-centred approach is to use the CIRS to celebrate and reinforce progress by providing the individual with an album of the photos across time. Some regions also use a CIS threshold to trigger a recommendation to refer the individual to fire service support, for example a CIS rating over 5.
- The Savings Inventory Revised (SI-R) is an example of a tool designed to measure hoarding-related distress and impact ( see Appendix E). There is again the potential to include guidance of thresholds for recommending referring / funding to stepped care CBT treatment options for people with insight into significant impact.

Ideally, this would form part of a person-centred best practice guide that integrates insights from national and international best practice and the current project with local information and pathways. Appendix F provides a list of some of the relevant agencies that may be involved, Appendix G provides a list of some examples of international person-centred educational resources, and Appendix H provides a list of New Zealand information on hoarding.

## Support public and family awareness.

The difficulties experienced by those who hoard have recently become more visible in the main stream media with reality television shows from overseas which depict forced clean-ups of severely hoarded houses. These shows do little to improve community understanding of pathological hoarding as a complex disorder with multiple possible causes. Without this perspective, hoarding and its impacts can be perceived disparagingly as the result of the individual's own choices that simply require a forced clean-up "for their own good". Increasing both awareness and understanding in the public may be beneficial for identification and support of people who hoard.

It can be difficult for family members and other non-professional supporters to understand and positively support a person who hoards. In our focus group discussions, this led to the suggestion of information resources aimed at family. An example of a resource aimed at families is the International OCD Foundation's "How to help a loved one with Hoarding Disorder". A possible step to consider is developing a local resource for families that can be available online and in hard copy to be given out by helping services. Hoarding is already included on the CDHB's HealthInfo Canterbury website so this provides a point of access for local information for families. Including hoarding as a topic on the Health Navigator website could be another point of dissemination.

To ensure that people who hoard are being identified and offered support, there must be a community network capable of referring people to services. Having clear and accessible referral pathways could have a positive impact, as members of the public who are concerned about themselves or others would be able to find and contact the relevant support services. In some places, programmes have trained non-healthcare workers who are engaged with the community to recognise signs of hoarding and refer individuals of concern<sup>Q</sup>. Increased clarity about when and where to refer, for example having a single point of entry that coordinated across agencies would enable clear messages about where to seek help to be included in any information materials.



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## Understanding the relationship

Great support for people in challenging living environments requires supporters to establish trust, support autonomy, and build motivation.

# It helps to establish trust

*“It’s taking that threat away that ‘here’s another stranger, coming into my home and is gonna chuck everything out, and tell me what to do, and judge me’ “*

## The challenge of trust

From both the literature and focus group discussions it is clear that working with people who hoard is complex and establishing trust is challenging. However, a pervasive theme throughout the focus groups was the need to establish trust with the individual and that the importance of this cannot be overstated. People who hoard are often very vulnerable, and the interviews of people with lived experience revealed the salience of being exploited or betrayed in the past. Letting someone into your home and accepting help can be incredibly exposing and requires a deep level of trust, yet trust is paramount for successfully supporting someone with hoarding difficulties.

*“I have had some really awful experiences and I’ve become very defensive”*

## Being non-judgemental

One of the largest barriers to building a trusting relationship that emerged was that people who hoard can feel judged or patronised. Judgement can be perceived in many forms and is often unintentional, making it vital for support workers to be aware of how they are communicating. Professionals in the focus groups stressed the

importance of language. For example, people are often uncomfortable with the term ‘hoarding’ and many professionals avoided this term entirely, instead mirroring the terms that the person themselves uses (such as ‘collecting’ or ‘keeping things’). Understanding other people’s experiences and acknowledging how interactions can affect them goes a long way.

Non-verbal communication was also discussed, such as the importance of keeping neutral body language and maintaining a ‘poker face’ rather than showing disgust, which can be challenging in squalid conditions. There was discussion that not every person is able to work in extreme conditions, or to build rapport with the individual, and it is important that there is permission for either party to be able to say when it would be more appropriate to use a different worker:

*“please do phone us and we can try somebody else. And that’s okay”*

Having protective gear on hand can be a valuable tool to enable support workers to safely enter squalid houses. The professionals were aware of the potential for the protective gear to be seen as judgmental or offensive, particularly when the person lacks insight into their living conditions. Generally, an honest but tactful approach was taken.

*“ I said ‘look, I know you like keeping things, and I’m not judging you for that because I keep things too’. She said ‘Do you?!’. I said ‘of course, everybody keeps things, but we just don’t want it to get to a stage where it’s going to be unhealthy for you ”*



*"I had one that came in...I stopped her as she was about to go out the door with something in her hand and it was a brand new mincer. I said 'where are you going with that' she says 'I'm going to donate it' and I said 'I haven't even used it!' And then I stopped her with some books and she said 'you've got far too many books'...*

*I lost any trust in anybody after that. Trust is something I value very much...*

*Who can you trust? I used to think that you've got to learn to trust. But then you get let down. So why even bother to trust? It's crazy, absolutely crazy. God, I'm going to cry. If I cry I've got 82 years of crying to do. If I let go of it there'll be a flood".*

*-lived experience of hoarding*

**“ I spent seven months talking to a gentleman through his kitchen window before he even opened the door so I could see him face to face . . . he’s a different chap, his sense of humour has come through, his personality. ”**



### Making a connection

The relationship between the supporter and the individual who hoards was discussed extensively as being a key to success. Finding common ground can be a powerful way to build a relationship. It can also help grow an understanding of the person and cultivate empathy for their situation. The focus group professionals were well versed in relating to a broad range of people and a common piece of advice was to observe cues in the home environment or from the individual’s language and use these to navigate the conversation. There were also examples where humour was used to help bond and relax.

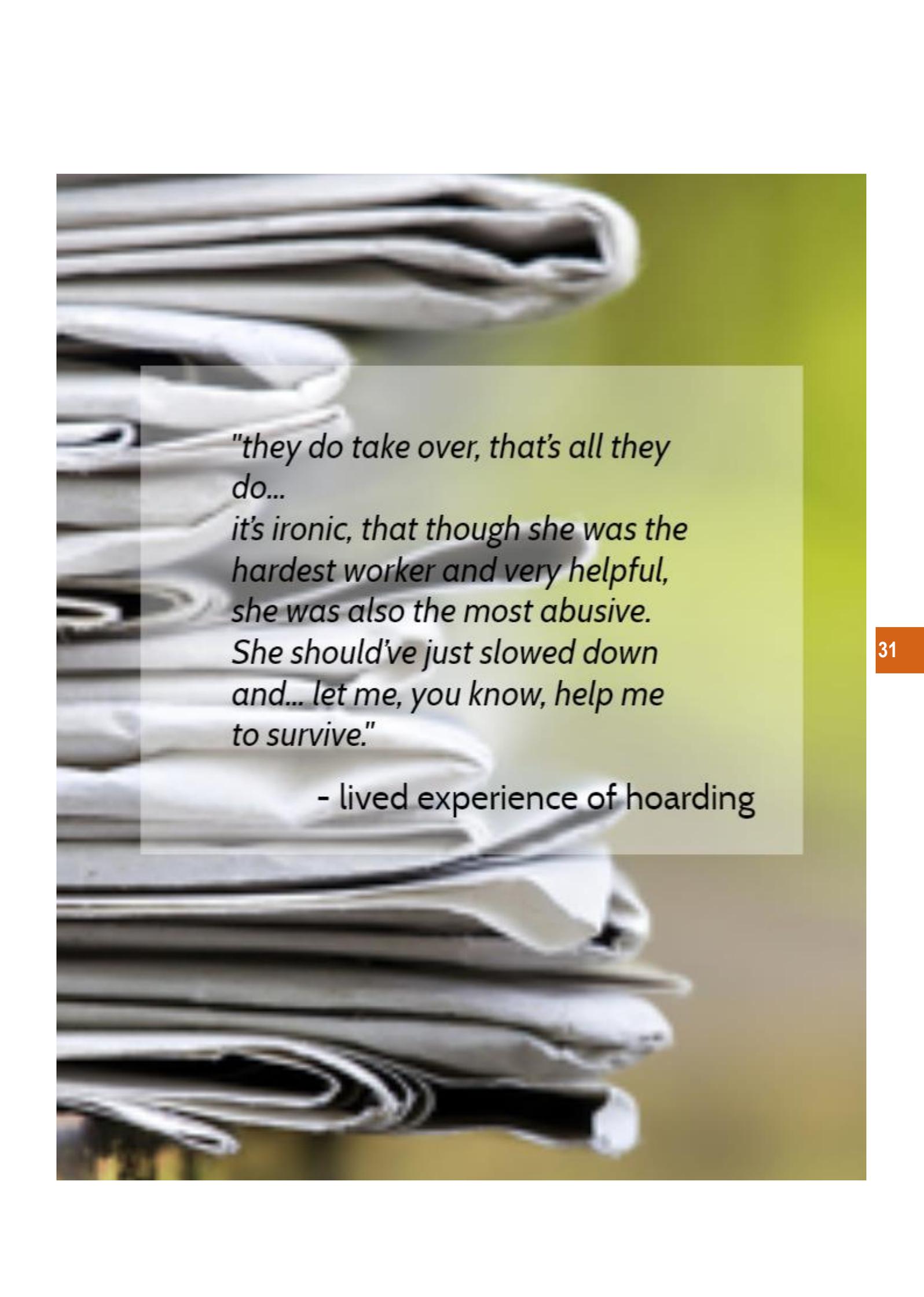
*“you can have a glance around. This guy, he threatened us with a spanner and it was obvious that there was a lot of car parts in the room...Then you can get it and say ‘Oh are you interested in repairing car parts? ...You try to use the cues that are in the room”*

