Self-neglect and hoarding

Multi-agency good practice guidance

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Contents

Introduction

This multi-agency protocol aims to support practitioners and managers in all agencies across the ADASS Eastern Region when they work with and support adults who self-neglect and hoard. The protocol provides guidance and promotes best practice. It encourages and supports practitioners to be active in responding to the risks of self-neglect and hoarding and to apply a multi-agency approach to the principles of 'Making Safeguarding Personal'.

Safeguarding partner agencies are committed to working together to support adults at risk of harm and abuse, including people who may be at risk of harm through self-neglect and/or hoarding. The development of this protocol was supported by each of the Safeguarding Adults Boards in the ADASS Eastern Region.

The Care Act 2014 (Statutory Guidance, Chapter 14) recognises 'self-neglect' as a category of abuse and requires public agencies to act to manage and reduce risks.

The purpose of this protocol is to support practitioners to reduce the significant risks from self-neglect and/or hoarding and to develop a consistent and effective approach across the ADASS Eastern Region.

Aims of the protocol

- Define what self-neglect and what hoarding are, and when interventions from professionals may be required, based on a shared understanding of risk.
- Provide information about the role of each agency and how agencies can work together to prevent and reduce harm caused by self-neglect and hoarding.
- Provide guidance about what is best practice and how to best respond to safeguarding concerns relating to self-neglect and hoarding.
- Ensure that the principles of Making Safeguarding Personal are fully applied, and that practitioners and professionals involve the relevant person in plans and decisions to address and minimise risks whenever possible.
- For professionals and agencies to be aware of legal remedies (not to be considered as a first resort) to address risks to the person and/or others.

Definition of self-neglect

The Care Act statutory guidance defines self-neglect as 'a wide range of behaviour neglecting to care for one's personal hygiene, health or surroundings and includes behaviour such as hoarding'.

More specifically, it is recognised that self-neglect includes:

- lack of self-care: this may include neglecting personal hygiene, nutrition and hydration or health
- lack of care of one's environment: this may include unpleasant or dirty home conditions or hoarding
- refusal of services: this may include the refusal of care services, treatment, assessments or intervention, which could potentially improve self-care or care of one's environment.

The following could indicate a person is self-neglecting:

- neglecting personal hygiene impacting upon health (including skin damage/pressure ulcers)
- poor diet and nutrition leading to significant weight loss or other associated health issues
- failure to manage finances
- neglecting the home environment
- hazards in the home due to poor maintenance
- not disposing of refuse leading to infestations
- failure to maintain social contact
- lack of engagement with health and other services/agencies
- refusing to allow access to other organisations with an interest in the property, for example, staff working for utility companies (water, gas, electricity)
- declining or refusing prescribed medication and/or other community healthcare support
- being unwilling to attend appointments with relevant organisations, such as social care or healthcare, etc.

It is important to understand that poor environmental and personal hygiene may not necessarily always be because of self-neglect. It could arise because of cognitive impairment, poor eyesight, physical difficulties and financial constraints.

Definition of hoarding

Hoarding is a complex and diverse phenomena, with multiple causes and factors which sustain it. Not everyone who hoards will have diagnosed mental health needs, but the definition of, and diagnostic criteria for, a hoarding disorder can also be helpful in recognising problematic hoarding:

> *A hoarding disorder is where someone acquires an excessive number of items and stores them in a chaotic manner, usually resulting in unmanageable amounts of clutter. The items can be of little or no monetary value.*

According to the ICD-11 (International Classification of Diseases 11th revision), hoarding disorder is characterised by:

'Accumulation' of possessions due to excessive acquisition of or difficulty discarding possessions, regardless of their actual value.

Excessive acquisition is characterized by repetitive urges or behaviours related to amassing or buying items.

Difficult discarding possessions is characterized by a perceived need to save items and distress associated with discarding them.

Accumulation of possessions results in living spaces becoming cluttered to the point that their use or safety is compromised.

The symptoms result in significant distress or significant impairment in personal, family, social, educational, occupational or other important areas of functioning.'

Source: World Health Organization (2022)

Hoarding is considered a significant problem if:

- the amount of clutter interferes with everyday living, for example, the person is unable to use their kitchen or bathroom and cannot access rooms
- the clutter is causing significant distress or is negatively affecting the quality of life of the person or their family, for example, they become upset if someone tries to clear the clutter and their relationships suffer
- the clutter poses fire risks, including due to flammable material or through blocking escape routes
- the clutter poses risks to other people through, for example, vermin infestation, insanitary conditions or fire.

Types of hoarding

There are three types of hoarding: inanimate objects, animal hoarding and data hoarding.

Inanimate objects

This is the most common. It could consist of one type of object or a collection of a mixture of objects such as clothing, newspapers, food, containers and papers, DVDs, CDs and books etc.

Animal hoarding

This is the collecting of animals, often with an inability to provide minimal standards of care. A person who hoards animals is often 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, the individual may also be unable to take care of themselves. Animal hoarding can lead to insanitary and unhygienic conditions for both the animals and the person. Joint working with animal protection agencies, such as the RSPCA, is required here.

Data hoarding

Data hoarding may not seem as significant as other types of hoarding; however, people who hoard data could still present with severe symptoms of hoarding. Data hoarding includes the need to store data as well as to collect equipment such as computers, electronic storage devices or paper.

The key factor in all forms of hoarding is the extent to which hoarding impacts on a person's wellbeing, their ability to keep themselves safe and their activities of daily living (for example personal care, maintaining their property).

