

West Dunbartonshire Adult Protection Committee Protocol for Working with People with Hoarding Behaviours April 2023

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1. Introduction

This protocol sets out the partnership approach to be taken by staff in West Dunbartonshire Council & the Health and Social Care Partnership (HSCP) when working with people who have hoarding difficulties. The procedure also covers the Private Rented Sector and Owner Occupied properties, when a concern has been raised over the living environment of the individual by a service provider.

Hoarding is one of the manifestations of self-neglect and is a highly complex issue. A collaborative and integrated approach is required in order to facilitate positivity and sustainable outcomes for individuals who exhibit hoarding behaviours.

This Protocol was developed through the contributions of representatives from West Dunbartonshire Adult Protection Committee, West Dunbartonshire Council Housing and Legal Services.

2. Aims of the Protocol

The aims of the protocol are:

When working with people who have hoarding behaviour, all services will ensure the person receives:

- A consistent service.
- > A coordinated response to their accommodation and support needs.
- > An action plan tailored to meet their individual needs and which is understood and agreed by them.
- Appropriate support during their transition to a decluttered environment and continued support to allow them to continue to live this way.

Agencies signed up to the protocol will:

- Investigate and share information on the problems relating to hoarding and address incidents in an evidence based, structured, coordinated and consistent way.
- Develop multi-agency solutions which maximise the use of existing resources and which support the use of compulsory/legal solutions as a last resort.

3. What is hoarding?

Hoarding involves the excessive collection and retention of materials to the extent that they affect day to day living and create a potential hazard. Hoarding may cause a nuisance or hazard to others as well as to the individual. Hoarding is distinct from the act of collecting, and is also different from people whose property is generally cluttered or messy. It is **not** simply a lifestyle choice.

The main difference between a person with hoarding difficulties and a collector is that those with hoarding difficulties have strong emotional attachments to their

objects regardless of their financial value.

Hoarding was previously considered a form of obsessive compulsive disorder (OCD) but is now recognised as a distinct mental health difficulty of its own, with specific issues affecting access to services and psychological intervention.

It can be the symptom of other underlying mental health issues and is also exhibited by people who have other issues that might make them vulnerable. For example anxiety, depression or obsessive compulsive disorder, or it can follow on from a traumatic experience.

Hoarding is one of the manifestations of self-neglect and is a highly complex issue. Self-neglect is the inability (intentional or unintentional) to maintain a socially and culturally acceptable standard of self-care with the potential for serious consequences to the health and well-being of the individual and potentially to their community. Extreme self-neglect can be known as Diogenes syndrome a disorder characterised by domestic squalor, social withdrawal, apathy, compulsive hoarding or garbage and lack of shame. Sufferers may also display symptoms of catatonia.

Hoarding can have a huge impact on a person's ability to function independently and can carry a high level of risk for themselves and others. It can cause high levels of distress for those sharing a home with or living close to the person who hoards, and can cause difficulties for communities working with people who hoard. Help for Hoarders is a registered charity that provides support for people and their families who excessively hoard. https://helpforhoarders.co.uk/

Hoarding is a chronic condition that requires a number of long term support interventions.

4. Characteristics of hoarding

Hoarding is a specific type of behaviour characterised by:

- Acquiring and failing to throw out a large number of items that would appear to have little or no value to others (e.g. papers, notes, flyers, newspapers, clothes)
- Severe cluttering of the person's home so that it is no longer able to function as a viable living space
- Reluctance of tenant/resident to give access, missed access arrangements for repairs & safety checks
- Smells coming from rooms
- Property being dirty or in disrepair
- Overstuffed cupboards
- Large number of pets
- > Self-neglect
- Curtains always drawn / house looking unoccupied
- Significant distress or impairment of work or social life

Other distinctive features include:

Fear and anxiety: may have started as a learnt behaviour or following a significant event such as bereavement. There is a genuine belief that buying or saving things will remove the anxiety and fear they feel.

Long term behaviour patterns: possibly developed over many years or decades of "buy and drop" and an inability to throw away items without experiencing fear and anxiety. Collections are likely to grow as people age so cases may be more often seen in older people. Older people may also be less physically able to take action with the problem.

