

Hoarding Protocol

2021



Summary

This interagency protocol has been developed co-produced by partners across Slough from health, mental health, housing, social care, fire, ambulance and environmental health services.

The aim of the protocol is to serve as a guide and toolkit for professionals and agencies so as to be more consistent in the way in which we jointly identify, assess and coordinate support and reduce risks that arise for adults with a hoarding disorder or exhibit hoarding-related behaviours.

Through development and use of the protocol we aim to:

- Fulfil our collective responsibility towards all adults in the community who are hoarding or displaying hoarding behaviours;
- Promote awareness of hoarding and how to respond;
- Support individuals and their advocates
- Provide a support network for agencies dealing with hoarding cases, coordinate an-interagency response where required and enable the sharing of best practice;
- Provide guidance on how to support people who are hoarding or display hoarding-related behaviours;
- Demonstrate and implement appropriate compliance with the statutory duties of cooperation and integration regarding adults who may have needs for care and support outlined within the Care Act 2014;
- Provide working tools for assessment, information gathering and processes relating to dealing with hoarding disorder;
- Provide a pathway for more effective and appropriate treatment and/or care and support plan for sufferers;
- Improve the effectiveness of integrated working between those involved to the benefit of the individual concerned, other residents and the different services involved;
- Avoid 'satellites' of information held by separate services and agencies

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Introduction

Between 2-5% of the population are estimated to have a hoarding disorder or manifest some elements of hoarding behaviours. By improving the way in which we respond and provide appropriate care and support to people who hoard, addressing both the cause and the impact of hoarding, we can bring greater benefits and improve longer term outcomes both for those who hoard and the professionals involved in their support.

Having a hoarding disorder is now recognised as a mental disorder in its own right meaning the potential options available for treatment have been significantly extended. Similarly avenues to the Court of Protection have been opened up as hoarding disorder may also be considered an impairment in or disturbance of the functioning of the mind of brain for the purpose of the Mental Capacity Act (2005, as amended).

Individual agencies can often face difficulties in trying to deal with cases of hoarding in isolation. This often falls to housing departments but other agencies such as the fire service, healthcare services, adult social care and environmental health can become involved. In some cases a lack of coordination between the various

agencies of people involved can mean that actions are much less effective than they could be. Through development and adoption of this protocol we want to coordinate our approach so that professionals and partner agencies do not work in isolation, bringing together partners as and where appropriate, particularly where hoarding becomes extreme and/or becomes a safeguarding matter.

In the vast majority of cases the person hoarding will not self-refer and therefore most cases come from either concerned families or neighbours, or via statutory services such as housing, fire and ambulance services or the police. A frequent challenge is the reluctance or refusal to engage with support, and in many cases the issues raised by severe cases require involvement of several agencies. It is therefore a key part of this protocol that we adopt a multi-agency approach to management of hoarding and jointly find ways to resolve and reduce risk in the most difficult and complex cases.

With thanks to Islington Council and all partners involved in creating this Hoarding Protocol.

Section A

Aims of the Protocol

- This protocol is for all professionals and partner agencies working within the borough of Slough including those in the health, mental health, housing, social care, fire, police and environmental health services. It is intended to assist them to plan, coordinate, assess, diagnose and treat and support adults who display symptoms of hoarding disorder or hoarding-related behaviours.

This protocol aims to:

- Introduce a standardised method for all partners to respond to hoarding and outline collective roles and responsibilities
- Generate awareness of how to respond to hoarding;
- Support individuals and their advocates
- Provide a support network for agencies dealing with hoarding cases and enable sharing of best practice;
- Provide guidance on how to deal with hoarding and those who may display hoarding-related behaviours;
- Provide working tools for assessment, information gathering and processes relating to dealing with hoarding disorder; as well as information on effective and appropriate treatment and/or care and support plan for sufferers;
- Acknowledge and develop the effectiveness of integrated working between partner agencies involved to the benefit of each individual, other residents and the different services involved;
- Avoid 'satellites' of information held by separate services and agencies; introduce the principle of information sharing and adopt a person centred approach to achieving the outcomes of the person who hoards.



Six Principles of Safeguarding

The protocol is based on the *Six Principles of Safeguarding* that underpin all adult safeguarding work.

Empowerment	Adults are encouraged to make their own decisions and are provided with support and information.	I am consulted about the outcomes I want from the safeguarding process and these directly inform what happens.
Prevention	Strategies are developed to prevent abuse and neglect that promotes resilience and self-determination.	I am provided with easily understood information about what abuse is, how to recognise the signs and what I can do to seek help
Proportionate	A proportionate and least intrusive response is made balanced with the level of risk.	I am confident that the professionals will work in my interest and only get involved as much as needed.
Protection	Adults are offered ways to protect themselves, and there is a co-ordinated response to adult safeguarding.	I am provided with help and support to report abuse. I am supported to take part in the safeguarding process to the extent to which I want and to which I am able.
Partnerships	Local solutions through services working together within their communities.	I am confident that information will be appropriately shared in a way that takes into account its personal and sensitive nature. I am confident that agencies will work together to find the most effective responses for my own situation.
Accountable	Accountability and transparency in delivering a safeguarding response.	I am clear about the roles and responsibilities of all those involved in the solution to the problem.