Why someone may hoard

The reasons why someone begins hoarding are not fully understood. It can be a symptom of another condition. For example, someone with mobility problems may be physically unable to clear the clutter they have acquired. People with learning disabilities and people living with dementia may be unable to categorise and dispose of items.

Hoarding can be associated with mental health problems, including:

- depression
- psychotic disorders, such as schizophrenia
- obsessive compulsive disorder (OCD)
- hoarding disorder
- trauma
- bereavement
- substance misuse
- isolation
- brain injury (including head injury, stroke, tumour)
- dementia
- Huntington's disease
- neurological conditions and other cognitive impairments (including frontal lobe syndrome, Wernicke-Korsakoff's syndrome)
- physical health conditions.

What can trigger hoarding?

People affected by hoarding are more likely to:

- self-neglect or not engage with services or agencies
- have suffered significant loss or trauma in the past
- have had a deprived childhood, with either a lack of material objects or a poor relationship with other members of their family
- have a family history of hoarding
- have grown up in a cluttered home and never learned to prioritise and sort items.

General characteristics of hoarding behaviour

One or more of the following may be present:

- **Excessive attachment to possessions:** people who hoard may hold an emotional attachment to items beyond their obvious monetary, artistic or emotional value. Attempts to discard possessions, including items that may be considered by others to be disposable or rubbish, often induce very strong emotions. These can be overwhelming to the extent that the person tends to put off, be indecisive or avoid making decisions about what can be thrown out.
- **Fear and anxiety:** compulsive hoarding may have started as a learned behaviour or following a significant event such as bereavement. The person hoarding believes that buying or saving things will relieve the anxiety and fear they feel. Hoarding provides comfort and any attempt to discard hoarded items can induce feelings varying from mild anxiety to panic attacks.
- **Strongly held beliefs** related to acquiring and discarding things. These beliefs include 'I may need this someday' or 'If I buy this, it will make me happy.'
- **Long-term behaviour patterns** 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.
- **Unrelenting standards:** people who hoard will often find fault with others or require others to perform to excellent standards while struggling to organise themselves and to complete daily living tasks.
- **Socially isolated:** people who hoard may be isolated from, and may alienate, family and friends and may be embarrassed to have visitors. They may refuse home visits from professionals.
- **Large number of pets:** some people who hoard may keep a large number of animals. These may become a source of complaints by neighbours. They may 'rescue' strays.
- **Mentally competent:** people who hoard are typically able to make reasonable decisions that are not related to the hoarding.
- **Extreme clutter:** hoarding may prevent the person from using several or all of the rooms of their property for their intended purpose.
- **Churning:** people who hoard may move items from one part of their property to another, without actually discarding anything.
- **Self-care:** a person who hoards may appear unkempt and dishevelled, due to lack of toileting or washing facilities in their home. Some people who hoard use public facilities in order to maintain their personal hygiene and appearance.

- **Embarrassment and shame:** some people who hoard may realise they have a problem but may be reluctant to seek help because they feel extremely ashamed, humiliated or guilty about it.

The Chief Fire Officers Association produced a document to dispel myths about hoarding (see Appendix 1).

Learning from Safeguarding Adult Reviews (SARs)

Learning from SARs involving self-neglect and individuals who hoard have highlighted the following:

- The importance of early information sharing, in relation to previous or ongoing concerns.
- The importance of thorough and robust risk assessment and planning.
- The importance of face-to-face contact and reviews.
- The need for a clear interface with safeguarding adults procedures.
- The importance of effective collaboration between agencies.
- The importance of recognising and responding to risks from untreated or poorly managed long-term physical health conditions including diabetes, lung and heart disease or cancer.
- The need for professional curiosity into a person's background and any events or factors that might have precipitated self-neglect or hoarding.
- Understanding of the personal meaning and significance of hoarding and self-neglect (is it, for example, about having control when the person feels that they have no control over anything else?).
- Increased understanding of the legislative options available to intervene to safeguard a person who is self-neglecting.
- The importance of the application and understanding of the Mental Capacity Act (2005).
- Where an individual refuses services, it is important to consider mental capacity and ensure the individual understands the implications and that this is documented. Services/support should be re-visited at regular intervals as it may take time for an individual to be ready to accept some support.
- The need for practitioners and managers to challenge and reflect on cases through the supervision process and training.
- The need for robust guidance to assist practitioners in working in this complex area.
- Assessment processes need to identify who carers are (and significant others – the 'whole family approach') and how much care and/or support they are providing.

Supporting people who self-neglect and hoard

Bearing in mind the complexity of self-neglect and hoarding behaviour, it is important that approaches taken are proportionate and compliant with statute and best practice.

Every self-neglect and hoarding situation will be different, although there may be similarities. Staff need to consider the particular circumstances and individual views of the person who self-neglects and/or hoards, to develop a personalised and supportive approach to resolving the situation. Such an approach is most likely to achieve a positive outcome.

Self-neglect and hoarding can often require long-term intervention to effectively support the person to achieve change.

Difficulties with engagement

Working with adults/families that self-neglect is difficult and often complex. The inability to engage with people who are self-neglecting (whether they have mental capacity or not) may have serious implications for, and a profoundly detrimental effect on, an individual's health and well-being. It can also impact on the individual's family and the local community. Organisations need to consider how they will overcome barriers such as:

- the perception that self-neglect and hoarding is a 'lifestyle choice'
- poor multi-agency working
- lack of information sharing
- an inability for an organisation to engage the individual or family
- individuals with chaotic lifestyles and multiple or competing needs
- inconsistency in thresholds across agencies and teams and the level of subjectivity in assessing risk.

