A SOUTH AUSTRALIAN GUIDE FOR INDIVIDUALS AND SERVICES TO ASSIST WITH IDENTIFYING AND DEALING WITH DOMESTIC HOARDING AND/OR SQUALOR

PRODUCED BY JUNCTION AUSTRALIA 2016
This guide offers a comprehensive information to understanding and assisting people who are living in domestic hoarding and/or squalor.

It is provided in order to help individuals, agencies, workers, family members and community members who are uncertain about what comprises domestic hoarding and/or squalor, with a comprehensive understanding of the disorder, best practice for treatment as well as referral pathways.

Although this guide is a good foundation for individuals, service providers and others to identify what constitutes hoarding and/or squalor it should not to be referred to in isolation as people’s circumstances vary significantly. ie: personal attributes, awareness of circumstances and acceptance of their circumstances. It is essential that any approach is flexible to the individual and addresses factors such as any presenting vulnerabilities and/or cultural factors.

Having good communication and strong partnerships with all agencies involved in the support process is fundamental.

The information listed in this guide was collated in 2016 and as far as is possible, is a comprehensive guide and action plan as to how best to deal with incidences of Hoarding and/or Squalor in South Australia. Nevertheless, we embrace any further comments and suggestions on the content provided for further development of the guide.

ACKNOWLEDGEMENTS

The following organizations have greatly contributed to this guide and their contributions are gratefully acknowledged and appreciated.

Junction Australia
Australian Redcross South Australia
Local Government Association of South Australia
Centacare Catholic Family Services South Australia
Ombudsman SA
Catholic Community Services NSW
Partners in Recovery
A Foot in the Door – Government of South Australia
City of Onkaparinga Council
Southern Hoarding & Squalor Group
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WHAT IS HOARDING & SQUALOR

Hoardings
“To acquire and have difficulty discarding a large volume of possessions which others would deem of no use or of insignificant value”

Squalor
“Severe domestic squalor refers to households that are extremely cluttered, in a filthy condition, and where the accumulation of items such as personal possessions, rubbish, excrement and decomposing food creates an environment that jeopardises the health and wellbeing of the occupant(s)” (A Foot in the Door, 2013).

DIAGNOSIS
Hoardings
Diagnostic and Statistical Manual of Mental Disorders – 5th Ed (2013), DSM V Published by the American Psychiatric Association states that hoarding is present when the following criteria are met:
1. Persistent difficulty discarding or parting with possessions, regardless of their actual value.
2. This difficulty is due to a perceived need to save the items and to distress associated with discarding them.
3. The difficulty discarding possessions results in the accumulation of possessions that congest and clutter active living areas and substantially compromises their intended use. If living areas are uncluttered, it is only because of the interventions of third parties (e.g., family members, cleaners, authorities).
4. The hoarding causes clinically significant distress or impairment in social, occupational, or other important areas of functioning (including maintaining a safe environment for self and others).
5. The hoarding is not attributable to another medical condition (e.g., brain injury, cerebrovascular disease, Prader-Willi syndrome).
6. The hoarding is not better explained by the symptoms of another mental disorder (e.g., obsessions in obsessive-compulsive disorder, decreased energy in major depressive disorder, delusions in schizophrenia or another psychotic disorder, cognitive deficits in major neurocognitive disorder, restricted interests in autism spectrum disorder).

Squalor
Squalor is not listed in the DSM 5; however has occasionally been associated with Diogenes syndrome (senile squalor syndrome). Individuals suffering from Diogenes syndrome generally display signs of collecting, hoarding, or compulsive disorder. Usually people who have suffered damage to the brain, particularly the frontal lobe, may be at more risk to developing the syndrome. The frontal lobes are of particular interest, because they are known to be involved in higher order cognitive processes, such as reasoning, decision-making and conflict monitoring.

The correlation between frontal lobe damage and functioning is supported by research discussed in Buried in Treasures: Help for Compulsive Acquiring, Saving and Hoarding – 2nd Ed (Tolin, D.F., Frost, R.O. and Steketee, G. 2014 pg. 67) and work currently conducted by Caulfield Hospital concluding there is “Increasing evidence for frontal lobe dysfunction in cases of hoarding and squalor” and “frontal executive dysfunction was a prominent finding, regardless of any underlying medical or psychiatric diagnoses” (Neuropsychology of Squalor. A/Prof Steve Macfarlane. 2013 https://www.ranzcp.org/Files/Conference/FPOA-Conference-2013/Neuropsychological-Profiles-of-Patients-with-Senil.aspx

TYPES OF HOARDING

Definitions of Hoarding and Squalor
Hoarding and Squalor are complex issues that can present in a number of different forms. To be able to properly tackle these issues a clear understanding of these different presentations and the possible reasons behind them is essential.

Hoarding
Hoarding involves an excessive collection of items (which appear to have little or no value) and a failure to remove or discard them. This often means that the environment in which they are being kept becomes so cluttered that it can no longer be used for the purpose for which it was designed. This will consequently impair the basic living activities (such as cooking, cleaning, sleeping, showering and moving) of the occupant.

(South Catholic Community Services NSW/ACT Squalor and Hoarding Toolkit)

Squalor / Severe Domestic Squalor
‘Squalor / Severe Domestic Squalor refers to households that are extremely cluttered, in a filthy condition, and where the accumulation of items such as personal possessions, rubbish, excrement and decomposing food creates an environment that jeopardises the health and wellbeing of the occupant(s). Furthermore, ‘normal’ household activities such as cooking bathing and sleeping are impeded or not possible.
In extreme cases, severe domestic Squalor may also have an impact on neighbours because the property may be a fire hazard, emit a foul odour and harbour vermin.’

(Government of South Australia, SA Health, 2013, p.8).
Animal Hoarding
Animal hoarding is more than just having a large number of animals, although numbers do need to be taken into account. The published definition of an animal hoarder [Patronek 1999] is someone who:
- Accumulates a large number of animals, and
- Fails to provide minimal standards of nutrition, sanitation, and veterinary care, and
- Fails to act on the deteriorating condition of the animals (including disease, starvation and death) or the environment (severe overcrowding and extremely unsanitary conditions), and
- Fails to act on the negative effect of the collection on their own health and well-being and that of other household members.
(International OCD Foundation: www.ocfoundation.org/hoarding/types.aspx)

Self-Neglect
Self-Neglect involves behaviours in which an individual does not (either intentionally or non-intentionally) appropriately address their basic personal needs. Issues of personal hygiene, appropriate clothing, feeding, bathing and medical needs often go unattended leading to an exacerbation of medical issues as well as social exclusion and isolation. It is important to note that self-neglect has serious implications for both the individual and the community.
Neglected Home Environments
Domiciliary Care also recognises that there are some homes which are not squalid or have evidence of hoarding, but are physically and structurally unmaintained and neglected. This may present some safety risks to both the client and service providers. It is important to know that this may not be associated with the other definitions.

SIGNS AND SYMPTOMS

Hoarding and Squalor is a complex set of conditions and may be identifiable by some or all of the following behaviours and conditions:

- Home environments and living conditions are filthy, unsanitary and could be classified by some as uninhabitable
- Large volumes of items are hoarded which impairs the functionality of the home and living areas. Residents of the home are therefore unable to undertake everyday living tasks such as bathing, cooking, sleeping and cleaning
- Neglecting of household maintenance both internal and external (including lack of functioning utilities)
- Utilities are not functioning
- Failure to attend to indoor and outdoor maintenance
- Unconventional behaviours and lifestyles
- Poor personal hygiene and insufficient nutrition due to a lack of self-care
- Significantly poor personal appearance. For example an individual may appear to have not changed their clothes or bathed for substantial periods of time including weeks, months and even years
- Social marginalisation and isolation, unwillingness to socialise with others
- Avoiding appointments with landlords, housing inspectors etc.
- Missing medication doses, not attending medical appointments
- Inability to sustain secure housing

The behaviours associated with Hoarding and Squalor may stem from one or more of the following factors/experiences:

- Traumas stemming from; violence, childhood abuse, war, physical and emotional abuse, neglect and more
• Previous and current substance abuse for example alcohol, illicit drugs and prescriptions medication

• Mental Health disorders can cause damage to the frontal lobe of the brain impairing concentration, problem solving, socialisation and impaired risk taking and rule obeying functionality. Some of these disorders include Schizophrenia, Depression, Personality Disorders, Autism, Obsessive Compulsive Disorder (OCD) and Attention Deficit Hyperactivity Disorder (ADHD)

• Dementia and other age related issues

• Poverty

• Physical health disorders

• Ongoing research is beginning to show the correlation between brain imaging abnormalities within people experiencing HD/squalor. (Professor McFarlane, Caulfield Hospital, Melbourne, Victoria).


