

Effective Service Responses HOARDING AND SQUALOR

An Educational Package for The Office of Local Government Developed by Catholic Healthcare

Participant Workbook



What is Hoarding and Squalor?

What do the words mean?

Hoarding

- Is derived from hord, a Middle English word which, in turn, has links to the Gothic word huzd meaning treasure.
- The word hoarding also is used to describe a fence put up around a building when it is being erected or repaired.
- In the context of this training package, *hoarding* means acquiring and having trouble discarding a large volume of possessions which others would consider useless or of limited value.

Squalor

- Is derived from squalidus, a Latin word meaning rough, coated with dirt, filthy.
- In relation to a place, squalor is used to describe somewhere that is cluttered, filthy or unclean through neglect.

Common characteristics of hoarding and squalor situations

The first thing to remember is that each person who hoards and is living in squalor is an individual with a unique set of life experiences, beliefs and values. Generally, a person who hoards and is living in squalor:

- cannot stop themselves bringing items into the home
- believes that the items are in some way part of themselves
- is unable to effectively categorise items
- is affected by indecision
- is unable to discard items without feeling distressed
- has lost control of their living environment
- feels shame about their situation
- may or may not seek help depending on their level of insight and feelings of shame.



How common is hoarding?

- International Research in Europe and North America suggests that 600,000 to 1.2 million Australians may have an issue with hoarding (Morgan, 2010).
- Up to 2% to 5% of population may exhibit compulsive hoarding behaviours (Mataix-Cols et al 2010:559).
- Hoarding is a contributing factor in 24% of fire fatalities over 50 in Melbourne (Aufiero, Carlone, Hawkins, Murdy, 2011)/
- Can begin
 - in childhood with mild symptoms in mid-teens, moderate symptoms in 20s
 - in adulthood after a stressful or traumatic event

Why Do People Hoard or Live in Squalor?

There is no easy answer to this question. There is a wide variety of causes and combinations of causes of hoarding and squalor. Health, medical and community service practitioners will cite different reasons to people who hoard.

Reasons given by health, medical and community services professionals

- Family influences and experiences
- In response to significant life events (e.g. war, trauma, extreme poverty)
- Difficulty with executive functioning (e.g. processing information, categorisation, decision making, memory)
- Emotionally driven reinforcement patterns
- Inability to form meaningful personal relationships
- Cognitive impairment caused by dementia, alcohol related brain damage
- Mental health issues (e.g. Hoarding Disorder, schizophrenia, depression)

Reasons given by people who hoard

- Protects them from emotional and other harm by prevents other people getting too close
- Possessions create a feeling of security
- Strong emotional attachments to items
- A belief that the items are worth valuing and/or might be useful in the future
- A strong desire not to be wasteful
- An intention to sort through accumulated belongings
- The situation is reflective of negative feelings about self (e.g. feeling like rubbish, not valued, broken).



What about Animal Hoarders?

Animal hoarders are people who accumulate a large number of animals, usually cats or dogs. They tend to be older women: 76% female, 46% over 60 years (Patronek, 1999). Animal hoarding is an extremely difficult behaviour to change. After animals are removed or the situation is brought under control, the recidivism rate is around 100%. (Ockenden, De Groef, Marston, 2014)

Sub-groups of animal hoarders include:

- Incipient hoarders in early stages of hoarding
- Overwhelmed caregivers who are strongly attached to animals, aware of the problem but cannot provide adequate care
- Rescuers who may oppose euthanasia, have tried initially to place animals but who only trust themselves to provide care
- Breeder hoarders who may initially selectively breed for shows or sale, continue to breed when conditions deteriorate and see themselves as animal care experts
- Exploiters who may claim to be breeders but lack empathy for people or animals (e.g. puppy farms).

Common key characteristics

Animal hoarders commonly:

- are unable to provide minimum standards of space, nutrition, sanitation or veterinary care
- cannot see the detrimental effect on the animals, other people or the environment
- continue obsessively to maintain or accumulate animals despite a usually deteriorating environment
- deny or downplay that there is a problem.



