Supporting Adults that Hoard in West Dunbartonshire

Inter-agency guidance

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Contents

Who is this guidance for?

This document aims to provide initial guidance for staff of **any West Dunbartonshire partner agency** who, in the course of their work, may come into contact with adults who neglect themselves and/or their property and possessions. This includes adults who are affected by Hoarding Disorder, and other chronic conditions that result in excessive clutter or disorganisation.

Often the staff this guidance has been designed for will have come into contact with the adult because they are providing support (e.g. Health and Social Care or Third Sector staff) or a service (e.g. Housing etc) and the self-neglect or hoarding issue may only come to light as a result of their involvement with the adult in relation to other issues. Education & Children's Services staff may come into contact with the adult because there are children in the household.

All staff should remember that an adult's self-neglect and hoarding behaviour may mean that a child or another vulnerable adult is at risk of harm or neglect.

This guidance is intended to provide a concise overview of what self-neglect and hoarding are and some of the issues that practitioners should take into account when supporting or providing a service to the people affected. It includes an escalation protocol to prompt consideration by a multi-agency panel where there are significant risks and concerns.

For those who are not directly working with those affected by Hoarding Disorder and other chronic conditions, this guidance will provide some information on how to identify hoarding issues and provide some helpful signposting information.

Section 1

What do we mean by Self-Neglect?

> The inability (intentional or non-intentional) to maintain a socially and culturally accepted standard of self-care with the potential for serious consequences to the health and well-being of the [adult] and perhaps even to their community.

S. Gibbons et al (2006) Self-Neglect: A proposed new NANDA diagnosis International Journal of Nursing Terminologies and Classifications 17(1)

Self-neglect can involve a failure to care for yourself or your property; or to seek, or accept, necessary care and support.

It may be associated with a mental health illness, learning disability or cognitive impairment which prevents the person from understanding the consequences of self-neglect.

Links have also been established between self-neglect and previous harm, trauma and bereavement, such as the loss of parents in childhood, child abuse, and wartime experiences. There are also complex links with problematic substance misuse, which is also often associated with earlier trauma. This means all partner agencies must apply a trauma-informed approach involving empathy and kindness whenever we come into contact with an adult who is experiencing self-neglect.

What do we mean by Hoarding Disorder?

> 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.
>
> Difficulty discarding possessions is characterised 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.

World Health Organisation (2022) International Classification of Diseases 11th Revision (ICD-11)

Prevalence and reasons for hoarding

We all have different standards and thresholds, often related to our own upbringing as well as to our circumstances at any given time. Although we might see a lot of clutter in the hall when we are at someone's front door, it may be just that, or a temporary measure, e.g. when another room is being decorated. It is more concerning when we can see the whole house is affected.

Not all clutter is linked to hoarding. A person who lives in a cluttered and chaotic home could be chronically disorganised as a result of a cognitive impairment. Alternatively, someone could be situationally disorganised – following a traumatic life event.

Hoarding is also different from collecting. Both activities involve acquiring items to which a person gives a special value that may go beyond the item's actual worth. Collectors tend to organise and display items carefully. They are usually proud of their items and like to talk about them or show them off. People who hoard, on the other hand, are often embarrassed about their living situation and may avoid inviting people into their homes. It is worth bearing in mind that a collector could also become a hoarder.

In most situations, hoarding is only problematic if it causes distress or creates a health or safety issue. Where this is the case, you should discuss your concerns with your line manager and consider making an Adult Support & Protection referral or Child Protection referral.

What are the signs of hoarding?

Someone who has a hoarding disorder may typically:

- Keep or collect items that may have little or no monetary value, such as junk mail and carrier bags, or items they intend to reuse or repair
- Buy new items and store these (sometimes unopened)

- Find it hard to categorise or organise items
- Have difficulties making decisions
- Become extremely attached to items, refusing to let anyone touch or borrow them
- Have poor relationships with family or friends
- Unable to use rooms for their intended purpose, i.e sleep in a bed, bathe, cook a meal.
- Social isolation can be high for people who hoard as is victimisation, often due to the impact that hoarding can have on neighbouring properties.

Hoarding can start as early as the teenage years and usually gets more noticeable with age. For many, hoarding become more problematic in older age, but the problem is usually well established long before then. It is thought that around one or two people in every 100 have a problem with hoarding that seriously affects their life.

The tools in Section 2 can help to identify signs of severe hoarding and self-neglect, and action that should be considered.

What kind of items may people hoard?