### Pacing

A strong sub theme that emerged from the discussions was that establishing trust takes time

and patience. It was described as a process of first establishing the trust and building a relationship *then* moving towards change. Professionals talked of patience and maintaining efforts to build the relationship, even through periods where no progress was being made. Sometimes patience was required with multiple visits before the professional was invited into the home. Where the role allows, actively maintaining a positive relationship by “popping in” even when the person was not receiving intensive support was seen as helping to provide a safety net and making the service more accessible if required in the future. This approach was noted to have funding implications, with funding options and service models sometimes not being flexible enough to reflect the ongoing support required to build a relationship with the individuals concerned.

Several instances were discussed in which support workers or family members had disposed of belongings without permission; even with the best of intentions these betrayals of trust caused major setbacks in support.



*"they do take over, that's all they do...  
it's ironic, that though she was the hardest worker and very helpful, she was also the most abusive. She should've just slowed down and... let me, you know, help me to survive."*

- lived experience of hoarding

# It helps to create mutual goals

*“For me, it was setting the goal. You know, cause there’s always this focus on we have to have goals for everything. I always make a joke of it ‘Look, my boss says I’ve got to have a goal, for us to work together we’ve got to have a goal. What do you think we could do, if there’s one thing that you could do, what is one thing’ she said ‘I want to spin, I want to be able to spin, my spinning wheel is over there’ “*

Supporting autonomy and building motivation were central to working towards joint goals between the support worker and person with hoarding difficulties.

## Autonomy

Collaborating with the individual to set joint goals was commonly raised as keeping the person’s wellbeing central to support work and acting to empower the individual. It was reiterated by many of the professionals that not only is autonomy important in maintaining a person’s rights and dignity, but it is also necessary for effective change to occur with any lasting benefit. As one professional summed up in respect of unilateral cleanups “It’s not a fix really, it’s just a temporary clearance”.

The ineffectiveness and trauma of forced cleanups was one of the most consistently emphasised themes in both the literature and focus groups. Even premature death was mentioned as a result of shock from forced cleanup and relocation. While this is only anecdotal, it serves as a reminder of the damage that can result from such approaches.

*“ A low-key approach has worked more frequently for me than a pushy one. In the past, I would use my health act authority to enter on the land and push it as far as it would go. But it didn’t always pan out very well. We’ve had times where we’ve served notices and the place has been cleared. But I have to admit that within 6 months, most of those people have died. Just the shock of that complete change.”*

Support workers can be viewed with suspicion, so many professionals spoke of the importance of clarifying their role to remove any threat of forced cleanup or relocation.

*“That’s paramount, that’s the first thing I say and that’s why I didn’t go into that lady’s house on the first visit. I said, ‘my role is to keep you safe and well in your own home’ and I will repeat and repeat and repeat that ...I think that’s made a huge thing because family, neighbours, friends, they’ve all wanted them out into a rest home”*

## Building motivation

Many people who hoard do not have insight that their accumulation is problematic. Building help-seeking behaviours and helping the individual to see how their hoarding is not serving them can be one of the largest roles of a support worker.

A strong theme that emerged in the way professionals communicated with people who hoard was avoiding instructing. People spoke of planting ideas and making careful suggestions as opposed to pushing their opinions.

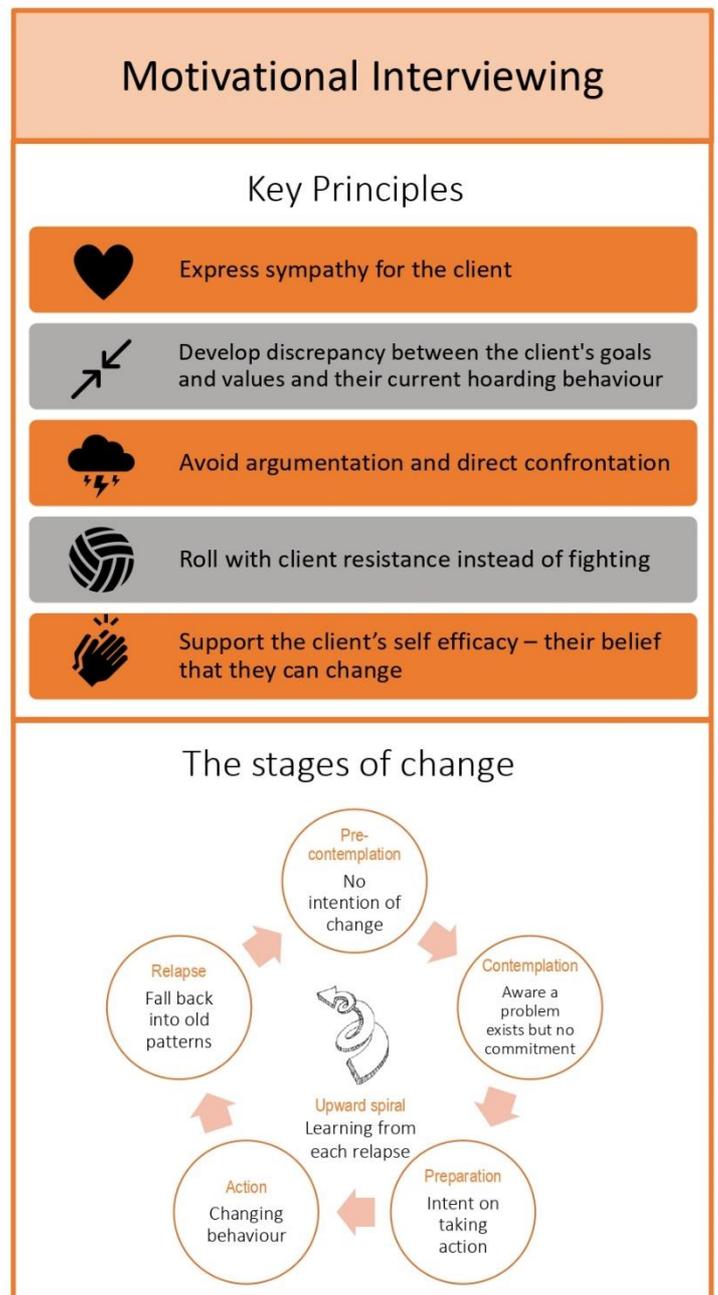
Shifting the focus from physical belongings to activities and the life the person wants to live can form the basis for forming joint goals. Promoting the value of enabling clear spaces for recreation, essential activities of daily living or for safety helps the individual to see the impacts of hoarding and moves away from the mindset of losing possessions.

