

Cumbria Safeguarding Adults Board

Multi-agency Hoarding Protocol and Toolkit

October 2022







Acknowledgments; this toolkit was developed by a multi-agency partnership in County Durham who have kindly agreed local adaptation for Cumbria Safeguarding Adults Board (CSAB).

1. Introduction

Compulsive hoarding is highly complex and requires a collaborative and integrated approach. This toolkit aims to ensure that practitioners are equipped with methods of working with people in a manner that is meaningful, co-ordinated multi agency partnership working. The toolkit aims to facilitate positive and sustainable outcomes for adults, by involving them in the process at all stages and provides guidance, advice and assessments which can be utilised and adapted by organisations to meet the needs of the individuals that they work with.

The toolkit includes reference to pieces of legislation that may be relevant to working with people who hoard.

2. Who should use the toolkit

This toolkit can be used by all practitioners working across health and social care, housing or other agencies to work in partnership using an outcome focused, solution-based model working with people who hoard. This toolkit can also be used in conjunction with CSAB Self-Neglect guidance and the Clutter Image Rating (CIR) Assessment Tool. There is an expectation that everyone engages fully in partnership working to achieve the best outcome for the customer, while meeting the requirements and duties of individual agencies.

3. What is our vision and commitment?

The aims of this toolkit are to promote:

- Investigation and sharing of information related to hoarding from different professional and community perspectives;
- Deal with incidents in an evidence based, structured, systematic, co-ordinated and consistent way;
- Develop 'informal' multi-agency solutions which maximise the use of existing services and resources and which may reduce the need for compulsory solutions;
- Ensure that when formal solutions are required, there is a process for planning solutions tailored to meet the needs of the customer. Possible solutions include professional support and monitoring, property repairs and permanent and temporary re-housing;
- To establish best practice and improve knowledge of legislation that relates to hoarding behaviour.

4. Definition of Hoarding

Hoarding is defined as the excessive collection and retention of any material to the point that it impedes day to day functioning (Frost & Gross, 1993). Pathological or compulsive hoarding is a specific type of behaviour characterised by:

- Acquiring and failing to throw out a large number of items that would appear to hold little or no value and would be considered rubbish by other people;
- Severe 'cluttering' of the person's home so that it is no longer able to function as a viable living space;
- Significant distress or impairment of work or social life (Kelly 2010).

5. Hoarding and Self-Neglect

The Care Act 2014 defines self-neglect as wide ranging & covering:

- Neglecting to care for one's personal hygiene
- Neglecting to care for one's health
- Neglecting to care for one's surroundings

Hoarding which can include:

- Inanimate objects (commonly clothes, newspapers, books, DVDs, letters & food/packaging)
- Animals
- Data

A decision on whether a response is required under safeguarding for self neglect will depend on the adult's ability to protect themselves by controlling their own behaviour. There may come a point when adults are no longer able to do this without external support.

This toolkit can be used in conjunction with **CSAB Self Neglect Guidance**.

6. What Is Hoarding Disorder?

Hoarding Disorder used to be considered a form of obsessive compulsive disorder (OCD). However, hoarding is now considered a standalone mental disorder and is included in the 5th edition of the Diagnostic & Statistical Manual Mental Disorders (DSM) 2013. Hoarding can also be a symptom of other mental disorders. Hoarding Disorder is distinct from the act of collecting, and is also different from people whose property is generally cluttered or messy. Hoarding is not simply a lifestyle choice. The main difference between a hoarder and a collector is that hoarders have strong emotional attachments to their objects which are well in excess of their real value.

Hoarding does not favour a particular gender, age, ethnicity, socio-economic status, educational / occupational history or tenure type.

Anything can be hoarded, in various areas including the resident's property, garden or communal areas. However, commonly hoarded items include but are not limited to:

- Clothes
- Newspapers, magazines or books
- · Bills, receipts or letters
- Food and food containers
- Animals
- Medical equipment
- Collectibles such as toys, video, DVD, or CDs

7. Types of Hoarding

There are three types of hoarding:

Inanimate objects

This is the most common. This could consist of one type of object or a collection of a mixture of objects such as old clothes, newspapers, food, containers or papers.