Hoarding, Squalor and Mental Health

Historical perspectives

- Diogenes Disorder, senile squalor syndrome, was recognised in 1966
- Until recently, people who hoard and live in squalor have been grouped uneasily with obsessive-compulsive disorder (OCD)
- DSM-5, which was released in May 2013, first classified Hoarding Disorder as a stand alone mental disorder.

DSM-5 criteria for hoarding disorder

According to the DSM-5, the following six criteria must be met for a diagnosis of hoarding disorder:

- A. The person always finds it difficult to discard an acquired item, regardless of its actual value.
- B. This difficulty is based on two things: a perceived need to save the item and distress at the thought of discarding it.
- C. The person's possessions accumulate and fill up living and working areas in the house (e.g. bedrooms, kitchens) so that they can't be used for the purposes they were designed. If living areas are uncluttered, it is due to the actions of others
- D. These factors cause significant disruptions to socialisation and function.
- E. These symptoms cannot be attributed to another medical condition.
- F. These symptoms cannot be solely attributed to another mental disorder like OCD or schizophrenia.



Hoarding and Problems with Categorisation







Hoarding, squalor and NSW law

The following Tasmanian legislation can be relevant to situations involving hoarding and squalor.

Mental Health Act 2007	Section 14 of this act includes provision for the involuntary treatment and admission of people to a mental health facility if the person is suffering from a mental illness and, because of that illness, is determined to require care, treatment or control to prevent them or another person coming to serious harm. Section 23 of the act gives Magistrates the power to authorise a medical practitioner to visit, examine or observe a person to determine if a mental health certificate should be issued. This section includes provision for entering premises by force to assist the medical assessment.
Guardianship Act, 1987	 A Guardian is a person who is appointed under the Guardianship Act to make decisions for someone who does not have capacity to make decisions. This can apply to people who: Do not have anyone to help them make decisions Has a disability and is at risk of abuse, neglect or exploitation In NSW, the need for appointment of a guardian is determined by the Guardianship Tribunal. The Tribunal considers written evidence provided in the guardianship application as well as evidence from people attending the hearing, including the person in question. The Tribunal can appoint a private guardian or the NSW public guardian and authorise them to make certain types of decisions
Residential Tenancies Act, 2010	 Covers private, public and social housing tenants Tenants have the right to: Have quiet enjoyment and use of the premises Have reasonable peace, comfort and privacy Have reasonable locks and security Have reasonable repairs and maintenance done Be given written notice if the landlord wants to end the tenancy agreement Refuse access to the landlord except in certain circumstances and with proper notice Not be unlawfully evicted Tenants have the responsibility to: Pay rent on time Care for the premises Pay for any damage caused by themselves or their guests Not alter, remove or add a lock or security device without the landlord's consent Not cause permit a public nuisance Not interfere with the peace comfort or privacy of neighbours Leave the premises in a similar condition to that when they rented.
Prevention to Cruelty of Animals Act, 1979	 This act includes the following list of offences: Committing act of cruelty to animals including exercising reasonable care to prevent cruelty; alleviate pain; and provide access to veterinary treatment if needed Failure to provide food drink or shelter