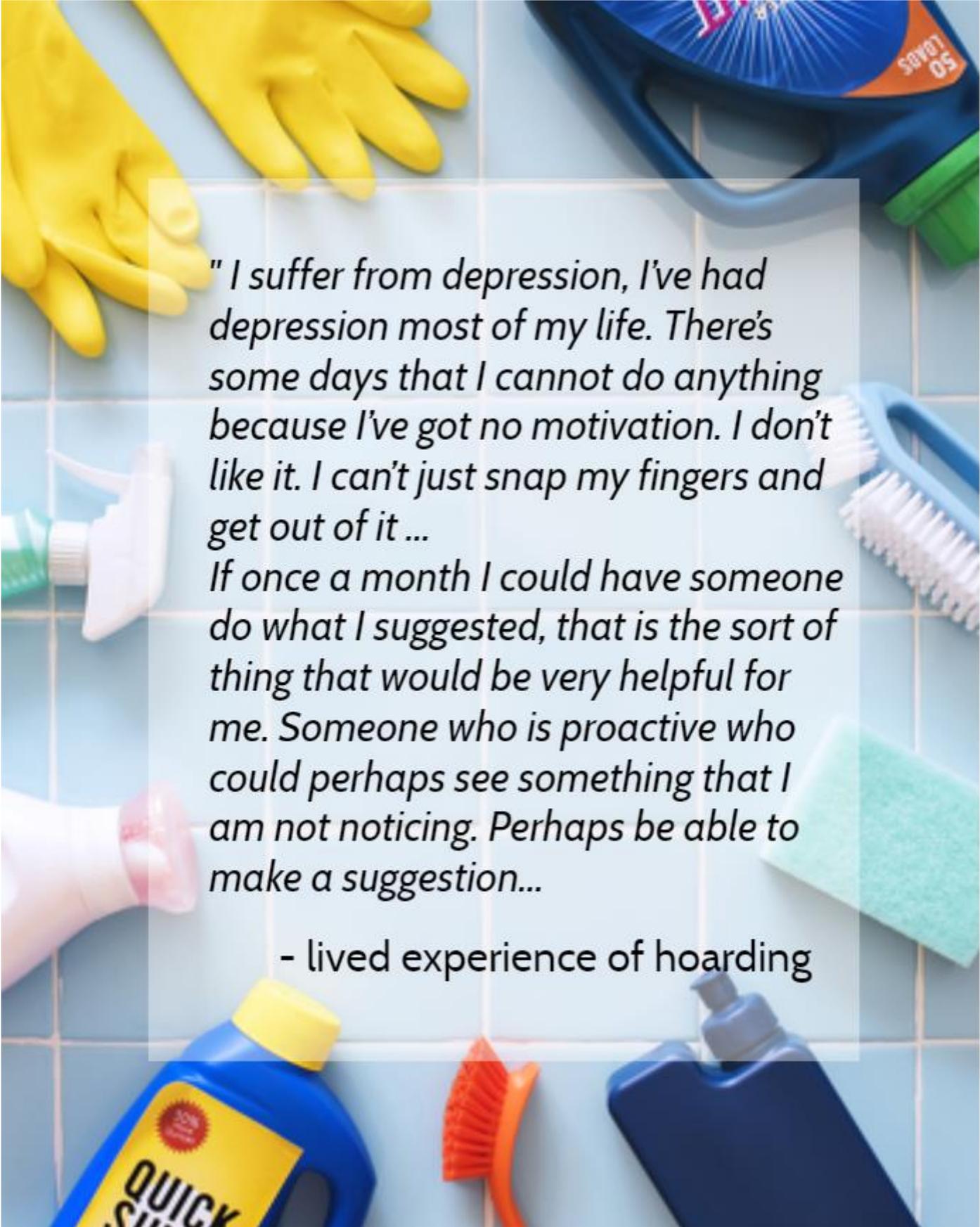
Some individuals were seen as being more responsive to considering the impact of hoarding on others, so encouraging reflection on the effects for dependents, friends, family or the community can be helpful: for example, an individual whose key was concern for the well-being of her cat.

**Small meaningful steps:** Setting realistic, achievable goals and focusing on small wins was also emphasised. This makes tasks more manageable and avoids overwhelming or pressuring the individual. Seeing progress can create momentum and give the individual a sense of control. Having the accountability of a support worker to check in with and receive praise from can reinforce this process. Examples of simple goals ranged from having space to reach a spinning wheel, to rehoming one or two bags of items at a time, to having space for emergency services to access the house.

*“She’d be so excited to show me the progress she had made and what she’d go rid of ... she actually took the stuff to the charity shop herself. But it worked for her because she wanted that change”*

**Motivational interviewing:** Motivational interviewing can be a helpful tool for building motivation. This approach guides the client through a “cycle of change” by empathically encouraging reflection on the pros and cons of making versus not making changes. The goal is to help the person reach a stage where they see the benefits of change compared to the status quo and believe that the change is possible<sup>47</sup>. This is summarized in the following infographic<sup>48,49</sup>.



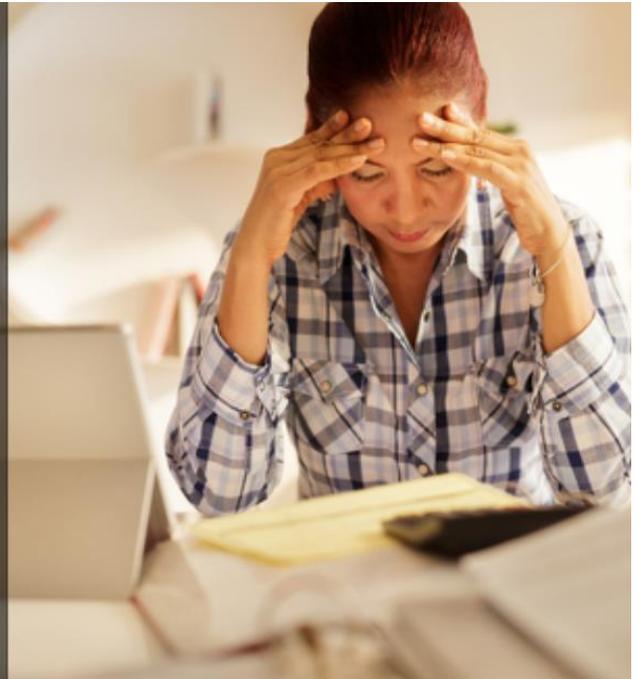


*" I suffer from depression, I've had depression most of my life. There's some days that I cannot do anything because I've got no motivation. I don't like it. I can't just snap my fingers and get out of it ...*

*If once a month I could have someone do what I suggested, that is the sort of thing that would be very helpful for me. Someone who is proactive who could perhaps see something that I am not noticing. Perhaps be able to make a suggestion...*

**- lived experience of hoarding**

“ Just about every family member with someone that's hoarding, they just want to go in and do the whole lot 'lock-stock and barrel' they don't get how distressing that can be for somebody. ”



**Safety:** One recurring focus for mutual goal setting was taking small steps to ensure safety, particularly fire safety. The fire service community liaison team is available to make home visits to discuss specific goals to reduce risk and will fit smoke detectors. fire safety.

Some of the professionals were generally successful in gaining consent to involve other agencies, particularly the fire service. Practical tips about possible effective approaches to gaining consent to share information included

- Ensuring rapport is built
- Recognising that trust may often be difficult, and clarifying the confidentiality requirements of other services
- Talking through the risks of concern, particularly safety
- Discussing the positive role that involving the relevant agency can have

- Emphasising that the agencies all have the goal of working together to help the person stay at home safely and
- Taking a very simple personal approach rather than formal scripted approach

*“The ones I've dealt with have often responded to the safety aspect of it. 'If you had a heart attack how would the ambulance people get in?' and gone from that angle”*

**Family:** Professionals spoke of the importance of integrating the individual's wider network into the support being provided. They spoke of how family members are often distressed and emotionally invested in trying to help. Some family members are 'burnt and gone' after years of frustration. Professionals often spoke of having to 'mediate' between the demands of family members and the reluctance of the person who hoards, and of giving family members invaluable knowledge about the best ways to support their loved ones.