Section B

Definition of hoarding

Hoarding disorder was added to the ICD-11 (International Classification of Diseases - 11th Revision) in 2018. The 11th edition of the ICD states that "hoarding disorder is characterised by accumulation of possessions due to excessive acquisition of or difficulty discarding possessions, regardless of their actual value".

People who hoard may also self neglect as they are unable to access facilities but it is recognised that self neglect is not a concern for all those that hoard.

People who hoard experience distress or difficulty living in their environment because of the following:

- Acquiring possessions
- Restricted use of living spaces because they are so full of objects
- Getting rid of possessions causes distress or is simply not possible, even when they no longer seem to be needed, are no longer useful or are causing real problems because of taking up too much space.

Hoarding disorder is not the same as Diogenes syndrome which is a behavioural disorder of the elderly, features of which include extreme self-neglect, domestic squalor, and tendency to hoard excessively (sylllogomania). This is associated with self-imposed isolation, refusal of help, and a marked indifference or lack of awareness.

Diogenes syndrome has been referred to as senile breakdown, social breakdown, senile squalor syndrome, and messy house syndrome.

The difference between OCD and hoarding disorder may be described as follows:

OCD: There is an anxiety - the act (usually a repetitive action) is done - the effect is to reduce the anxiety. The emphasis is on reduction of a feeling.

Hoarding Disorder: There is a value placed on an item/items - the act (usually accumulation) is done - the effect is that the items become difficult to discard. The emphasis is on increasing accumulation of items.

(Sophie Holmes, 2016)

How is hoarding different from collecting?

There are some significant differences between people who identify as a 'collector' and those who have a hoarding problem. People who collect are more likely to share their interest with others. They tend to trade items, swap, use online market places and attend specialist fairs to acquire the 'missing' item from their collection. In contrast, people who hoard are much less likely to share their interest with others. Another significant difference is in the ability to organise possessions in and around the home. People who collect organise, clean and catalogue their things. They tend to be quite methodical in looking after their belongings. In contrast, people who have difficulties with hoarding are unlikely to be organised about sorting and cataloguing. People who hoard find it hard to solve the issue of clutter and tend to procrastinate about making a start. When they do make a start, they may lose momentum quickly when faced with the scale of the task.

Understanding hoarding

We all have a personal way of valuing our possessions, whether because of:

- **Intrinsic value** - valuable in and of itself, such as precious stones or foreign currency
- **Instrumental value** - valuable because of a future use, such as old car parts which can be used to repair other cars
- **Sentimental value** - valuable because it is associated with feelings and personal memories, such as old photos or diaries.

In addition to this, there are cultural beliefs and social norms which contribute to how we treat our possessions. For instance, in some cultures owning possessions is a sign of wealth and status; and in some societies, there is a focus on re-using things and not wasting.

When people have problems with hoarding, this relationship we all have with possessions shifts and becomes a problem.

There is no one cause for hoarding, but research suggests that it is thought that its origins can begin in childhood but tend to most severely interfere with the individual's life in their mid-30s and then worsen as they get older. Hoarders may harbour distorted beliefs in the importance of their possessions or their responsibilities towards them, with excessive emotional attachment. They may also demonstrate or suffer from information processing deficits such as indecisiveness, perfectionism, procrastination and/or disorganisation.

Sufferers may be unable to cope with distress and thereby avoid it by accumulating clutter and end up disabled because of it.

It is not uncommon for there to have been a triggering traumatic event in the hoarder's life after which point they started hoarding, such as bereavement, a loss or some personal trauma experienced.

Refusal by hoarders to engage with professionals or other intervention poses a challenge to progress. Good professional practice would explore all remaining avenues for the individual to engage. This is because being met with a "shut door" is in the nature of the disorder or hoarding behaviour. It is worth remembering that non-engagement is not exclusive to those suffering from hoarding disorder. It should be treated within the same practical, professional and legal framework as someone who suffers from any other condition or disorder (for example, Alzheimer's disease, schizophrenia etc).

Mental Capacity and Hoarding

When a person's hoarding behaviour poses a serious risk to their health and safety, professional intervention will be required. With the exception of statutory legal requirements, any intervention or action proposed must be with the person's consent.

The Mental Capacity Act 2005 provides a statutory framework for people who may lack capacity to make their own decisions.

Working with a person who hoards is likely to raise issues of whether the person lacks mental capacity to make particular decisions. This may particularly be the case when the person is reluctant or refusing to accept help for their hoarding, and practitioners may question whether the person has the capacity to refuse.

The first three principles of the Mental Capacity Act 2005, set out in section 1 of the act, support people's right to make decisions where they have the capacity to do so:

- A person must be assumed to have capacity unless it is established that he lacks capacity.
- A person is not to be treated as unable to make a decision unless all practicable steps to help him have been taken without success.
- A person is not to be treated as unable to make a decision merely because he makes an unwise decision.

