Fife Adult Support & Protection Committee

Interagency Self-Neglect and Hoarding Guidance

Author's name	Ronan Burke
Designation	ASP Coordinator
Date	30.4.25
Last Review	May 2025
Next Review	May 2027

Contents

Fife Adult Support and Protection Committee would like to acknowledge London Borough of Merton Adult Safeguarding Board for the use of their Practitioners Hoarding Assessment Toolkit included within this document in the assessment and management of self-neglect and hoarding.

This protocol was also informed by the East Lothian and Midlothian Public Protection Committee Multi-agency Protocol on Self-neglect and Hoarding 2019.

1) Introduction

The aim of this document is to provide a clear procedure for inter agency staff to use when working with adults who may be at risk of harm as a result of self-neglect and/or hoarding. Self- neglect is an extreme lack of self-care and can be associated with hoarding. Self-neglect can be difficult to assess, specifically when attempting to assess whether an individual is making an informed choice to live in a particular way. The individual may also be unable to identify the impact on their wellbeing, have a lack of insight into their living circumstances which can also affect assessment of whether the adult's decision-making ability is impaired. Managing the balance between the adults' right to self-determine and their right to be supported and protected is a challenge for professionals. The adult's understanding is crucial to determining what action may or may not be taken in situations of self-neglect and/or hoarding. All adults have a right to take risks and behave in a way that may be construed as self-neglectful if they have the capability and capacity to do so.

In the years since the inception of the ASP Act, hoarding has been recognised as aclassified disorder in its own right, often alongside other conditions. In extreme cases, it can lead to some people living in dangerous and/or unhealthy conditions, resulting in a risk of harm. All the circumstances in a person's life must be considered together when applying the three-point criteria.

2) Information Sharing

This guidance is underpinned by the Data Protection Act 2018 and the General Data Protection Regulation (GDPR). All agencies have a responsibility to share information where there is an identified risk to a person and/or to others. Where there is suspicion and/or evidence of self-neglect and/or hoarding consideration must be given to interventions within the following legislative frameworks: Adult Support and Protection (Scotland) Act 2007; Mental Health Care and Treatment (Scotland) Act 2003; Adults with Incapacity (Scotland) Act 2000.

3) Legislation

This guidance reflects the national adult protection legislation and policy context.

The following legislation may be relevant:

· Adult Support and Protection (Scotland) Act 2007.

· The Mental Health Care and Treatment (Scotland) Act 2003.

· The Adults with Incapacity (Scotland) Act 2000.

· Public Services Reform (Scotland) Act 2010.

· The Human Rights Act 1998.

· The Social Work (Scotland) Act 1968, Section 12. 4.

· The Data Protection Act 2018.

· The General Data Protection Regulation (GDPR) 2019.

4) Aim of Procedure

The aims of this procedure are to:

· Provide a framework through which to investigate and share information on the problems related to hoarding from different professionals and community perspectives. This will enable practitioners to work with individuals in an evidence based, structured, systematic, co-ordinated and consistent way.

· Develop multi-agency solutions which maximise the use of existing services and resources and which may reduce the need for compulsory solutions which always have to be led by Social Work

· Ensure that there is a process for planning solutions which is person-centred. Possible solutions include professional support and monitoring, property repairs and permanent and temporary re-housing.

· To establish best practice and improve knowledge of legislation that relates to hoarding behaviour.

5) Definitions

Self-neglect

Whilst there is no standard definition of self-neglect, research has suggested that there are three recognised forms which include:

· Lack of self-care – this may involve neglecting personal hygiene, nutrition and hydration or health. This type of neglect would involve an assessment being made regarding what is an acceptable level of risk and what constitutes wellbeing.

· Lack of care of one's environment – this may result in unpleasant or dirty home conditions and an increased level of risk in the domestic environment such as health and safety and fire risks associated with hoarding. This may again be subjective and require a multi-agency assessment to determine whether the conditions within an individual's home environment are acceptable and/or safe.

· Refusal of Services that could alleviate these issues – this may include the refusal of care services, treatment, assessments or intervention, which could potentially improve self-care or care of one's environment.

Hoarding

Hoarding is the excessive collection and retention of any material to the point that it impedes day to day functioning (Frost & Gross 1993). Importantly, hoarding disorder is distinct from the art of collecting and is also different from people whose property is generally cluttered or messy. Hoarding does not favour a particular gender, age, ethnicity, social-economic status, educational/occupational history or tenure type. It also cannot simply be called a lifestyle choice.