# Steps to consider

## to support best practice

While some of the professionals involved in the scoping study had extensive experience supporting people who hoard, others reported occasional encounters and 'learning on the job'. Some spoke of feeling unsupported and uncertain. Some stakeholders such as home-based support services or housing providers may be involved in supportive non-clinical roles. Some possible steps forward include:

- **Facilitate awareness of online resources:** Increasing the awareness of existing resources for professional supporters would be worthwhile. Appendix G provides a selection of some of the online education and guidance resources about working with people who hoard. Health Navigator is a potential central point for disseminating health information, including separate sections for professionals.
- **Develop local person-centred practice resources:** Two suggestions of local resources for professionals arose from this research. One is a policy document, to be discussed later in the report. The other is a shorter 'engaging tips' booklet for service personnel about the practicalities of engaging with people who hoard in a person-centred way. The information from this scoping study could contribute to the development of such a resource.
- **Record video resources:** Recent educational opportunities in Christchurch include a panel discussion on hoarding at the CDHB's Older Person's Mental health day in 2019, and a seminar by an Australian expert in January 2020. The impact of such events could be expanded in the future by creating video resources of the content and hosting them on an appropriate web platform.
- **Train homebased support workers:** Canterbury District Health Board's person-centred dementia care training programme ("Walking in Another's Shoes") is available for home-based support service providers. This has resulted in a pool of support workers who already have a knowledge of person-centred care and who are sometimes called on for more complex presentations such as people who are reluctant to accept services. There is a mechanism for post-graduation 'booster' training sessions, called "masterclasses". A masterclass on hoarding and non-purposeful accumulation could be considered.
- **Establish a hoarding specialist role.** A further step to consider would be the establishment of a focal regional clinical position for hoarding (possible models include a clinical nurse specialist or designated social worker role). Such a person could act as a contact point for the provision of professional support and education, including opportunities for health, social service and other related workers to discuss their experiences. This role could also encompass taking a lead in organising cross-agency case meetings for crisis interventions for people who hoard, and for streamlining referrals.



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## Understanding policies

Great support for people in challenging living environments requires a supportive resourcing and policy environment.

# It helps to have resources

*“There’s nothing to come in to support you to support this person”*

## Long-term resources

Because of the need for multiple services and often large time commitments, there are often major resource constraints on hoarding services. One of the prominent themes amongst professionals was that of not having enough resources for the ongoing support that is required.

*“I’ve had to fight to keep my ladies on my books. Our [senior doctors] have said no...it’s not recoverable, not going to work...every three months”*

## Flexible resources

Where people are motivated to declutter, few are able or willing to self-fund cleanup services. One of the individuals with lived experience of hoarding described how services can seem inflexible

*“they will not move anything, they will not do the rooms that you are in. They’ll only do the very minimum.”*

Funding was sometimes seen as being too rigidly constrained to adapt to the needs of the person – for example allowing simple cleaning but not decluttering support because this was “considered a “spring clean”. Some of the professionals were aware that there were possible community source of support or funding for decluttering but there was no clear awareness of how this could be accessed. Some of the NGOs contacted during the research process reported that they had been active in the area in the past but did not currently have the capacity. An ideal scenario raised by some of the professionals is that there would be discretionary funding available for selected clients.

## Therapy resources

As discussed earlier, there is an evidence base to support a multi-component Cognitive Behavioural Therapy (CBT) protocol developed by Steketee and Frost<sup>25, 26</sup>. The programme is available as a book which can be used as self-help or a guided therapy. This CBT model has also been adapted for group therapy<sup>29</sup>. There was interest amongst some of the professional participants to build on an initial pilot group in Canterbury and broaden access to this support. A group format has the benefits of delivering therapy in a cost-effective way along with offering peer support and enhanced social connections for those involved.

*“The book is in the library, Steketee’s latest book “Buried in Treasures”. It’s all there, just pick it up and do it”*

## Stepped care

Introduction of a stepped care model was suggested in one group, as well as by some researchers<sup>27</sup>. Many jurisdictions have social workers as the lead workers<sup>27, 50</sup>, which can allow more time and resource intensive services to be brought in only when necessary.

*“We’ve got some models, lets pilot it. Stepped care would be great. I think something needs to be done at primary or secondary care and then...because we are gatekept at tertiary care”*

# It helps to have integration

*“You can’t do it on your own, it’s too big. You need an interagency commitment and it would ideally be not individually based but role based. So that if someone retires or moves it doesn’t collapse and I really like that idea of some sort of single point of entry where cases come to note and there’s some discussion around the table of who could respond to this? What are the needs?”*

## A multidisciplinary approach

Because of the multifaceted nature of hoarding, it is recognised internationally that hoarding is best managed by a multidisciplinary team<sup>7,11,17,18, 20,22,42, 50,51</sup>. As hoarding impacts so many areas of life, an individual whose hoarding has reached a problematic level is often engaged with multiple services. A multidisciplinary team integrates the responses of these services and allows the multifaceted needs of a person who hoards to be met more efficiently and effectively, providing practical, medical, psychological, emotional, legal and safety-oriented support. Some jurisdictions have specialist teams or ‘task forces’ to address hoarding<sup>50, 52</sup> but this is not the case in Canterbury.

Ultimately, the services that are included in the support approach will depend on the needs of the individual. Key players are likely to involve Fire and

Emergency services, Mental Health services, Social workers, Home-based support services, Public Health agencies, City Council and Non-Governmental Organisations involved in housing, mental health, or with vulnerable populations (see Appendix F). A coordinated approach benefits both the individual and the agencies involved by providing integrated biopsychosocial support<sup>4</sup> and allowing greater efficiency and sharing of expertise from agencies<sup>42</sup>. In the Southern DHB a “Joint Agency Panel” model has been adopted.

Even in lieu of a specialised team there are a number of key organisational features of services which can greatly assist in providing an effective multidisciplinary support system. The following features are emphasised in the research and the grey literature from other jurisdictions, and/ or were discussed by professionals in the focus groups.

**“ the first element of recovery is ‘what support does the person need?’ Whether it be from health, whether it be from council, whether it be from Red Cross or other support services for just basic means and sustainability. .. and assess whether it’s dangerous or not to continue occupancy... But then it’s the notification of cooperative agencies .... So we’ve got health, and we’ve got CCC ...[fire service]... and then the practitioners, and the practitioner being the agent of connection with the person. ”**



**“ I get the impression that people who work with hoarding have also become isolated from each other in Christchurch, that’s what seems to be happening from where I’m sitting. ”**



**Coordination.** For effective collaboration between multiple agencies there must be strong inter-agency communication. While there were instances of inter-agency meetings for individuals with council / emergency services / public health involvement, these were far from the norm.

Having a central coordinating agency which is able to act as a single point of entry for referrals and delegate cases can be extremely valuable<sup>20,50</sup>. The usefulness of such a focal point was commented on by the professionals in focus groups and interviews, and a lack of clarity about referral pathways was also emphasised by many professionals. It was also noted that there has been awareness of the need for these features in Canterbury for some time.

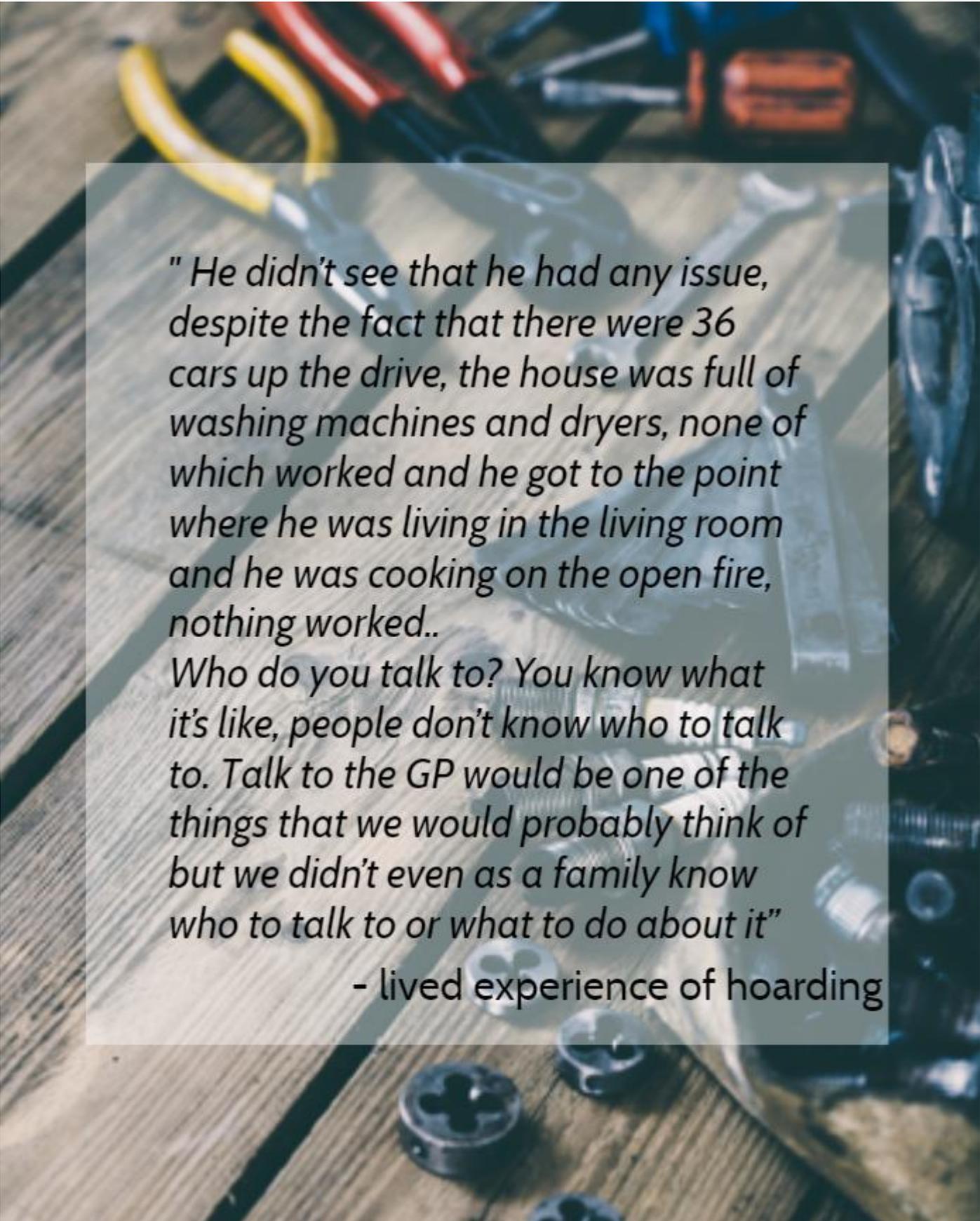
**Communication.** Inter-agency communication can be hindered by privacy restrictions on sharing the information of individuals with other agencies. This was a recurrent point of discussion in focus groups, with multiple agencies holding information on individuals who hoard but little sharing between agencies. The lack of clarity about what can be appropriately shared and when safety concerns might override confidentiality was reiterated.