The third principle is perhaps particularly relevant to working with a person who hoards.

Section 2(3) of the act also makes clear that a person's lack of capacity cannot be established simply by "an aspect of his behaviour, which might lead others to make unjustified assumptions about his capacity".

However, the Mental Capacity Act code of practice 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" (4.35, MCA code of practice, p52). Arguably, extreme hoarding behaviour meets this criteria and an assessment of capacity should take place.

Under section 2 of the MCA, a person lacks capacity to make a decision if they are unable to make the decision at the material time because of an impairment or disturbance in the functioning of the mind or brain. As set out above, this is likely to apply to a person who hoards because it is often a symptom of a mental health condition or can be seen as a disorder in its own right.

Under section 3, a person is unable to make a decision if they are unable to:

- Understand the information relevant to the decision.
- Retain that information.
- Use or weigh that information as part of the process of making the decision.
- Communicate their decision, whether by talking, using sign language or other means.

In cases of extreme hoarding behaviour, the very nature of the person's environment must mean that professionals question whether the person has capacity to consent to their proposed action/intervention, and this should therefore trigger a capacity assessment.

Any mental capacity assessment carried out in relation to hoarding behaviour must be time specific, and relate to a specific intervention/action, in line with the Act. This may include decisions about where a person should live, their tenancy agreement, care provision, healthcare or more generally accepting support for their hoarding.

The professional responsible for undertaking the capacity assessment will be the person who is proposing the specific intervention/action, and this person is referred to as the 'decision-maker'. Although capacity assessments sometimes require input from other people and professionals, it is the responsibility of the decision maker to coordinate and 'own' the capacity assessment overall.

Where the person is subject to multi-disciplinary care, the professional with greatest responsibility for the specific decision is likely to be the decision maker and should ideally assess capacity. Where this is in doubt agreement should be sought within the multidisciplinary team. If it is evidenced that a specialist capacity assessment (such as by a psychologist) is needed, and which is being relied on for this decision, the decision-maker must be satisfied that this assessment is fit for purpose. Due to the complexity of such cases, there must be a 'best interests meeting' with relevant professionals to oversee the process. The decision-maker is responsible for making the final decision about the person's capacity.

If after assessing mental capacity it is found that the person does lack capacity to consent to the specific action/intervention, then the decision-maker must be able to demonstrate that they have met the requirements of the 'best-interests checklist' and that a formal mental capacity assessment has been undertaken which demonstrates that the person lacks capacity to make an informed decision.

The mental capacity assessment would be in addition to the Comprehensive Risk assessment.

In particularly challenging and complex cases, it may be necessary to refer to the Court of Protection to make the 'best interests' decision. The new Court of Protection was set up under the Mental Capacity Act 2005. It can make decisions on whether people have capacity in relation to particular decisions, make decisions on their behalf, appoint or remove people who make decisions on people's behalf.

For very specific cases, where an adult has mental capacity but continues to place themselves at risk and is not engaging with services, you should refer to the Multi-Agency Risk Assessment.

The Multi-Agency Risk Assessment must only to be used where the adult:

- has the mental capacity to understand the risks posed to them
- continues to place themselves at risk of serious harm or death
- refuses or is unable to engage with necessary care and support services.

Section C

Recognising hoarding

A household can start to resemble an obstacle course, full of trip hazards. It can become impossible to keep the place clean; infestations can follow. A tower of hoarded items can topple over and cause injury. The hoard can grow so large that it causes structural damage, increases fire risk, and, in the event of an emergency, responders might not be able to access parts of the residence. (Burki, 2018)

The most commonly hoarded items are old clothes, magazines, CDs/video tapes, letters, pens, old notes, bills, newspapers, receipts, cardboard boxes, pins, clothing rags, old medication, bodily products (hair, nails, faeces etc), used nappies, rotten food, animals (dead and alive), wool or fabric. (htt1)

(www.hoardinguk.org/about/hoarding/)

Please refer to appendix B, the clutter scale to categorise the different scales of hoarding. This will enable professionals to have a shared language and introduce a standardised way of recognising hoarding.