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	 Failure to provide animals with adequate exercise including provision for enough space to exercise for caged animals Tethering animals for unreasonable periods of time.
Public Health Act, 2010	This act contains the following provisions relevant to situations involving hoarding and squalor:
	 Power to enter premises to seize, disinfect or destroy noxious articles (i.e., articles and animals infested with vermin)
Drug and Alcohol Treatment Act 2007	 The objectives of this act are to: Provide for involuntary treatment of people with severe substance dependence to protect their health and safety Facilitate comprehensive assessment and stabilisation through medical treatment Provide an opportunity to engage in voluntary treatment and restore capacity to make decisions about substance use and personal welfare. An accredited medical practitioner must first issue a dependency certificate. A magistrate then reviews its issuing. The person can be detained for 28 days after the issuing of the certificate.
Children and Young Persons (Care and Protection) Act, 1998	Reporting to Department of Communities and Justice with suspicion on reasonable grounds that a child is at risk of significant harm
Common Law and Nuisance (doesn't come under statutes or legislations)	Common law is a set of laws and principles that have been developed over time through the courts. Common law can be used to protect the rights of private landowners in relation to their properties. This covers:
	 Private nuisance when a person substantially and unreasonably interferes with another person's right to use and enjoy their land. This can include interference by noise, sewerage or odour.
	 Public nuisance when a person endangers the life, health, property morals or comfort of the public or substantially or unreasonably interferes with the public's rights.
	Examples of nuisances interfering with the comfort, convenience, or health of an occupant are foul odours, noxious gases, smoke, dust, loud noises, excessive light, or high temperatures.



An important consideration – How hoarding and squalor situations are uncovered

People who hoard and live in squalor are less likely to seek intervention than to have intervention imposed upon them. The most likely scenarios for identification occur:

- After the person has been hospitalised by emergency services, nursing staff or social workers
- After hospital discharge by community care services
- After a fire hazard notification has been made by neighbours or the Council
- After a fire incident and attendance by the Fire Brigade
- When there is risk of eviction by the landlord or housing provider.

Animal hoarding situations came to attention when:

- There are complaints from neighbours about the noise made by the animals
- There is a strong smell of faeces or ammonia
- Stains, faeces or animal hair at entry doors and windowsills are noticed
- Stained curtains are noticed
- The person is very suspicious of visitors and reluctant to permit entry.



Engagement

Key Engagement Issues

The following factors will influence the engagement process. The person:

- may not have chosen for, and may be resistant to, others getting involved
- may not see it as a problem or have insight into the situation
- may be ashamed about their behaviour and living environment
- may be living in unsanitary conditions with severe health and safety issues that need to be addressed immediately.

The 1st Step: Developing Trust

Trust is the most essential ingredient to successful engagement with a person who hoards or lives in squalor. So:



- Remember that trust is based on acceptance
- Get as much background information as possible before the initial approach
- Accept the person for where they are 'at'
- Give the person a sense that they are okay
- Understand the fears they may have about change
- Offer to help in resolving another area of life that may be related or unrelated to their hoarding
- Establish trust before targeting the hoarding behaviour.

Engagement Strategies

- First and foremost, accept the person for where they are now and listen, listen, listen.
- Do not show or verbalise judgments you might make.
- Control your reactions to sights and smells.
- Be prepared to make multiple visits and talk through the front door or windows before being invited in.
- Keep turning up at regular, scheduled times until that occurs.
- Offer help and then follow through in getting landlords, Council, Police off their immediate backs and getting room to breathe.