The potential benefits of enhanced information sharing are particularly evident in respect of risk

reduction for emergency situations. The fire service has mechanisms to flag addresses where the accumulation of clutter is of concern and send the appropriate number of appliances, and likewise the St John ambulance service is able to flag addresses with known special response needs. Ambulance and fire services have to make decisions about whether it is safe for officers to assist an individual inside a challenging domestic environment, so information about safe routes within a severely cluttered home could make the difference in some situations. There are no established mechanisms for sharing this kind of emergency response information. Shared information is also obviously necessary for any and all coordinated action plans between agencies or individual case workers of various kinds.

*“You’ve had people who won’t let you talk to the emergency services. I’ve always said to them, well, being in the fire or ambulance service, they’re bound to the same confidentiality as I am”*

**Support.** Given the wide range of agencies that can be involved, many of the people who support individuals who hoard learned through experience, rather than receiving formal training about hoarding. The discussion recognized the value of local educational resources, training events. and opportunities to network.



*" He didn't see that he had any issue, despite the fact that there were 36 cars up the drive, the house was full of washing machines and dryers, none of which worked and he got to the point where he was living in the living room and he was cooking on the open fire, nothing worked..*

*Who do you talk to? You know what it's like, people don't know who to talk to. Talk to the GP would be one of the things that we would probably think of but we didn't even as a family know who to talk to or what to do about it"*

*- lived experience of hoarding*

# Steps to consider

## A supportive policy environment

Possible steps to consider include

### Facilitate coordination

#### Establish protocols and pathways

The development of a regional policy guide by a multidisciplinary group is a step to consider. Southern<sup>51</sup> and Taranaki<sup>53</sup> DHBs already have guidelines that could serve as a model, based on work from Sydney<sup>54</sup>. These guides provide

- A step-by-step guide and simplified procedures
- Clear roles and responsibilities of agencies and service providers
- Practical information regarding referrals and intervention options

It is important to note however that these guides sometimes focus on domestic squalor, not on hoarding or accumulation per se, necessitating a slightly different focus. Two of the professionals involved in the scoping group have offered to coordinate a task group with the development of a guideline document as a primary focus.

#### Gain traction on a central point of contact

There was a recognition that having an identified central point of contact is an important step to consider to facilitate inter-agency referrals and co-ordinate input so that the right help is provided by the right agency to the right person in a timely way. Some of the stakeholders emphasised that this idea has been mooted for some time without any concrete progress. Establishing such a point of contact would seem to be a priority. If it is not possible for Canterbury's multiple lead agencies to mutually agree on the resourcing of such a role, one agency will presumably need to take the initiative.

#### Simplify information sharing and referrals

There were different approaches and perspectives on sharing information amongst agencies, and a desire for clarity. One simple step forward may be to develop an interagency consent form for information sharing. An example is a form used in Victoria, Australia<sup>1</sup>. This would need to be backed up by guidance on policies around information sharing in the regional guidance document.

The focus group discussion also suggested that it would be useful to provide guidance on pathways for gaining expert advice and for referrals for capacity assessments.

## Fund hoarding support as a longer-term commitment

A recurring emphasis in the literature and discussions was that forced quick 'spring cleans' are ineffective and traumatic. Instead, there is a need for long-term support and maintenance. It seems that several services are already directing significant resources over long periods of time for certain individuals, however this is unevenly and inequitably spread depending on where a person with serious difficulties first comes to light. Therefore, a step to consider for the future is to create options for access to discretionary funding and funding routes for longer-term support to support people who hoard, from a whole-of-system perspective.

# A final word

There are a surprising number of people living in Canterbury whose hoarding is leading or has already led them into domestic clutter to the extent that it is causing significant risks to themselves or others, significant distress, or significant disability. Most of us will be aware of a house somewhere in our neighbourhood that is likely to be the home of such a person and a quick look at Google Maps satellite view can confirm how serious the problem is: you can see hoarding from space!

Many of these people are elderly and therefore the numbers of people affected by serious hoarding difficulties are going to steadily increase with the rapid ageing of Canterbury's population.

Effective support for people who hoard requires different skills and different management strategies depending upon the individual person, the social and environmental contexts in which they live, and the underlying reasons hoarding-related problems have developed. One size most certainly does not fit all.

It is not surprising, therefore, that a wide range of Canterbury services are already providing services to try and help these people, from statutory bodies to emergency services, from private businesses to NGOs, and from health services to social services. However, the resources already being utilised would seem to be uncoordinated and piecemeal, and therefore being distributed in an unfair and inequitable manner, if not also inefficiently or even spent in futile ways.

The people engaged in these helping services are often learning 'on the job' and have developed wonderful skills, but they are also reporting being under-prepared for their roles in terms of knowledge, understanding effective interventions, and knowing what other services are available to help their clients and to support their work. They describe a dis-integrated sector.

It is time to invest in an integrated, person-centred, effective approach to hoarding in Canterbury. More resources will inevitably be spent on this issue because of the growing population in which hoarding is most common - that is not a choice. What is within our grasp is to choose whether we will keep using these resources in a disjointed, inefficient, and perhaps ineffective way like we have been doing; or whether we will invest as a society in a coordinated, evidence-based, and person-centred approach to this most human of problems.

We hope that this report has honoured the wonderful participants of our focus groups and individual interviews, especially the people with lived experience of hoarding; and that it has brought together the best of New Zealand and international literature on this topic. Holding in mind that person we all hardly know who lives with some degree of vulnerability in the cluttered property just around the corner, we entrust this summary of our findings to you. We trust that our community service leaders and workforce champions will use it to take the steps forward that our participants have so clearly pointed us all towards.