PREVALENCE

• It is estimated that 1.5%-4.6% of the population have hoarding disorder (Mataix-Cols et al., 2010). Much of the research focus has been on U.S. samples, but there is evidence that clinical hoarding also occurs elsewhere

• OCD researchers, Stewart et al. (2007) and Mataix-Cols et al. (2004) used factor analysis to identify hoarding as a distinct symptom factor in the United States, Brazil, Canada, Costa Rica, France, Germany, Italy, Japan, the Netherlands, Poland, Turkey, Egypt, Singapore, and South Africa (cited in Saxena, 2008b)

• Research suggests that between 400,000 and 1.1 million Australians may have an issue with hoarding

• Hoarding is a contributing factor in 24% of fire fatalities, over 50 fires in Melbourne have been relating to hoarding issues. (Catholic Community Services NSW/ACT 2012 p, 3)

• In lay terms high estimate is 1 in 20 people are affected by Hoarding Disorder

ONSET AND COURSE

• The onset of hoarding behaviours typically happens in childhood or adolescence (Steketee & Frost, 2003), with a mean age of onset between 12 and 13 (Grisham, Frost, Steketee, Kim, & Hood, 2006; Samuels et al., 2002; Wheaton, Timpano, LaSalle-Ricci, & Murphy, 2008 (p14)

• Hoarding in childhood appears to be less acute than in adults. The reason for this may be related to the fact that parents have more control over the child’s acquisitions and organizational efforts (Plimpton, Frost, Abbey, & Dorer, 2009)

• The disorder is inclined to follow a chronic and progressive course, which affects individuals more significantly with each decade of their lives (Ayers, Saxena, Golsham, & Wetherell, 2010)
Research has identified that hoarding behaviours typically, become increasingly harder to manage later in life. This is evidenced by the advanced age at which such individuals pursue, or are forced to seek professional help, which can be brought on by a crisis, such as health issues, legal proceedings by council etc. (i.e., Frost, Steketee, Williams, & Warren, 2000; Seedat & Stein, 2002)

There has also been speculation that hoarding behaviour with an onset after childhood and adolescence is frequently related to trauma, significant loss, or stressful life events (Grisham et al., 2006; Tolin, Meunier, Frost, & Steketee, 2010)

Most people who seek help for hoarding are middle-aged, averaging about 50 years, according to our research and the research of others (Bratiotis, Christiana, Steketee, Gail, Schmalisch, Cristina Sorrentino 2011, p 4, The Hoarding Handbook: A Guide for Human Service Professionals

**CAUSES AND CO-MORBIDITY**

There is no one answer to the cause of why a person hoards or lives in squalor. Research does identify multiple potential reasons, many of which are combined together further exacerbating the cognitive process involved. Catholic Community Services NSW/ACT (2012) highlighted the different reasons given by service professionals compared to people who hoard.

<table>
<thead>
<tr>
<th>Service professionals</th>
<th>People who hoard</th>
</tr>
</thead>
<tbody>
<tr>
<td>Genetic predisposition in family</td>
<td>Protects them from emotional and other harm by preventing other people getting too close.</td>
</tr>
<tr>
<td>In response to significant life events (eg. War, trauma, extreme poverty)</td>
<td>Possessions create a feeling of security.</td>
</tr>
<tr>
<td>Difficulty with executive functioning (eg. Processing information, categorisation, decision making, memory)</td>
<td>Strong emotional attachments to items.</td>
</tr>
<tr>
<td>Emotionally driven reinforcement patterns</td>
<td>A belief that the items are worth valuing and/or might be useful in the future.</td>
</tr>
<tr>
<td>Inability to form meaningful relationships</td>
<td>A strong desire not to be wasteful.</td>
</tr>
<tr>
<td>Cognitive impairment caused by dementia, alcohol related brain damage</td>
<td>An intention to sort through accumulated belongings.</td>
</tr>
<tr>
<td>Mental health issues</td>
<td>The situation is reflective of negative feelings about self (eg. Feeling like rubbish, not valued, broken).</td>
</tr>
</tbody>
</table>

(Hoarding and Squalor: Effective Service Responses. Catholic Community Services NSW/ACT, 2012)

Co-morbidity of other ailments can contribute to Hoarding and/or Squalor behaviours. Approximately 75% of people with HD have a comorbid mood or anxiety disorder. The most common comorbid conditions are:

- Major Depressive Disorder (MDD)
- Generalized Anxiety Disorder (GAD)
- Social Anxiety Disorder (Social Phobia)
- Approximately 20% of individuals with hoarding disorder also have symptoms that meet diagnostic criteria for OCD (Frost et al. 2011b).

(Frost et al. 2011b; Pertusa et al. 2008).
RISKS AND CONSEQUENCES ASSOCIATED WITH HOARDING AND SQUALOR

There are multiple and complex risks and consequences associated with Hoarding and Squalor. The level to which Hoarding and Squalor impact both individuals and communities varies from case to case. The following section gives a brief overview of such risks and consequences:

Risks to Individuals

- Social isolation and marginalisation – as a result of Hoarding and Squalor, individuals may become quite introverted and withdrawn, and often will not have anyone coming to their homes and will not socialise with anyone at all. It is important to understand that Hoarding and Squalor is a form of crisis and although it is not an immediate form of crisis it is chronic and continues over time to intensify.

- Unstable and poor relationships – often, hoarding and squalor contributes to the breakdown of relationships and families. It is not uncommon when compulsive hoarders are given ultimatums to choose between people and objects they choose the objects. This could be a result of personifying objects and their values. Some compulsive hoarders may have experienced a sense that people have always let them down and caused them pain in contrast to their objects which have not let them down. Therefore they form attachments to objects rather than people.

- Anxiety and fear of eviction - the unacceptable state of home and risks to the community such as fire and other health hazards

- Increased risk of health problems due to: - Falls - Loss of medication - Lack of medical attention

- Negative Financial impacts - due to the costs involved in fees (lost bills and occurrence of late payment of bills), the cost of storage, heavy cleaning and removal service costs, risks to employment as a result of disorganisation within the home and the chaos attributed to Hoarding and Squalor

Risks to the Community

- Safety risks from fires
- Health risks as a result of squalid environments
- Neighbours may face consequences such as damages to common property, vermin infestation etc.
- Poor relationships with neighbours and other community members; stress caused by the difficult nature of these relationships
- Large financial costs for repairs of damage and clean-ups
• Costs for health care and community well-being involved with people living in Squalor (healthcare is often more expensive as there are a larger number of presenting problems due to long periods of time without medical attention)
• Unsightly homes contributing to the value and status of a community
• Minimisation of community pride


Risk to Workers
• Workers visiting the homes of people who hoard and/or squalor often have strong reactions such as astonishment, dismay, fear, and frustration. (Bratiotis, Christiana, Steketee, Gail, Schmalisch, Cristina Sorrentino 2011)
• Health and safety risks as mentioned above.

Risk to Firefighters
• Firefighters are at a high level of risk when responding to hoarding fires. Hoarding is known to increase the risk of fires because:
  • The accumulation of possessions causes an abnormally high fuel load which significantly increases the chances of ignition.
  • Blocked exits and narrow internal pathways hinder escape for occupants and make fire fighting problematic.
  • Due to utilities such as electricity being misused or disconnected can result in the occupant performing unsafe cooking and heating practices

Risk to Animals
• Illness and disease
• Malnutrition due to inadequate diet or contaminated diet
• Poor posture and disability caused by confined spaces
• Mental suffering caused by ill treatment

(Beyond Overwhelmed. Catholic Community Services NSW/ACT. 2014 p 33-37)
TREATMENT OPTIONS

Treatment can help people with Hoarding Disorder (HD) to decrease their saving, acquisition, and clutter, and live safer, more enjoyable lives. There are two main types of treatment that help people with Hoarding Disorder:
1. Cognitive-Behavioural Therapy (CBT)
2. Medication (medication in its own right, does not treat hoarding disorder but may complement other co-morbid conditions.

During CBT, individuals gradually learn to discard unnecessary possessions with less distress, diminishing their exaggerated perceived need or desire to save for these possessions. They also learn to improve skills such as organization, decision-making, and relaxation. For many people, certain anti-depressant medications may be helpful and may produce more rapid improvement.

(https://www.psychiatry.org/hoarding-disorder)

LEGAL ISSUES

Legislation in South Australia
- The Department of Health is the corporate policy wing of SA Health and works closely with local government environmental health officers (EHOs)

- State and local government EHOs are authorised under the Public and Environmental Health Act 1987.
- Section 12 of the Act imposes a statutory obligation on the Minister for Health and each local council to promote proper standards of public and environmental health within the state and each jurisdiction respectively

- Local Government can intervene using the Public and Environmental Health Act 1987

- Local councils are called to intervene in situations of severe domestic squalor primarily as a result of complaints to local councils about the condition of a property

- Cases of severe domestic squalor (and some cases of compulsive hoarding) may be deemed to constitute an ‘insanitary condition’.
- An ‘insanitary condition’ is defined as premises which:
  - gives rise to a risk to health
  - is so filthy or neglected that there is a risk of infestation by rodents or other pests
  - causes justified offence to the owner of any land in the vicinity
o emits offensive materials or odours
o for some other justified reason
o A premises can be deemed unfit for human habitation by reason of an insanitary condition

(A Foot in the Door: The Management of Compulsive Hoarding & Severe Domestic Squalor in South Australia, Andrew Brown, Environmental Health Officer, Michaela Hobby, Manager Environmental Services)

Laws you need to know about that correlate to hoarding and squalor:

**ANIMAL PROTECTION** - Animal Welfare Act 1985

Code of Practice for the keeping of security dogs in South Australia Prepared by The South Australian Animal Welfare Advisory Committee 10th December 2012


**CHILD PROTECTION** – Children’s Protection Act 1993

**DISABILITY** - The Disability Discrimination Act 1992

**DUTY OF CARE** - South Australia Work Health and Safety Act 2012

**HOUSING** – South Australia Residential Tenancies Act 1995

South Australia Fire and Emergency Services Regulations 2005 under the Fire and Emergency Services Act 2005 – Fire Prevention, Part 3A

**HUMAN RIGHTS** – Charter of human rights and responsibilities Act 2006

**LOCAL GOVERNMENT REQUIREMENTS**

South Australian Public Health Act 2011


CHILD PROTECTION
Under the Children’s Protection Act 1993 a number of health clinicians and health workers are required by law to report suspected child abuse and neglect. SA Health supports the reporting of child abuse and neglect by all employees since every person has a responsibility to ensure children are kept safe from harm. Child abuse and neglect has immediate and lifelong impacts on health and wellbeing. SA Health has developed a number of policies and processes to meet its statutory obligations.