Animal Hoarding

Animal hoarding is on the increase. This is the obsessive collecting of animals, often with an inability to provide minimal standards of care. The hoarder is unable to recognise that the animals are or may be at risk because they feel they are saving them. In addition to an inability to care for the animals in the home, people who hoard animals are often unable to take care of themselves. As well, the homes of animal hoarders are often eventually destroyed by the accumulation of animal faeces and infestation by insects.

Data Hoarding

This is a new phenomenon of hoarding. There is little research on this and it may not seem as significant and inanimate as animal hoarding, people that do hoard data could still present with same issues that symptomatic of hoarding. Data hoarding could present with the data collection equipment such as computers, electronic storage paper. A need to store copies of emails, and other information in format.

8. General Characteristics of Hoarding

- Fear and anxiety: compulsive hoarding may have started as a learnt behaviour or following a significant event such as bereavement. The person hoarding believes buying or saving things will relieve the anxiety and fear they feel. The hoarding effectively becomes their comfort blanket. Any attempt to discard hoarded items can induce feelings varying from mild anxiety to a full panic attack with sweats and palpitations.
- Long term behaviour pattern: possibly developed over many years, or decades, of "buy and drop". Collecting and saving, with an inability to throw away items without experiencing fear and anxiety.
- Excessive attachment to possessions: People who hoard may hold an inappropriate emotional attachment to items.
- **Indecisiveness:** people who hoard struggle with the decision to discard items that are no longer necessary, including rubbish.
- **Unrelenting standards:** People who hoard will often find faults with others, require others to perform to excellence while struggling to organise themselves and complete daily living tasks.
- **Socially isolated:** people who hoard will typically alienate family & friends and may be embarrassed to have visitors. They may refuse home visits from professionals, in favour of office based appointments.
- Large number of pets: people who hoard may have a large number of animals that can be a source of complaints by neighbours. They may be a self confessed "rescuer of strays"
- **Mentally competent:** People who hoard are typically able to make decisions that are not related to the hoarding.
- **Extreme clutter:** hoarding behaviour may prevent several or all the rooms of a person property from being used for its intended purpose.
- **Churning:** hoarding behaviour can involve moving items from one part a person's property to another, without ever discarding anything.
- **Self-Care:** a person who hoards may appear unkempt and dishevelled, due to lack of toileting or washing facilities in their home. However, some people who hoard will use public facilities, in order to maintain their personal hygiene and appearance.
- **Poor insight:** a person who hoards will typically see nothing wrong with their behaviour and the impact it has on them and others.



9. How should I talk to someone who is Hoarding? Do's and Don't's

DON'T

- **Use judgmental language.** Like anyone else, individuals with hoarding behaviours will not be receptive to negative comments about the state of their home or their character (e.g. "What a mess!", "What kind of person lives like this?") Imagine your own response if someone came into your home and spoke in this manner, especially if you already felt ashamed.
- Use words that devalue or negatively judge possessions. People who hoard are often aware that others do not view their possessions and homes as they do. They often react strongly to words that reference their possessions negatively, like "trash", "garbage" and "junk".
- Let your non-verbal expression say what you're thinking. Individuals with compulsive hoarding are likely to notice non-verbal messages that convey judgment, like frowns or grimaces.
- **Make suggestions about the person's belongings.** Even well-intentioned suggestions about discarding items are usually not well received by those with hoarding behaviours.
- Try to persuade or argue with the person. Efforts to persuade individuals to make a change in their home or behaviour often have the opposite effect the person actually talks themselves into keeping the items.
- Touch the person's belongings without explicit permission. Those who hoard often have strong feelings and beliefs about their possessions and often find it upsetting when another person touches their things. Anyone visiting the home of someone with hoarding should only touch the person's belongings if they have the person's explicit permission.