Some people with a hoarding disorder will hoard a range of items, whilst there may be a prevalence of one particular item, people who hoard will generally have an excess of several categories. Items that are often hoarded include:

- Books
- Clothes
- Newspapers and magazines
- Leaflets and letters, including junk mail
- Bills and receipts
- Containers, including plastic bags and cardboard boxes
- Household supplies
- Food
- Animals – this can be common amongst those who have experienced childhood trauma.
- Biohazard – the individual is unable to access the bathroom for its intended purpose.

More recently, hoarding of data has been identified as a common problem. This is where someone stores huge amounts of electronic data and emails that they are extremely reluctant to delete.

Why people hoard

This can be complex. Each case of hoarding disorder can be as unique as the individual it emanates from, no two cases are the same. It is normal for us to experience the desire to collect and keep items of importance to us. Evidence would suggest that people who hoard can often experience significant emotional attachment to objects and this makes these hard to part with this can be caused by Anthropomorphism, Genetic Vulnerability, Executive Function, Brain Injury and Dementia.

There is evidence of a ‘cognitive bias in some people who attribute beauty to objects that others do not (eg an old bottle cap, the cardboard inside of a toilet roll) and some people can become very anxious that they will need a certain item at a later date.

Often the reasons for this strong attachment can be complicated and are informed by someone’s past, their psychological make-up, their beliefs and attitudes.

Hoarding often runs in families and can frequently accompany other mental health disorders, like depression, social anxiety, bipolar disorder and impulse control problems. A majority of people with compulsive hoarding issues can identify another family member who has the problem. There may be several overlapping issues impacting on someone who has developed Hoarding Disorder.

When does hoarding become problematic?

First and foremost, in the beginning hoarding is not a problem it is a solution to an unresolved problem. It is important to recognise that while a number of difficulties can arise as a result of hoarding behaviours, the individual themselves may not consider this to be a problem and be “clutter blind”.

Often people will come to the attention of services due to concern raised by others (neighbours, family members) rather than approaching services for help directly. This is also the case with self-neglect in general. This is extremely important to recognise, as it underlies a number of barriers or

issues which can arise when working with people who experience Hoarding Disorder, including low motivation to change, resistance to help and support, and feelings of shame. Not knowing where to start, emotional attachment to items, impaired executive function also factor hugely. Understanding why the hoarding started is crucial.

Practical difficulties from having too many items and materials in their house can make it difficult for a person to actually move from room to room. This can detrimentally affect someone's personal hygiene, health and ability to engage with day-to-day activities. Often, as a result, their performance at work may suffer and interpersonal relationships can become strained.

The person hoarding is often reluctant or unable to have visitors or even allow tradespeople in to carry out essential repairs, which can cause isolation and loneliness, and increase risks within the home.

People who hoard often suffer emotionally as a result of these factors, but also because of the perceived stigma and shame they feel because of the condition of their living environment.

The clutter can pose a health and safety risk to the person and anyone who lives in or visits their house. It can raise specific concerns for partner agencies, such as:

- Impact on activities of daily living e.g. accessing the toilet, cooker etc.
- Fire risk: clutter can both increase the risk of fire in the home and the adult's ability to leave a building safely in the event of a fire. Additionally, in shared or flatted living arrangements the fire risk may extend to neighbours.
- Health and personal care: insanitary environments pose risks in terms of wound management, pressure sores related to sleeping on chairs because their bedroom is inaccessible, as well as a heightened risk of falls and difficulties with moving and handling.
- Structure and Safety e.g. structural implications due to the sheer weight of the hoard.

There can be other environmental impacts which go beyond the home. These can include odours, waste, vermin and other conditions which may cause a nuisance or public health risk for neighbouring households. In such situations, the Environmental Health Service must consider its

legislative responsibilities to address the impact on neighbours and the wider community.

A Local Authority or Social Landlord may also have a responsibility to other tenants living in the vicinity.

Supporting People who hoard

Not only can people who experience significant hoarding issues become very distressed at the thought of parting with items which they have been hoarding, they can understandably become distressed and upset about others seeing their clutter and being within their home environment therefore it is critical we:

- Use a trauma informed approach
- Understand why the hoarding started
- Give choice and control where possible
- Listen
- Work collaboratively
- Celebrate the smallest of victory's
- Remain consistent in support
- Communicate

All of these point can help the person who hoards feel less anxious or distressed.

Consequently, it is not uncommon for someone to be reluctant about seeking support, or to be defensive about the fact that their hoarding behaviours are problematic.