Families SA Child Abuse Report Line – 13 14 78
HOARDING AND SQUALOR SA WEBSITE


Published in June 2015, created to assist service professionals and the wider community easily acquire information relating to H&S. A lot of the information discussed today can be found online. The site compromises of multiple subheadings.

“About Hoarding and Squalor”
- Definitions of Hoarding and Squalor
- Hoarding
- Squalor / Severe Domestic Squalor
- Animal Hoarding
- Self-Neglect
- Neglected Home Environments
- How do Compulsive Hoarding behaviours develop?
- Characteristics and Behaviours of Hoarding and or Squalor
- Risks and consequences connected to Hoarding and Squalor
- Treatment options
- DSM5 definition of Hoarding Disorder

“Making Positive Change”
- Where to from here
- ‘Finding your way’ flowchart
- Professional support
- Self-support
- How to support somebody
- Assessment and Tools
- ITS programs in metro Adelaide

“Resources”
- Recommended Guides
- A Foot in the Door
- HD: A GP’s Guide to supporting Patients
- HD: Are things piling up on you?
- Recommended Books – suggest workplace obtain these for referencing.
- BIT
Overcoming Compulsive Hoarding

Recommended Assessment Tools
- The Severe Domestic Squalor Assessment Scale
- Clutter Image Rating Scale
- Hoarding Rating Scale

Recommended websites

Other Resources

“Service Directory”
Lists over 200 services across South Australia which are recommended by the service sector as having an empathy of working with people with H&S.

Broken into vulnerability categories
- Aboriginal and Torres Strait Islander
- Aged
- Disability
- Domestic Violence
- Family
- Mental Health
- Youth
- Which is further broken into 22 sub-categories
- Accommodation/Housing Providers
- Animals
- Community Services
- Domestic support and Cleaning
- Donation of furniture and clothes
- Gardening Services
- Health Services
- Legal & Financial
- Mental Health
- Ongoing Support
- Pest Control
- Professional Organisers
- Rubbish Removal
- Short Term Support
- Utilities

WHY DO PEOPLE HOARD AND/OR LIVE IN SQUALOR?

The reasons why people feel the need to acquire possessions are often different from person to person.

- For example, tax invoices may be saved by someone in case they are audited, for others they may be trophies representing past success. According to Neziroglu, Bubrick, Yaryura-Tobis, fear is the basic reason behind the drive to save (2004, p 31). This fear is catastrophized to an extreme
- Hoarding is not just a house problem, it’s also a person problem (Tolin, Frost, Sketekee, p 66). Research has shown that the problem can be attributed to the brain, thoughts, emotions, and in behaviour (p 66)
- Variants in degrees of hoarding and squalor but important to remember that volume of items is often irrelevant it’s about the impact it is having on the person
- Hoarding is thought to stem from several vulnerability factors
• **Biological factors**
  o Biological factors play an important role, such as inherited genes or neurobiological structures and metabolism that might predispose a person to hoarding

• **Environmental factors**
  o Hoarding can run in families. Ongoing research is currently studying the specific genetic markers for this problem and how genetic versus environmental aspects influence hoarding behaviour and how the chronic indecision that appears to hinder normal discarding may be an inherited trait.

• **Brain Structure**
  o Particular brain structures such as the prefrontal cortex may influence acquiring and other behaviours in people who hoard.

• **Learnt behaviours**
  o Family behaviour and learned belief systems some of which are also entrenched in the person’s culture. Bratiotis, Steketee, Schmalisch 2011, p 12 report that many clients specify that hoarding is most likely learned behaviour from observing parental behaviour
  o Many clients recall parental commands such as ‘waste not, want not’ and ‘better safe than sorry’ which have cultivated guilt and anxiety when trying to make decisions on discarding items. (Bratiotis, Steketee, Schmalisch 2011, p 11-12)

• **Comorbidity and mental health**
  o Concurrent mental health problems and mood-states such as depression and anxiety could be a factor in the development or expression of hoarding.
  o According to Bratiotis, Steketee, Schmalisch 2011, p 12-13), major depressive disorder is prevalent in more than half of people who seek help for hoarding
  o Severe depression could play a contributory role if the low mood stops somebody from making effective decisions or everyday caretaking of themselves or their homes. Depression is likely to be a result of severe hoarding, as the problem becomes more and more debilitating

• **Personality features**
  o Personality features can contribute to hoarding
  o Obsessive compulsive personality disorder (OCPD) where people have rigid thinking that prevents them from discarding
  o Perfectionism can interfere with decision making about discarding and adds to negative moods as people fail to meet their overstated standards
  o ADHD – can be more prone to hoarding because they are unable to focus on sorting/organizing tasks for a long enough period of time to complete task (Bratiotis, Steketee, Schmalisch 2011, p 11-14)

**CURRENT RESEARCH**
Research is ongoing and gaining momentum on a global scale. Randy Frost, David Tolin and Gail Sketekee are amongst international authorities who are continuing their research. Due to the research carried out so far, Hoarding Disorder has become its own entity in the DSM IV. Research is continuing on the issues surrounding squalor which will eventually lead to being included in future Diagnostic Statistical Manuals (DSM). In Australia, Professor Stephen McFarlane (Caulfield Hospital, Melbourne) is involved in ongoing research into the correlation between dysfunction within the frontal cortex and conditions of squalor.
DISPEL MYTHS

What are some of the myths surrounding hoarding/squalor?

Myth: Removing clutter and property will remove the issue of hoarding.
Truth: Large scale clean-ups without the client’s permission do not work – it is likely to have a long term negative impact on the client’s mental health. Large scale clean-ups even with the client’s permission may not work.

Myth: People with hoarding issues can’t see all the stuff and dirt and/or they don’t mind it.
Truth: Clutter blindness is the term used whereby the condition of the property is mentally blocked out. When a person starts to talk about it, this can be a sign they are ready for change and help.

Myth: There is nothing we can do about it.
Truth: With appropriate and relevant support help and guidance conditions of hoarding and squalor can be resolved.

Myth: People with hoarding issues are just dirty and lazy.
Truth: Usually just the opposite is true. But they have often undergone a traumatic experience or had a huge period of instability in their lives. They experience shame and fear which paralyses them and makes it very difficult to understand how they can return to the way they were before. Incorrect intervention can often cause further trauma if they feel they have been perceived to be someone who they are not. Often a person who demonstrates hoarding behaviours is constantly thinking about their items and trying to make decisions about them.

Myth: All people with hoarding issues have OCD
Truth: OCD and Hoarding Disorder are distinct conditions which were once linked when studies first started.

Myth: Fires in hoarding properties will behave in the same way as they do anywhere else.
Truth: Data shows fires were contained to the room of origin in 90% of all residential fires. In hoarding homes, however, that percentage dropped to 40%, indicating that hoarded materials promote the spread of fire through a dwelling.

Myth: People only hoard things at home
Truth: Hoarding in offices and other business premises is not uncommon, and can lead to blocked escape routes and increased risk of a fire. Storage units can be utilised to further acquire items when there is insufficient space within the home environment.

Myth: Evicting people with hoarding issues teaches them a lesson and stops them hoarding again.
Truth: Being evicted is a traumatic experience, and can create such anxiety for a person with hoarding issues that their tendency to hoard can increase.

Myth: All people with hoarding issues live in squalid conditions or own numerous pets, or both.
Truth: Not all people with hoarding issues live in unhygienic conditions, or are animal hoarders.
Myth: Every room in a hoarder’s home is packed full of stuff.  
Truth: People with less extreme hoarding issues may have parts of their home which are less cluttered, or live with people who aren’t hoarders and who do what they can to keep parts of a home tidy.

Myth: People with hoarding tendencies are uneducated and have lower levels of intelligence. 
Truth: Individuals with hoarding tendencies are often intelligent and highly educated. Hoarding Disorder and Squalor do not differentiate between socio-economic backgrounds.

Myth: Hoarding is a ‘lifestyle choice’.  
Truth: In May 2013, Hoarding Disorder was re-classified as a condition in its own right under the US Diagnostic Statistical Manual-V (DSM-V) (American Psychiatric Association, 2013).

Myth: Hoarding is caused by a traumatic life event.  
Truth: It’s not clear what causes hoarding therefore it is important not to assume that a traumatic life event is the reason behind an individual’s hoarding behaviour – there could be a number of contributory factors and events. It is far more likely to affect those with a family history of hoarding; genetics and upbringing are likely to be among the contributing factors.