Assessing 'protective factors'

Assess how effective any protective factors in the person who hoards and/or self-neglects are or might be. For example, a family member or individual in a household may be identified as a carer but may not have a clear understanding of what their role is or know what to do. This can lead to professional assumptions that they are providing support and are being protective when they are not.

Similarly, they may have become de-sensitised and may minimise apparent risk. They may also have support needs themselves and require assessments in their own right.

Hoarding assessments

Three assessments are recommended to be undertaken to provide a holistic view:

- Assess the level of clutter using the Clutter Image Rating Tool (CIR) (Appendix 3).
- Assess risk using local risk assessment tool.
- Assess the person's insight into their (hoarding) behaviour.

Depending on the results of these assessments the following steps are recommended:

CIR score 1–3:

- Provide advice to the person about risks and safety, ask for fire safety advice from the local Fire and Rescue Service.
- Encourage the person to self-refer to appropriate agencies for assistance.
- Encourage/enable them to talk about routines, storage, etc.

Ideally, complete an action plan based on the results of the CIR, risk and hoarding insight characteristics assessments.

CIR score 4–9:

- Instigate a multi-agency meeting with the relevant agencies present.
- Complete an action plan based on the results of the CIR, risk and hoarding insight characteristics assessments. The action plan, and date when it will be reviewed, will be agreed at the multi-agency meeting and a next meeting date will be arranged.

Insight into hoarding

Use the guide in this section to describe the person's attitude(s) towards their hoarding. This is useful when sharing information and concerns with other agencies and will be helpful to know when creating an appropriate action plan with the person who is hoarding or self-neglecting.

- **Good or fair insight:** the person recognises that hoarding-related beliefs (relating to difficulty discarding items, clutter or excessive acquisition) are problematic. The person recognizes/accepts these beliefs as their own.
- **Poor insight:** the person is mostly convinced that their hoarding-related beliefs (relating to difficulty discarding items, clutter or excessive acquisition) are not problematic despite evidence to the contrary. The person might recognise a storage problem but has little self-recognition or acceptance that this is caused by hoarding.
- **Absent (delusional) insight:** the person is (fully?) convinced that their hoarding-related beliefs (relating to difficulty discarding items, clutter or excessive acquisition) are not problematic despite evidence to the contrary. The person accepts their living environment despite the various risks to safety and health and denies, minimises or ignores the risks.

- **Detached insight with assigned blame:** the person has been away from their property for an extended period. The person has formed a detachment from the hoarded property and is now convinced a 'third party' is to blame for the condition of the property, for example a burglary has taken place, or it is the result of the actions of, or interference by, squatters or other household members.

It is therefore important to encourage a person who is hoarding to seek help, as their difficulties discarding objects can not only cause loneliness, environmental and mental and emotional problems, but may also pose a significant risk to health, safety or fire risk. This risk may only affect the person themselves but can often affect others, including neighbours and family members.

Clearances

The person who self-neglects or hoards may not respond favourably to a simple clearance of their property. Such action, particularly in the absence of their agreement or consent, is likely to be extremely upsetting for them and will almost certainly exacerbate any emotional distress and increase any mental health or emotional needs. Enforced clearance is a last resort and is often not a longer-term solution. It is highly likely that hoarding behaviour will continue/recommence.

Instead, the way forward is to work with the person to make positive changes. Other agencies will also need to be involved.

Enforced clearance of items against the person's will should only be undertaken when these four points are satisfied:

- other approaches have been exhausted
- the risks caused by the hoarding warrant clearance
- the agreement of the multi-agency group has been obtained
- it is proportionate to the risk.

By 'proportionate' we mean the areas of highest fire risk may be the only areas that need to be cleared, and not the whole house. For the rest of the property it may be enough to clear sufficient areas to enable the person to access all of the rooms and their facilities.

The action plan should note the relevant agency that will work with the person who self-neglects and hoards and provide support during any clearance process, while at the same time encouraging the person to tackle some of it on their own. It is important to encourage the person to engage with actions to clear the property in a way that they can 'own' the process, working if possible with family, friends and voluntary agencies. Finding out what will motivate the person to participate in the clearance, and to sustain their involvement, is important.

There are a few simple tips that will support the person and that can be adapted to suit their needs and preferences, for example:

- **Start the clearance in one important area first**, for example around the cooker, or heating source.
- **Apply the 'fifteen-minute rule' –** set a timer for 15 minutes to clear clutter. Once this has been completed encourage the individual to do something they like to do and then return to undertake another 15 minutes later the same day.
- **Keep a clutter free success diary or chart –** note every success such as a bag of clutter that leaves the property, for example, 10 bin liners of clothes to a charity shop, 2 bags of medicines to the doctor's surgery, 1 bag of books to a charity shop.

- **Clearances that require a third party** to facilitate the work are likely to need to be paid for by the person who is self-neglecting or hoarding. The person can source and employ a contractor themselves, or the council may arrange for a company to do the job and recharge the person, especially if enforcement action is required.

After the clearance the multi-agency group must identify how ongoing/regular support will be provided to prevent the re-accumulation of hoarded items.

Safeguarding and self-neglect and hoarding

When do the local safeguarding adults policy and procedures apply?

Anyone can raise an adult safeguarding concern. They do not have to consider if the concern will meet the criteria for individuals as set out in Section 42(1) Care Act 2014:

a) *has needs for care and support (whether or not the authority is meeting any of those needs),*

b) *is experiencing, or is at risk of, abuse or neglect, and*

c) *as a result of those needs is unable to protect himself or herself against abuse or neglect or the risk of it.*

However, a local authority must undertake an adult safeguarding enquiry if it has reasonable cause to suspect that an adult in its area (whether or not ordinarily resident there) meets these criteria. The guidance is clear that decisions must be made on a case-by-case basis that consider the person's ability to prevent harm to themselves.