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# Appendices

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A. Summary of professional participants	Page - 49
B. Interview impressions	Page - 50
C. CCC Hoarding assessment tool	Page - 52
D. Clutter image rating scale	Page - 56
E. Saving Inventory - Revised	Page - 60
F. Agencies that may be involved	Page - 62
G. Selected international educational resources	Page - 65
H. New Zealand literature and resources	Page - 66

# Appendix A: Summary of professional participants

CDHB	
Clinicians from a range of disciplines and roles within the Canterbury District Health Board	
✓	COMMUNITY MENTAL HEALTH NURSE
✓	COMMUNITY MENTAL HEALTH NURSE
✓	GERIATRICIAN
✓	CLINICAL ASSESSOR
✓	COMMUNITY SOCIAL WORKER
✓	CLINICAL PSYCHOLOGIST
✓	CLINICAL PSYCHOLOGIST
✓	OCCUPATIONAL THERAPIST

AGENCIES	
Professionals from a range of stakeholder agencies	
✓	FIRE SERVICE RISK MANAGEMENT
✓	UNIVERSITY ACADEMIC RESEARCHER
✓	CITY COUNCIL ENVIRONMENTAL HEALTH
✓	NGO LEADERSHIP
✓	HOME BASED SUPPORT SUPPORT WORKER
✓	PUBLIC HEALTH HEALTH PROTECTION
✓	COMMUNITY AGENCY COMPLEX CASE MANAGER
✓	COMMUNITY AGENCY SUPPORT WORKER

## Appendix B: Interview impressions

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Interview 1:

### My uncle

'My uncle' was quirky and she loved him for that. After he died, they found he had probably been eating jelly meat and they feel guilty. They knew it was bad but not that bad. What could have been done? They looked in to it, talked with psychiatrists, maybe he should have been sectioned. He may have met the criteria for harm to himself. But he would have resented them for it. It may have even been the right thing to do, for them, for him, for both? 'My uncle' had been an engineer- he now collected all sorts. Probably to one day do something with. He was once quite organised but later lived amongst chaos. It started when his mother died. He was lost and grieving. Perhaps having things meant he didn't need to let anything go or lose anything. Perhaps she had protected him and mitigated his general functional and coping deficits. No one is really sure. But there wasn't a lot of service around who could help. There probably still isn't anything much either. The lines between the law, public health, rights, mental health and frontline services are unclear. Who does what when no one can do anything?

50

Interview 2:

### My husband's things

This house is hoarded by "my husband's things". He was a photographer who developed dementia. She cared for him. I wonder if getting rid of his things means she gets rid of his memory. The house is hoarded by her things. She is a crafter with a social consciousness. She will give her things away when she has no use for them, she plans to make quilts, knit and sew once it is all sorted out. If she does not use it, she will give them away. Perhaps in exchange for some gardening or to people in need. Time is a useful currency- if the world worked in sharing of time, things would be better in life. People would not be ill or lonely. She is both. During her earthquake repairs, she rearranged things. Her daughter ordered in a skip. Throwing away her things was like throwing away her memories. She was upset. Eventually she will sort the things, maybe she will move in to residential care. The garden is also hoarded out. There are thousands of terracotta pots. The empty pots may one day be filled. The empty pots almost represent an empty life.

Interview 3:

## The inheritance

This house was untidy, cluttered in parts with belongings in piles. It could have bordered on poor house-keeping if not for the themes and amount of her things. This lady loved to cook, but it seems she doesn't, there were hundreds of cook books and recipes stacked between the lounge, kitchen and back bedroom. Brand new, unopened. She plans to cook from them one day. She told me this as she ate a meal delivered by meals on wheels. She was due to have KFC for Christmas lunch the next day. She worries about money...her son needs some because he lost his job. She tells me this as she sits amongst thousands of dollars of unopened books, make up and kitchen utensils. She tells me she got a huge inheritance from her parents though it has gone. She is vulnerable. Her decisions over her time have been questioned by others. She doesn't see her family much- they are busy and stressed. Home help comes, but they will not clean amongst the belongings. They call that a spring clean. What is cleaned instead I am unsure of. She is alone. And lonely. Who she defines herself as and who I see her as being in that moment could not be further apart.

Interview 4:

## Let me tell you my why

This was not only hoarding but squalor. To walk through the house, I had to shuffle on my side, stepping over and between items before eventually perching on a stool, two feet from the participant in order to hear her "why". This lady was charming-funny, generous and strong in spirit. It was with pride she told me about the visiting hedgehog and cats she feeds in the home, she was not bothered rats had eaten through the electrics in her roof rendering the back of the house powerless. She maneuvers through the house bent in on herself, clutching door frames and tenuously stacked objects, often falling, at times becoming stuck amongst her things. Her things are precious to her, but really have no monetary value per se. Empty margarine containers, clothes that will never be worn, old fans, books and papers. The fridge has little food but there is plenty of biscuits for the cats. She defines herself as a weaver and proudly showed me wool that she washes, then washes again before spinning. This is amongst the unwashed floors, dishes and windows. The stark contrasts between who she is and who she wants to be (or was) is overwhelming. She is generous in helping others, but she is alone. People come to offer health services or cold call only. If she upsets her daughter, she may stop coming. Her 'why' stems from having nothing, now she has lots, but I still was left wondering what gap these things really filled. She says she will get to a clean-up, a dust and a sort out...eventually.

# Appendix C: Christchurch City Council Hoarding Assessment Tool

## CHRISTCHURCH CITY COUNCIL HOARDING ASSESSMENT TOOL

### SOURCE INFORMATION

Date Referral Received: \_\_\_\_\_ Time: \_\_\_\_\_

Referrer's name: \_\_\_\_\_ Agency: \_\_\_\_\_

Referrer's Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Relationship to Client: \_\_\_\_\_

Client's Name: \_\_\_\_\_ Age: \_\_\_\_\_ DOB: \_\_\_\_\_

Address: \_\_\_\_\_

Phone/other contact: \_\_\_\_\_

Will client allow access?  Yes  No \_\_\_\_\_

### HOUSEHOLD INFORMATION

Type of dwelling: \_\_\_\_\_ Own/Rent: \$ \_\_\_\_\_ per week

Household members:  
\_\_\_\_\_  
\_\_\_\_\_

Family or other support - include names and phone number:  
\_\_\_\_\_  
\_\_\_\_\_

Pets/Animals: \_\_\_\_\_

Other agencies involved: \_\_\_\_\_

Has the person been helped in the past? By whom? When?  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

## ASSESSMENT OF CLIENT

### Physical or mental health problems of client:

- Does not seem to understand seriousness of problem
- Does not seem to accept likely health consequences of problem
- Defensive or angry
- Anxious or apprehensive
- Unaware, not alert, or confused

### Client's attitude towards hoarding/living conditions:

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Are basic needs being met? (*ie. food/shelter*)     Yes     No    \_\_\_\_\_

Is client's safety compromised?     Yes     No    \_\_\_\_\_

Is client's wellbeing compromised?     Yes     No    \_\_\_\_\_

### Other Issues/Problems/Needs (*Medication, mobility etc*)

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---

### Other agencies etc involved in initial assessment:

---

Sketch of dwelling:

North

## ACTIVITIES AFFECTED BY CLUTTER OR HOARDING

	Can do it easily	Can do it with a little difficulty	Can do it with moderate difficulty	Can do it with great difficulty	Unable to do it
1. Food preparation	1	2	3	4	5
2. Use refrigerator	1	2	3	4	5
3. Use stove	1	2	3	4	5
4. Use kitchen sink	1	2	3	4	5
5. Eat at table	1	2	3	4	5
6. Move about house	1	2	3	4	5
7. Use toilet	1	2	3	4	5
8. Use bath/shower	1	2	3	4	5

## LIVING CONDITIONS – PROBLEMS IN THE HOME

	None	Few	Moderate	Substantial	Severe
9. Structural damage	1	2	3	4	5
10. Water not working	1	2	3	4	5
11. Heat not working	1	2	3	4	5
12. Power not working	1	2	3	4	5
13. Presence of waste/rotten food	1	2	3	4	5
14. Presence of human faeces	Absent	Present	Degree:		
15. Animal welfare issues	1	2	3	4	5
16. Animal urine/faeces	1	2	3	4	5
17. Vermin infestation	1	2	3	4	5
18. Insect/fly infestation	1	2	3	4	5

## SAFETY ISSUES

	None	Few	Moderate	Substantial	Severe
19. Fire hazards (e.g. paper on stove/flammable objects near the heater etc)	1	2	3	4	5
20. Unsanitary areas (bathrooms, WC/strong odours)	1	2	3	4	5
21. Presence of mould/mildew	1	2	3	4	5
22. Visitors/services moving around the home	1	2	3	4	5
23. Clutter outside the house (porch, yard, common areas etc)	1	2	3	4	5

Additional information or comments, eg Asthma/Alcohol)

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Clutter image rating scale - [link](#):

Living room  1  2  3  4  5  6  7  8  9  
 Kitchen  1  2  3  4  5  6  7  8  9  
 Bedroom  1  2  3  4  5  6  7  8  9

Photos taken? Y/N By \_\_\_\_\_

What does this home score? \_\_\_\_\_

## RECOMMENDATION FOLLOW-UP ACTION/S:

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Officer: \_\_\_\_\_

Position: \_\_\_\_\_

Inspection Date & Time: \_\_\_\_\_

# Appendix D: Clutter Image Rating Scale

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## Clutter Image Rating (CIR)

---

Date: \_\_\_\_\_

Using the three series of pictures (CIR: Living Room, CIR: Kitchen, and CIR: Bedroom), please select the picture that best represents the amount of clutter for each of the rooms of your home. Put the number on the line below.