Pathological or compulsive hoarding is a specific type of behaviour characterised by:

· Acquiring and failing to throw out a large number of items that would appear to hold little or no value and would be considered rubbish by other people.

· Severe "cluttering" of the person's home so that it is no longer able to function as a viable living space.

· Significant distress or impairment of work or social life (Kelly 2010).

Hoarding Disorder used to be understood as a form of obsessive compulsive disorder (OCD)**. It is now considered a standalone mental disorder**: "Hoarding disorder is characterised by excessive accumulation of and attachment to possessions regardless of their actual value. Items may be hoarded because of their emotional significance, perceived potential usefulness, or intrinsic value. Excessive acquisition is characterised by repetitive urges or behaviours related to buying, stealing or amassing items, including those that are free. Difficulty discarding is due to perceived need to save items and distress associated with discarding them. Hoarding behaviour is sufficiently severe to result in significant distress or significant in personal, family, social, educational, occupational or other important areas of functioning".

There are three types of hoarding:

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

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

3) Data hoarding - This is new phenomenon of hoarding, with very little research on the matter, and it may not seem as significant as inanimate and / or animal hoarding. However, People that do hoard data present with the same issues that are symptomatic of other types

of hoarding. Data Hoarding can present with the hoarding of computers, electronic storage devices or paper. A need to store copies of emails, and other information in an electronic format. It is recognised that hoarding is a complex condition and that a variety of agencies will come into contact with the same person. It is also recognised that not all persons will receive support from statutory services such as Mental Health and will require a multi-agency response.

6) Why do people self-neglect and / or hoard?

Trauma

Traumatic events have been defined as: "an event, a series of events or a set of circumstances that is experienced by an individual as physically or emotionally harmful or life threatening" (SAMHSA, 2014, p7). Trauma has now been hypothesised by researchers as a contributing factor to compulsive hoarding.

There are two types of Trauma:

1) Type 1 Trauma – these events are usually single incident events such as sexual assaults, physical assaults or serious accidents.

2) Type 2 Trauma or "Complex Trauma" – this form of trauma and abuse is usually experienced interpersonally, persists over time and is difficult to escape from. Complex trauma is often experienced in the context of close relationships (e.g. Childhood Adverse Experience or domestic abuse) and can also be experienced in childhood or adulthood. Each person who lives through trauma is unique and will not respond in the same way. This depends on many different factors including what their life and relationships were like before the trauma(s) occurred, how they were responded to during and after the trauma, their personality, strengths and resources, their other life experiences and cultural context in which they live their lives. Research highlights that traumatic life events and early material deprivation have been identified as potential environmental risk factors for the development of pathological hoarding behaviour (Danielle Landau et al March 2011).

Poor Mental Health

It is also important to note that hoarding can also be a symptom of other mental disorders for example: dementia, depression, psychotic disorder.

A range of contributing factors

There can be a number of intertwining causes of self-neglect and / or hoarding. These may contribute to or escalate self-neglect and/or hoarding and can include:

· Age related changes, in physical and / or mental health.

· Bereavement / traumatic event.