What if the adult does not have care and support needs?

Not every adult who hoards and/or self-neglects can be defined as an adult at risk as described by the Care Act 2014. Even in circumstances when the criteria set out in s42 Care Act 2014 are not met, practitioners and professionals are encouraged to work together to identify how best to minimise risk and to work with the person using other duties and powers defined in legislation.

What if it is unclear if the adult can protect themselves (or not) because of their care and support needs?

It is sometimes hard to determine if the criteria in s42(c), about whether or not the adult is unable to protect themselves because of their care and support needs, have been met. Additional information gathering may be required.

The conclusion from the national guidance is that if sections 42(a) and (b) have been met, the concern should be recorded as requiring a safeguarding enquiry, even if there is uncertainty about whether s42(c) has been met.

If during information gathering there is reasonable belief that s42(c) does not apply then the local authority can decide not to pursue the matter as a safeguarding concern.

This does not mean, however, that the matter is not pursued further as another form of concern such as service quality or a criminal or civil law matter.

What if children are at risk?

Safeguarding children is everybody's business. Growing up within a hoarded household can put a child at risk by affecting their development and in some cases, might lead to their neglect. Whenever children are at risk of harm through self-neglect and/or hoarding, local authorities should be alerted using local safeguarding children policies and procedures.

Where children and adults are at risk a joint approach involving both children and adult services should be taken and involving other agencies (Fire and Rescue, mediation, etc.) as required.

Using the safeguarding adults procedures

Supporting people who self-neglect and/or hoard is a multiagency responsibility. Adult Social Care (ASC) may not always be best placed to lead work with people who self-neglect and/or hoard. Workers from other agencies may already have a good working relationship with them.

People who self-neglect and/or hoard may experience abuse and neglect from others. In these circumstances they should be asked if they would like to initiate safeguarding processes.

Challenges can also be encountered in multi-agency working. For example, the involvement of a particular agency may have been identified but requests for its involvement may not have been responded to or prioritised. In these situations, safeguarding meetings can be used as a forum to bring multi-agency professionals together.

Where there is no separate self-neglect and hoarding workstream, and where the risks of harm are already high but the usual care, support and treatment options have been unsuccessful in reducing risks, the concerns should be referred to the local safeguarding team for advice.

The Care Act Guidance outlines Making Safeguarding Personal as the preferred approach to safeguarding adults. Although work with people who hoard and/or self-neglecting may not progress though adult safeguarding, this approach is still relevant. The guidance states, 'Making Safeguarding Personal means [safeguarding] should be person-led, and outcomes focused. It engages the person in a conversation about how best to respond to their safeguarding situation in a way that enhances involvement, choice and control as well as improving quality of life.'

Underpinning the spirit of the Care Act 2014 is the need for involvement of the relevant person in their assessment, planning and decision making as well as in any subsequent actions. Professionals should consider whether the adult has 'significant difficulty and requires support from advocacy services.

Approaches that are likely to be successful with people who self-neglect and/or hoard

Early intervention in hoarding is vital. It is much easier to deal with hoarding when the amount of clutter is relatively low. The traumatic event that might have led to hoarding or self-neglect as a coping response might also be more recent. This might make it more easily identifiable and amenable to therapeutic interventions.

Consequently, it is important to become familiar with local resources to support people who hoard or self-neglect. These can include clinical approaches including cognitive behavioural therapy, dialectical therapy and cognitive processing therapy for trauma and self-help approaches including peer support groups.

More widely, it is also useful to network with other areas to share learning and different possible approaches. There are also useful resources available online. These can also be accessed by people who hoard and self-neglect and include podcasts by 'That Hoarder', YouTube videos and the Hoarding Disorders UK website.

Engage the person about something other than the hoard, for example, their interests and enthusiasms or previous job. This engagement could be done by someone who has the best, or most trusting, relationship with the person who hoards and/or self-neglects. Approaches that involve negotiation (for example, one new item in but one old item out) and breaking down dealing with a hoard into small chunks might also be helpful. Pausing a hoard so that it does not get worse may be a successful outcome.

Focus any discussions and plans on the person and their safety rather than the hoarding and consider how any proposed interventions can support this. Agree timescales for any interventions and, where possible, include the person who hoards or self-neglects in this agreement.

Evidence from research and from Safeguarding Adults Reviews shows that work with people who self-neglect and/or hoard is more effective where practitioners:

- build rapport and trust, showing respect, empathy, persistence and continuity and consistency
- seek to understand the meaning and significance of the self-neglect/hoarding, taking account of the individual's life experience
- work at the pace of the individual but know when to make the most of moments of motivation to secure changes
- constantly keep in view the question of the individual's mental capacity to make decisions
- communicate about risks and options with honesty and openness, particularly where coercive action is a possibility
- ensure options for interventions are rooted in sound understanding of legal powers and duties

- think flexibly about how family members and community resources can contribute to interventions, building on relationships and networks
- work proactively to engage and coordinate agencies with specialist expertise to contribute towards shared goals.