Myth: Everyone with lots of clutter is a hoarder.  
Truth: Just because someone owns lots of stuff or lives in a cluttered home, doesn’t necessarily mean they’re a hoarder.

Myth: People with hoarding issues don’t like to talk about it.  
Truth: This is entirely dependent on the individual and where they are in their Stage of Change.  
http://www.cfoa.org.uk/17642 Chief Fire Officers Association, UK Hoarding Awareness Week 2014

HOW TO IDENTIFY IF THERE IS A PROBLEM WITH HOARDING AND/OR SQUALOR

1. The following rating scales and questionnaires will help workers and clients identify the severity of a hoarding/squalor issue: 
   • Hoarding Rating Scale
   • Is my home safe? 
   • Are your daily activities impaired by hoarding? 
   • Home Environment Index

2. Taking photographs. 
   Although this can be difficult for clients, it is important to have a record of how things look right now. Later as client’s progress with their treatment they can look at the original photos to see how they are progressing.

HOW DID THIS HAPPEN?

There are multiple and very personal reasons why people demonstrate Hoarding and Squalor behaviours.
   • It becomes a part of the ‘landscape’ and is incorporated rapidly meaning it no longer looks out of place, ie: Clothes
• The person may have tried to sell or dispose of once but without success. Can either
  (1) justify to others they have tried to dispose of it and could, so can keep and/or
  (2) reinforces that unable to dispose of and is too difficult, easier to keep.
• If purchased unwanted/unsuitable item there may be a fear of returning to the
  shop as this could imply they aren’t able to make correct decisions and will look
  foolish.
• Develop habits over time.
• Enjoy the anticipation of starting new projects
• Safety – from poverty, financial hardship etc
• Anthropomorphism - the attribution of human characteristics or behaviour to a
  god, animal, or object

MEET THE BAD GUYS
• According to the Buried in Treasures program, the ‘Bad Guys’ are the ways of
  thinking that stop people who hoard from making positive changes.
• The more understanding we have about the ‘Bad Guys’, the better equipped
  workers and clients will be to beat the hoarding and/or squalor issues.

Bad Guy #1 - It’s just not my priority
The most prominent reason people do not overcome hoarding issue is that they don’t
spend the time necessary to work on the problem.

Bad Guy #2 - Letting Unhelpful Beliefs Get in Your Way
Clients often hold very strong beliefs about their possessions.
These include:
  • Beliefs about usefulness
  • Perfectionism and fear of making mistakes
  • Beliefs about responsibility
  • Attachments to possessions
  • Beliefs about objects as a source of identity
  • Underestimating memory
  • Beliefs about control

Bad Guy #3 - Overthinking or confusing yourself
Clients can often get into trouble because of their intelligence and creativity, for example,
the tendency to think of multiple uses for an object.

Bad Guy #4 - Avoidance and Excuse-Making
Avoidance and Excuse-Making
Avoidance is possibly the most detrimental of the bad guys. Frequently, the outlook of
discarding brings up powerful emotions such as sadness and anxiety.

Bad Guy #5 - Going for the Short-Term Payoff
• People who hoard often find their ability to foster their sense of pleasure is limited to
  acquiring possessions. In effect, one of the only ways they can feel happy is to keep
  acquiring. This pleasure is often short lived and fades in comparison to the long-term
  sadness that comes from excessive clutter and limitations of other fun social activities.
  o What is needed is to strike the right balance between what feels good and what is
    good.
• It is critical that clients understand the ROLE the Bad Guys play in their lives. Encourage clients to use the self-assessment tools which are an essential part of helping clients gain awareness. Addressing the Bad Guys now and spending time having a good hard look at them will make it more likely clients will be able to overcome them as they make changes to their lives and start the de-clutter process.

N.B. As we are all different, not everyone will experience all five of the bad guys. The Self-Assessment Tools will give clients a sense of which bad guys are likely to cause the most prevalent problems in clients lives.

EFFECTIVE ASSESSMENT
The client and their choices should be respected at all times, for this reason a client focused approach should be applied for harm minimisation outcomes.

• Respect their right to make their own decisions – whether you agree with their decisions or not, they have a right to make the decisions that affect them.
• Work as a team – work together rather than telling them what to do or doing things for them.
• Help the person stay focused on the task – people who hoard can be easily distracted so remind them of what they are supposed to be doing and their motivation for doing it.
• Provide encouragement – show them that you believe in them and praise their achievements.
• Remain non-judgemental to their circumstances.
• Follow the assessment tools to ensure consistent assessment and baselines.

What NOT to do:
• DO NOT judge or criticise them – this is only likely to make somebody defensive and less likely to change.
• DO NOT argue with them about their hoarding– again this will also likely induce defensive responses and less likely to change.
• DO NOT try to make decisions for them – people have a right to make their own decisions and if you make decisions for them they will not learn to make decisions for themselves.
• DO NOT touch or move anything without permission – this could cause them to become angry and resentful, which could damage your relationship with them and make it more difficult to support them in the future.
• DO NOT tell them how they should feel – you might not understand why they feel the way they do about their possessions, but their feelings are legitimate.
• DO NOT try to do too much – it is important to take care of yourself so you don’t become overburdened with the problem.


INCREASE EMPATHY
Demonstrating an increase in empathy is critical in building rapport and helping people with HD and/or squalor.

• Showing empathy doesn’t just mean that you agree with everything the client says.
• Empathy means that you are willing to listen and try to see things from their perspective.
• Empathy must be genuine – don’t patronize the client.
• If you don’t mean what you are saying, don’t say it.

Here is a quick clip to demonstrate the difference between Empathy and Sympathy
https://www.youtube.com/watch?v=1Evwgu369Jw

Some good ways to show empathy are:
• Ask open ended questions. This means questions that cannot be answered with a simple ‘yes’ or ‘no’.
  • For example
    o “What are some things you like about these items?”
    o “What does it feel like when you pick something up?”
    o “How are you feeling right now?”
  • Summarize your understanding of what the client says:
    o “I think I hear you saying that right now cleaning up the clutter is not a high priority for you; do I have that right?”
  • Make statements about what the client seems to be feeling, so they know you are listening to them:
    o “It looks like you are feeling anxious right now: Your voice sounds sad; do you want to talk about that?”
  • Use compliments and statements of appreciation and understanding:
    o “You are showing real courage right now?”
    o “I know how hard this is, and I appreciate the fact you are willing to work on it”
  • Do not argue with a client ever.
  Be aware of:
    o Ordering or commanding
    o Warning or threatening language and non-verbal communication
    o Persuading with logic, arguing, or lecturing
    o Moralizing, preaching, or telling the client what they “should” do
    o Judging, criticizing, or blaming
  • Respect a client’s autonomy
    o A client has the freedom of choice about their own possessions.
      (Frost, Tolin, Steketee, p 103, 2014)

BUILDING RAPPORT
• Building genuine rapport and trust with a client is intrinsic to a sustainable supportive and interactive relationship by enabling greater and easier communication.
• Sometimes rapport can occur naturally, at other times it needs to be worked upon and developed.
• Be aware of how you may be presenting yourself at every interaction (phone, text, face-face) and how the client may be interpreting this. Often there is a power imbalance with a client and service professional’s relationship.
• Don’t go straight into talking about the property condition. Create small talk for 5-10 minutes
  o Open up the possibility of other conversations
  o “How has your week been?”
  o “How have you been since we last spoke?”
  Be cautious not to engage in small talk for too long as otherwise the client may make this the focus of your support thus becoming a barrier to momentum to outcomes. (Tompkins, 2014)
• Try and find a commonality and shared experiences
• Active listening – focus fully on the conversation and what is being discussed. Provide an opportunity for the client to explore their thoughts and feelings in a supportive manner.
• Admit when you don’t know an answer or have made a mistake.

BEST PRACTICE OF ASSESSMENT TOOLS

“We cannot change that which we do not acknowledge”

• The purpose of assessment tools and surveys is to assist identify:
  o A person’s strengths and weakness
  o Provide evidence of a baseline which can be reflected on in the future
  o Ideally should be completed as ongoing record of any change.

There are multiple Assessment Tools which have being developed specific to Hoarding and Squalor. There is no one mandated approach to either which Assessment is used or completing it - each are in place to promote a consistent, supportive, and risk based identification within a best practice framework which acknowledges the uniqueness of each person’s circumstances.

As highlighted no two cases will ever be the same, it is fundamental to therefore thoroughly assess each new case at the onset of support and for the duration.

HOW TO EFFECTIVELY USE ASSESSMENT TOOLS

We will focus on 3 Assessment Tools which are commonly used:
  o Severe Domestic Squalor Assessment Scale - Based on the Environmental Cleanliness and Clutter Scale (Halliday, G & Snowdon, J 2009, ‘The Environmental Cleanliness and Clutter Scale (ECCS)’, International Psychogeriatrics, vol 21, no. 6, pp 1041 – 1051)
  o Clutter Image Rating Scale
  o Hoarding Rating Scale

Severe Domestic Squalor Assessment Scale (SDSAS) (SA Health)

Adapted from the Environmental Cleanliness and Clutter Scale (ECCS) which is commonly used as it has been demonstrated to be a reliable measure of squalor (Halliday & Snowdon 2009).
• 10 questions
• Scale responses
• Based on 0 – 3 scoring
• Variation definitions
• % variations
• Maximum score = 30

Scoring explained:

The score is less than 12 indicating the person(s) is not living in moderate or severe squalor
• Immediate intervention is not required.
• In some cases professional judgement may indicate that some risks are present that require attention (sometimes immediately).
• It may also be appropriate to provide the client with some basic support services to prevent the situation from escalating.