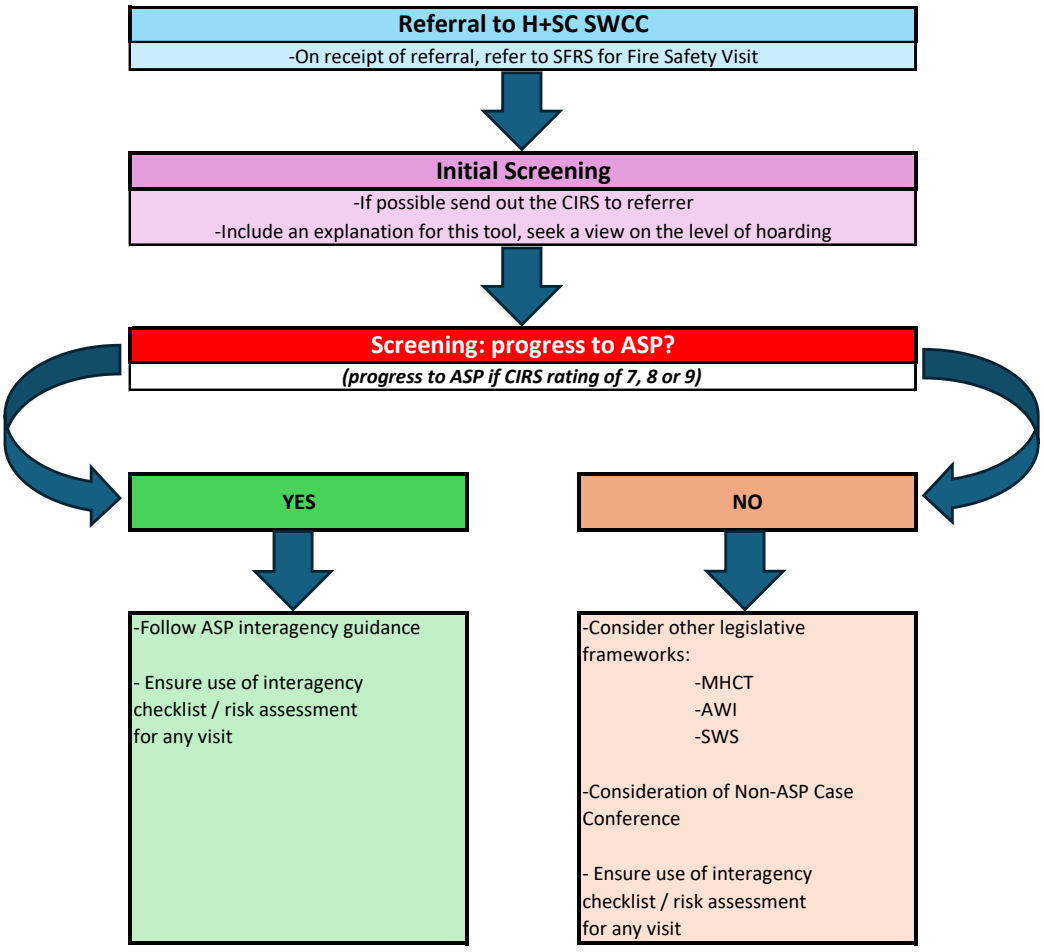
· Severe and enduring mental illness.

· Alcohol or substance misuse.

· Social isolation.

· Fear and anxiety.

7) Process Map for Hoarding / Self-Neglect



ASP	*Adult Support and Protection*
AWI	*Adults with Incapacity (Scotland) Act 2000*
CIRS	*Clutter Image Rating Scale*
H+SC	*Health and Social Care*
MHCT	*Mental Health (Care and Treatment) (Scotland) Act 2003*
SFRS	*Scottish Fire and Rescue Service*
SWCC	*Social Work Contact Centre*
SWS	*Social Work (Scotland) Act 1968*

8) Where the Adult refuses to cooperate

Learning Reviews have identified a theme where agencies have difficulty engaging due to the refusal of the adult to cooperate. This can lead to increased risk with the potential of social isolation and a risk to the health and wellbeing of the adult. In these circumstances, and consistent with the scope of this protocol, a Non-ASP Adult Case Conference should be considered.

A Non-ASP Adult Case Conference should be considered, particularly in circumstances where the risk to self or others is high, to discuss and agree strategies and approaches which may encourage the adult to engage and therefore reduce the risk it is believed they are exposed to.

This will include consideration of –

- the agency that may have the best opportunity of initiating, or building on any current connection that exists, with continuing support from the inter-agency partnership;
- an inter-agency chronology developed for the purposes of guiding understanding and discussion, and helping identify any channels to engagement that have not yet been explored;
- how to maximise engagement, reduce risk, reduce duplication, and aim to achieve a positive outcome;
- Undue Pressure that may influence the adult to decline support and should be considered;
- A Risk and Protection Plan (detailed as above) should be populated at the meeting and circulated to all participants and key actions and contingencies recorded on profile notes.
- Encouraging staff and their agencies to work at the adult's pace, and appreciate that the case may remain open and active for a long period.

Moving forward, a single point of contact should be identified to –

- Maintain contact with the individual if possible;
- Receive updates from partner agencies and maintain the inter-agency chronology.

The Case Conference may require to convene again, or until there is evidence that the level of engagement has increased and level of risk has decreased to a point where the adult no longer poses significant risk to self or others. Please see appendix 3 for further details as to the process map for the Non-ASP Adult Case Conference.

Appendix 1-Clutter Image Rating Scale (CIRS)

CIRS is an internationally recognised assessment tool developed by clinical psychologists and published by Oxford University Press (2014). CIRS is a visual assessment tool showing a series of pictures was created of rooms in various stages of clutter – from completely clutter-free to very severely cluttered.

