

Hoarding & Squalor Training





Acknowledgements

This material and the previous training sessions were made available through Murray Primary Health Network's Partners in Recovery.

Particular thanks also go to the following contributors:

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Hoarding and Squalor Reference group and Working group

Partners in Recovery (PIR)

Murray Primary Health Network (formerly Medicare Local Loddon Mallee Murray) Housing Justice.

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Introduction

People living with hoarding behaviour or in a squalid living environment need to be acknowledged and supported to enable them to manage their behaviour so they might live safely with *minimal risk* to themselves and the community. (1)

New Australian population research estimates more than 600,000 people (2.6%) may suffer from hoarding disorder, putting themselves and their families at risk of squalor and health risks, fire hazard, eviction and homelessness. (2)

Hoarding behaviour and squalid living conditions define quite different circumstances, but under certain conditions may coexist.

Definitions: hoarding



Hoarding behaviour is the persistent accumulation of, and lack of ability to relinquish, large numbers of objects or living animals, resulting in extreme clutter in or around premises. (1)

This behaviour compromises the intended use of premises and threatens the health and safety of people concerned, animals and neighbours. (1)

Definitions: hoarding

- People who hoard actively acquire things or animals from external sources, while others might passively accumulate over years without relinquishment (for example: with regard to animals, a person could just allow their animals that are not de-sexed to keep breeding without acquiring more).
- The word 'relinquish' captures the fact that objects or animals are valued by the person and not easily given away or surrendered.
- Objects (for example, piles of newspapers) may be neatly piled up along corridors and not necessarily fill or clutter living areas, which may remain available for their intended use.
- Some objects and animals may be hoarded outside the home in other buildings or spaces, in nonliving areas (sheds). (1)

Definitions: squalor



Squalor describes an unsanitary living environment that has arisen from extreme and/or prolonged neglect, and poses substantial health and safety risks to people or animals residing in the affected premises, as well as others in the community. (1)

Definitions: animal hoarding

The accumulation of large numbers of animals that overwhelms the person's ability to provide a minimum standard of nutrition, sanitation and veterinary care. (1)



Definitions: co-existing hoarding & squalor

When the client has both hoarding and squalor behaviours together.



Definitions: neglect

Neglect involves a failure to remove household waste and other rubbish as well as a failure to appropriately maintain the structure (both internal and external) of a house, the yards, gardens and utilities (such as plumbing, gas and electrics). (10)



Definitions: multi-facet neglect

- Multi-Faceted 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. (10)

Why do people hoard?

- Hoarding may be *hereditary*. Up to 85% of people with hoarding behaviour can identify another family member who displays this behaviour.
- Hoarding may begin after *brain damage*, such as strokes, surgery, injuries, or infections.
- Intellectual / cognitive reasons such as acquired brain injury or physical disability.
- Family/life experiences and psychological factors may also play a role in the development of hoarding and emotional stress may heighten symptoms. (1)

Why do people hoard?

People who hoard have a variety of reasons for doing so:

to avoid wasting things that might have value.

•they have a fear of losing important information.

the emotional meaning of objects.

•they appreciate the aesthetic appeal of objects, especially their shape, colour, and texture. (1)

Why do people live in squalor?

Possible reasons include:

- Lack of living skills i.e. cleaning.
- Health issues- physical/mental

Whether someone lives in 'squalor' is subjective and often influenced by the attitude, exposure to an unclean environment and personal living conditions of the person making the assessment.

Why do people hoard animals?



Animal hoarders often fall into one of the following three categories, but can sometimes exhibit characteristics across categories:

•*The overwhelmed caregiver* initially provides adequate care for the animals and believes that while a problem has slowly developed, it's not as serious as others think it is. The overwhelmed caregiver may be socially isolated, but is willing to accept intervention.

•*The rescue hoarder* develops a compulsion based on a strong desire to rescue animals from possibly deadly situations, actively acquiring animals, believing no one else is capable of caring for them. They often work with a network of enablers, gaining proximity to the animals and finding it difficult to refuse to take in any new animals.

•*The exploiter hoarder* takes in animals to serve their own needs and is indifferent to any harm caused to the animals. (1)

Characteristics of hoarding

Three behaviours characterise hoarding:

1.acquiring too many possessions.