Excessive attachment to possessions: people who hoard may hold an inappropriate emotional attachment to items.

Indecisiveness: struggle with the decision to discard items that are no longer necessary, including rubbish.

Social isolation: can include the alienation of family, friends and visitors. Reluctance for home visits from professionals, in favour of office based appointments.

Mental competency: ability to make decisions that are not related to the hoarding. That said, hoarding is now considered a standalone mental health disorder and can also be a symptom of other mental health issues.

Extreme cluttering: hoarding behaviour may prevent several or all of the rooms being used.

Self-care: may neglect their self-care

Poor insight: generally see nothing wrong with their behaviour and the impact it has on them and others

5. Types of hoarding

There are three types of hoarding:

- i. **Inanimate objects.** This is the most common and could consist of one type of object or a collection or a mixture of objects such as old clothes, newspapers, food containers or papers.
- ii. **Animal hoarding.** This is the obsessive collecting of animals, often with an inability to provide minimal standards of care. The hoarder is unable to recognise that the animals are or maybe at risk because they feel they are saving them. In addition, people who hoard are often unable to take care of themselves.
- iii. **Data hoarding.** This is a relatively new phenomenon and relates to the

hoarding and storage of data collection equipment such as computers and other electronic storage devices or papers.

6. Supporting someone who hoards.

Its important agencies have an understanding of the need to work at the pace of the person they are trying to support and that supporting people who hoard to change their behaviour and environment is likely to require a long term approach.

Points to Consider:

Staff identifying that a person has a hoarding problem should also bear in mind the following points:

- ➤ Hoarding maybe an indicator of an underlying mental health problem
- ➤ Hoarding increases the risk of fire in a property and can impede the rescue services where materials block doors and windows
- ➤ It can compromise the health and safety of neighbors and the wider community especially where the tenant occupies a flat and/or where the material hoarded encourages infestations of mice or insects
- People with hoarding behaviours can be socially isolated. They may not be used to dealing with other people in their daily lives
- Be aware that hoarders are often reluctant to seek help and may even refuse it when offered
- > Be objective and do not prejudge the underlying causes. Judging a hoarder may alienate them and make it harder for staff to work with them
- You should not devalue the importance of the hoarded items or touch them without the person agreement, also do not refer to them as 'rubbish' as they are likely to have some personal value to them
- > Hoarders often see their behavior as normal
- ➤ Focus and concentrate on tackling the problems hoarding causes nuisance, and health and safety of themselves and others
- You should not use confrontational language when referring to the problem or the hoarders possessions
- Animal welfare must be considered if the person has pets. Concerns should be raised with the SSPCA or another animal welfare organisation
- The likelihood of hoarding reoccurring is quite high and ongoing close monitoring will be needed

Good Practice Principles

Any forced cleanup will rarely work in the long term.

When talking with someone who is hoarding:

DON'T:

Use judgmental language.

Like anyone else, individuals with hoarding behaviours will not be receptive to negative comments about the state of their home or their character (e.g. "What

a mess!" "What kind of person lives like this?") Imagine your own response if someone came into your home and spoke in this manner, especially if you already felt ashamed.

Use words that devalue or negatively judge possessions.

People who hoard are often aware that others do not view their possessions and homes as they do. They often react strongly to words that reference their possessions negatively, like "trash", "garbage" and "junk".

Let your non-verbal expression say what you may be thinking.

Individuals with compulsive hoarding disorders are likely to notice non-verbal messages that convey judgment, like frowns or grimaces.

Make suggestions about the person's belongings.

Even well-intentioned suggestions about discarding items are usually not well received.

Try to persuade or argue with the person.

Efforts to persuade individuals to make a change in their home or behaviour often have the opposite effect – the person actually talks themselves into keeping the items.

Touch the person's belongings without explicit permission.

The person is likely to have strong feelings and beliefs about their possessions and find it upsetting when another person touches their things. Anyone visiting the home of someone with hoarding behaviour should only touch the person's belongings if they have the person's explicit permission.

DO:

Imagine yourself in the person's situation.