To gain an accurate sense of a clutter problem, rate each individual room in the home by selecting the picture in each sequence that reflects the level of clutter in the room. This requires some degree of judgment because no two homes look exactly alike and clutter can be higher in some parts of the room than others. In general, clutter that reaches the level of Picture 4 or higher impinges enough on people's lives that they are likely to need some help.

CIRS can also be used to facilitate a discussion with the householder to assess their level of insight into their hoarding behaviour and whether they may be willing to seek help or support. In addition, assess the general state of repair of the house and check for any signs that utilities to the home have been disconnected or are unusable, i.e. alternative methods of lighting, cooking, heating and sanitation are in use.

If the CIRS images were going to be shown to a householder, consider blanking out the word Clutter on them as some feedback has been received that this term can be seen negatively by the person.

10.2.1 Clutter Image Rating Scale: Part 1 of 3 – 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

10.2.2 Clutter Image Rating Scale: Part 2 of 3 – 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

10.2.3 Clutter Image Rating Scale: Part 3 of 3 – Living Room

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

Appendix 2-Hoarding Safety Plan

Hoarding Safety Plan / Risk Assessment		
People Who lives in your property?	Do they have any mobility or capacity issues that would prevent them being able to leave the property in an emergency?	What is your plan for leaving the house quickly in the event of e.g. a fire or gas leak? **Answer –**
Daily Personal Care How do you manage you daily personal hygiene?	Do you have access to your bathroom / bath, hot water? Do you have any mobility issues that make it difficult for you to carry out your personal hygiene tasks?	What help might you need to make this safer for you? **Answer –**
Sleeping Arrangements Do you have a clear path to your bedroom / bed?	If not, where do you normally sleep? How long has it been since you have been able to use your bed?	What support would you like to help you to be able to use your bedroom / bed again? **Answer –**
Access to Kitchen / Food Preparation Do you have a clear path to your kitchen? Are you able to prepare food for yourself in the kitchen? How do you store your prepared food / groceries?	If you don't have a clear path to the kitchen how do you prepare food? Are you using a portable device, buying take-away or eating straight from packets? Where do you store the food that comes into the house? Have you seen any signs of infestation as a result of food not being able to be stored properly?	If you are currently unable to use your kitchen or prepare food in this area, what would be your priority if help was provided to help you make this possible again? **Answer -**
Pets Do you have any pets in your home?	Depending on what comes up will depend on the next questions e.g. a dog, how does it get walked, vet	Will be determined by middle section **Answer -**

	checked etc versus fish in a tank needing regular changes of water etc.	
Smoking / Drinking Do you smoke – is this cigarettes or a vape machine or both? Do you drink at home – do you mind saying how much and how often?	Where do you smoke e.g. sitting room, bedroom, outside or all of them. If cigarettes, how do you dispose of them? If you drink, do you drink alone or do others join you?	Would you like help from any support services to cut down or change any of your current smoking and / or drinking habits? **Answer -**
Floors Do you have clear pathways to the front and / or back doors to allow them to open freely, if you have to exit the property quickly in an emergency?	Are there other trip hazards on the floor other than belongings e.g. missing or broken floorboards, trailing electrical cables etc.	How can we help you create a clear space to enable you to leave your property safely? **Answer –**
House Layout Does your house have upstairs accommodation – if so, how would you and any others exit the property in the event of e.g. a fire or gas leak? Is there belongings on the stairs or a clear path up and down? If carpet on the stair, could it cause a trip hazard?	Do you have an exit ladder fitted to enable you to leave in the event of e.g. a fire or gas leak downstairs? Are the stairs safe enough for you and any others to use? What condition are the stairs in?	What help might you need to make the upstairs safer in the event of an emergency downstairs? **Answer -**
Alarms Are there working / linked alarms in the property?	Who supplied them and when were they last checked?	If the alarms need attention, would you be happy for Fife Fire and Rescue Service to come and help you with this? **Answer –**
Security	Is this somewhere within easy access?	What could we do to help make this safer and easier for you?