It's generally not a good idea to get extra storage space or call in an agency to provide a quick clean up. This won't solve the problem and the clutter often quickly builds up again. Research indicates that there is a 97% likelihood of hoarding recurring after an enforced "deep clean":

Someone may think they are helping by removing clutter or throwing items out on behalf of someone who hoards, but this is more likely to be perceived as a breach of trust if not an outright violation of their privacy and autonomy and could be potentially very damaging to the relationship. In one case, an adult described the removal of things from her home as

feeling like ***"somebody stripping you naked and standing you outside in the cold on your own"***[1]

Therapeutic Approaches

The main psychological therapy approach for difficulties with Hoarding is Cognitive Behavioural Therapy (CBT).

The therapist will help the person to understand the reasons why the clutter has built up and may explore, for example, why throwing things away is difficult, or why they have compulsively bought in the past. If desired, a systematic approach to reducing clutter is then taken.

It is important to note that ambivalence to change is very common. Often, the most effective way to support someone with hoarding behaviours is to work on developing a trusting relationship with them until they are motivated and ready. This means accepting that it may require time – quite a lot of time - to help support a change in behaviour and environment. Frequently, this support will be provided by someone who is not a 'mental health professional'. People who hoard report a great benefit from feeling understood and validated.

[1] Birmingham Adult Safeguarding Board, 2

Section 2

Supporting People in West Dunbartonshire

If you are going to be helping the person yourself, there are many useful resources available. We have highlighted the collection developed by the Social Care Institute of Excellence (SCIE) in this guidance.

If you are not going to be the person helping the individual who is hoarding, you may want to signpost the individual to an appropriate service. If you wish to discuss if and how another service may be able to support the individual, contact the West Dunbartonshire HSCP Single Point of Access duty system for adults or Children and Families Access Help and Support duty system for a supportive discussion. Service information and contact details are listed at the end of this guidance.

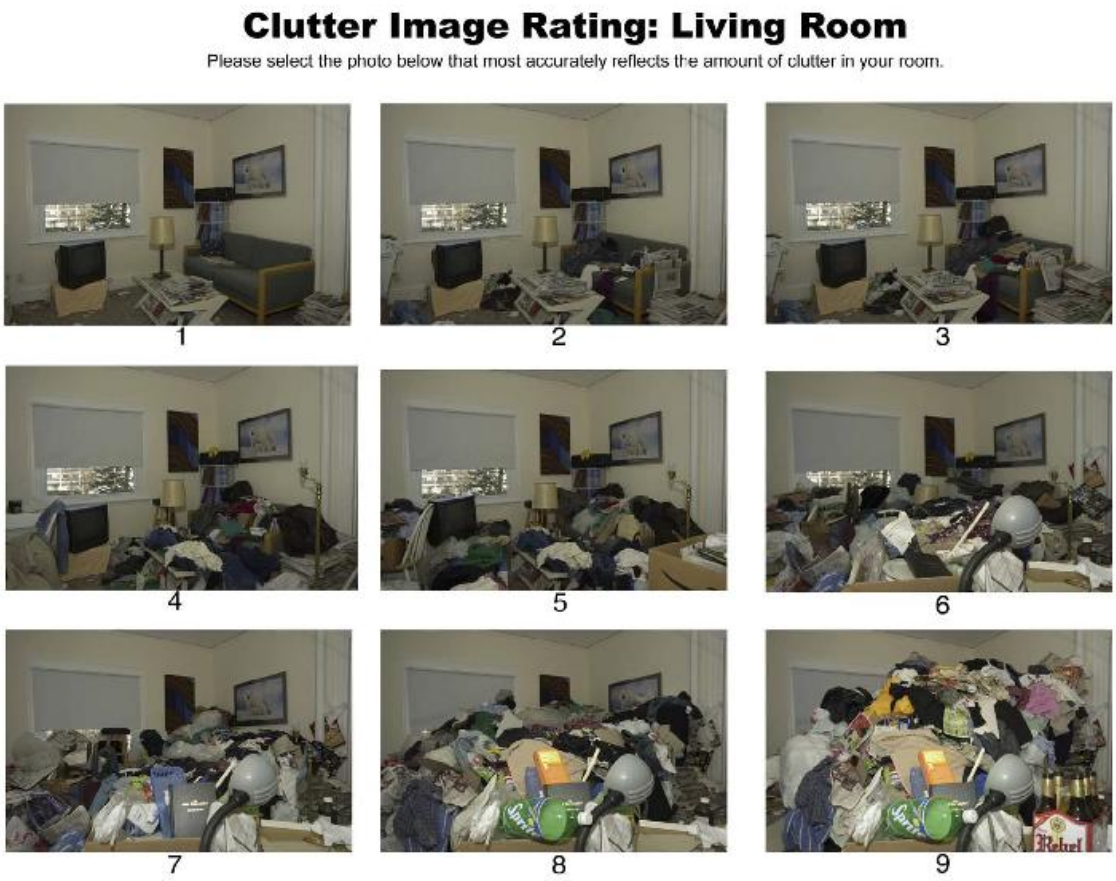
We have included a visual tool which will assist you firstly to assess how serious a hoarding issue is and secondly to decide when further action may be required. This is the **Clutter Image Rating Scale**.