Interventions to support people who hoard

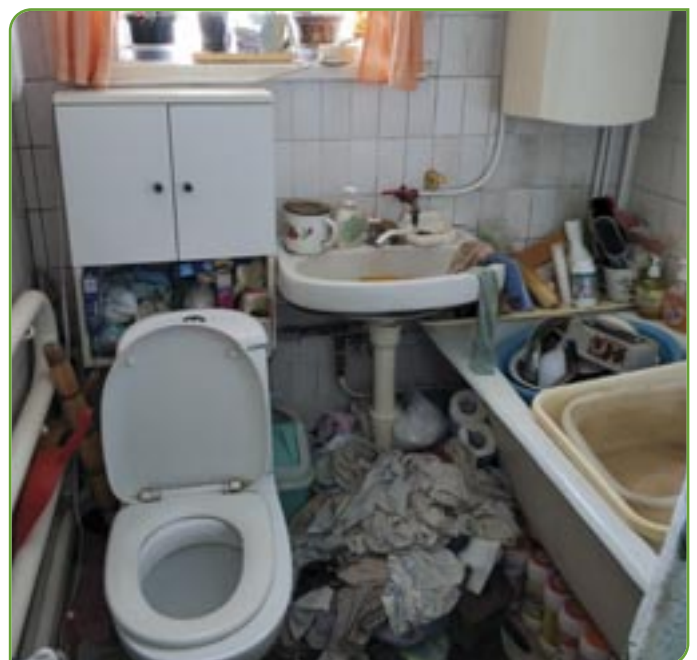
Blitz Cleans: one of the most popular responses to hoarding is to perform a “blitz clean” - the clearing out all or most of the offending items. Blitz cleans often feature repeatedly in the individual’s case notes or history. Whilst there may sometimes be a need for a blitz clean to deal with environmental health or fire safety concerns it more often only serves the person or agency that is concerned or complaining about the hoarding rather than offering a long-term solution for the hoarding sufferer. Blitz cleans are likely to significantly distress the hoarder and is a costly action to take. It does not address the cause of the hoarding behaviour and may exacerbate their symptoms. Without a longer-term solution such as hoarding specific cognitive-behaviour therapy (CBT) and/or other professional intervention the individual could well resume their hoarding activities.

Housing Providers and Environmental Health

Departments: Housing providers (including the local authority and housing associations) and environmental health departments are often the first to receive complaints or concerns and will often face a clash of responsibilities between their tenants and seeking to ensure that a potentially vulnerable adult receives appropriate care and support.

Without appropriate intervention and support by relevant agencies housing providers’ only other option will be to initiate proceedings in the county court for possession of the property, an access injunction or other action to assert their rights as landlords under housing or antisocial behaviour legislation. This could see an individual involved in legal proceedings when it may not be the most effective route for their personal progression through their manifesting condition.

Mental Health Services: those who display hoarding behaviours or who suffer from hoarding disorder are more likely to be dealt with by Mental Health Services if hoarding disorder is a recognised severe and enduring mental illness. This service will often be the key liaison and conduit between the social services and clinicians involved with the individual concerned.



Working with a clinical psychologist

Talking to a clinical psychologist can be really helpful in working out ways to deal with hoarding difficulties. They are trained in a range of therapy approaches including cognitive-behaviour therapy (CBT). There is some research showing that CBT can be helpful for hoarding difficulties. CBT is a collaborative non-judgemental therapy that pays attention to negative automatic thoughts (NATs), and behaviours that are driving the problem. Taking part in this kind of therapy is hard work and will involve doing work between sessions, as well as trying out new ways of doing things. Not only are clinical psychologists trained in CBT but they can also provide information and support in dealing with other agencies, such as your landlord or social worker.

The first port of call for getting this kind of help would be through the person's GP, who will be able to give advice about accessing NHS services. The use of the hoarding ice breaker form (<https://hoardingicebreakerform.org/>) may be a helpful tool to support communication between the person who is hoarding and the GP.

Suggestions to encourage and support people that hoard

Support the person to make the decision to do something about it. The following suggestions to the person that is hoarding may help

- Enlist help
- Put a stop to 'acquiring' things first.
- Practice disposing or 'setting free'.
- Make some decisions: It may be helpful for them to ask the following questions - *Do you have enough time to review/use/read? Would you buy it again if you didn't already own it?*
- Have a time limit for making decisions and stick with it
- Do small jobs daily.
- Choose one place to work on and stick with it.

- If they find themselves becoming anxious, suggest they take a break: physical exercise may help, or doing relaxation exercises.
- Celebrate successes and let go of setbacks.

Suggestions when working with a person that hoards

Firstly establish whether the person does appear to be displaying hoarding related behaviours or suffering from hoarding disorder and that they are not just exercising their right to collect items or express different lifestyles and habits. Some things to look for:

- Are rooms in their property (bathroom, toilet, bedroom, kitchen) not used or unusable for the purposes to which they have been designed, because of an excess of clutter?
- Can appliances and furniture (cooker, fridge, settee, chairs etc) be used?
- Are they unable to freely open their front or back door?
- Are all plug sockets and pipes hidden from view or trapped in by possessions?
- Are rooms packed with items to such an extent that it could pose a fire, health or safety hazard?
- Is their mobility around the property or otherwise limited by the amount of items?
- Do the items pose any environmental or other health and safety related obstacle/issue?
- Is there evidence of a pest infestation or are there accumulations of waste food?

Assess the level of the hoarding by using the CIRS (clutter image rating scale) for each room. See Appendix B.

If it is 1-3 have a conversation with the person to consider the impact and risks. Consider a self funding cleaner, or routine for cleaning. Consider the community and voluntary sector to provide support.

If the person has a scale of 4-6 a hoarding assessment tool should be completed. See Appendix C.