The score is 12 or more indicating the person(s) is living in moderate or severe squalor
• Desirable to convene a task force so that the required services can be provided (note: Information Sharing Guidelines required).
• No remedial action is generally required until the task force meets unless there are immediate risks requiring urgent corrective action.
  o Identify the following
  o Identify a key worker
  o Identify associated risks
  o Develop an action plan

The score is less than 12 but professional judgement indicates further action is required
• In some cases professional judgement may indicate that some risks are present that require attention (sometimes immediately).
• 6 additional considerations with yes / no answers and prompts of best practice responses
• Are there animals living on the property?
  o Yes
• Do they appear neglected? (thin, sick, injured, in pain?)
  o Yes – Contact RSPCA
  o No – Contact local animal control officer (local council)

When using the SDSAS, it is important to consider the following:
• The scale does not address all aspects of the living conditions and additional notes should be provided where possible to aid in the assessment and referral process
• The assessment descriptions are not intended to be judgemental. They have been designed to achieve consistent assessment results without the need for specific training on how to use the SDSAS
• In some situations it may not be appropriate to complete the SDSAS in front of the client (i.e. the client may view the SDSAS as judgemental and insensitive)
• Professional judgement should always be exercised when using the SDSAS regardless of the score (i.e. intervention may be warranted when the score is below 12)
• In some cases it may not be possible to assess all of the living spaces (e.g. if the client refuses access to the property). In such cases, the assessor should complete as many sections in the SDSAS as possible and use professional discretion on whether further action is necessary
• Items of little value refer to items that most people would consider useless or should be thrown away. In general, it does not include items that have monetary value or personal significance to the client, such as a birth certificate or family photos. It should be noted that although most people regard items such as bottle caps or old newspapers to be useless, care should be taken when referring to these items as they may be significant to the client
• Having utilities that are working correctly is essential for maintaining one’s personal hygiene and care requirements. If the utilities are not working correctly, the client may design alternative makeshift arrangements that create additional household hazards (e.g. unconventional cooking equipment can increase the fire risk). If the task force identifies utilities that are not working correctly, they should identify why they are not working (e.g. the client is unable to pay the bills, the infrastructure is damaged / broken) and attempt to resolve the problem in the action plan
Any WH&S hazards that are identified while completing the SDSAS should be noted so that other task force members can take adequate precautions during subsequent home visits.

(A Foot in the Door: Stepping towards solutions to resolve incidents of severe domestic squalor in SA. A guideline. SA Health)

Clutter Image Rating Scale (Frost, Steketee, Tolin, & Renaud, 2008)
- 9 photos at different levels of clutter for
- Kitchen
- Bedroom
- Living Room
- Provides an accurate reference for discussion on the degree of acquired items
- The client selects the photo which they feel most accurately mirrors their property. Some degree of judgement is required on the part of the client.
- If they score higher than image #4 it can be considered that the clutter impinges on the person’s life that they would be encouraged to seek supports.

Hoarding Rating Scale (Tolin, Frost & Steketee, 2010)
- 5 questions
- Scale responses
- 0 – 8
- Not difficult Extremely difficult
- Maximum score = 40
- Interpretation of HRS Total Scores (Tolin et al., 2010)
- Mean for Nonclinical samples: HRS Total = 3.34; standard deviation = 4.97.
- Mean for people with hoarding problems: HRS Total = 24.22; standard deviation = 5.67.
- Analysis of sensitivity and specificity suggest an HRS Total clinical cut off score of 14.
- Criteria for Clinically Significant Hoarding: (Tolin et al., 2008) A score of 4 or greater on questions 1 and 2, and a score of 4 or greater on either question 4 or question 5.

UNDERSTANDING STAGES OF CHANGES MODEL, ENHANCING MOTIVATION, MOTIVATIONAL INTERVIEWING AND REDUCING ACQUIRING.

STAGES OF CHANGE MODEL

The Stages of Change Model is a model of intentional change which focuses on decision making developed by Carlo DiClemente and James Prochaska (1977). The process that leads to making meaningful changes can be broken down into 6 steps.
Pre-Contemplation (Not ready)

- People in this stage are not considering changing their behaviour and are unaware that they have a problem
- During this stage the main task for the worker is to help raise awareness of the problem. This may call for an open and honest conversation about the amount of clutter in the home and compare this with the amount of clutter in other people’s homes
- Potential risks and problems (such as fire, health or falling risk) that may arise from their hoarding behaviour should be discussed

Contemplation (Getting ready)

- In this stage, people have some understanding that there is a problem but are ambivalent about changing
- They may swing back and forth between saying they want to do something about the problem and then deny there is a problem
- It is important not to get into arguments with clients as this may push them in the opposite direction

Preparation (Ready)

- This stage signifies a window of opportunity for change
- People in this stage may say “I’ve got to do something about the problem” or “I see that my hoarding is a serious issue, but what can I do?”
- This is the time clients are most receptive to suggestions for getting help
- Be realistic about expectations, for many people with hoarding problems it can a long and difficult process when seeking help
Action

- In this stage people are actively taking steps to reduce their clutter
- They may have sought the advice of a trained professional and are following the plan drawn up
- Remember, expressing a desire to change is not the same as actually doing it. Until clients have started treatment and are actively following the treatment plan they must be considered to still being in the contemplation stage
- In the action stage, it is important to encourage and support the client’s efforts. This can be done by commenting on improvements in clutter, appreciated their actions so far and empathizing with the client’s personal struggle.
  - Using comments such as “I know this is really hard for you” and “I think you’re doing a great job” is a useful way of encouraging and supporting the client.

(Motivation and Compulsive Hoarding Treatment (Maltby, N, Tolin, D, The Anxiety Disorders Centre, Hartford, Conncticutt drsharris.com/.../Motivation%20and%20Compulsive%20Hoarding.doc)

Maintenance

- By this stage, clients are working to establish and strengthen any changes in their behaviour, to maintain the ‘new’ status quo and to prevent relapse or temptation
- The former behaviour is now seen as no longer desirable and a number of coping strategies have been put in place and are working
- Workers will need to keep in mind there is a need for them to remind clients of the progress that has been made already and to stay on the course of change. The risk of relapsing is significantly less than in earlier stages
- Queensland Department of Health
- The use of photos, questionnaires and rating scales are useful to refer back to at this point to recall previous circumstances.

Relapse

- During the process of change, most people will experience relapse.
- Although relapses can be important for helping the client to become stronger in their resolve to change, relapses can be a trigger for giving up.
- Workers can support their clients identify personal strengths and weaknesses, and develop a plan to resolve those weaknesses to solve similar problems the next time they occur.

Australian Government Department of Health
**PRE-CONTEMPLATION/MOTIVATION OF CHANGE**

**Reasons to Change vs Reasons not to Change**

People start working on their hoarding problem when the reasons for change outweigh the reasons for not changing (Tolin, Frost, Sketekee, 2014, p 36)

The Balance of Change Scale

<table>
<thead>
<tr>
<th>Reasons to Change</th>
<th>Reasons Not to Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clutter is hurting my social life</td>
<td>My clutter’s not hurting anyone</td>
</tr>
<tr>
<td>My hoarding problem makes me feel bad about myself</td>
<td>Working on the problem would be like “giving in” to people who have been nagging me</td>
</tr>
<tr>
<td>My family argues a lot about my hoarding problem</td>
<td>Acquiring is one of the few things that bring me pleasure</td>
</tr>
<tr>
<td>I want to get my life under control</td>
<td>I’m perfectly happy with things as they are</td>
</tr>
<tr>
<td>I want to feel comfortable in my own home</td>
<td>Acknowledging the problem would make me feel bad</td>
</tr>
<tr>
<td>All of this clutter is not safe for me</td>
<td>Nothing’s worked before, so why bother trying?</td>
</tr>
<tr>
<td>People would get off my back if I could improve this situation</td>
<td>Eventually I’ll just get a bigger home that all my stuff can fit into</td>
</tr>
<tr>
<td>I want to set a better example for my kids and give them a better living environment</td>
<td>I couldn’t stand doing a difficult program</td>
</tr>
<tr>
<td>I need to work on the problem in order to avoid legal problems</td>
<td>I just don’t have the time</td>
</tr>
<tr>
<td>I’d have a lot more money if I could cut back on acquiring</td>
<td></td>
</tr>
</tbody>
</table>
Activity notes:

Which way does your balance of change seem to tip?

- If it tips toward change, you are probably ready to start working on the problem.
- If the balance tips towards not changing, this indicates that working on hoarding may not be a high priority for the client at this time. Unless the client can find more reasons to change, there will be very little to be gained in trying to clear clutter. The client will find excuses and there will little if any success.

Meet the Good Guys

After tackling the Bad Guys, clients can become overwhelmed. This is where it is important to introduce the Good Guys who are here to help.