One of the major challenges is finding ways to engage with people who self-neglect and/or hoard. Techniques that can work include the following:

- Take an indirect approach and concentrate on forming a relationship first before talking about self-neglect and/or hoarding.
  - Don't underestimate the role that fear of the consequences of your involvement might have or that feelings of shame and embarrassment may have in difficulties with engagement.
- Find out who the person gets on best with.
  - You may find someone in the network who already has a relationship with the person who self-neglects and/or hoards.
  - They may not be professionally qualified or especially skilled but you could work with them to support your efforts to engage with the person.
- Be persistent and use different methods of contact. You can try some or all of the following methods at the same time:
  - phone calls
  - text messages
  - virtual meetings
  - meetings in a neutral location
  - knocking on the door
  - putting a note through the letter box.
- Use strengths-based approaches. Find out:
  - what the person is or was good at
  - what they like or used to like
  - what motivates or motivated them
  - what they enjoy or enjoyed doing.

This may require finding out more about them first but can be used to engage the person who hoards and/or self-neglects in conversation or invitations to participate in an activity they enjoy.

- Be trauma informed:
  - Be aware that the person who self-neglects and/or hoards may have a window of tolerance which means that you are best approaching them at certain times of day and for certain lengths of time.
  - Remember that the person may be suspicious or distrusting and may negatively misinterpret ambiguous written, verbal or body language so try to be clear and concise. Remember, too, to be willing to repeat/simplify messages and information.
  - Remember that the person may find it hard to travel or to keep appointments and if so, adapt your approach to suit them.

  - Remember that they may be easily distracted by noise or bright light so try to choose a calming and not overly stimulating environment to meet them in.
  - Remember that they may 'disassociate', which means that they do not really feel physically present. Using grounding techniques such as asking them to drink water or to describe what they can sense (see, hear, smell, touch or taste) can help.
- Do not discharge to 'no service'. If your organisation's policies put a limit on the number of contacts that can be attempted, then ask yourself:
  - Who/where else can I refer this person to and how can I ensure that they accept the referral?
  - If I have to discharge them, then who do I need to alert?

Mental capacity and self-neglect and hoarding

Assessment of mental capacity will often be the starting point for deciding on interventions. Please refer to the Mental Capacity Act (MCA) 2005, its statutory practice guidance and any local policies and procedures for guidance on this. The following points in this section, however, are of particular relevance to mental capacity and people who self-neglect and hoard.

The five statutory principles of the MCA 2005 must be considered and applied in practice, whenever there is doubt about a person's capacity to make decisions or when they lack mental capacity to make decisions (see below). The principles must underpin all acts carried out and decisions made on a person's behalf.

Principles 1 to 3 support the process before or at the point of determining whether a person lacks mental capacity. Once a decision is made that capacity is lacking, principles 4 and 5 are used to support the process for making decisions on their behalf.

For all the people at all times

Principle 1

A person must be assumed to have capacity unless it is established that he/she/they lacks capacity.

Principle 2

A person is not to be treated as unable to make a decision unless all practicable steps to help him/her/them to do so have been taken without success.

Principle 3

A person should not be considered incapable of making a decision simply because they choose an option that others may see as unwise.

For people assessed as lacking mental capacity

Principle 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/her/their best interests.

Principle 5

Before taking any action or making a decision, consideration must be given to whether the intended outcome could be achieved in a way that is less restrictive of the person's rights and freedom.

The five statutory principles of the Mental Capacity Act 2005 (gov.uk)

A mental capacity assessment is required when there are sufficient grounds to doubt a person's capacity to make a particular decision. The MCA Statutory Code of Practice states there may be cause for concern if a person 'repeatedly makes unwise decisions that put them at significant risk of harm or exploitation' or 'the person's behaviour or circumstances cause doubt as to whether they have capacity to make a decision'.

Mental Capacity Act 2005 mistakes to avoid when working with people who hoard and/ or self-neglect

Remember that in cases of hoarding, the nature of the person's environment could raise doubts about their capacity to consent to proposed action/intervention, and this should therefore trigger a formal assessment of their mental capacity. The higher the level of risk and concern, the more important it is to assess and record mental capacity and to explore with the person their ability to understand and process relevant information (including the likely foreseeable consequences of action or inaction).

The House of Lords concluded that:

> *The presumption of capacity, in particular, is widely misunderstood by those involved in care. It is sometimes used to support non-intervention or poor care, leaving vulnerable adults exposed to risk of harm. In some cases this is because professionals struggle to understand how to apply the principle in practice. In other cases, the evidence suggests the principle has been deliberately misappropriated to avoid taking responsibility for a vulnerable adult.*
>
> *Source: House of Lords Select Committee post-legislative scrutiny of MCA 2005, para 105*

Do not:

- Misuse the presumption of mental capacity (Principle 1) or beliefs that a decision was 'unwise' (Principle 3)', to justify not making a thorough and robust evidence-based mental capacity assessment.
- 'Walk away' when a person appears to have mental capacity to make a particular decision, especially if that decision involves serious risk of harm to themselves or others. This means practitioners should not simply refer to notions of 'lifestyle choice' or the presumption of capacity without a thorough exploration of mental and decisional capacity.
- Oversimplify complex situations. It can be hard to tell if a person is unwilling or is unable to keep themselves safe. Practitioners must remain open to the possibility that a person's apparent choice may be masking difficulties in either making decisions or putting them into action.

Mental capacity assessment

Assessments of the mental capacity of people who hoard or self-neglect may require:

- ongoing engagement and relationship building over time
- liaison with other professionals and those who know the person well
- involvement of other professionals in the assessment
- the provision of Care Act 2014 advocacy or an Independent Mental Capacity Advocate
- repeated mental capacity assessments to keep the person's decision making at the forefront

- clarity about the decision(s) to be made and the options available and not just the ones that practitioners consider to be desirable
- provision of all information relevant to the decision/situation.