How would you want others to talk to you to help you manage your anger, frustration, resentment, and embarrassment? Match the person's language. Listen for the individual's manner of referring to his/her possessions (e.g. "my things", "my collections") and use the same language (i.e. "your things", "your collections").

Use encouraging language.

Use language that reduces defensiveness and increases motivation to solve the problem (e.g. "I see that you have a pathway from your front door to your living room. That's great that you've kept things out of the way so that you don't slip or fall. I can see that you can walk through here pretty well by turning sideways. The thing is that somebody else that might need to come into your home, like a fire fighter or an emergency responder, would have a pretty difficult time getting through here. They have equipment they're usually carrying and fire fighters have protective clothes that are bulky. It's important to have a pathway that is wide enough so that they could get through to help you or anyone else who needed it.")

Highlight strengths.

Everyone has strengths, positive aspects of themselves, their behaviour, or even their homes. A visitor's ability to notice these strengths is likely to help forge a good relationship and pave the way for resolving the hoarding problem (e.g. "I see that you can easily access your bathroom sink and shower," "What a beautiful painting!", "I can see how much you care about your cat.")

Focus the intervention initially on safety and organisation of possessions and later work on discarding.

Discussion of the fate of the person's possessions will be necessary at some point, but it is preferable for this discussion to follow work on safety and organisation.

Clutter Image Rating (CIR) is an internationally recognised assessment tool developed by clinical psychologists and published by Oxford University Press (2014). CIR is a visual assessment tool which shows a series of pictures of rooms in various stages of clutter. This tool can be used as a visual aid to evaluate the client's perception of the level of clutter in their home. Additionally, it can be used as a visual aid for service providers to assess the severity of clutter in a client's house. Clutter Image Ratings - Hoarding Disorders UK

7. Working together to provide support.

It is likely the staff this guidance has been designed for will have come into contact with individual's because they are providing some level of support or a service and the hoarding issue may only come to light as a result of involvement with the person in relation to other issues.

When a person who hoards is identified there must be consideration of a multiagency approach, especially when any early intervention by a service does not achieve a safer and healthier environment for the person or others affected.

Each agency and service area has their own skills, knowledge and resources, and by working in a multi-agency way we can approach care and support in a tailored way.

Typically an invite to attend a case discussion by the initial identifying agency would be circulated to a range of partner agencies. Depending on individual circumstances this may include representatives from, Housing, Police, G.P, Social Work, Fire and Rescue, and Health Services.

The outcome of the initial case discussion would be expected to:

- Identify an appropriate lead agency.
- > Discuss how best to meet any initial identified risks and needs including inviting other partners to future case discussions.
- > Agree on the role of each partner.
- Agree who will be required to communicate directly with the person needing support and how this will be managed, e.g. joint visits.

➤ The person being supported should be involved in and ideally consent to information being shared and if not involved in the discussion informed of the multi-agency discussion. If it is considered necessary to continue to share information without consent this will be communicated to the person and clearly recorded in the persons file.

Where there is likely mental illness and concern for an individual's mental health and wellbeing, the GP should be contacted in the first instance. Mental Health Officers within the mental health teams will be happy to give advice on any matter where colleagues are uncertain how best to support an individual with apparent mental health issues, or where consent is not given.

Staff should contact the appropriate emergency service immediately if there is any concerns about immediate safety and wellbeing.

Where a risk of harm to the person or to others is identified consider whether anyone within the home requires a referral under local Child Protection or Adult Support and Protection Processes (consent is not required for this, although for adults, where possible, it is good practice this is sought).

All adult referrals should be completed on the Adult Protection Referral Form (AP1) and sent to: wdadult@west-dunbarton.gov.uk in the first instance and followed up by a telephone call to confirm receipt of the referral:

- Clydebank Area 01389 811760
- Dumbarton Area 01389 776499



The process for referrals in relation to a Child Protection matter is to call and request to speak to a Duty Social Worker about a Child Protection concern. Basic identifying information around child/young person and an outline of the circumstances which are felt to be placing child/young person at risk of significant harm should be provided. Where it is not exactly clear on this threshold a discussion can be held with the Duty Social Worker and agreement reached around how best to progress. The telephone number is **0141 562 8800**

It's important to remember a person that hoards has unique needs that call for a person centered approach, therefore, how services respond and work together is likely to differ in each individual circumstance.