An Overview of Hoarding and Squalor Assessment Tools

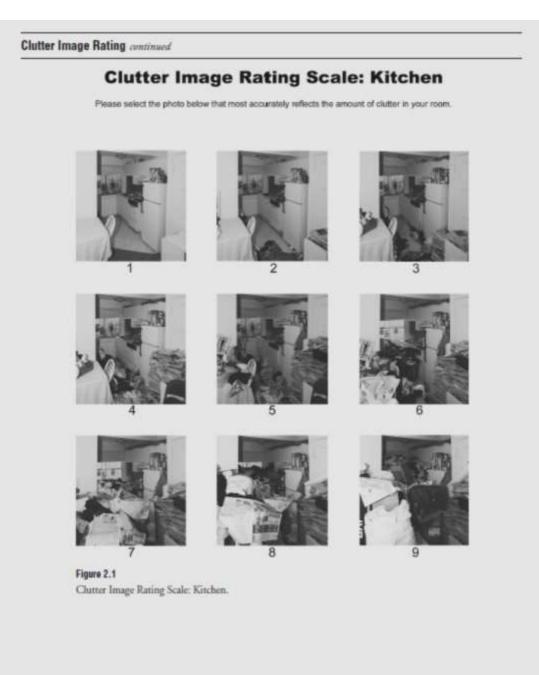
Self-assessment Tool	 A self-administered tool in Buried in Treasures Book Hoarding Severity Scale gives a Clutter and a Difficulty Discarding score Activities of Daily Living (ADL) Scale gives an ADL, a living conditions and a safety issues score
Clutter Image Rating Tool	 Self-administered tool that can be done by assessor A series of 9 photographs showing escalating clutter in a bedroom, kitchen, living room Asks to pick the picture closest to being accurate
Environmental Cleanliness and Clutter Scale	 Records demographic details 0-3 point rating on accessibility, accumulation, rooms, cleanliness, odour, vermin, effect on activities, need for repairs, WHS



Client initials:		Date:	Therapist:
select the pictu			t: Kitchen, and CIR: Bedroom), please atter for each of the rooms of your home.
Please pick the	picture that is closes	t to being accurate	, even if it is not exactly right.
If your home d	loes not have one of 1	the rooms listed, ju	st put NA for "not applicable" on that line.
	Number of closest		
Room	corresponding picture (1-9)		
Living Room		5	
Kitchen		-	
Bedroom #1		-	
Bedroom #2			
the CIR Living	g Room pictures to m	ake these ratings.	fected by clutter on the lines below. Use
Dining room			
Hallway			
Hallway Garage			
Hallway Garage Basement		•	
Hallway Garage Basement Attic		•	
Dining room Hallway Garage Basement Antic Car		- - -	
Hallway Garage Basement Amic Car		Please specify:	
Hallway Garage Basement Attic		Please specify:	
Hallway Garage Basement Artic Car		- - Please specify:	
Hallway Garage Basement Artic Car		- - Please specify:	·
Hallway Garage Basement Amic Car		Please specify:	·
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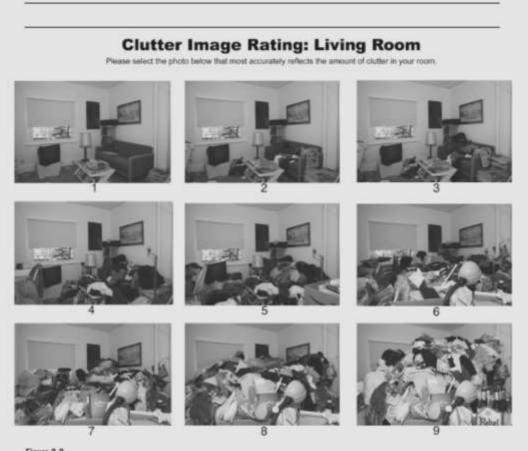


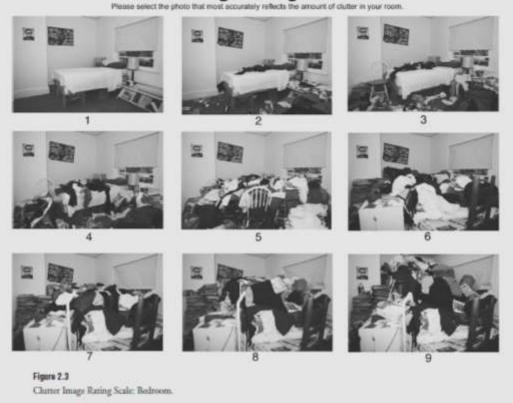
Figure 2.2 Clutter Image Rating Scale: Living Room.