Good Guy #1 - Keeping Your Eyes on the Prize

- Encourage clients to keep their personal values and goals in mind and find the strength to keep going
- The goal is for clients to be able to celebrate the things they own and use them to achieve their goals

Good Guy #2 - Downward Arrow

- The downward arrow is a strategy clients can use to learn more about their beliefs and to help them begin to challenge them
- When clients find themselves getting stuck, you can ask them what they think might happen. For each answer, clients will keep asking more questions about what would be bad about that, and then what would be bad about that, until they get to the heart of their concern

Good Guy #3 - Thinking it Through

- During the sorting or non-acquiring tasks, clients can be asked to think critically by talking through their decisions
- When sorting, the client can be encouraged to say aloud the thoughts they have about the possession (be mindful to respect the client’s privacy, they may want to do this alone)
- Clients may find that their initial judgements about the value of the object will change.
- Clients can be encouraged to keep a record of the questions they ask and this will help to speed up their decisions about saving
- Typical questions clients use in the process which are helpful are:
  - “How many of these do I already have?”
  - “How many would be enough?”
  - “Do I have a specific plan to use this item within a reasonable timeframe?”
  - “Have I used this in the past year?”
  - “Is this of good quality?”
“Do I really need it?”
“Will discarding this help me solve my hoarding problem?”

**Good Guy #4 - Testing it Out**

- Some people will find that thinking-related strategies such as the downward arrow or thinking through is not enough or they don’t have the capacity to think abstractly.
- Clients can be encouraged to act like a ‘curious scientist’ who is studying hoarding behavior to test to see whether their thoughts are true, false, or to some extent true.
- Firstly, it is crucial to come up with specific predictions about what you think will happen. Predications can be phrased as “if-then” statements such as “If I do X, then Y will happen.”

Some examples of hoarding-related predictions are:

- **“If statement”**
  “If I don’t buy this item...”
  **“Then statement”**
  “...then I won’t be able to stop thinking about it.

- **“If statement”**
  “If I throw away this item...”
  **“Then statement”**
  “...then I’ll feel terrible forever and won’t be able to function.

These predictions may/may not be true. How do we find out? Encourage the person to test their predictions.

- **“If statement”**
  “If I don’t buy this item...”
  **“Then statement”**
  “...then I won’t be able to stop thinking about it.

- **“If statement”**
  “If I throw away this item...”
  **“Then statement”**
  “...then I’ll feel terrible forever and won’t be able to function.

Now check the outcome. Did the prediction come true?

- **“If statement”**
  “If I don’t buy this item...”
  **“Then statement”**
  “...then I won’t be able to stop thinking about it.

- **“If statement”**
  “I don’t buy the item and pay attention to my thoughts over the next 24 hours.

- **“If statement”**
  “If I throw away this item...”
  **“Then statement”**
  “...then I’ll feel terrible forever and won’t be able to function.

- **“If statement”**
  “I throw away the item and pay attention to my feelings and functioning over the next 24 hours.

**Outcome**

- After an hour I wasn’t thinking about it as much and by the next day I wasn’t thinking about it at all.
The outcome for testing it out is to make a clear prediction, to try doing whatever it is the client is afraid of and to see whether or not the prediction will come true.

- Revising and testing out feelings is a powerful way for clients to be feel better and more in control.

**Good Guy #5 - Developing the Right Skills**

- Defeating hoarding forever is not just a question of throwing away clutter or stopping acquisition
- Many people with hoarding issues have difficulty with organizing their possessions.
- They may keep their possessions in a random or chaotic fashion with important items mixed up with unimportant ones
- Working on specific organizational skills may be necessary
- Another skill that may be necessary to work on is taking a systematic approach to problem solving and this includes problems not related to their hoarding. A step by step strategy is needed for addressing problems as they arise

**Good Guy #6 - Your Practice Muscle**

- In order to change longstanding behaviour patterns, clients will need to spend time practicing not acquiring and discarding.
- Clients can think about this as a muscle that has not been exercised for a long time. They can be encouraged to start out with a small goal in mind and gradually working up to achieve bigger goals
- Workers can support their clients to start spending 5 minutes each day practicing working on making changes and increase in the next week up to 10 minutes, the following week 15 minutes, and so on...
- Clients can rate how strong their Practice Muscle is based on how many minutes they can work on hoarding every day

<table>
<thead>
<tr>
<th>Practice Muscle Strength</th>
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<tbody>
<tr>
<td>0</td>
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</table>

**Minutes per day**

**Minutes**

**Goals**

- Understanding why people hoard
- Optimism and feelings of empowerment are promoted when people understand their behaviours, thoughts and feelings toward their possessions. The feelings of stigma, shame and isolation are also decreased
- Create a healthy happy living space that can be used
- Improve organizations skills so that people can find their possessions. This adds to a feeling of competency and self-esteem to help people keep going
- Improve decision-making skills. Often people who hoard have difficulty making decisions. The can be borne out of a fear of making mistakes and/or difficulty with concentration
- Reduce acquiring and enjoy other activities
- Reduce clutter
Ambivalence

- Many people who hoard experience ambivalence
- Ambivalence is different to apathy. Apathy means that people don’t care at all about the problem
- Ambivalence means to have opposite feelings or beliefs at the same time
- For example: Clients may feel desperate to discard of piles of newspapers in their living room but at the same time feel they can’t afford to lose the information contain in them. Clients may desire to have more space in their bedroom but parting with any of their clothing (even clothes they no longer wear) appears to be impossible

It is critical to understand two important factors about ambivalence:

- Ambivalence is natural and normal. All people experience ambivalence and it is particularly likely to happen when people have conflicting needs, wants, or values. There is nothing wrong with being ambivalent.
- Ambivalence needs to be faced directly, with determination and work to through it with the strategies (laid out in Buried in Treasures book? Do you want this bit in there?)
- Encourage the client to understand fully the Balance of Change is an important step

Motivational Interviewing (MI) Techniques

- “MI is a person centred, goal-orientated method of communication for eliciting and strengthening intrinsic motivation for positive change” (Miller, 2009)
- Developed (in part) by clinical Psychologists Prof. William R Miller, Ph.D and Prof Stephen Rollnick, Ph.D in 1983
- The principles of Motivational Interviewing are
  - Develop Discrepancy
  - Express Empathy
  - Amplify Ambivalence
  - Roll with Resistance
  - Support Self-efficacy

Known as DEARS

- People are often more likely to believe and act on what they hear themselves sat – however in order to hear, they must firstly say. MI encourages people to this ‘say’ stage through thought and reflection
- Internal motivation not external pressure provides the impetus for the focus, effort and energy required to move through the entire process of change (DiClemente, 1999) and is essential to the long-term management of a severe hoarding problem
- MI often works within Hoarding and Squalor as it aims to work with individuals to resolve their ambivalence about changing their behaviours, without evoking resistance to change which is part of the Pre- Contemplation stage

There are 4 basic skills required to effectively conduct MI

- Open-ended questions
- Affirmations
- Reflective Listening
Summary Statements

Known as OARS

MI is not necessarily a lengthy process, sometimes a few carefully timed, incisive questions and reflective listening is enough to create some motivation of change. (Tompkins, M.A, 2014)

Open-ended questions

- The asking of an open ended question cannot be answered with a limited yes/ no response
- They are the door-openers that encourage clients to talk with the goal of eliciting statements that develop discrepancy and reflect self-efficacy. As mentioned, people are more likely to believe and act upon what they hear themselves say

Affirmations

- Making affirmations encourages the client to acknowledge their positive behaviours and strengths which in turn builds confidence in their ability to make positive change.
- Affirming statements provide the opportunity to identify difficulties and to celebrate and support their strengths. Reinforcing that their concerns and issues are both valid.

Reflective Listening

- The practice of paraphrasing the clients comments, this lets them know you understand what they have said rather than what you think you’ve heard.
- Additionally this allows the client to hear again what they’ve said which should help them understand their own thoughts better.

Summary Statements (or Self-motivational Statements)

- These pull together everything stated in the conversation, allowing transition to the next topic.
- There is an opportunity to ask what they have learnt or got out of the conversation.
- The client can both recognise and verbalise the issues they are dealing with by pointing out observations and asking for further thought and input.
- This is similar to reflective listening, but can be a major help in developing discrepancy.

People do not make change because

- They do not perceive that change as being important, in which case the benefits of the behavior outweigh the perceived consequences,
- Or because they are not confident that they are able to make the change
- Motivational Interviewing seeks to increase the perceived importance of making a change and increase the person’s belief that change is possible
- Moving from problem sustaining (resistance) to problem changing statements
CONTEMPLATION/ENHANCING MOTIVATION

“Even the most highly motivated person will eventually reach a point where their motivation wavers”
(Tolin, Frost, Sketekee 2014, p 87)

Motivation is a complicated issue. Even the most highly motivated people sometimes reach a point where their motivation falters.

READINESS TO WORK ON THE PROBLEM

It is important to note that at some point, motivation will decline.

Strategies to help client’s keep going are:

1. Recognising the problem.
   How accurate is the client’s perception of the severity of the hoarding problem?

2. Willingness to Work on the Problem
   Be aware that people’s level of readiness will fluctuate from day to day

3. Telling Your Story.
   When client’s make a major life change, it can be useful to review what brought them to their current situation.