If your doors are kept locked, where are the keys kept if exit from the house is needed in an emergency? Is anyone else a keyholder for your property? Do you know how to ask for help, alert services?	Does anyone else know who they are, so they can be contacted in an emergency? Do you have numbers to call for help?	**Answer -**
Level of Engagement Did the client engage with the process of completing this Safety Plan or was there a level of resistance that made it difficult to progress?	What do you think the blocks were for the client in managing any progression?	If they have agreed to any of the above but not the total plan can this be seen as a positive start? **Answer -**

Appendix 3-Non-ASP Adult Case Conference Flowchart

THE ADULT	THE PROCESS	LEAD AGENCY
Adult does not meet ASP criteria		Agency engaged with the Adult
	Risk Identified Informal local discussion to remove/reduce risk	
Adult presents continued risk concerns		Agency checks if Adult meets criteria for another relevant Multi-Agency approach
'Lead Agency' continues to engage with the adult	**Risk Assessed** Concern doesn't fit in existing risk management frameworks (e.g. ASP, MARAC, MAPPA)	
		'Lead Agency' communicates the need for Case Conference and schedules it
	Case Conference Scheduled Relevant agencies invited	
Adult encouraged and supported to attend Case Conference		'Lead Agency' highlights risk concerns and seeks relevant information and engagement from others
	Case Conference Held Chaired & Minuted by the 'Lead Agency'. Relevant agencies attend	
Adult participates		Relevant & informed staff attend and contribute
	Risk and Protection Plan agreed	
Adult engaged		Plan recorded in each agency data base
	Case Review in agreed timescale	

Appendix 4-Resource List for Practitioners

British Psychological Society-Understanding Hoarding

Understanding Hoarding

British Psychological Society-A Psychological Perspective on Hoarding: Good Practice Guidelines

A psychological perspective on hoarding (hoardingdisordersuk.org)

Self-Care Easy Read-Adapted from "Self Care" by Dr Stephen Tomkins

LD self care booklet HIGH RES (southwest.nhs.uk)

Tayside Practitioner's Guidance: Self-Neglect and Hoarding Protocol and Toolkit

Tayside Practitioner's Guide Self Neglect and Hoarding.pdf (angus.gov.uk)

Appendix 5-Social Work Case Study

	Sharing Good Practice
Storyboard completed by	
Service	Social Work – adults
Name / job title	SWA/Student
Date	June 2024
SU SW ID Number	Number 3
The journey…	
Please provide brief background (anonymised) of circumstances	D lives in a social landlord one bed bungalow with her dog. She is in her early 60's and there are no concerns about her mental capacity to make welfare decisions. She is active in the community and attends groups and clubs. She enjoys crafts. She has a car. She has health conditions including depressional and anxiety. Mobility ok and an assessment of need concluded did not met the eligibility criteria for funded support. Has significant trauma history and worries will get dementia like her mother. Home is filled with functional items like gifts, pots, pans, cleaning equipment etc. If she cannot find something e.g. a toothbrush she will buy another. Her car is also filled with items and has to be emptied when needing repairs or services. D demonstrates insight into her situation, referring to various television programmes about the subject and identifies that her behaviours are similar There have been ASP referrals from the housing provider. The current issue is that there is a mouse infestation which cannot be addressed due to the level of clutter. With D's consent removal of some items was done when in hospital but this caused more trauma and D quickly replaced the items. She was very specific about the look and use of items such as a dustpan and brush and spent a considerable amount of time finding an exact replacement.

	She was angry with the worker for the removal of these items although it was thought that she had originally consented. Although a good working relationship continued. Decanting he items into storage was considered but discounted due to cost and was thought to only move the issue. The case was discussed at the mental health MDT meeting and a referral to psychology was agreed but D did not consent. The MHO advised that the threshold for an admission under the Mental Health Act was not met. The level of harm was assessed by the worker and the Team Manager as not to be critical. Currently D's social care needs do not meet the eligibility criteria and the primary need is environmental so the case was closed to social work and D was in agreement with this.
Who was involved in the Adult Protection Journey	Social Work, District Nurses, GP, mental health, MHO, fire service
Was there a diagnosis e.g hoarding disorder Diogenes syndrome, mental health condition?	No
What number on the Clutter scale	
In what ways was the adult supported to give their views about what they wanted to happen	The social worker adopted a person centred approach and wishes were respected. C was invited to meetings and updated on outcomes. The social worker used their knowledge of trauma informed practice, hoarding disorder, diogenes syndrome, Human Rights Act 1998, Adult Support & Protection (Scotland) 2007, Adults with Incapacity (Scotland) Act 2000 (AWI) and Mental Health (Care & Treatment) (Scotland) Act 2003 to inform their social work practice.

What support was agreed and how did this help the adult to keep safe from harm/ achieve outcomes	Perhaps a specialist service that supports people with a lived experience of hoarding may have supported D more successfully.
Any other comments.	