continued



Clutter Image Rating continued

Clutter Image Rating: Bedroom





Environmental Cleanliness and Clutter Scale – page 1

	To rate c	SCALE (ECO	CS) 🥮 client's accomm	nodation		
	different items. Thes	e descriptions are mear bry and another based o	st fits their observations in t to be indicative but rate n aspects not mentioned in	ers may decide		
	's phone no:		Date://			
А.	ACCESSIBILITY (clutter):				
	O EASY TO ENTER and move about dwelling.	1 SOMEWHAT IMPAIRED access but can get into all rooms.	2 MODERATELY IMPAIRED access. Difficult or impossible to get into one or two rooms or areas.	3 SEVERELY IMPAIRED access, e.g. obstructed fro door. Unable to reach most all areas in the dwelling.		
	0-29%	30 to 59%	60 to 89%	90 to 100%		
		of floor-space inacces	ssible for use or walking across			
	none	A LITTLE Bins overflowing and/or up to 10 emptied containers scattered around.	Pers (tins, bottles, cartons, 2 MODERATE Garbage and refuse littered throughout dwelling, accumulated bags, boxes	A LOT Garbage and food waste pi knee-high in kitchen a ebewhere. Clearly no reco		
			and/or piles of garbage that should have been disposed of.	attempt to remove refuse a garbage		
	ACCUMULATION	ACCUMULATION OF ITEMS OF LITTLE OBVIOUS VALUE: In general, is there evidence of accumulation of items that most people would consider are useles or should be thrown away?				
С.	In general, is there e	vidence of accumulation	or items that most people i			
С.	In general, is there e	vidence of accumulation away? SOME ACCUMULATION but collected items are organised in some way and do not much impede movement or prevent cleaning or access to	2 MODERATE EXCESSIVE ACCUMULATION Items cover furniture in most areas, and have accumulated throughout the dwelling so that it would be very difficult to	3 MARKEDLY EXCESSIVE ACCUMULATION Items piled at least waist-hi in all or most areas. Cleani would be virtually impossib most furniture and applianc		
С.	In general, is there e or should be thrown a O NONE	Vidence of accumulation sway? SOME ACCUMULATION but collected items are organised in some way and do not much impede movement or prevent cleaning or access to furniture and appliances. ES OF ITEMS THAT HAVE BE whets, etc Clothing	2 MODERATE EXCESSIVE ACCUMULATION Items cover furniture in most areas, and have accumulated throughout the dwelling so that it would be very difficult to keep clean. EN ACCUMULATED Other items	MARKEDLY EXCESSIVE ACCUMULATION Items piled at least waist-ha in all or most areas. Cleani would be virtually impossib		