Each agency and service area offer different skills and knowledge when it comes to supporting people with and affected by hoarding behaviour, a few examples are given below.

Housing and Homelessness Services (Local Authority tenants only)

Hoarding poses a significant risk to the council in managing and sustaining

tenancies. Tenants who have difficulties with hoarding can struggle to manage their homes and tenancy too. Rent and bills can be left unpaid as mail remains unopened and the home becomes increasingly unmanageable. Repairs and structural damage are much more likely to go unreported as tenants are unwilling or too embarrassed to ask for help.

Housing has adopted a sustainable and comprehensive approach to tackling hoarding in tenancies. A pre tenancy guidance, due for release in spring 2023 will offer support for staff to help them spot the signs of hoarding, such as looking out for behavioural signs like missed appointments and reluctance to allow access into the property. Housing and Homelessness Officers then take direct ownership of cases to make sure that they're managed effectively and work closely with Housing Support Officers and other agencies so that extra, tailored support can be delivered to help tenants regain control of their homes and their lives. This includes helping tenants to connect to statutory or non-statutory services.

As a supportive landlord West Dunbartonshire Council will always seek a positive person centred outcome for tenants. However, where there is a serious breach and a failure to engage and all other available courses of action have failed enforcement action under the Housing (Scotland) Act 2001 may be taken but only as a last resort.

Housing and Homelessness Officers should also take into account whether a tenant has a disability that would impact on their case. Housing and Homelessness Officers should ensure that the tenant is receiving / has been offered the appropriate support and that any legal action is proportionate to achieving the desired outcome. In some instances, the tenant may need to be temporarily rehomed to facilitate cleaning of their homes. Due to the stress and upheaval that may result from doing so, this will only be used in extreme cases.

The Scottish Fire and Rescue Service

As part of a commitment to building a safer Scotland, the Scottish Fire and Rescue Service in West Dunbartonshire area offer a free home fire safety visit to all households, and will work closely with partners to promote home safety and offer support in cases of hoarding and other fire safety issues. The Scottish Fire and Rescue Service will also alert relevant partners to concerns encountered whilst engaging with the public. The SFRS can securely hold information linked to an address which can be shared with attending crews should a 999 call come in for that address.

Hoarding is a fire hazard which restricts means of escape within a home. In the event of a fire, a compromised escape route can lead to serious injury or even death. A fire death is tragic and can have a devastating impact on neighbours and the wider community. Additionally, in a fire situation, hoarding can intensify a fire making firefighting conditions extremely challenging.

West Dunbartonshire Health and Social Care Partnership (HSCP)

The HSCP deliver a range of health and social care services to and within the communities of West Dunbartonshire. This includes integrated community care, learning disability, addiction and community mental health service teams arranging and or delivering care and support to adults, older people and carers.

Social Work Duty is the first point of contact when looking for support or advice.

This may include;

- An assessment of care and support needs
- ➤ Crisis Intervention
- ➤ Adult Protection
- Carer Support
- ➤ Care at Home Services
- Respite Care Services
- ➤ Day Care services
- Care Home Placement
- > Community alarms
- ➤ Assisted technology
- Benefits advice
- ➤ Occupational therapy
- > Social Work intervention and support
- Reablement
- ➤ Information and advice regarding Self Directed Support

Where there is a risk of harm to an adult due to hoarding behaviour a referral may be passed to the Adult Support and Protection Duty Team. This team provides a focused and multidisciplinary response to adults at risk of harm concerns and is staffed by staff from across a range of HSCP community care teams.

Community Mental Health

NHS WD Adult Mental Health Service operates a tiered model of intervention; the aim of this is to ensure that a person receives a stepped care approach where the level of intervention is closely matched to their clinical and care needs. Within the stepped care model, various interventions can be delivered within G.P services, Primary Care Mental Health Team, (psychological therapy service), multi-disciplinary Community Mental Health Teams, and within inpatient care.