2.difficulty discarding or getting rid of them when they are no longer useful or needed.

3.difficulty organising possessions.

When these behaviours lead to enough clutter and disorganisation to affect someone's health or safety, or they lead to significant distress, then hoarding becomes a 'disorder'. (1)

Characteristics of hoarding

People who hoard may have personality traits that include avoidance, anxiety, indecisiveness, difficulty trusting others, perfectionism and poor socialisation skills. (1)

The person is often resistant to change, procrastinates or may agonise over decisions, leaving items that may previously have been of value to decay or deteriorate to the point where the items are perceived by others to be worthless. (1)

Characteristics of squalor

Individuals who live in squalor may frequently exhibit poor initiative, drive, and motivation.

May have physical and mental health issues. (1)

Diagnosis

The DSM-5 edition (published May 2013)⁵⁹ classified hoarding as a distinct disorder with its own diagnostic criteria within the chapter about obsessive-compulsive and related disorders.

Before the DSM-5, hoarding could be misdiagnosed as a form of obsessive-compulsive disorder.

Hoarding disorder is new to DSM-5 and is supported by extensive scientific research. The behaviour usually has harmful effects – emotional, physical, social, financial and even legal – for a hoarder and family members. (1)

What does DSM-5 stand for? Diagnostic and Statistical Manual http://www.dsm5.org/about/Pages/Default.aspx

Implications of hoarding and squalor

- Every situation is different, and the impact of a person's hoarding behaviour can be anywhere on a continuum of severity from low to high.
- Hoarding and Squalor not only effects the person who hoards and/or lives in squalor but also potentially dependants, partners, family, carers and neighbours and communities. Everyone has different perceptions on how to best deal with this issue.
- Expensive and emotionally devastating evictions or other court actions can lead to hospitalisations or homelessness.
- Conflict with family members and friends who are frustrated and concerned about the state of the home and the hoarding. (1)

Effects of hoarding and squalor

Sunrise Interview

Click on link to go to you tube video.

Discussion:

In this clip who were effected by hoarding?What legal implications were there as a result of hoarding?



Laws you need to know about that can relate to hoarding and squalor, some examples:

Personal Safety- Occupational Health & Safety (OHS)

Physical Health- Health Records Act 2001, GUARDIANSHIP AND ADMINISTRATION ACT 1986

Mental Health- Mental Health Act 2014, GUARDIANSHIP AND ADMINISTRATION ACT 1986

Privacy- Privacy Act 1988, Information Privacy Act 2000

Child Protection- Child, Youth and Families Act 2005, Child Wellbeing and Safety Act 2005

Animal Protection- Domestic Animals Act 1994, Prevention of Cruelty to Animals Act 1986,

Code of Practice for Private Keeping of Dogs, Code of Practice for Private Keeping of Cats

Sanitation- Public Health Regulation 2000

Housing- Residential Tenancies Act 1997

Building- Occupational Health & Safety (OHS), Environmental Local Law (visibility from streets etc.), Housing Act 1983

Duty of Care

Human Rights- Charter of human rights and responsibilities Act 2006



Hoarding disorder, whether or not it is linked to squalor and self-neglect, is an issue that cuts across many areas.

These areas can include mental health, aged and community care, housing, children's welfare, homelessness, fire and rescue, local government, councils, and trustee and guardianship issues.

Roles within each of these areas will be both regulatory and support (case management) roles.

Two basic roles can help motivate the change process – regulatory roles and support roles.

Regulatory Roles

Articulate the regulatory requirements (eg local council laws) and enforce the consequences of not meeting these requirments.

Examples of regulatory roles:

Police

Housing Providers (if applicable)

Council

RSPCA

Child Protection

Support Roles

Provide assistance to meet regulations to avoid a negative outcome (may be case management roles).