Questions that are helpful for clients to understand how this occurred are:

1. When did this problem begin?
2. When did it get out of control?
3. How have your family and friends reacted?
4. Are there major life events or trauma associated with this?
5. What things have you lost out on because of the clutter/hoarding?
6. What have you tried to control it? How did that work out?

It is important to recognize that clients probably feel conflicted about changing the way they acquire and save possessions.

VALUES AND PERSONAL GOALS

Talking to the client about their values and personal goals

Encourage the client to clarify what their values and personal goals are. (See handouts)

Be careful not to impose your values or your goals on the client. Clients People are best motivated when they are working towards their own goals.
• Make sure client’s goals are realistic and manageable. If goals are set too high the client could become very discouraged if they do not reach them
• Encourage the client that as they meet their goals, they can then set new ones
• It is helpful for people to think about why they are selecting their goals (why they are important to them)

The following questions are useful in helping clients understand:

I want to beat hoarding because:

1. ________________________________
2. ________________________________
3. ________________________________
4. ________________________________
5. ________________________________

If I work on my hoarding problem, the following things are likely to happen:

1. ________________________________
2. ________________________________
3. ________________________________
4. ________________________________
5. ________________________________

If I don’t work on my hoarding problem, the following things are likely to happen:

1. ________________________________
2. ________________________________
3. ________________________________
4. ________________________________
5. ________________________________

When things become difficult, it will be critical to remember these goals and consequences. When a client is having difficulty discarding of clutter or acquiring more clutter, they can encourage the client to look back at these goals and values.

Ask the client whether the object in their hand is more important to them than their personal goals and values. This will help them to keep their long-term focus when tackling short term wishes.

PREPARATION/MOTIVATION BOOSTERS

The following exercises are designed to help clients with their motivation.
People are more likely to follow through on a plan when they are encouraged to make a clear-cut, affirmation of intent. It is recommended that clients sign an agreement with the person they are most accountable to, themselves. Giving a copy to a trusted person can be even more effective.

**ACTION/REDUCING ACQUIRING/SORTING AND REMOVING STUFF**

**The Avoidance Solution**

- A good place to start to gain control over acquiring is to avoid the places where the urges are the greatest to acquire, such as ‘cheap shops’, garage sales, car boot sales etc.
- Keep in mind that long term, avoidance is not a very effective long term solution
- The client will eventually find themselves in a situation where they will have a strong urge to acquire. They will need strategies to help give them control over their urges and to be able to face situations without the fear of losing that control

**The Control Solution**

- The most difficult part of solving acquiring problems is resisting strong urges. This is the battle between a short term payoff – feeling good now and the long term cost – that is exacerbating the hoarding problem
- A four step process teaches people to learn new ways to control their urges to acquire and, to remove emotion from the process of acquiring:
  - Discover what, how and why people acquire
  - This can be achieved by tracking why they acquire
  - Encourage clients to track their acquiring for a two week period.
  - Commonly a buying or acquiring episode starts with an **EMOTIONAL VULNERABILITY**
    - As all people are different, people acquire for different emotional situations.
    - A trigger usually sets off the emotional episode
    - Thoughts about self and acquiring govern what will happen next
    - When the item is acquired, people experience an **INSTANTANEOUS EMOTIONAL PAYOFF**
      - This leads to a doing it over and over again
      - However, this PAYOFF isn’t long lasting. Eventually regret kicks in and this often leads to very NEGATIVE assumptions about self
  - In order to break the vicious cycle, it is critical to understand how the cycle works starting with:
    - Beginning emotional state
    - Acquiring trigger
    - Thoughts that lead to acquiring
    - Immediate emotional consequences
    - Regret and negative assumptions about self

1. **Changing thoughts about Acquiring**
   - People who compulsively acquire lose themselves in the moment – that is transfixed and overlook the other parts of their lives and only focus on the item in front of them
Clients can be encouraged to keep the rest of their lives in focus as they make decisions about acquiring.

A forthright way to think differently while acquiring is to establish firm rules to follow:

Thinking Through the Advantages and Disadvantages

Another useful strategy to deal with thoughts is to give some thought to the advantages of buying something new versus the disadvantages of doing so.

<table>
<thead>
<tr>
<th>Advantages of buying more clothes</th>
<th>Disadvantages of buying more clothes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeling good about having new things to wear</td>
<td>Spending more money than I should</td>
</tr>
<tr>
<td>Reducing bad feelings if I’m in a mood</td>
<td>Feeling guilty</td>
</tr>
<tr>
<td>Not losing out on a good bargain</td>
<td>Making it harder to go on the holiday I really want</td>
</tr>
</tbody>
</table>

2. Learning to Tolerate the Triggers to Acquire

- Powerful urges can be unleashed that seem impossible to control. As mentioned earlier, avoidance is only helpful in the short term.
- What is needed long term is a strategy of how to tolerate the urges.
- Once people start practicing to tolerate their urges over time they become less powerful.
- The key is for people to expose themselves gradually to more powerful acquiring triggers.
- Starting first with weak triggers using the thinking strategies discussed earlier.
- Gradually over time, clients will be able to expose themselves to more intense triggers and urges.
- It is important to allow people to do this in their own time, at a slow enough pace for them to deal with it.

3. Developing Alternative Sources of Enjoyment and Coping

- Another crucial factor is finding other activities to replace the enjoyment of acquiring.
- Brainstorming a short list of choices that someone can do (in particular, at short notice).
- It is recommended to put the most interesting ideas at the top of the list and then placing them in a prominent place that will catch their attention such as fridge or calendar.

STRATEGIES AND SUGGESTIONS

- As mentioned key to success is to reduce acquiring whether this is road side items, food, newspapers, bric-a-brac.
  - Notice that not asking to ‘stop’ acquiring but to reduce in initial stages.
  - This will have an instant effect on the cluttered nature of the property.
  - Provide emotional support – sorting, discarding and resisting urges to acquire can be extremely difficult and stressful and they will need emotional support, so be there for them and listen when they need to talk.
  - Help them make decisions – encourage them to think through decisions out loud, and help them to consider the pros and cons of any decision.
  - Accompany the person on non-acquiring trips - for people to overcome hoarding they need to build up a tolerance for triggers and urges to acquire new items. The only way they will be able to overcome them is by gradually exposing themselves to the urges and learning to resist them.
HANDS ON STRATEGIES

- Discuss thoughts to find an items before acquiring
- Take photo of the item before acquiring
- Discuss how many projects have currently?
- How many need or are realistic?
- Cover up items/areas that not planning on sorting today (reduces overwhelming emotions)
- Set up direct debits where possible to reduce anxiety of missing paying bill (utilities, credit cards, council rates etc).
- Use electronic reminders ie: set alarm on phone to remind at 10am and 2pm everyday = spend 60 minutes sorting evening prior to bin collection to empty bins in house and put bins onto roadside (follow neighbours to know which weekly).
- Make visual reminders (text and image).
- Progress posters using photos of the changes in home. (include dates).
- Utilise technology – “My Services” App as a reminder of what’s due and when.
- As service providers get to know local councils and their policies including hard rubbish policies.
- Encourage clients to monitor their use of items. The Pareto Principle states you will probably find that your usage follows the 80:20 rule - that you use the same 20% of something 80% of the time.
- Sell, free cycle, recycle or give away anything you are comfortable to discard.
- If that’s too big a step in one go, put everything (i.e. that considering discarding) in a holding space e.g. spare bedroom, loft space, cupboard. Anything that’s still there, unused, after 3 months review discarding process (mark a date in your diary to do this). You’ve then got 3 months to get used to living without those items and to test to see which you really have a need/desire/attachment for.
- If it’s someone else’s, they can take responsibility – give it back, renegotiate a storage arrangement for a limited time only, or get rid of it.
- Reflect back when gone on holiday – could only take limited items.
- Discuss how this made person feel.
- What strategies did they use to cope with being away from personal items.

REFERRAL PATHWAYS, TREATMENT AND RELAPSE

REFERRAL PATHWAYS

Knowing which services are available is the key to making long term change. For many people, contacting their GP will be the first step in making change.

Mental Health Care Plan

GP’s through the Better Access initiative are able to access mental health professions and team based mental health care which include working collaboratively with psychiatrist, clinical psychologists, registered psychologists, accredited mental health social workers and occupational therapists.

Chronic Disease Management

- A Medicare rebate is available for a maximum of five services per patient each calendar year for referral to allied health professionals which include
  o Aboriginal Health Workers or Aboriginal and Torres Strait Islander Health Practitioners
- Audiologists
- Chiropractors
- Diabetes Educators
- Dieticians
- Exercise Physiologists
- Mental Health Workers
- Occupational Therapists
- Osteopaths
- Physiotherapists
- Podiatrists
- Psychologists
- Speech Pathologists

Fact sheet can be accessed at

The Hoarding and Squalor website at www.hoardingandsqualorsa.com.au provides a directory of services that may be available.