Safeguarding considerations

If children reside in the affected household, Children's Services/Slough Children First must be contacted.

Where there is a concern that the individual or another adult within the household is either vulnerable or may have care and support needs due to a physical or mental disability a referral should be made to Adult Social Care Safeguarding Procedures. Adult Social Care will work with the person to assess their needs and where appropriate lead a Safeguarding Enquiry to enable the person to achieve their safeguarding outcomes with the support of partner agencies.

Tenancy conditions enforcement

Consider whether the problem can be resolved purely by taking steps to ensure that the resident complies with their conditions of tenancy or lease or whether the resident needs some assistance to try to deal with the hoarding behaviours in issue (for example because they are elderly or appear to be vulnerable.)

It may be possible to obtain an injunction to remedy and prevent further incidents of hoarding but in the most extreme cases, where all other ways of resolving the problem have failed it may be necessary to commence possession proceedings.

Possession proceedings are unlikely to be helpful where a person does display hoarding related behaviours because:

- there are likely to be mental capacity issues which may impact their ability to understand or participate in proceedings, or
- the individual may be breaching their tenancy because of a potential mental illness rather than for cooperation reasons.

The result would be counter-productive as it may lead to just "moving the problem around" as opposed to resolving the issue. Relying on strict contractual or tenancy rights should only be considered once this protocol has been exhausted and there are no capacity issues relating to the individual.

Anti-social behaviour enforcement

It is possible, if complaints have been received from neighbouring properties that the hoarding-related behaviours could be classed as antisocial behaviour, in which case proceedings can be brought against an individual in this manner. A thorough assessment as to whether the individual manifesting the hoarding-related behaviour is vulnerable should be made before any action is considered. Persons demonstrating hoarder-related behaviours or who suffer from hoarding disorder are likely to consider that their behaviour is not problematic or irrational, so it may be counter-productive to argue the case with them on the basis of what is normal, rational or acceptable. However, it may be possible to lead the person to understand that their hoarding is having a detrimental effect on others. Informal action should be taken first, usually a letter confirming the steps that need to be taken. This may be followed by formal action if necessary. However, this must be done with the involvement of any support officer such as a social worker or personal assistant.

Care and Support

A local authority has a duty to conduct a Needs Assessment where it appears that they may have needs for care and support. The duty is likely to be triggered in such circumstances and social services would need to be notified so they can commence a Needs Assessment under the Care Act 2014.

Arranging for the removal of hoarded material

(This section needs to be read in conjunction with paragraph Blitz Cleans above)

In cases where the resident is not vulnerable and the only reason for mass accumulation of items is because the resident concerned has not made proper arrangements to dispose of large amounts of material or an accumulation of bulky items, you should aim to come to an agreement with the resident concerned to dispose of the items and prevent a repeat of the activity.

Consider staggered time frames for clearance; i.e. over a period of 6 or 12 months, agreeing a small area to be cleared each month and re-visiting to ensure compliance.

In all cases you should carry out a health and safety risk assessment of the property and consider employing specialist contractors where appropriate.

Cleaning the property

(This section is also to be read in conjunction with Blitz Cleans above)

It may be appropriate for a 'special cleanse' of the property to be arranged. Again, consider a staggered cleanse if possible.

A "one-off" cleanse or the removal of a couple of bulky items will not offer a solution to the potential or actual hoarding problem, either because of the nature of the hoarding related behaviours, the need for a more general clean-up of the property or the continued vulnerability of the resident concerned. In these cases it will be necessary to seek assistance from other sources.

Pest Control Services

You may encounter situations where, in addition to the hoarding, there are infestation problems such as rats, mice, cockroaches, ants, bed bugs, beetles, or wasps. The council's pest control service provides a chargeable service to all council residents (regardless of tenure). The service is heavily subsidised and there is a reduced rate for those on benefits or receiving pension. However in hoarding cases, to ensure that infestations are dealt with promptly and that preventative action is taken immediately to prevent further infestation, the charge to individual residents may be initially covered by the council. This is more likely to be where the enforcement team have needed to serve a notice on the occupier for an infestation. The money can then be re-claimed at a later date. This is of particular importance where the infestation has or is likely to spread to neighbouring properties.

Where the individual dwelling infestation is of fleas, this problem is deemed to be the responsibility of the occupier. If the council's pest control service undertakes the works the normal practice would be to recover the cost direct from the occupier. However, the service can use its discretion about whether to recharge the resident concerned in cases of hardship or vulnerability. It may also be advisable to carry out treatment to prevent other people from being infested.

The council's contracted pest control services, SDK (Dial-a-Pest) may be contacted on 03444 828 322.

Fire safety

Referrals are to be made to RBFRS in cases where people who hoard would benefit from a visit from the RBFRS. safeandwelleasthub@rbfrs.co.uk. This visit can enable the fire service to agree an evacuation plan and route. The fire service can give advice on preventative measures to ensure the safety of the person(s) in the property as well as the firefighters.