Please pick the picture that is closest to being accurate, even if it is not exactly right. If your home does not have one of the rooms listed, just put NA for “not applicable” on that line. Also, please rate other rooms in your house that are affected by clutter on the lines below.

Room	Number of closest corresponding picture (1–9)
Living Room	1 _____
Kitchen	1 _____
Bedroom #1	1 _____
Bedroom #2	1 _____

Use the *CIR: Living Room* pictures to make these ratings.  
Scores in the 3 to 4 range in any room are cause for concern.

Dining room	1 _____
Hallway	1 _____
Garage	1 _____
Basement	1 _____
Attic	1 _____
Car	1 _____
Other	1 _____

Please specify: \_\_\_\_\_

**Clutter Image Rating: Living Room**

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



1



2



3



4



5



6



7



8



9

---

## Clutter Image Rating

---

### Clutter Image Rating Scale: Kitchen

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



1



2



3



4



5



6



7



8



9

**Clutter Image Rating: Bedroom**

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



1



2



3



4



5



6



7



8



9

# Appendix E: Savings Inventory - Revised

---

## Saving Inventory – Revised

---

Date: \_\_\_\_\_

For each question below, circle the number that corresponds most closely to your experience DURING THE PAST WEEK.

0 ----- 1 ----- 2 ----- 3 ----- 4  
 None      A little      A moderate amount      Most/Much      Almost All/ Complete

- |   |                       |                       |                       |                       |                       |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| 1. How much of the living area in your home is cluttered with possessions? (Consider the amount of clutter in your kitchen, living room, dining room, hallways, bedrooms, bathrooms, or other rooms). | <input type="radio"/> |
| 2. How much control do you have over your urges to acquire possessions?   | <input type="radio"/> |
| 3. How much of your home does clutter prevent you from using?   | <input type="radio"/> |
| 4. How much control do you have over your urges to save possessions?  | <input type="radio"/> |
| 5. How much of your home is difficult to walk through because of clutter?   | <input type="radio"/> |

For each question below, circle the number that corresponds most closely to your experience DURING THE PAST WEEK.

0 ----- 1 ----- 2 ----- 3 ----- 4  
 Not at all      Mild      Moderate      Considerable/ Severe      Extreme

- |   |                       |                       |                       |                       |                       |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| 6. To what extent do you have difficulty throwing things away?  | <input type="radio"/> |
| 7. How distressing do you find the task of throwing things away?  | <input type="radio"/> |
| 8. To what extent do you have so many things that your room(s) are cluttered?   | <input type="radio"/> |
| 9. How distressed or uncomfortable would you feel if you could not acquire something you wanted?  | <input type="radio"/> |
| 10. How much does clutter in your home interfere with your social, work or everyday functioning? Think about things that you don't do because of clutter. | <input type="radio"/> |
| 11. How strong is your urge to buy or acquire free things for which you have no immediate use?  | <input type="radio"/> |

---

## Saving Inventory – Revised

---

For each question below, circle the number that corresponds most closely to your experience DURING THE PAST WEEK:

0 ----- 1 ----- 2 ----- 3 ----- 4  
Not at all      Mild      Moderate      Considerable/  
Severe      Extreme

12. To what extent does clutter in your home cause you distress?      0      1      2      3      4
13. How strong is your urge to save something you know you may never use?      0      1      2      3      4
14. How upset or distressed do you feel about your acquiring habits?      0      1      2      3      4
15. To what extent do you feel unable to control the clutter in your home?      0      1      2      3      4
16. To what extent has your saving or compulsive buying resulted in financial difficulties for you?      0      1      2      3      4

For each question below, circle the number that corresponds most closely to your experience DURING THE PAST WEEK.

0 ----- 1 ----- 2 ----- 3 ----- 4  
Never      Rarely      Sometimes/  
Occasionally      Frequently/  
Often      Very Often

17. How often do you avoid trying to discard possessions because it is too stressful or time consuming?      0      1      2      3      4
18. How often do you feel compelled to acquire something you see? e.g., when shopping or offered free things?      0      1      2      3      4
19. How often do you decide to keep things you do not need and have little space for?      0      1      2      3      4
20. How frequently does clutter in your home prevent you from inviting people to visit?      0      1      2      3      4
21. How often do you actually buy (or acquire for free) things for which you have no immediate use or need?      0      1      2      3      4
22. To what extent does the clutter in your home prevent you from using parts of your home for their intended purpose? For example, cooking, using furniture, washing dishes, cleaning, etc.      0      1      2      3      4
23. How often are you unable to discard a possession you would like to get rid of?      0      1      2      3      4
-

# Appendix F1: Agencies that may be involved in supporting older Cantabrians who hoard

COMMUNITY	<p><b>CDHB Community services for older people</b></p> <p><b>Needs assessment:</b> Needs assessment assists older people with long-term disabilities/health problems (i.e. longer than 6 months) to remain living at home, safely and independently, for as long as possible. Needs Assessors complete an assessment of needs with the older person, and Service Coordinators use this assessment to develop care packages of support services to assist at home</p> <p>Phone Adult Community Referral Centre (ACRC): 03 337 7997</p>
	<p><b>Older Persons Mental Health, Community Mental Health Nurses:</b> OPMH provides clinical home-based support for older people with mental health issues, including dementia. Community Nurses who visit homes and assist older people with mental health difficulties</p>
	<p><b>Community social work:</b> Helps patients and those that support them solve and cope with problems in everyday life. Some clients have hoarding issues and work with them to overcome problems associated with this.</p>
SPECIALIST	<p><b>CDHB outpatient support</b></p> <p><b>Clinical Psychology:</b> Clinical psychologists with the CDHB are involved in supporting people who hoard, although the individuals are usually referred for other issues.</p>
	<p><b>Anxiety Disorders Service :</b> The Anxiety Disorders Service is an outpatient service that provides treatment for people with anxiety disorders. They offer treatment options that directly address hoarding with patients, using hoarding-specific CBT.</p>
	<p><b>Geriatricians:</b> Geriatricians provide assessment and advice as part of the multidisciplinary team older persons mental health team, including for people living with hoarding.</p>
HOME-BASED	<p><b>Home-based support</b></p> <p><b>CDHB contract holders:</b> The CDHB holds contracts with agencies who provide home based support with daily living activities and nursing services, including occasionally for people who hoard.</p> <p>Access Community Health: <a href="https://www.access.org.nz/Our-Services">https://www.access.org.nz/Our-Services</a></p> <p>Healthcare NZ: <a href="https://www.healthcarenz.co.nz">https://www.healthcarenz.co.nz</a></p> <p>Nurse Maude: <a href="https://nursemaude.org.nz">https://nursemaude.org.nz</a></p>
	<p><b>Comcare:</b> Comcare is a Charitable Trust whose purpose is to assist people who experience mental illness and addictions through the provision of community services, including assistance with the activities that form part of an individual’s daily life and a Continuing Support Service for people with long term support needs. They support numerous clients who hoard.</p> <p><a href="https://www.comcare.org.nz/what-we-do/community-support-services/community-support-work/">https://www.comcare.org.nz/what-we-do/community-support-services/community-support-work/</a></p>

## PUBLIC

### Public Health

**Christchurch City Council:** Environmental health officers investigate, monitor, assess and advise on public health and environmental hazards. The City Council is responsible for investigating insanitary living conditions that may be causing a “nuisance”.

Phone: 03 941 8999 (or 0800 800 169 for Banks Peninsula)

**Community and Public Health:** Community and Public Health has a responsibility to address health risks caused by insanitary living conditions. Staff can work with Environmental Health Officers from the council to make an initial visit to determine if there is a health risk, and who needs to be involved in any resulting intervention.

<https://www.cph.co.nz/your-health/insanitary-housing/>

## EMERGENCY

### Emergency Services

**Fire and Emergency NZ:** The fire service are able to offer home visits to talk through risk reduction strategies and install a fire alarm. They may also be involved in multi-agency recovery planning following a response to a domestic hoarding fire. Having a database of properties with hoarding risks helps the fire service to plan appropriate responses to fires (for example number of appliances, safe access routes etc).