Paragraph 4.16 of the MCA Code of Practice stresses the importance of not assessing a person's understanding before they have been given all relevant information and in a way that is appropriate to the person. Relevant information must include, as a minimum, details of:

- the nature of the decision (including options available)
- the reason why the decision is needed
- the likely effects of deciding one way or another or making no decision at all.

For decisions involving risk it is especially important to guard against the 'protection imperative' unduly influencing the assessment. The aim is for an objective assessment of the person's functional ability (their decision-making ability, not an assessment based primarily on the desirability of their decision or its likely outcome).

Executive capacity

Executive capacity refers to a person's ability to turn their decisions into actions. It is related to executive functioning, which includes motivation, planning and social behaviour. Executive capacity can be affected by many things, but certain neurological conditions and mental health problems are known to impact negatively on executive functioning. This list is not exhaustive but includes dementia, frontal lobe syndrome, Wernicke-Korsakoff's syndrome, specific executive functioning impairment and emotionally unstable personality disorder/borderline personality disorder. It is worthwhile becoming familiar with the local mental health service arrangements for diagnosing and treating these disorders.

While the Mental Capacity Act does not explicitly recognise the difference between decisional capacity (the ability to make a decision) and executive capacity (the ability to turn that decision into action), it is an important distinction in practice, especially with people who self-neglect and feign compliance or avoid contact. Executive capacity can be explored through the assessment of a person's ability to use and weigh information in order to make a decision (see for example).

The proposed revised Code of Practice for the Mental Capacity Act will, subject to approval, include guidance on assessing mental capacity where there is an impairment in executive functioning and a mismatch between what a person says and what they do. The proposed revisions include that, 'A person who makes a decision which others consider to be unwise should not be presumed to lack capacity. However, a series of unwise decisions may indicate an inability to use or weigh information.'

If a person is deemed to have mental capacity

If a person is assessed to have the mental capacity to make decisions about a relevant matter, but continues to hoard or self-neglect and risks are still present, then practitioners should:

- remain involved to identify patterns or changes and consider ways to reduce risk and to identify opportunities to intervene
- consider and review the person's decision-making capacity to identify the opportunity for further assessments

- liaise, share information and coordinate any actions with other involved agencies as appropriate, and offer, signpost or refer to other services such as s9 Care Act 2014 assessments, fire safety visits, hoarding support groups, etc.
- consult with legal services and consider if interventions under Public Health and Environmental Health legislation, the Mental Health Act 1983 or the Human Rights Act 1998 or to the High Court under the inherent jurisdiction are appropriate
- record the actions or decisions they have taken and the reasons for them.

If a person refuses an assessment of needs

If a person who hoards or self-neglects refuses an assessment of needs or services that they are assessed to require, then practitioners should:

- record what steps have been taken to involve the adult and any carer, as required by section 9(5) of the Care Act 2014
- make the assessment of needs without consent if the person is experiencing or is at risk of abuse of neglect (s11(2b) Care Act 2014)
- provide relevant information, including about how to access care and support, and signpost to any relevant services
- remain involved to identify patterns or changes and consider ways to reduce risk and to identify opportunities to intervene
- record the actions or decisions they have taken or made and the reasons for them.

Where practitioners or others foresee serious or critical harm to a person who has the mental capacity to make relevant decisions, the duty of care includes gathering all the necessary information to inform a thorough risk assessment and subsequent actions, even without the consent of the person. While it may be determined that there are no legal powers to intervene, there will/should be documented and recorded evidence to demonstrate that risks and possible actions have been fully considered.

If a person is assessed to lack mental capacity to make decision(s)

Decisions may need to be made on behalf of people who have been assessed to lack the mental capacity to do so themselves. All actions taken, or decisions made, on behalf a person who lacks capacity must be done in his/her best interests (Principle 4, MCA). This means that the focus must be on making the right decision for the person concerned and may include consideration of the decisions that they had made before they lacked the capacity to make them, if this is relevant. A holistic approach should be taken and there should not be a disproportionate focus on personal safety. The 'best interests' decision must consider wider aspects of the person's welfare and wellbeing, such as emotional welfare, relationships, belonging and happiness as well as their needs for safety and security.

Any decisions made on the person's behalf must be the least restrictive of their rights and freedoms whilst also seeking to effectively achieve the desired purpose (Principle 5, MCA). This could be particularly important when considering the careful balance between personal safety and rights to private and family life (Article 8, European Convention of Human Rights).

Disagreements

Do not let unresolved disagreements leave people who hoard and/or self-neglect at risk of harm.

Where there is uncertainly, or there are disagreements or disputes about what may be in the person's best interests, and this cannot be resolved by the professionals involved, then this should be escalated through the management hierarchy using the relevant organisation's escalation routes. The reasons for the disagreement and what has been tried in order to resolve it should be specified. Formal escalation processes or managing professional difficulties' processes or policies should be used if available. Unresolved disagreements can also be brought to the attention of the local Safeguarding Adults Board for resolution.

In some situations, there may be a need to ask the Court of Protection to consider the matter. Relevant/appropriate (prior) legal advice and support is recommended in such cases.

Defensible and evidenced decision making

Defensible decision making is making sure that the reasons for decisions, as well as the decision itself, have been thought through, fully recorded and can be explained. The duty of care in relation to decisions made will be considered to be met where:

- there are clear records of all decisions and why they were made is maintained
- all reasonable steps have been taken to obtain to achieve a consensual decision
- all relevant agencies have been involved
- reliable assessment methods have been used
- information related to the decision has been collated and thoroughly evaluated
- relevant policies (including the Safeguarding Adults Policy), procedures and guidance have been followed
- professionals and their managers adopt a person-centred and investigative approach and are proactive.