A Safe and Well Visit would be beneficial for the occupant i.e. they are vulnerable or at risk of fire for example hoarding. The Safe and Well provision also forms part of the Pan Berkshire Adult safeguarding Policy and Procedures and can be found on the following link www.berkshiresafeguardingadults.co.uk/

In cases where there is hoarding the address and the clutter scale level should be emailed to RBFRS using the following email address - safeandwelleasthub@rbfrs.co.uk

RBFRS can also provide training to organisations as part of their 'Adults at Risk Programme.

Section D

Duties for supporting people with hoarding

Safeguarding

The Care Act 2014, which requires local authorities to protect adults in their areas where they have reasonable cause to suspect that, an adult in its area (whether or not ordinarily resident there):

- a. Has needs for care and support (whether or not the authority is meeting 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 him/herself against the abuse or neglect or the risk of it.

Where staff identify that a resident is at risk from hoarding they have a duty to refer the situation to Adult Social Care, either directly or using their organisations Safeguarding Adults Procedure. Local authorities have a duty to make or cause to be made whatever enquiries they think necessary to enable the local authority to decide whether any action should be taken in the adult's case, and if so by whom. Greater detail about these procedures and requirements can be found in the Berkshire Safeguarding Policies and Procedures at www.berkshiresafeguardingadults.co.uk/

This protocol supports all agencies Safeguarding duties under the Care Act 2014. This protocol is intended to facilitate and enable more effective cooperation between relevant agencies at the initial stages of identifying, assessing, planning for, supporting and treating those who display hoarding related behaviours and/or are diagnosed with hoarding disorder.

Multi Agency Risk Tool

In some complex cases where a number of partner agencies are involved a partnership approach can be initiated via the Multi Agency Risk Tool Process. The lead organisation will organise this meeting.

For information on accessing training please see the Slough Safeguarding Partnership website [here](#)

Health

Where an individual who has hoarding behaviour is unwell or injured medical attention should be called by the staff member at the scene. This may be by contacting the individuals GP surgery or in an emergency an Ambulance should be called.

If the person declines essential medical services, medical practitioners will make the assessment under the Mental Capacity Act to make a decision on how to proceed.

Information sharing

The Berkshire Safeguarding Information sharing protocol can be found here www.berkshiresafeguardingadults.co.uk/slough/procedures/?proclid=1451

Principles of partnership working

The aim of this protocol is to ensure that agencies feel able to manage hoarding cases independently in the first instance and then have avenues to explore.

Appendix A: Hoarding Ice Breaker



www.hoardingicebreakerform.org

HOARDING, CLUTTER & DISORGANISATION Ice-Breaker Form

Empowering people whose health has been adversely affected by **clutter, disorganisation, compulsive acquiring/shopping** or **hoarding** to start a conversation with their GP or other medical professional, and get professional help and support

Dear Medical Professional

PLEASE HELP ME - I have a problem which is affecting my health

**I think I have / I live with / I know someone who has a problem with
hoarding / clutter / decluttering / compulsive shopping/acquiring**

(delete as applicable)

I/my family member/my friend have *(tick all the boxes that apply):*

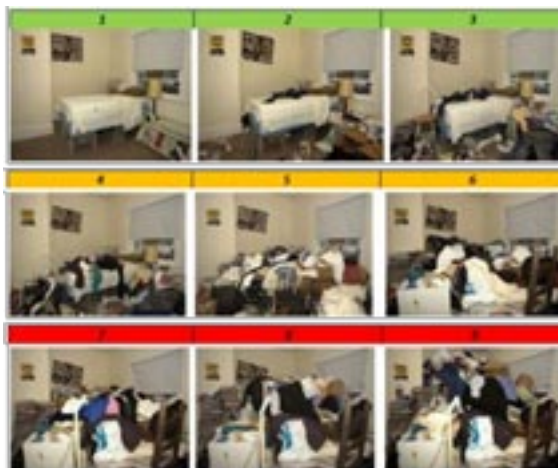
- A difficulty stopping acquiring things and accumulating them at my home
- Persistent difficulty discarding or parting with personal possessions
- Strong urges to save items
- A large number of possessions that fill up the active living areas of the home, workspace or other personal surroundings, and prevent normal use of the space (eg. can't use the toilet or kitchen; can't access the boiler or radiators; no heating/lighting, etc).
- Safety dangers in the home caused by too many belongings or faulty equipment (eg. slip/trip/fall hazards and/or fire risks)
- Become overwhelmed and find making progress to reduce the problem very difficult
- Severe difficulty with things like prioritising, planning, time-keeping, organising paperwork or paying bills regularly

The most cluttered area of my/their home is rated _____ on the **Clutter Image Rating Scale** (it can be any room or outside space, not just a bedroom, as shown here).

I'm now at the stage at which I need to appeal to you, as a professional, to help me/them.