Where you have wider and more significant concerns about the individual, the **Self-neglect Thresholds Framework** will assist you to assess the level of risk and decide if you need to use the **Self-Neglect Escalation Protocols.**

You should also consider if the adult, child or young person is at risk of harm and if you think this is the case, you must make an **Adult Support and Protection referral** to the West Dunbartonshire HSCP Single Point of Access duty system or Child Protection referral to the Access Help and Support duty system.

The Clutter Image Rating Scale[2]

The Clutter Scale has a series of images showing increasing levels of clutter within different areas of someone's home and aims to assist a common understanding about when hoarding becomes a significant concern.



In general, clutter that reaches the level of picture number 4 or higher has enough of an impact on people's lives that we would want to encourage them to seek support.

You can also find images which help rate clutter in a kitchen and bedroom in the full guide which is available at https://hoardingdisordersuk.org

[2] Frost RO, Steketee G, Tolin DF, Renaud S. Development and validation of the Clutter Image Rating. Journal of Psychopathology and Behavioral Assessment. 2008;32:401–417.

Social Care Institute for Excellence (SCIE): Self Neglect At-a-glance guidance

SCIE's guidance highlights that; "In the past we may have intervened in ways that prioritised the views and wishes of others, rather than trying to work from the perspective of the person who hoards. Research has shown that those who self-neglect may be deeply upset and even traumatised by interventions such as 'blitz' or 'deep cleaning'." The When developing an approach, it is important to try to understand the individual and what may be driving their behaviour. There are some general pointers for an effective approach: guidance summarises the features of a Best Practice approach utilising the key principles of a trauma informed approach and identifies key practical tasks.

Best Practice Approach

When considering an approach, it is important to try to understand the individual and what may be driving their behaviour. When did hoarding start? Here are some general pointers for an effective trauma informed approach.

- **Understand** how the hoarding behaviour started.
- **Multi-agency** – work with partners to ensure the right approach for each individual.
- **Person centred** – respect the views and the perspective of the individual, listen to them and work towards the outcomes they want
- **Acceptance** – good risk management may be the best achievable outcome, it may not be possible to change the person's lifestyle or behaviour
- **Non-judgemental** – it isnt helpful for practitioners to make judgements about cleanliness or lifestyle; everyone is different
- **Empathy** – it is difficult to empathise with behaviours we cannot understand, but it is helpful to try
- **Patience and time** – short interventions are unlikely to be successful, practitioners should be enabled to take a long-term approach
- **Trust** – try to build trust and agree small steps

- **Reassurance** – the person may fear losing control, it is important to allay such fears
- **Bargaining** – making agreements to achieve progress can be helpful but it is important that this approach remains respectful
- **Exploring alternatives** – fear of change may be an issue so explaining that there are alternative ways forward may encourage the person to engage
- **Always go back** – regular, encouraging engagement and gentle persistence may help with progress and risk management

Practical tasks

- **Risk assessment** – have effective, multi-agency approaches to assessing and monitoring risk
- **Consider capacity** – ensure staff are aware of capacity issues and what to do if there are concerns that a person lacks decision-making capacity
- **Alcohol & Drugs or Mental health assessment** – it may be appropriate to refer an individual for support to recover from alcohol or drug issues, or a mental health issue
- **Signpost** – with a multi-agency approach people can be signposted to effective sources of support
- **Contact family** – with the person's consent, try to engage family or friends to provide additional support
- **Decluttering and cleaning services** – Ideally this would be done with the lead practitioner or assigned worker familiar with the person who hoards, it is vital that the person who hoards feels in control.
- **Utilise local partners** – those who may be able to help include the SSPCA, the Scottish Fire and Rescue Service, West Dunbartonshire Council's Environmental Health service, the housing provider, third sector organisations
- **Occupational therapy assessment** – physical limitations that result in self-neglect can be addressed
- **Help with property management and repairs** – people may benefit from help to arrange much needed maintenance to their home