Examples of support roles:

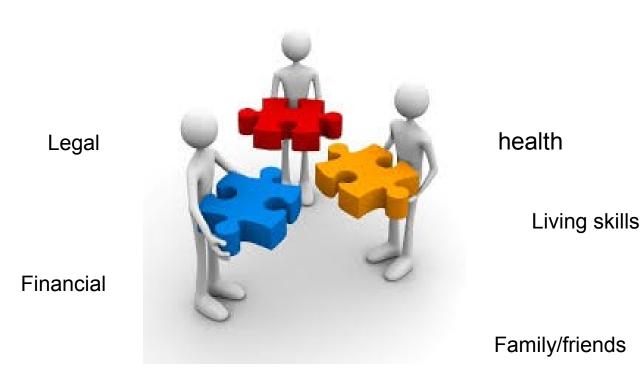
- Case Management Services
- Tenant advocacy services
- Tenancy support services
- Mental health services
- Family support services
- Home Care Services
- Any other form of community services

Having two roles helps individuals separate out the negative feelings from the positive feelings so that (with support) they can act on their positive feelings and engage in resolving their hoarding problem.

The regulatory and support roles work best when they are two different individuals or agencies, communicating together.

Roles need to maintain a "united front"- this is where joint case management is effective. (4)

To successfully address this issue we need to look at all aspects of the persons life



Mental Health

Service coordination

- Without coordination, people fall through service gaps, often because agencies need the specialist knowledge and expertise of additional agencies to respond effectively.
- Sometimes the physical environment where hoarding and/or squalor are present is excessively risky and people's complex needs require share care planning.
- Service coordination is essential for preventing harm, or deteriorating living conditions, for family members and the hoarder themselves.
- Intervening in hoarding and squalor cases is a complex process that requires significant knowledge, understanding, expertise and time. (1)
- It is vital for services to have a thorough understanding of a wide range of services in their area to address client needs holistically.
 www.hoardingresources.org.au

Approaches

Hoarding and Squalor are two different issues and at times they co-exist.

It is important workers understand there are different approaches when working with both of these issues.



Hoarding usually requires:

A focus on building rapport first (meet the person outside the home first i.e. out for coffee).

A longer-term strategy includes more frequent, regular visits to assist the person to reduce and/or store excessive items.

Sensitivity to the fact that many people who hoard have not allowed anyone into their home in years; a useful goal can be to encourage the person to allow family and friends into their home on a regular basis.

Meetings with the person and appropriate services to review progress.Planning to achieve short term goals.

Discussing impediments to the process and fostering continued cooperation is paramount. (1)

There is little evidence to indicate that the nature of items hoarded makes a difference to the type of strategy applied, with two exceptions:

1.when animals are collected and kept in great numbers, the condition of the home is typically compromised, and

2.when hoarded items include rotten food, body products or similar items, a squalid living condition can be severe. (11)

Squalor often requires:

A short term, intensive plan with the need for ongoing services commencing soon after the initial intervention is complete.

The initial intervention to include a clean-up with permission of the person concerned.

Effective interventions in cases of severe domestic squalor are commonly expensive and require good inter-agency collaboration.

Budgetary support must be available to enable appropriate services to take on cases and provide case management. (1)

Approaches: animal hoarding

- Depending on if there are signs of neglect to animals it may be necessary to involves regulatory services i.e. Council and RSPCA.
- You may also need to discuss with regulatory services regarding legislation and animals.
- If a hoarder believes that animals may be going to a home in which they will be cared for and loved, this may assist in removing excess animals from a property. There may be animal rescue/adoption services in your area.
- Explore discounted de-sexing and animal care services to minimise increase in animals- possibly discuss with council, RSPCA or animal rescue/adoption services.

Approaches: no "quick fixes"

Discussion:

Who has been involved in hoarding and squalor cases where a "quick fix" has occurred?

Did it bring about long term change for the clients hoarding and squalor behaviour?

What impact did the "quick fix" have on the client?

Trying to address Hoarding through a quick fix, such as an enforced physical clean-up, has proven to be ineffective and is discouraged for the following reasons:

It will severely impact on the person living there, in most cases causing extreme anxiety and trauma as the clean-up was not willingly done or enforced by the person with the hoarding behaviour.

the home will return to its original state very quickly, filled to the brim with newly collected items.