Email: [chchfirerisk@fireandemergency.nz](mailto:chchfirerisk@fireandemergency.nz)

**Ambulance:** St Johns can face difficulties safely accessing a person requiring help in challenging living environments, and in extracting the individual while maintaining dignity. Having a database of homes that have risks associated with hoarding helps the ambulance to plan appropriately (for example safe access routes, the parts of the house that the person uses and is likely to be in etc). <https://www.stjohn.org.nz/contact-us/other/>

## OTHER

### Other

**Housing. Housing Kāinga Ora (formerly Housing New Zealand):** Kāinga Ora are responsible for the efficient and effective management of state houses and the tenancies of those living in them, and work with other agencies to ensure tenants have access to support services including in the context of hoarding. Phone: [Kāinga Ora 0800 801 601](tel:0800801601)

Where accumulation is creating a threat of eviction in a rental property, the private property owner, Community Law, and the Tenancy Tribunal may be involved.

**NGOs: Age Concern:** Age Concern provides home support, visiting services and community health support services. They see numerous clients who hoard. While they have previously been a go-to agency for support for people who hoard, their capacity has reduced to personnel changes. <https://ageconcerncan.org.nz/>

Other NGOs such as the Salvation Army may be involved but on an individual case basis.

**Risks to others:** If a situation involves animal hoarding the SPCA may be relevant, and if there is a risk to young people Oranga Tamariki may become involved.

**Primary Care:** The individual’s GP can have an important role as a trusted figure and access point for referral to services.

# Appendix F2: Local agencies that may be able to assist improving living situations

COSTS	<p><b>Possible sources of financial assistance</b></p> <p><b>Mayor’s welfare fund:</b> A welfare fund for Christchurch city residents who are in extreme financial distress, as a last resort measure for when people have exhausted other appropriate sources. Applicants can only be assisted once in a twelve month period.  <a href="https://ccc.govt.nz/culture-and-community/community-funding/mayors-welfare-fund">https://ccc.govt.nz/culture-and-community/community-funding/mayors-welfare-fund</a>.</p> <p><b>Hyman Mark’s trust:</b> Provides assistance to individuals or families experiencing financial hardship who have limited access to the basic necessities, in particular in relation to health and warmth. Funding is also available for community support groups/projects. Applications must be made by an accredited community worker.  <a href="http://www.hymanmarkstrust.co.nz/pages/apply.html">http://www.hymanmarkstrust.co.nz/pages/apply.html</a>.</p> <p><b>Ngāi Tahu Pūtea Manaaki:</b> Provides assistance for members of the Ngāi Tahu tribe towards essential living costs in situations of serious hardship.  <a href="https://ngaitahu.iwi.nz/whanau/opportunities/putea-manaaki/">https://ngaitahu.iwi.nz/whanau/opportunities/putea-manaaki/</a></p>
	<p><b>Cleaning companies who work with challenging domestic situations</b></p> <p><b>A Woman’s touch:</b> Private cleaning business that can provide specialty services to people who hoard. Can work with the individual or independently.  <a href="https://awomanstouch.co.nz/services/hoarding-clean-up/">https://awomanstouch.co.nz/services/hoarding-clean-up/</a></p> <p><b>Sunshine cleaners:</b> ‘Extreme’ private cleaning service who will go beyond the scope of regular cleaning services. Possibly appropriate for severely squalid conditions.  <a href="https://www.sunshinecleaners.co.nz/forensic-cleaning-services-christchurch">https://www.sunshinecleaners.co.nz/forensic-cleaning-services-christchurch</a></p> <p><b>Jani-King:</b> Commercial cleaning company that offers hoarding remediation services to property owners.  <a href="https://jke.co.nz/services/trauma-scene-and-hoarding-remediation/">https://jke.co.nz/services/trauma-scene-and-hoarding-remediation/</a></p>
	<p><b>Community groups who may be able to assist with labour</b></p> <p><b>Comcare home rescue:</b> Community service which provides urgent intervention where there is a risk of housing loss due to a deterioration of mental health, or ongoing barriers to maintaining the tenancy. Provide environmental cleans and rubbish removal, liaison with landlords and assistance with neighbour disputes.  <a href="https://www.comcare.org.nz/what-we-do/housing-support-services/home-rescue/">https://www.comcare.org.nz/what-we-do/housing-support-services/home-rescue/</a></p> <p><b>Papanui baptist freedom trust:</b> Charitable trust which provides practical, social and emotional support for individuals.  <a href="https://www.papbap.org.nz/freedom-trust/">https://www.papbap.org.nz/freedom-trust/</a></p>
HELP	

## Appendix G: Selected international educational resources

Children of hoarders: Awareness, understanding and support for family of people who hoard.

<http://childrenofhoarders.com/wordpress/>

OCD foundation hoarding information: International OCD foundation page on hoarding disorder and related information.

<https://hoarding.iocdf.org/about-hoarding/is-it-hoarding-clutter-collecting-or-squalor/>

Buried in treasures: Informative and self-help book written by David F. Tolin, Randy O. Frost and Gail Steketee based on the CBT model of hoarding developed by Frost and Steketee.

Can also be used to run group CBT. Recommended for people who hoard, family or support workers.

[https://books.google.co.nz/books/about/Buried\\_in\\_Treasures.html?id=cUwGAQAAQBAJ&printsec=frontcover&source=kp\\_read\\_button&redir\\_esc=y#v=onepage&q&f=false](https://books.google.co.nz/books/about/Buried_in_Treasures.html?id=cUwGAQAAQBAJ&printsec=frontcover&source=kp_read_button&redir_esc=y#v=onepage&q&f=false)

The British Psychological Society good practice guidelines: Extensive document with information on the nature of hoarding, guidelines for successful support and clinical recommendations for psychologists.

Accessible for anyone working with people who hoard.

<https://hoardingdisordersuk.org/wp/wp-content/uploads/2019/03/A-Psychological-Perspective-on-Hoarding-%E2%80%93-DCP-Good-Practice-Guidelines.pdf>

Hoarding Best practice Committee guide: Practical guide with recommendations for support services on successful interventions.

Developed in the US but much of the information is relative in an NZ context.

<https://umassmed.typepad.com/files/best-practice-hoarding-guide-final-.pdf>

Victoria hoarding and squalor practical resource for service providers: A lengthy resource providing direction, context and practical tools to help strengthen the capacity of funded or regulated services to work together when responding to hoarding or squalor.

<https://www2.health.vic.gov.au/Api/downloadmedia/%7B852C57C9-89CC-4492-9DF3-D985B8291FD5%7D>

## Appendix H: New Zealand literature and resources related to hoarding

Taranaki hoarding and squalor guidelines: Guidelines for personnel who are asked to intervene in cases of hoarding leading to severe domestic squalor. Based on PAH committee guidelines from Sydney South West Area Health Service.

[https://www.tdhb.org.nz/misc/documents/tdhb\\_hoarding\\_squalor\\_guidelines.pdf](https://www.tdhb.org.nz/misc/documents/tdhb_hoarding_squalor_guidelines.pdf)

Southern District Health Board Good Living Conditions Southern: Guidelines for front-line workers of various organisations to constructively intervene and improve the situation of people who are living in severe domestic squalor. Based on Taranaki guidelines.

[https://www.southerndhb.govt.nz/files/23420\\_20181017113906-1539729546.pdf](https://www.southerndhb.govt.nz/files/23420_20181017113906-1539729546.pdf)

Coping with hoarding: Three health professionals talk about the challenges of dealing with elderly people whose hoarding has been revealed following the Christchurch Earthquakes.

<https://www.thefreelibrary.com/Coping+with+hoarding%3A+three+health+professionals+talk+about+the...-a0391460670>

Hoarding, A disorder that can be distressing for everyone: Auckland geriatrician discusses experience dealing with hoarding.

<http://carers.net.nz/information/hoarding-a-disorder-that-can-be-distressing-for-everyone/>

Personality, mental health and demographic correlates of hoarding behaviours in a midlife sample: Research on the prevalence of hoarding in Canterbury and the associated personality traits, demographic features, and physical and mental health variables.

<https://www.ncbi.nlm.nih.gov/pubmed/28028484>

Identifying hoarding disorder in elderly using the interRAI: Research on the prevalence of hoarding disorder in older people using the InterRAI elderly assessment carried out by the Southern District Health Board.

<https://www.ncbi.nlm.nih.gov/pubmed/30391686>

Health info NZ hoarding: Canterbury health resource with links to other informative websites.

[https://www.healthinfo.org.nz/index.htm?hoarding\\_1.htm](https://www.healthinfo.org.nz/index.htm?hoarding_1.htm)