- **Peer support** – others who self-neglect may be able to assist with advice, understanding and insight
- **Counselling and therapies** – some individuals may be helped by counselling or other therapies. Cognitive Behaviour Therapy, for example

Assessing Risk and Thresholds for Intervention

The matrix below sets out different types and patterns of harmful behaviour in terms of the level of risk they pose to the service user, aligned to appropriate levels of reporting and response as a guide. As a general rule, incident types and patterns categorised as presenting a lower level of risk to service users can be dealt with on a single agency basis. Escalation through the West Dunbartonshire HSCP duty systems, case discussion at the Multi-Agency Forum, or an ASP or CP referral should be considered where the risks are higher – is that what we want to say.

Intervention	**Single Agency Response.** If risk rises to moderate level, consider escalation		**Serious risk of harm: Make ASP referral to HSCP Single Point of Access duty system**		**Very high risk of harm: Call Emergency services**
Level of Risk	Low	Moderate	Significant	Substantial	Critical
Self-harm & self-neglect	• Self-care causing some concern - no signs of harm or distress • Property neglected but all main services work • Some evidence of hoarding - no major impact on health/safety	• First signs of failing to engage with professionals • Property neglected • Evidence of hoarding (Clutter risk scale 4+) • Lack of essential amenities • No access to support	• Refusing medical treatment • High level of clutter/hoarding (Clutter risk scale 4-9) • Insanitary conditions in property • Won't engage with professionals • Problematic substance use • Weight reducing/increasing • Self-injury/poisoning on one occasion • Others affected by self-neglect re public health infection control advice	• Lack of self-care results in significant deterioration in health/wellbeing • Environment injurious to health • Behaviour poses risk to self/others • Others affected by self-harming or self-neglect • Chaotic substance use • Self neglect accompanied by suicidal ideation • Self-injury/poisoning requiring emergency treatment on one occasion • Multiple reports from other agencies	• Self-harm/neglect is life threatening • Environment injurious to health • Potential or Imminent fire risk/gas leaks • Critical public health infection concerns • Life in danger without intervention • Chaotic substance misuse • Repeat self-injury/self-poisoning accompanied by suicidal ideation • Access obstructed within property • Behaviour poses risk to self/others

Hoarding Escalation Protocol

1. The Hoarding Escalation protocol should be considered when the level of risk is assessed as moderate, but the person who hoards is not **at this stage** considered to be an adult at risk of harm.

2. The protocol can be triggered by staff of any agency. This includes where an individual has been referred under ASP or CP, but Social Work have decided that they are not an adult or child at risk of harm.

3. There must be evidence of public or environmental health risks in addition to any concerns about the person who hoards, to justify information-sharing without consent. The individual should be advised that advice will be sought from other agencies on these grounds.

4. The staff member who has assessed that the hoarding risks have increased should alert their line manager about their concerns. If it is agreed that their service cannot manage the risks on a single-agency basis, they should identify other agencies that may be able to support or provide services to the individual to reduce the risks.

5. It may be considered appropriate to convene a Case Conference to provide a forum for multi-agency discussion. In line with best practice, the person who hoards should be invited to participate and supported to do so should they wish to attend.

7. The Case Conference Chair will introduce the individual's case and invite the individual and other agencies to share any relevant information

8. Decisions to be made by the panel will include:

- If support and/or services are required
- Which agencies can offer the individual such support and/or services
- Inter-agency communication and liaison arrangements
- Any review timescales
- Any contingency measures required
- If information shared at the meeting suggests that an ASP or CP referral should be made.

9. The Chair will arrange for a note to be taken of the decisions and circulate this within seven days.

Self-Neglect Escalation Protocol

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3. There must be evidence of public or environmental health risks in addition to any concerns about the individual, to justify information-sharing without consent. The individual should be advised that advice will be sought from other agencies on these grounds.

4. The staff member who has assessed that the self-neglect risks have increased should alert their line manager about their concerns. If it is agreed that their service cannot manage the risks on a single-agency basis, they should identify other agencies that may be able to support or provide services to the individual to reduce the risks.

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Service Information and Contact Details

Adult Support and Protection

Clydebank 01389 811760

Dumbarton 01389 776499

Out of Hours 0300 343 1505

Access Help and Support Team (Concerns relating to Children)

0141 562 8800

Out of Hours 0300 343 1505