Discussion with an individual's GP prior to a decision to refer to Adult Mental Health Services is highly recommended. This assists in the implementation of any treatment interventions that should be delivered within the Primary Care context and allows for consideration of referral on to the most appropriate Team within the Adult Mental Health Service.

People experiencing severe and/or enduring mental health problems that

require intervention are usually referred to West Dunbartonshire Community Mental Health Teams (CMHT). The Teams are multidisciplinary, encompassing Clinical Psychologists, Community Mental Health Nurses, Community Support Workers, Community Pharmacist, Consultant Psychiatrists and other medical staff, Mental Health Officers, and Occupational Therapists. We also benefit from access to a mental health specialist Dietician, Physiotherapist, and Speech and Language Therapist.

Referrals must be discussed with the individual being referred to the CMHT in all circumstances. A comprehensive initial mental health assessment will be undertaken by the CMHT and an individually tailored treatment plan agreed with the individual.

Where clarification is required regarding when and how to ask for specialist mental health services for an individual then contact can also be made with the CMHTS Duty Worker.

8. Welfare Rights - Scottish Welfare Fund

The cost of clearing and cleaning a home can be funded through the Scottish Welfare Fund where a tenants financial circumstances are eligible. There is a limited pot of money so only those with the greatest need are most likely to be given a grant. This will not be awarded for repeat cases.

The fund is discretionary meaning there is no right to a grant. Decisions are made based on personal circumstances and as everyone's circumstances are different, grant awards can differ from person to person. Grants do not have to be paid back. More information can be found by visiting https://www.spso.org.uk/scottishwelfarefund/

9. Legal Intervention

Legal action will only be considered as an absolute last resort in all cases, and after all other available courses of action have been exhausted. If an Adult is under threat of eviction the use of Adult Support & Protection Legislation must be considered to assess if the Adult meets the 3 Point Test. An Adult Support & Protection Referral should be submitted for screening to the Social Work Adult Support and Protection Duty Team. Anyone can make a referral.

10. Information sharing and data protection

An essential element of the successful implementation of the protocol is ensuring that information is shared by partners to enable the individual person's housing or homelessness situation to be resolved as quickly as possible.

Information will be shared with the joint aims of supporting tenants to access the most appropriate services to meet their needs but whilst doing so preserving their dignity and privacy.

Each of the partners of the protocol have existing confidentiality and data protection policies and will adhere to data protection legislation when carrying out tasks relating to the protocol. The following eight principles of data protection will be met by all parties:

- i. Personal data shall be processed fairly and lawfully.
- ii. Personal data shall be obtained only for one or more specified and lawful purposes, and shall not be further processed in any manner incompatible with that purpose or those purposes.
- iii. Personal data shall be adequate, relevant and not excessive in relation to the purpose or purposes for which they are processed.
- iv. Personal data shall be accurate and where necessary kept up to date.
- v. Personal data processed for any purpose or purposes shall not be kept for any longer than is necessary for that purpose or purposes.
- vi. Personal data shall be processed in accordance with the rights of data subjects under this act.
- vii. Appropriate technical and organisational measures shall be taken against unauthorised or unlawful processing or personal data and against accidental loss or destruction of, or damage to personal data.
- viii. Personal data shall not be transferred to a country or territory outside the European Economic Area unless that country or territory ensures an adequate level of protection for the rights and freedoms of data subjects in relation to the processing of personal data.

All agencies need to ensure that where it is decided appropriate to share information about an individual and their housing situation that this is on a need to know and case by case basis. The information shared should be:

- Transferred in a secure format
- Necessary for the purpose for which it is being shared
- Shared with only those who need it
- > Be accurate and up to date
- ➤ Be shared in a timely fashion

11. Training

In order to successfully deliver the aims and objectives of this protocol it will be necessary to ensure that key staff within Housing Services, Scottish Fire and Rescue, Community Mental Health and West Dunbartonshire HSCP Community Care Services are familiar with the protocol and understand their role in supporting people who have hoarding behaviours. Responsibility for this lies with individual agencies.

12. Review

This protocol will be reviewed annually by West Dunbartonshire Adult Protection Committee.