- I/we feel unwell because of this situation
- It's hard for me/them to talk about this
- I/they feel alone and need support
- Other people don't seem to understand
- I/they feel distressed, and/or indecisive about what to do to make things better
- I've/They've become secretive/ withdrawn about this situation

CLUTTER IMAGE RATING SCALE (bedroom)



I/they feel anxious and/or depressed because: (tick all that apply):

- I/they worry about my/their safety/wellbeing/risk of abuse
- My/their self-confidence/self-esteem is very low
- I/they feel very uncomfortable about/reluctant to change
- It can be hard for me/them to live normally/work/study/travel/pay bills/make or keep friendships and relationships
- I/they have been notified by the Local Authority/my Landlord/other agency that action will be taken if I/they don't do something soon (explain which agency - eg. bank, landlord, Environmental Health, Family Liaison, boss, etc)
- Family/friends/neighbours have taken (or have threatened to take) matters into their own hands
- I/they don't feel I/they have anyone to talk to who would actively listen empathetically and/or non-judgementally to my/their concerns
- I feel out of my depth with my knowledge of how to help and/or support my relative/ friend/colleague, or myself



Please talk me through the types of help and support that could empower me to feel better

INFORMATION FOR MEDICAL PROFESSIONALS

- In 2018 the **World Health Organisation (WHO)** classified **Hoarding Disorder** as a **mental illness**, and it has included it in **ICD-11**.
- Managing hoarding behaviours and clutter-related issues requires a **person-centred, collaborative and integrated approach** between agencies.
- **The Care Act 2014** recognises hoarding behaviours as one of the manifestations of **self-neglect**, and requires all public bodies to **safeguard** people at risk.
- For information and guidance about **hoarding protocols**, refer to your local **Hoarding (and Self-Neglect) Protocol, Guidelines or Safeguarding Policies**.
- **Local agencies** (such as Social Workers; the Fire & Rescue Service; Environmental Health Officers and Professional Hoarding Practitioners) should be familiar with the **Clutter Image Rating Scale**.
- Not everyone who owns lots of possessions exhibits hoarding behaviours.
- A **combination** of factors can result in hoarding behaviours or accumulating lots of possessions. Examples include **life events** (eg. bereavement); **traumas** (eg. Adverse Childhood Experiences - **ACES**); **mental health issues** (eg. Anxiety; Depression; PTSD; OCD; Dementia); **neurological conditions** (eg. ADHD; Autism; Dyslexia; Dyspraxia; Chronic Fatigue Syndrome/ ME); conditions related to **frontal lobe impairments** (eg. Acquired Brain Injury - ABI), and, anything likely to affect **Executive Functioning. Executive Dysfunction/ Dysregulation** can inhibit a person's ability to plan; organise; prioritise; start/finish tasks; make decisions; be flexible with their thinking; remember things; control their impulses; self-monitor; and regulate their emotions.
- Living in a **chronically disorganised** home can be as overwhelming, incapacitating and disabling as living in a hoarded home, and **there may still be safety or self-neglect issues**.

Resources

Insightful book

"**Understanding Hoarding**" – by Jo Cooke of **Hoarding Disorders UK CIC** (Sheldon Press) ISBN 978-1847094537

GP leaflet about hoarding

<http://hoardingawarenessweek.org.uk/resources/>
 "A **Psychological Perspective on Hoarding**" – Sophie Holmes (**The British Psychological Society** 2015)
https://www1.bps.org.uk/system/files/Public%20files/a_psychological_perspective_on_hoarding.pdf
Hoarding Support Groups – HoardingUK (charity)
<https://hoardinguk.org/support/support-groups/>

www.hoardingicebreakerform.org

@HoardingIcebreakerForm @HoardingIce

Like and follow the Hoarding Ice-Breaker Form on **Facebook** and **Twitter**, and download it from the website, **Facebook** or these websites.



Appendix B: Clutter rating scale

Clutter Image Rating Scale: Kitchen

Please select the photo below that most accurately reflects the amount of clutter in your room.



1



2



3



4



5



6



7



8



9

Clutter Image Rating Scale: Bedroom

Please select the photo below that most accurately reflects the amount of clutter in your room.



1



2



3



4



5



6



7



8



9

Clutter Image Rating Scale: Living Room

Please select the photo below that most accurately reflects the amount of clutter in your room.



Appendix C: Slough Hoarding Assessment Tool

Date of assessment:	
Assessed by:	
Organisation:	
Department:	

Client information	
Name:	Age:
Consent obtained: Yes <input type="checkbox"/> No <input type="checkbox"/>	Reason if consent is not obtained
Address:	Telephone:
Other residents living in the property:	

Property details	
Occupation status: Owner <input type="checkbox"/> Tenant <input type="checkbox"/>	Landlord organisation:
Landlord contact name:	Landlord contact details:
Flat <input type="checkbox"/> Maisonette <input type="checkbox"/> House <input type="checkbox"/> Sheltered Accommodation <input type="checkbox"/>	
Other:	
On what floor is the front door?	On what floor is the bathroom?
On what floor is the toilet?	How many steps to the front door?
How many steps in the property?	How many rooms (excluding kitchen and bathroom)?