•it does not deal with the psychological disorder which is of course, the cause of the resulting behaviour to hoard. (11)

Approaches: no "quick fixes"

- Trying to remove evidence of the psychological disorder does not bring about change, health (including mental health) and community services need to work with the person concerned to ensure sustained gradual change.
- Many people who have experienced a quick fix have had terrible reactions such as severe depression and in some cases suicide. In some USA states or counties, quick fixes as a compulsive hoarding intervention have been banned for those reasons.
- It may be necessary to do quick clean-ups etc if the safety to others and the neighbouring community. If this is to occur its vital emotional support is linked in prior to this occurring. (11)

Video: Lee Shuer

Lee lives in America with his wife Becca. Here Lee shares his experiences and success to manage his hoarding tendencies.



Click on green box for video

Assessing risk

Hoarding and squalor environments pose risks for fire, physical falls, collapse of buildings, poor sanitation and other health risks that potentially affect people and animals. Mental health is also a risk factor.

Risk includes:

Risk to self (person living in hoarding and/or squalor)

- Risk to others (family, carers, dependents, animals)
- Risk to workers
- Risk to neighbours

Note:

Each organisation will also have their own risk assessment polices and procedures that should be considered

Risk to workers

The following possibilities should be considered:

•When managers/workers or supervisors are planning for workers to access a dwelling, consider whether the environment is impacted upon by hoarding (which would restrict movement) or squalor (which provides greater ability to walk around, but may present organic concerns) or both hoarding and squalor which would combine both considerations when planning worker protection and support.

Before entering a squalid environment, workers would benefit by wearing protective clothing (for example, gumboots or heavy waterproof shoes, overalls or older clothing and disposable gloves if needed.

•Workers may need to take clean newspapers for multiple uses (for example, to cover chairs if workers want to sit down, for table tops, to wrap things in and so on). Keep in mind that stepping in or over organic matter is likely to occur, and that the risk of slips and falls is heightened.

•Workers may only meet at the door or where they can visually see it is safe. This may need to happen to assist first in building rapport. (1)

Risk to workers

- Some workers will wear head protection of some kind (for example, hats to protect themselves from fleas, if animals are involved) or different types of face masks to allow the worker to breathe more easily in dwellings with high ammonia levels (due, for example, to high levels of animal urine or faeces
- In the case of a hoarding household or property, be aware of stacked items (no matter how high), and don't lean on them for support. Make sure workers are instructed to always walk on the ground, and not on scattered material. Workers also need to be aware of their own safety with regard to electricity, gas and water.
- The fire risk inside a hoarding household is significant, and it is recommended that smoke alarms are arranged to be installed inside the home prior to the introduction of workers, including those involved in large-scale removal. (1)
- Tools to assist with risk assessment will be discussed later in training

Tools: ECCS

The Environmental Cleanliness and Clutter Scale (ECCS)

This scale rates the degree of various aspects of cleaning. Areas with varying functions (such as toilet, kitchen, and bedroom) are rated, along with other indicators of squalor (for example, odour, and vermin).

•The ECCS can be used by workers to gain an objective rating of the degree of squalor in a living environment. It also provides a measure of risk of entry for workers.

Ratings (from none to severe) are indicated on a scale. A score greater than
12 usually indicates moderate to severe hoarding. (1)

Please watch this You Tube video from a self proclaimed Hoarder.

Activity: Based on video just watched- complete ECCS individually- discuss as group

Tools: CIR

The Clutter Image Rating (CIR) Scale

The CIR scale was developed to overcome problems associated with people who over-report or under-report the severity of hoarding symptoms.

This tool is one of the most effective for objectivity recording the change in clutter in the standards of room of the home (living room, kitchen and bathroom).

To gain an accurate perspective of a clutter situation, this series of nine pictures in each room was developed in various stages of clutter from completely clutter free to very severely cluttered. (1)

Tools: CIR cont

The Clutter Image Rating (CIR) Scale (cont.)

People (either the person themselves, a worker or both together) can select a picture in each sequence they think comes closest to the clutter scale in the living room, kitchen and bedroom.

The decision requires some degree of judgment, because no two rooms look exactly alike and clutter can be higher in some parts of the room than others.

This rating scale works well to measure clutter. It also eliminates reliance on language, enhancing ease of use.

In general, clutter reaches the level of picture #4 or higher impinges enough on people's lives that the person should be encourages to seek assistance with hoarding behaviour. (1)

Activity: Based on video just watched, complete CIR individuallygroup discussion.