- All services listed within the Service Directory are recommended due to having an understanding and sensitivity working with people who experience Hoarding and/or Squalor

Information Sharing Guidelines (ISG)

- In 2013 the South Australian Cabinet directed that the scope of the guidelines should be broadened to include information sharing for all vulnerable population groups, including all adults, irrespective of their status as parents or caregivers, where there are threats to safety and wellbeing.
- It was also decided to relocate responsibility for the ISG to Ombudsman SA. This decision enables service providers to apply the expanded guidelines, the Information sharing guidelines for promoting safety and wellbeing (ISG), to all clients with whom they work and aligns information sharing practice across both adult and child services.
- The Information Sharing Guidelines can be accessed at:

“The Information Sharing Guidelines clearly state that information may be shared about all people when there is a risk of harm to themselves or others. The level of risk of harm and how it impacts obtaining consent will determine whether information is shared with or without consent.” Information Sharing guidelines, Ombudsman SA for promoting safety and wellbeing, p 7.

- The ISG delivers a consistent state wide approach to appropriate information sharing practice when there are threats to safety and wellbeing. The aims include:
- Reduce the risk of different service providers adopting conflicting information sharing practices
- Increase the likelihood that the actions taken are based on a complete understanding of clients’ circumstances and needs
- Respect the privacy of individuals to the extent possible when further the aims above
- This limits the possibility of agencies and organisations working at cross-purposes to each other or missing vital details that could expose clients to harm.
How to Share Information
ISG Decision Making Steps and Practice Guide

Important Note: Staff must be inducted and trained in the use of the ISG as they would any other organisational procedure.

TREATMENT OPTIONS
Professional Support
Accessing professional support provides a coordinated approach to helping people make sustained positive change.

There are many positives to engaging with a support worker including:
• Utilising their experience of working with people living with hoarding and/or squalor;
• Accessing additional services that are referral only and
• Supporting people through the overwhelming times.

When is it Time to Seek Professional Help?
Seeking professional help is a very personal decision.
Best practice for considering professional help is:
  a) If the problem is too overwhelming for someone to manage on their own even with the help of friends or family
  b) If other measures such as reading the Buried in Treasures book are not helping
  c) Mental health conditions such as depression and anxiety are standing in the way of overcoming the hoarding issue (Tolin, Frost, Steketee 2014 p 7)

Types of Treatment Available
THERAPY
CBT is beneficial for people with hoarding.
• CBT is an active solution-focused treatment where the therapist and client work collaboratively to learn how to sort and let go of possessions, think more clearly about their possessions and control the urges to acquire.
  o Best practice indicates that the therapist attends the person’s home to help with learning how to achieve this (Tolin, Frost, Steketee 2014, p. 7-8)).
• Traditional talk therapy does not appear to be beneficial on the whole.

Note of Importance: When selecting a therapist it is important they are skilled in CBT. It is recommended for therapists to have read Buried in Treasures by Tolin, Frost, Steketee and Treatment for Hoarding Disorder by Gail Steketee and Randy Frost.
MEDICATIONS
- To date, there has been limited research on the use of medication to treat hoarding.
- Medications used to treat obsessive-compulsive disorder (OCD) have also been used for hoarding. These include serotonin reuptake inhibitors (SRI) such as clomipramine, as well as selective serotonin reuptake inhibitors (SSRI) such as fluvoxamine, fluoxetine, sertraline, and paroxetine.

PROFESSIONAL ORGANIZERS
- Professional Organizers are a valuable addition to the treatment team.
- Information on how to access professional organizers can be found by following the links on the Hoard & Squalor Website at: http://www.hoardingandsqualorsa.com.au/service-directory.php

STEPPED CARE
- Stepped care involves starting with one treatment – usually something that is somewhat easy and inexpensive and then move up to more intensive treatments if they are required.
- For many people, a good place to start is the Buried in Treasures help book and accessing a specialized therapeutic hoarding group.

MAINTAINING SUCCESS
Once an action plan is in place and success is being achieved in de-cluttering or controlling hoarding, the prospect of maintaining this success must be tackled.
The following steps are useful in maintaining success:

1. **Make an honest appraisal of what has been accomplished.**
   - Revisit the original photos taken and encourage the client to give an honest appraisal of the situation at present.
   - What’s better? What’s not better?
   - Being balanced is important – if an area of the person’s home looks better, celebrate their success! If an area doesn’t look better, acknowledge that these areas will need more work.

2. **Revisit and complete new questionnaires on the following:**
   - “Hoarding Rating Scale”
   - “Is My home Safe”. A score of 21 or higher indicates they may be living in an unsafe home. Scores of 3 or higher on any question, should be a high priority item to address immediately.
   - “Are your Daily Activities Impaired by Hoarding?” Questionnaire.
   - Only rate the difficulties the client has because of hoarding issues, (not because of physical difficulties).
   - “Home Environment Index” questionnaire, a score of 2 or above on any question merits attention.
3. **Establish a Schedule for Organizing.**
   - By adhering to a stringent schedule the easier it becomes.
   - In order to be successful at adhering to a schedule, the client will have to face the fact that there will numerous times when the task seems too difficult because of tiredness, being too upset, too busy or uninterested. If the client gives into these feelings, their hoarding problems are likely to return.
   - People must develop strength to work despite feeling tired, upset, busy or bored.
   - Keeping up with this schedule must be the person’s highest priority.

4. **Clutter is a Magnet for Clutter**
   - The Broken Window Theory
   - [https://www.youtube.com/watch?v=vj9WsGbaNAY](https://www.youtube.com/watch?v=vj9WsGbaNAY)
   - What does the Broken Window Theory have to do with hoarding?
   - How are a person’s actions influenced by clutter in their home?
   - How is a person’s actions influenced by cleanliness?

5. **Make Rules for Organizing and Letting Go**
   Encourage taking a few minutes to set up five rules for the client to maintain control over their hoarding.

6. **Bring other People into the Home**
   - Many people with severe hoarding issues stop inviting people into their homes. Their social lives often have suffered as a result. This is often a vicious cycle with the hoarding problem exacerbating because of their diminishing social life.
   - Inviting people into the home is a dependable way of improving motivation to clean and organize. Visitors are a great motivator for anyone to clean up!
   - As well, inviting visitors in will get people into the habit of make their home a place to entertain. The more often people are invited into the home, the easier it is to maintain what has been accomplished.

7. **Identify What has Worked Best For The Client**
   - How Good Guy #1: Keeping Your Eyes on the Prize Helped Me
   - How Good Guy #2: Downward Arrow Helped Me
   - How Good Guy #3: Thinking it Through Helped Me
   - How Good Guy #4: Testing it Out Helped Me
   - How Good Guy #5: Developing the Right Skills Helped Me
   - How Good Guy #6: Your Practice Muscle Helped Me

**Challenging Thinking**

If the hoarding problem has been longstanding, there is likely to be difficulties with making decisions about certain things.

**Review the Bad Guys that have been most troublesome.**

- How I will Challenge Bad Guy #1: “It’s just not my priority”
- How I will Challenge Bad Guy #2: Avoidance and Excuse-Making
- How I will Challenge Bad Guy #3: Going for the Short-Term Payoff
- How I Will Challenge Bad Guy #4: Letting Unhelpful Beliefs Get in My Way
- How I Will Challenge Bad Guy #5: Overthinking or Confusing Myself
RELAPSE

- During the change process, most people will experience relapse.
- Relapses can be viewed as important for learning and helping people to become stronger in their determination to change.
  - On the other hand, relapses can be a trigger for giving up in the pursuit for change.
- The key to recovery from a relapse is to review the attempt to quit up to that point, identify personal strengths and weaknesses.
- The next step is to develop a plan to resolve these weaknesses to solve similar problems the next time they happen.
- Relapse is an aspect in the action or maintenance stages. Many people who change their behaviour decide for a number of reasons to resume their hoarding or return to old patterns of behaviour.
- Research unmistakeably shows that relapse is the rule rather than the exception.

Lapse versus relapse

A note about lapse versus relapse: A lapse is a slip-up with a swift return to action or maintenance where a relapse is a full-blown return to the original problem behaviour.

Adapted from


The Stages of Change Model
• White (2013, p. 152) identified some issues with the change model involving relapse.
• In this model, relapse involves the person going back to the beginning, or at least it is a regression.
• The diagram also shows relapse as a deviation away from maintenance.
• This does not take into account the different contexts of relapse, and their different psychological meanings.
• In the latter stages of change, a relapse has a positive side to it. It moves the person closer to the point of maintenance, and in that sense is not a backward step.
• It can be more accurately described as:

  ![Diagram](image.png)

• It is important to recognize when the clutter is building up again and/or for example: the credit card bills are increasing.
  
  o If this happens, re-visit the appropriate exercises that will be helpful. Keep in mind, the client has had success in the past and that they can succeed again.

• Many people worry about relapse once their hoarding is under control. Encourage them to keep going, even though they have had a setback.
• It is important to remind people that stressful events are a part of everyone’s life and that we all must find ways of coping while at the same time maintaining ongoing responsibilities such as cleaning and organizing.
  
  o Everyone needs to take care of tasks daily, such as bathing, eating and dressing, and keeping our living space habitable is critical to how we cope with stress.

**The future**

Take time to reflect back on your own or your client’s circumstances with them – acknowledge the positive changes that have been made. Talk about how life has been in the past. What was good about these times? What was bad? What gave you joy or held you back?

Hopefully you have a new insight into how different life can be now that acquiring is no longer controlling you but that you are able to control it. Take time to enjoy the new activities in your life that provide satisfaction and fulfilment.

Good luck with the journey whether it is your own, a loved one or a client.


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