Hoarding		
Brief description of the problem		
What is the client's attitude to the hoarding?		
Will she/he allow access?		
Clutter index rating (1 to 9)		
Kitchen	Living Room	Bathroom
Bedroom 1	Bedroom 2	Bedroom 3
Other rooms		

Fixtures and appliances							
Please indicate whether the following are in working order							
	Yes	No	Unknown		Yes	No	Unknown
Stove/Oven				Fridge/Freezer			
Kitchen sink				Bathroom sink			
Washer/Dryer				Toilet			
Electricity				Water Heater			
Boiler/Heating				Shower/Bath			

Living conditions				
	None	Some	Severe	Comments
Structural damage to house				
Rotten food in house				
Insect or rodent infestation in house				
Large number of animals in house				
Animal waste in house				
Clutter outside of the house				
Cleanliness of the house				
Other (e.g. human faeces)				

Safety				
	Not at all	Some	Very much	Description
Does any part of the house pose a fire hazard? (e.g. unsafe electrical cords, flammable object next to heat sources like boiler, radiator, stove)				
How difficult would it be for emergency personnel to move equipment through the home?				
Are the exits from the home blocked?				
Are any of the stairwells unsafe?				
Is there a danger of falling due to the clutter?				

Daily Living					
Please indicate the extent to which clutter interferes with the ability of the client to do each of the following activities					
	N/A	Can do	Can do with difficulty	Unable to do	Comments
Prepare food (cut up food, cook it)					
Use refrigerator					
Use stove					
Use kitchen sink					
Eat at table					
Move around inside the house					
Exit home quickly					
Use toilet (getting to toilet quickly)					
Use bath/shower					
Use bathroom sink					
Answer door quickly					
Sit in your sofa and chairs					
Sleep in your bed					
Clean the house					
Do laundry					
Find important things (e.g. bills)					
Care for animals					

Preliminary client assessment
Mental health issues
Dementia
Mental capacity
Frail/elderly
Disability
Other factors
Family and other social support
Financial situation, ability/willingness to pay for services

Hoarding interview			
1. Because of the clutter or number of possessions, how difficult is it for you to use the rooms in your home?			
Not at all <input type="checkbox"/>	Mildly <input type="checkbox"/>	Moderately <input type="checkbox"/>	Extremely <input type="checkbox"/>
2. To what extent do you have difficulty discarding (or recycling, selling, giving away ordinary things that other people would get rid of)?			
Not difficulty <input type="checkbox"/>	Mild <input type="checkbox"/>	Moderate <input type="checkbox"/>	Extreme <input type="checkbox"/>
3. To what extent do you currently have a problem with collecting free things or buying more things than you need or can use or can afford			
No problem <input type="checkbox"/>	Mild problem <input type="checkbox"/>	Moderate problem <input type="checkbox"/>	Extreme problem <input type="checkbox"/>
4. To what extent do you experience distress because of clutter, difficulty discarding or problems with buying or acquiring things			
No distress <input type="checkbox"/>	Mild distress <input type="checkbox"/>	Moderate distress <input type="checkbox"/>	Severe distress <input type="checkbox"/>
5. To what extent does the clutter, problems discarding, or problems with buying or acquiring things impair or interfere with your life (daily routine, job/school, social activities, families activities, financial difficulties)?			
Not at all <input type="checkbox"/>	Mildly <input type="checkbox"/>	Moderately <input type="checkbox"/>	Extremely <input type="checkbox"/>

Other agencies to be used

Conclusion/recommendations

Appendix D

Multi Agency Risk Tool

- Below, you will find the YouTube link to a video regarding the Slough Multi agency Risk Framework and tool for adults who do not access services. The video is for all staff across all agencies who work with people who refuse/do not access support, even when offered.

https://youtu.be/CVm_S3FeK4Q

This video has been produced as a substitute for the training sessions that have been cancelled due to Covid-19. It is less than 15 minutes and is intended as an introduction to the tool and framework. The framework and tool can be accessed from the safeguarding Partnership:

www.sloughsafeguardingpartnership.org.uk/sasp/sasp/professionals-area/multi-agency-risk-tool-for-adults-now-published

References

- 'Hoarding Disorder: What is it and what it is not' By Dr David Mataix-Cols, Ph.D
www.helpforhoarders.co.uk/what-is-hoarding/
- 'Hoarding a medical disorder' written by Talha Burki. Published in the Lancet on 25 August 2018.
www.hoardinguk.org/abouthoarding/
- 'Understanding Hoarding - When our relationships with hoarding goes wrong' written by Sophie Holmes (Lead Consultant Clinical Psychologist) Sussex Partnership NHS Trust, Dr Stuart Whomsley (Clinical Psychologist) Division of Clinical Psychology Dr Stephen Kellett (Consultant Clinical Psychologist), University of Sheffield and Sheffield Social and Healthcare NHS Foundation Trust, The British Psychological Society - Division of Clinical Psychology
www.helpforhoarders.co.uk/
- Islington Protocol

This document can be made available on audio tape, braille or in large print, and is also available on the website where it can easily be viewed in large print.

Hoarding Protocol