Tools for assessing risk: fire

- Fires in hoarding homes increase the risk for the occupant, their neighbours and firefighters. Metropolitan Fire Brigade (MFB) research has identified that people who hoard aged 50+ are at particular risk and account for 24 per cent of all preventable fire deaths between 1999 and 2009.
- MFB recommends that in the first instance, individuals or agencies assisting those affected by hoarding should:
 - Unblock exits
 - Widen internal pathways
 - Check utilities are connected
 - Prioritise removing clutter from around cooking area and stove tops, as 39 per cent of fires in hoarding homes result from cooking
 - Ensure clutter is removed from around heaters and electrical items and discourage the use of open flame as combined these factors account for 44 per cent of fires in hoarding homes (1)

Tools for assessing risk: fire

Hoarding and Fire Risk Flyer

Hoarding Fire Video

Advice from Fire Brigade is there is no legislation that workers MUST notify the Fire Brigade if hoarding poses as a major fire risk. It is suggested to minimise risk to the client and fire crew, workers can notify Fire Brigade of the address. If confidentiality is an issue, an anonymous notification can be provided.

Practical strategies: language

- Seek to understand the hoarder's perspective (i.e., be curious)
- Asking instead of telling



- ✤ I see you have some books by the window here.
- What led you to put them here?
- I don't see why you have books by the window. They go on a book shelf. (4)

Practical strategies: language

Use "I" statements to express your concern rather than telling the person what to do



I'm concerned that if you don't clear this area, you won't pass the next inspection



You have to clear this area or you'll fail the next inspection next inspection (4)

Practical strategies: language

Match the person's language

Avoid speaking about the person as a 'hoarder'.

Match the person's language:

E.g., Use their words (e.g., "collections" "things")

Use respectful language

Avoid judgmental expressions, whether verbal (e.g., "trash") or non verbal, be aware of body language (e.g. facial expressions) (4)

Practical strategies: progress

Photos:

•Using photos are an effective tool to show the person you are working with progress that is being made.

Photos are also an effective tool to demonstrate to regulatory bodies progress that is being made.

Photos can also assist in boosting motivation to demonstrate what the client has previously achieved.

Photos can also be used as a tool to assess progress against the clutter image rating scale.

Technology:

•Use of computers can show that any information can be sourced, this can elevate the stress of relinquishing literature/newspapers/magazines.

Practical strategies: progress



Kitchen before

Kitchen after



Practical strategies: work "hands on"

- Working hands on with the person at a slow pace i.e. pack 2 boxes a week to start cleaning entries and exits to prevent churning
- Worker to take goods away ONLY with persons consent.
- You may clean with the client (if your role). You may decide to work on entries and exits first.
- Set up "plans of action". See example in training folder.



Practical strategies: sorting

Only Handle It Once (OHIO) Rule

If you pick something up, make a decision then and there about it, and either put it where it belongs or discard it. Don't fall into the trap of moving things from one pile to another, again and again. (6)

Suggestions when assisting someone to work at discarding goods:

- Keep/donate/maybe approach
- Stickers- put difference coloured stickers on goods to keep/donate/throw away



Practical strategies: sorting

Questions to help with the sorting process

- How many do I have, and is that enough?
- Have I used this in the past year?
- Do I have a specific plan to use the item again, in what timeframe?
- Does this seem important just because I am looking at it now?
- Is it current?
- Is it of good quality, accurate, and/or reliable?



Practical strategies: maps

MAPS

Many people who hoard are extremely visual.

They often fear that if they put something away they will not remember where it is because it is not out in the open. A trick could be to label the outside of a draw, a storage bin, or create a map of where important items have been put away. (1)

Set guidelines for 'helpers'

■i.e. only disregard when client is present. May draw up an agreement as to what can/can't be thrown out. (8)

Practical strategies: rewards

Examples:

Take person out for lunch/to movies when reached a certain point (if your role allows it, if now be creative on rewards).

•Have the grandchildren over to play if there is a clear space.

Encourage the person to set personal rewards

i.e. once they have sorted for 10 minutes they can reward themselves.