Consent and information sharing

In principle, consent should be obtained from the individual whenever possible in order to share information. If consent cannot be obtained or the person lacks mental capacity to consent, the right of a person to confidentiality must be carefully weighed against a professional's duty to prevent harm and abuse as well as consideration of the risk to the person and others. Therefore, practitioners may have sufficient reason to legitimately share information with other organisations in order to prevent harm and abuse, even without the consent of the relevant person. In the case that the relevant person lacks mental capacity to consent, the principles of the Mental Capacity Act must be applied in making decisions relating to safeguarding.

It is always good practice to obtain consent to share information. However, remember that there is a difference between explaining your concerns to another professional, such as a GP, and breaching confidentiality. For example, the General Medical Council states that:

> *In most cases, discussions with those close to the patient will take place with the patient's knowledge and consent. But if someone close to the patient wants to discuss their concerns about the patient's health without involving the patient, you should not refuse to listen to their views or concerns on the grounds of confidentiality. The information they give you might be helpful in your care of the patient.*
>
> *Source: 'Using and disclosing patient information for direct care', s39, General Medical Council*

Decisions about which information is shared and with whom, need to be taken on a case by-case basis. Regardless of whether information is shared with or without the consent of the person, the information shared should be:

- necessary for the purpose for which it is being shared, i.e. shared only with those who have a need for it
- justifiable and proportionate
- accurate and up to date
- shared in a timely fashion
- shared securely
- retained only for as long as necessary.

There is an expectation that each agency ensures compliance with the General Data Protection Regulations (although commonly referred to, GDPR is part of the Act) This means that personal and sensitive data is appropriately stored, shared, managed and destroyed.

Multi-agency coordination and meetings

A coordinated response with a person-centred approach will lead to improved outcomes. The lead coordinating agency will be the agency best placed to coordinate the process. This could be for example the local authority, fire service, housing, mental health services, public health or environmental health. When considering which agency is the best to coordinate the process the following factors should be considered:

- The agency concerned is already involved with the individual.
- That agency has a duty of care to that individual because of their needs.
- They hold the majority of information relating to the individual.
- The individual engages well with that organisation.
- The individual's main needs relate to the service provided by the agency.
- The degree and immediacy of risk to the individual and/or the wider community.

Cases involving self-neglect and/or hoarding are complex and often pose dilemmas between promoting a person's autonomy and rights (consistent with Article 8 of the Human Rights Act 1998) and a duty to safeguard adults and possibly others from risk of harm (consistent with Article 2 of the Human Rights Act 1998). The adult may not wish to engage with professionals and may not accept offers of support, leaving practitioners (and often family and friends) with concerns for their safety.

Responses by a range of organisations are likely to be more effective than a single agency response. A multi-agency approach should be used, with all agencies involved in a dynamic assessment of risk in consultation with the person. Contingency plans need to be made, which include warning signs that indicate risks are increasing and actions that must be taken. It may be useful to hold a multi-agency meeting to discuss and coordinate responses and identify a lead agency. The meeting should:

- involve the person as far as possible
- update the support plan and risk assessment
- set actions – including contingency plans should the person refuse the support plan decided at the meeting, change their mind or be unable to follow the plan, and the role of each involved agency. The actions should be informed by the views of the person about how changes can realistically be achieved, and risks reduced
- establish monitoring and reviewing arrangements
- decide how communication is maintained with the person and who will take responsibility to liaise with the person and advocate (if necessary) in order that they understand what support plan is in place.

The lead agency is responsible for checking progress with the person against the plan and, as necessary, arranging reviews with the multi-agency group (ideally with the person present) where further actions can be agreed to make progress.

Friends, relatives and supportive neighbours may be helpful in negotiating changes in behaviour, supporting the person to make the changes and both monitoring the situation and raising issues.

If the person will engage, the plan will:

- allow time to build trust to maximise the likelihood of success and to work in a sensitive way to engage the person
- be agreed by all agencies and should, if possible, be signed by the individual to indicate their agreement and willingness to accept support and engage with the relevant agencies
- set a realistic pace of change
- consider enforcement action if the person will not engage and the risk of harm cannot otherwise be managed.

Priority risks are for example, combustible items piled up near the central heating boiler, items blocking exit routes, routes to the toilet and washing facilities and essential appliances such as the cooker, items covering electrical sockets and switches. Any responsible housing officers or social landlords should be involved in monitoring and intervening in self-neglect and hoarding.

See also:

Appendix 1: Hoarding myths and truths

Appendix 2: Powers of entry to a private home

Appendix 3 (online): International OCD Foundation, Hoarding Center, Clutter Image Rating

References

General Medical Council (2026) *Using and disclosing patient information for direct care*. (Accessed 11.5.26)

Mental Health Capacity Act 2005 (Accessed 11.5.26)

Select Committee on the *Mental Capacity Act 2005 (2014) Mental Capacity Act 2005: post-legislative scrutiny*. London: The Stationery Office (HL Paper 139, 2013–14) (Accessed 11.5.26)

World Health Organization (2022) ICD-11: International Classification of Diseases (11th revision) (Accessed 11.5.26)

Appendix 1:

Hoarding myths and truths

Source: Chief Fire Officers Association

Myth: **Removing clutter and property will remove the issue of hoarding.**

Truth: Large scale removals without the permission of the person with hoarding behaviour do not work. Instead, this is likely to have a long-term negative impact on their mental health. The short-term, quick-fix approach also does not deal with core issues. Large-scale clean-ups, even with the person's permission, may not work.