DO

- **Imagine yourself in the hoarding client's shoes**. How would you want others to talk to you to help you manage your anger, frustration, resentment, and embarrassment?
- Match the person's language. Listen for the individual's manner of referring to his/her possessions (e.g. "my things", "my collections") and use the same language (i.e. "your things", "your collections").
- Use encouraging language. In communicating with people who hoard about the consequences of hoarding, use language that reduces defensiveness and increases motivation to solve the problem (e.g. "I see that you have a pathway from your front door to your living room. That's great that you've kept things out of the way so that you don't slip or fall. I can see that you can walk through here pretty well by turning sideways. The thing is that somebody else might need to come into your home, like a fire fighter or an emergency responder, would have a pretty difficult time getting through here. They have equipment they're usually carrying and fire fighters have protective clothes that are bulky. It's important to have a pathway that is wide enough so that they could get through to help you or anyone else who needed it. In fact, the safety law states that exits/ ways out must be clear, so this is one important change that has to be made in your home".
- Highlight strengths. All people have strengths, positive aspects of themselves, their behaviour, or even their homes. A visitor's ability to notice these strengths helps forge a good relationship and paves the way for resolving the hoarding problem (e.g. "I see that you can easily access your bathroom sink and shower," "What a beautiful painting!", "I can see how much you care about your cat.")
- Focus the intervention initially on safety and organisation of possessions and later work on discarding. Discussion of the fate of the person's possessions will be necessary at some point, but it is preferable for this discussion to follow work on safety and organisation.

10. Mental Capacity

The <u>Mental Capacity Act 2005</u> provides a statutory framework for people who lack capacity to make decisions for themselves. The Act has 5 statutory principles and these are the values which underpin the legal requirements of the act. They are:

- 1. A person must be assumed to have capacity unless it is established that they lack capacity.
- 2. A person is not to be treated as unable to make a decision unless all practical steps have been taken without success.
- 3. A person is not to be treated as unable to make a decision merely because he makes an unwise decision.
- 4. An act done or decision made, under this act for or on behalf of a person who lacks capacity must be done, or made in his or her best interests.
- 5. Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

When a person's hoarding behaviour poses a serious risk to their health and safety, intervention will be required. With the exception of statutory requirements, any intervention or action proposed must be with the customer's consent. In extreme cases of hoarding behaviour, the very nature of the environment should lead professionals to question whether the customer has capacity to consent to the proposed action or intervention and trigger a capacity assessment. This is confirmed by the MCA Code of Practice which states that one of the reasons why people may question a person's capacity to make a specific decision is "the person's behaviour or circumstances cause doubt as to whether they have capacity to make a decision". Arguably, extreme hoarding behaviour meets this criterion and an assessment should take place. Consideration must be given where there is dialogue or situations that suggest a person's capacity to make decision with regard to their place of residence or care provision may be in doubt.

Any capacity assessment carried out in relation to hoarding behaviour must be time specific, and relate to a specific intervention or action. The professional responsible for undertaking the capacity assessment will be the person who is proposing the specific intervention or action, and is referred to as the 'decision-maker'. Although the decision-maker may need to seek support from other professionals in the multi- disciplinary team, they are responsible for making the final decision about a person's capacity.

If the customer lacks capacity to consent to the specific action or intervention, then the decision maker must demonstrate that they have met the requirements of the best-interests checklist. Due to the complexity of such cases, there must be a best interests meeting, chaired by a manager to oversee the process.

In particularly challenging and complex cases, it may be necessary for the Local Authority to refer to the Court of Protection to make the best interests decision. Any referral to the Court of Protection should be discussed with legal services and the relevant service manager.

You can access further information and reosurces relating to the Mental Capacty Act 2005 on the Cumbria Safeguarding Adults Board website <u>here</u>.

11. Information Sharing

Under the Data Protection Act 1998, we all have the responsibility to ensure that personal information is processed lawfully and fairly. All customers have a right to view any information held about them. Practitioners should consider this when they are recording information about that person.