Joint case coordination

Joint case coordination

One plan for all services involved if possible

See resources for tools to assist with joint case planning:

- •Shared Support Plan
- •Review of shared support plan
- •Shared action plan check list

•Additional tools can be found at http://www.health.vic.gov.au/pcps/sctt.htm to assist with joint planning

Resource to find other services: www.hoardingresource.org.au

Supporting families/carers

Click on green square for video with Becca Shuer. (partner of Lee Shuer)



Tips that may be helpful for families/carers see Resources for Helping others with motivation. (7)

Supporting children

Working with children and hoarding

Children of people who hoard are also significantly effected.

Children may experience social isolation due to not being able to have other children over and may have exclusion from other family members due to inability to have visits.

•May be child protective factors due to risk within the some.

As support is important to also support children around these issues or refer to the most appropriate service.

There is a children's book around hoarding:

An Ordinary House- Written by Tania Reid. Published by For Crowded House.

Caring for yourself?

- Have regular supervision with your supervisor.
- Debrief with work colleagues regularly where relevant.
- Know your limits.
- Seek advise when needed- when working with hoarding and squalor you should not be doing it alone.
- Adopt self care strategies such as:
 - Taking regular leave
 - External supervision



Client self help

Buried in treasures has a number of tools that can be used by clients (7)

Contract with yourself

Client to complete contract

Is my home Safe?

Client to complete to determine what safety issues need to be addressed in house.

Home Environment Index

Client to complete to determine any sanitation issues

Are your daily activities impaired by hoarding?

Client to complete to determined impact of hoarding and/or squalor on daily living

•Weekly calendar, My Category List, My Preparing for Organizing Form.

Assist client with weekly planning for discarding of items/goal setting

More resources can be found in Buried in Treasures book (7)

Challenges

Lack of resources – not being able to pay for big clean outs/industrial cleans or ongoing cleaning services is a challenge for many people who do not qualify for very low income programs.

Lack of counselors/psychologist- individuals trained to work with people who hoard are limited.

Lack of reporting- first responders need to report to protective services as a means of identifying people who are selfneglecting. Without the initial report hoarding stays unknown until a crisis happens, this is often when workers become aware of the severity of the situation.

Hoarding knowledge and expertise

This training has been developed using:

- existing resources around hoarding and squalor (paper and web based).
- lived experiences of Lee and Becca Shuer and other clients to compliment training material from a client and carers perspective.
- Buried in Treasures resources.
- Hoarding and squalor specialists are available in Australia such as Dr Chris Mogan, Tania Reid and many others.

References

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3. Hoarding; a lethal fire risk

http://www.mfb.vic.gov.au/Community-Safety/Home-Fire-Safety/Hoarding-a-lethal-fire-risk.html

4. How to talk to someone with a hoarding problem

file:///C:/Documents%20and%20Settings/caddier/My %20Documents/Downloads/How_to_Talk_to_Someone_with_Hoarding_Problem.pdf

5. Squalor Survivors

http://www.squalorsurvivors.com/pictures/index.shtml

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http://psychcentral.com/blog/archives/2011/03/19/compulsive-hoarding-and-6-tips-to-help/

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Tolin, D.F., Frost, R.O., Steketee, G. (2014) Buried in Treasures: Help for Compulsive Acquiring, Saving, and Hoarding, 2rd edition. New York, Oxford University Press.

Buried in treasures downloadable tools http://global.oup.com/us/companion.websites/umbrella/treatments/hidden/pdf/Tolin_Worksheets_Online_Final.pdf

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9. Hoarding Web Based Resource

Web based resources- www.hoardingresources.org.au.

10. Catholic Community Services: Squalor & Hoarding Toolkit

http://squalorandhoarding.catholiccommunityservices.com.au/getting-started/definitions-of-squalor-and-hoarding.

11. Discussion Paper :Hoarding & Squalor

http://www.health.vic.gov.au/agedcare/publications/hoarding/hoarding_squalor.pdf.

Training Video's

<u>Sunrise Interview-</u> https://www.youtube.com/watch?v=HLYZb-Y_DJE

<u>Hoarding Assessment Video-</u>https://www.youtube.com/watch?v=EbZxjNRCm2o

Hoarding Fire Video-http://www.tlc.com/tv-shows/hoarding-buried-alive/videos/buried-alive-fire-in-the-kitchen/