Environmental Cleanliness and Clutter Scale – page 2

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D.	CLEANLINESS of floors and carpets (excluding toilet and bathroom) :					
	0	1	2	3		
	Acceptably clean in all rooms.	MILDLY DIRTY Floors and carpets look as if not cleaned or swept for days. Scattered rubbish,	VERY DIRTY Floors and carpets very dirty & look as if not cleaned for months. Rate 1 if only one room or	EXCEEDINGLY FILTHY With rubbish or dirt througi dwelling. Excrement usually merits		
			small area affected.	score.		
E.	CLEANLINESS o	f walls and visible furn	iture surfaces and win	dow-sills :		
Е.	0	1	2	3		
	Acceptably clean in all rooms.	MILDLY DIRTY Dusty or dirty surfaces. Dirt comes off walls on damp rag or finger.	VERY DIRTY Grime or dirt on walls, Cobwebs and other signs of neglect. Greasy, messy, wet and/or grubby furniture.	EXCEEDINGLY FILTHY Walls, furniture, surfaces so dirty (e.g. with face urine) that rater wouldn't to fouch them.		
~	BATHROOM and	TOILET :	*			
<i>F</i> .	0	1	2	3		
	Reasonably clean.	MILDLY DIRTY Untidy, uncleaned, grubby floor, basin, toilet, walls, etc. Toilet may be unflushed.	MODERATELY DIRTY Large areas of floor, basin, shower/bath, are dirty, with scattered rubbish, hair, cigarette ends, etc. Faeces and/or urine on outside of toilet bowl.	VERY DIRTY. Rubbish and/or excrement floor and in bath or sho and/or basin. Uncleaned months or years. Toilet be blocked and bowl ful excreta.		
G.	KITCHEN and F	KITCHEN and FOOD:				
G,	0	1	2	3		
	Clean Hygienic.	SOMEWHAT DIRTY AND UNHYGIENIC Cook-top, sink untidy and surfaces dirty, maybe with some split food. Refuse mainly in garbage bin. Food that could go off (e.g. meat, remains of meal) left uncovered and out of fridge. Rate 1 If no food but fridge dirty.	MODERATELY DIRTY AND UNHYGIENIC Oven, sink, surfaces, floor are dirty, with piles of unwashed crockery and utensils etc. Bins overflowing. Some rotten or mouldy food. Fridge unclean.	VERY DIRTY AND UNHYGIENIC Sink, cook-top, insides of cuptoards filthy. L amount of refuse and gart over surfaces and floor. It of the food is putrid, cow with mould and/or rotten, unsafe to eat. Rate 3 if maggots seen.		
	ODOUR.					
Н.	ODOUR:	1	2	3		
	Nil / pleasant	UNPLEASANT e.g. urine smell, unaired.	MODERATELY MALODOROUS. Bad but rater can stay in room.	UNBEARABLY MALODORO Rater has to leave room soon because of smell.		
I.	VERMIN (Please of	nicle: rats, mice, cockroaches	s, flies, fleas, other):	0		
	0	1	2	3		
	None	A FEW (e.g. cockroaches)	MODERATE. Visible evidence of vermin in moderate numbers e.g. droppings and chewed newspapers.	INFESTATION, Alive and/or dead in i numbers.		

Environmental Cleanliness and Clutter Scale – page 3

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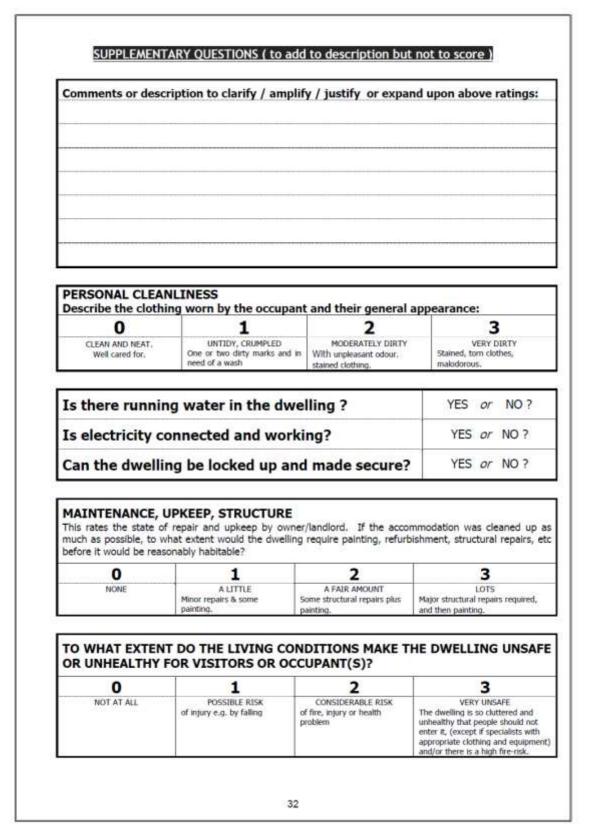
7	SLEEPING AREA:					
۶.	0	1	2	3		
	Reasonably clean & tidy.	MILDLY UNCLEAN. Untidy. Bed unmade. Sheets unwashed for weeks.	MODERATELY DIRTY. Bed sheets unclean & stained, e.g. with faeces or urine. Clothes and/or rubbish over surrounding floor areas.	VERY DIRTY. Mattress or sleeping surface unclean or damaged. Either no sheets or (if present) extremely dirty bedding/linei Surrounding area fithy.		