All agencies need to ensure that where we do decide it is appropriate to share information about hoarded properties with local fire brigades, we are doing this on a need to know basis. All information should be transferred in a secure format.

For the purpose of this protocol information will be shared in line with the **CSAB Information Sharing guidance**

Information should be shared within and between organisations in line with the principles set out below:

- Adults have a right to independence, choice and self-determination. This right extends to them being able to have control over information about themselves and to determine what information is shared. Even in situations where there is no legal requirement to obtain written consent before sharing information, it is good practice to do so.
- The person's wishes should always be considered, however, protecting adults at risk establishes a general principle that an incident of suspected or actual abuse can be reported more widely and that in so doing, some information may need to be shared among those involved.
- Information given to an individual member of staff belongs to the organisation and not to the individual employee. An individual employee cannot give a personal assurance of confidentiality to an adult at risk.
- An organisation should obtain the adult at risk's consent to share information and should routinely explain what information may be shared with other people or organisations.
- Difficulties in working within the principles of maintaining the confidentiality of an adult should not lead to a failure to take action to protect the adult from abuse or harm.
- Confidentiality must not be confused with secrecy, that is, the need to protect the management interests of an organisation should not override the need to protect the adult.
- Staff reporting concerns at work (whistleblowing") are entitled to protection under the Public Interest Disclosure Act 1998.

The decisions about what information is shared and with who will be taken on a case by case basis. Whether information is shared and with or without the adult at risk's consent, the information shared should be:

- Necessary for the purpose for which it is being shared.
- Shared only with those who have a need for it.
- Be accurate and up to date.
- Be shared in a timely fashion.
- Be shared accurately.
- Be shared securely.



12. Fire Safety

Hoarding poses a significant risk to both the people living in the hoarded property and those living nearby. Where a hoarded property is identified regardless of the risk rating, customers need to be advised of the increased risk and identify a safe exit route. Appropriate professional fire safety advice must to be sought and information shared with appropriate emergency services by alerting them to hoarded properties. This will allow crews to respond appropriately.

You can contact Cumbria Fire & Rescue Service for fire safety advice via their website by phone **0800 358 4777** or email hart@cumbria.gov.uk

Cumbria Fire and Rescue Service have also produced a <u>leaflet about Hoarding and the fire risks</u> which you can share with adults who are hoarding to support them to understand the risks.

13. Environmental Health powers

Public Health Act 1936

Section 79: Power to require removal of noxious matter by occupier of premises

The Local Authority (LA) will always try and work with a householder to identify a solution to a hoarded property, however in cases where the resident is not willing to co-operate the LA can serve notice on the owner or occupier to "remove accumulations of noxious matter". Noxious not defined, but usually is "harmful, unwholesome". No appeal available. If not complied with in 24 hours, The LA can do works in default and recover expenses.

Section 83: Cleansing of filthy or verminous premises

Where any premises, tent, van, shed, ship or boat is either;

- a) Filthy or unwholesome so as to be prejudicial to health; or
- b) Verminous (relating to rats, mice other pests including insects, their eggs and larvae) LA serves notice requiring clearance of materials and objects that are filthy, cleansing of surfaces, carpets etc. within 24 hours or more. If not complied with, Environmental Health (EH) can carry out works in default and charge. No appeal against notice but an appeal can be made against the cost and reasonableness of the works on the notice.

Section 84: Cleansing or destruction of filthy or verminous articles

Any article that is so filthy as to need cleansing or destruction to prevent injury to persons in the premises, or is verminous, the LA can serve notice and remove, cleanse, purify, disinfect or destroy any such article at their expense.

Prevention of Damage by Pests Act 1949

Section 4: Power of LA to require action to prevent or treat Rats and Mice

Notice may be served on owner or occupier of land/ premises where rats and/ or mice are or may be present due to the conditions at the time. The notice may be served on the owner or occupier and provide a reasonable period of time to carry out reasonable works to treat for rats and/or mice, remove materials that may feed or harbour them and carry out structural works.