Myth: **Fires in hoarding properties will behave in the same way as they do anywhere else.**

Truth: 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: **Hoarding only takes place in certain types of property.**

Truth: Hoarding can be found in all property types. Hoarding in high-rise premises pose very particular risks to the community and to fire fighters. Hoarding in privately-owned residences creates some specific issues with regards to the application of legislation.

Myth: **People with hoarding issues can't see all the stuff and dirt/they don't mind it.**

Truth: People with hoarding behaviours can see the clutter but are able to mostly mentally block it out. This has been called clutter blindness. When a person does begin to recognise the problems, this can be a sign they are ready for change and help.

Myth: **There is nothing we can do about it.**

Truth: With the proper support, help and guidance, hoarding problems can be resolved.

Myth: **People with hoarding issues love their belongings more than their family.**

Truth: People with hoarding behaviours have a strong attachment to belongings for a range of reasons. This attachment is likely to be stronger than the average person's. The difficulty in discarding items is as a result of these complex issues but does not reflect that the person's love for family members is lesser, simply that it is too difficult a process for the person to deal with.

Myth: **People with hoarding issues are just dirty and lazy – it's a 'life-style' choice.**

Truth: Usually just the opposite is true. In fact, people with hoarding behaviours have often undergone a traumatic experience and/or had a huge period of instability in their lives. Incorrect interventions can often cause further trauma because their relationship with their belongings acts as a coping mechanism. Discarding this haphazardly often results in retriggering of the trauma and/or escalation of the behaviours.

Myth: **All people with hoarding issues have obsessive compulsive disorder (OCD).**

Truth: Hoarding Disorder has been classified by the American Diagnostic Statistical Manual (DSM) and is published in ICD-11 (International Classification of Diseases (11th revision)). A unique classification was seen to be necessary because interventions which have succeeded in OCD were not as effective in treating hoarding behaviours.

Myth: **People only hoard things at home.**

Truth: Communal areas, gardens, storage spaces, friend's/neighbour's homes and vehicles can also be used. There is legislation in place in regard to all but storage spaces, which would mean that belongings which created unacceptable clutter could be in breach of a range of laws. Hoarding in offices and other business premises is not uncommon and can lead to blocked escape routes and increased risk of a fire.

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. This also does not deal with the core issues. As such, it can be seen as simply shifting the problem.

Myth: **People with hoarding issues don't like to talk about it.**

Truth: There are currently support groups across the UK, although more support is needed.

Myth: **All people with hoarding issues live in squalid conditions or own numerous pets or both.**

Truth: Most people with hoarding issues do not live in unhygienic conditions, nor are they animal hoarders.

Myth: **Every room in a hoarder's home is packed full of stuff.**

Truth: People with hoarding tendencies 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: Hoarding is found within all populations.

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.

Appendix 2:

Organisations with powers of entry to a private home

Police

- Police officers can enter and search premises under the Police and Criminal Evidence Act 1984 (PACE) and the Protection of Freedoms Act 2012.
- They can enter to make an arrest, after an arrest, or to search for evidence of a crime.
- They can also enter premises with a warrant issued by a justice of the peace.
- They can enter with a warrant under s135 Mental Health Act 1983 to remove someone with mental health problems to a place of safety.
- Local authorities
- Local authorities, including trading standards officers, have powers of entry to enforce regulations and conduct inspections.
- They may enter premises to investigate potential breaches of regulations or to ensure compliance.
- Under the Environmental Protection Act 1990, environmental health officers have the power to enter any premises at any reasonable time to determine if a statutory nuisance exists or to carry out relevant work. If the premises are a private residential address, then 24-hours' notice of entry must be given except in cases of emergency. If necessary and where a Justice of the Peace is satisfied that there is an emergency yet, amongst others, entry has been denied or denial of entry is anticipated, then entry can be made by force with a warrant. In these cases an environmental health officer can take other people with them as necessary.
- An emergency is where there is reasonable cause for belief that the situation endangers life or health and that immediate entry is necessary to verify the existence of those circumstances or to ascertain their cause and to effect a remedy.
- According to Shelter England (2026), prejudicial to health is defined as circumstances that are 'injurious, or likely to cause injury, to health'. Where the state of the premises is enough to cause a well person to become ill or the health of a sick person to deteriorate, the courts will normally be satisfied that it is prejudicial to health.
- Private nuisance occurs when something in one property interferes with the use and enjoyment of a neighbouring property, or constitutes a violation of legal rights of the owner or someone else with exclusive possession of that property. This could be encroachment on a neighbour's land, direct physical injury to a neighbour's land or interference with the neighbour's quiet enjoyment of their land. Nuisance can include noise and smells.

Regulatory bodies

- Enforcement staff of regulatory bodies, such as the Environment Agency (EA), the Health and Safety Executive (HSE) and Natural England, have powers of entry to inspect premises and ensure compliance with regulations.
- They may enter premises to investigate potential environmental breaches, health and safety violations or breaches of other regulations.

Bailiffs/enforcement agents

- Bailiffs, also known as enforcement agents, can enter a home to enforce debts, such as Council Tax bills, parking fines, court fines and judgments from county, high or family courts.
- They can enter through any open or unlocked door and can visit households between 06:00 and 21:00.
- They can also force entry in certain circumstances, such as when enforcing a magistrate's court fine.
- Other agencies
- The Department for Work and Pensions (DWP) has powers of entry for certain purposes, such as investigating potential benefit fraud.

Reference

Shelter England (2026) Local authority statutory nuisance duties (Accessed 11.5.26)

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