Add up circled numbers to provide a TOTAL SCORE:

DO YOU THINK THIS PERSON IS LIVING IN SQUALOR? (circle one)	NO	YES, mild <i>Not clutter</i>	YES, moderate <i>Not clutter</i>	YES, severe <i>Not clutter</i>
	Clutter (lots), not squalor	Yes, mild + clutter (lots)	Yes, moderate + <i>clutter (lots)</i>	Yes, severe + clutter (lots

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Environmental Cleanliness and Clutter Scale – page 4





What are the potential roles for other service/support providers in a support plan addressing hoarding and squalor issues?

Support/Service Provider	Potential Roles
Case Management Service	 Comprehensive assessment Consultation/liaison with stakeholders Advocacy and referral Support planning and implementation
Aged Care Assessment Teams/RAS	 Comprehensive assessment of care and support needs of people over 50 (45 for indigenous people) Assessment of eligibility for Home and Community and residential aged care Assessment of the home environment by an OT Referral to support services
Psychologists, Psychiatrists	 Diagnosis Assessment of capacity Counselling Therapy
CHSP, Home Care Packages, NDIS	 Domestic assistance Community transport Social support (individual and groups) Food services ie Meals on Wheels Shopping Personal care Home modification & maintenance Allied Health – Physio, OT, Podiatry, Nutritionist etc
Public/Social Housing Providers	 Supporting people to maintain their tenancies Negotiating with tenant about health, safety and access issues Arranging property repairs Taking action to gain access to premises
Mental Health Teams	Assessment and support of people with mental health issues
RSPCA	 Making applications to access the property Assessment of living conditions of animals Seizing and removal of poorly cared for animals Referrals to animal welfare groups
Financial Advisory Services	 Financial counselling Assistance with budgeting Re-negotiation of payment arrangements and schedules
Emergency services	 Establishment of emergency response protocols Fire safety inspections

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٠	Accompanying support workers identified at risk
	of harm (Police)

Support plan implementation

Do:

- Be patient and allow all the time necessary
- Encourage, motivate and applaud progress and change
- Start with small steps and focus on one part of the home at a time
- Screen and select all direct support staff for their appropriateness before they go into the home
- Develop formal service level agreements
- Adequately brief and debrief agency partners and support staff.

Don't

- Pass judgment
- Argue with the person
- Make decisions for the person
- Touch or remove the person's belongings without asking permission
- Consider or treat the support plan as a clean-up service
- Go for the quick fix, the big clean-up
- Leave a skip at the property
- Expect that hoarding behaviours will miraculously stop or not re-appear

What is capacity?

Capacity describes an adult's ability to make informed decisions for themselves. A person who has capacity for decision making:

- understands the relevant facts
- understands the available options
- can evaluate the possible consequences of each option
- can see how these consequences could affect them
- can communicate their decision to others.

Balancing duty of care with dignity of risk

Key **duty of care considerations** in regard to situations involving hoarding and squalor include:

- the need to address threats to the person's health and safety
- the person's physical and cognitive functionality and their potential to improve aspects of their functionality



• the level and effect of the person's insight into their hoarding and squalor behaviour and situation.

Key **dignity of risk considerations** in regard to situations involving hoarding and squalor include the person's rights to:

- choose from the available range of options
- freedom and independence
- take calculated risks.

Key Messages

- There are different causes and combinations of reasons for hoarding and living in squalor
- The support response depends on treating each person as an individual and each situation as unique
- The overall aim of interventions is to enable the person and equip them with strategies for exerting control over their hoarding behaviour and their living environment
- The case management response rests on effective engagement with the person and the development of a trusting partnership
- It is important to take all the time necessary to engage, assess, plan, implement and monitor a support intervention

• A team approach by all people and agencies involved in the support plan is essential to progress.



Your notes