The LA may carry out works in default and charge for these.

Environmental Protection Act 1990

Section 80: Dealing with Statutory Nuisances (SNs)

SNs are defined in section 79 of the Act and include any act or omission at premises that prevents the normal activities and use of another premises, including the following:

- Section 79 (1) (a) any premises in such a state as to be prejudicial to health or a nuisance
- Fumes or gases emitted from [private dwellings] premises so as to be prejudicial to health or a nuisance
- · Any accumulation or deposit which is prejudicial to health or a nuisance
- Any animal kept in such a place or manner as to be prejudicial to health or a nuisance

The LA serves an Abatement Notice made under section 80 to abate the nuisance if it exists at the time or to prevent its occurrence or recurrence.

14. Safeguarding Children

Growing up in a hoarded property can put a child at risk by affecting their development and in some cases, leading to the neglect of a child, which is a safeguarding issue. The needs of the child at risk must come first and any actions reflect this. Where children live in the property are at risk you can raise a safeguarding children concern.

15. Adult at Risk

Safeguarding Adult processes described in the Cumbria Safeguarding Adults Policies and Procedures should be utilised.

An "adult at risk" may also be living with the hoarder in the property. There may be a safeguarding concern about that adult if they are at risk of harm due to the living circumstances. If you have concerns that an adult is at risk you should contact the Single Point of Access to raise a concern.

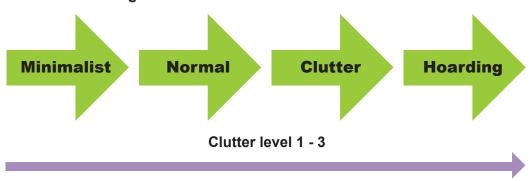
16. Multi-Agency Response

It is recognised that hoarding is a complex condition and that a variety of agencies will come into contact with the same person. It is also recognised that not all customers will receive support from statutory services.

Any professional working with customers who may have or appear to a have a hoarding condition should ensure they complete an assessment and use the Clutter Image Rating (CIR) tool kit to decide what steps to take.

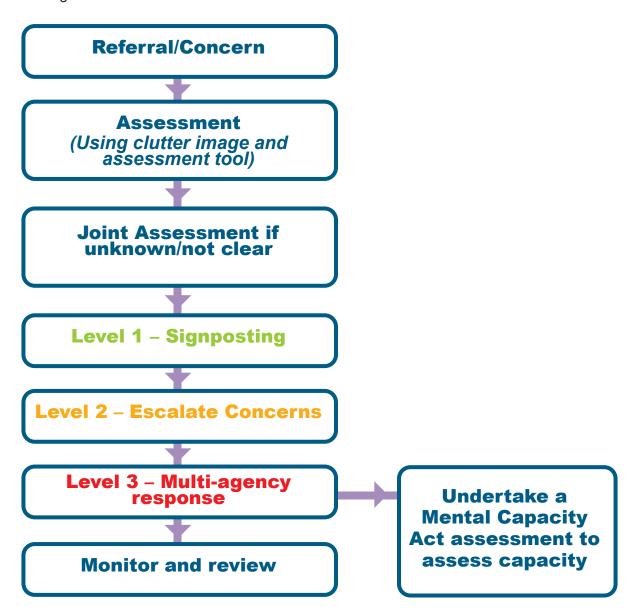
Evidence of animal hoarding at any level should be reported to the RSPCA.

Continuum of Hoarding Behaviour



17. Process for Clutter Image Rating (CIR) Assessment Tool

The flow chart below sets out the process clearly. If in doubt, please ask your supervisor/manager for assistance.



Please use the CIR to assess what level the customer's hoarding problem is at:

Images 1-3 indicate level 1 Images 4-6 indicate level 2 Images 7-9 indicate level 3

Once you have completed the CIR you should then refer to the Clutter Assessment Tool for guidance as to the appropriate action you should take. Practitioners should record all actions undertaken in your agency's recording system, detailing conversations with other professionals, actions taken and action yet to be taken.

