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

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Introduction

This *Tayside Self-Neglect and Hoarding Protocol* has been developed to provide a clear overview of the approach to Self-neglect and Hoarding across Tayside and provide practitioners with a toolkit to aid assessment and intervention.

This Protocol is for *all* practitioners and managers working across the public, private and third sectors across Tayside and should provide an overarching framework to complement any single agency protocol or guidance and the supporting Practitioner's Toolkit.

Legislative and Policy Context

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

The following legislation may be relevant:
- The Adult Support and Protection (Scotland) Act 2007
- Adults With Incapacity (Scotland) Act 2000
- The Data Protection Act 2018
- The General Data Protection Regulation (GDPR)
- Mental Health Care and Treatment Act (Scotland) 2003 - Section 33
- Public Health etc. (Scotland) Act 2008
- Housing (Scotland) Act 2006
- Anti-Social Behaviour etc. (Scotland) Act 2004

Who is an Adult at Risk?

Under Section 3 of the Adult Support and Protection (Scotland) Act 2007 'Adults at Risk' are adults over 16 years of age who:

- Are unable to safeguard their own well-being, property, rights or other interests
- Are at risk of harm, and
- Because they are affected by disability, mental disorder, illness or physical or mental infirmity, are more vulnerable to being harmed than adults who are not so affected.

All three elements of the definition must be met. The presence of a particular condition does not automatically mean an adult is an 'adult at risk'.

Self-Neglect

Self-neglect differs from the other forms of harm as it does not involve a perpetrator. Self-neglect is included in the Adult Support and Protection (Scotland) Act 2007, which places a statutory duty to make inquiries if it is suspected that someone may be at risk of harm.

What is Self-Neglect?

Self-Neglect is the inability (intentional or unintentional) to maintain a socially and culturally accepted standard of self-care with the potential for serious consequences to the health and well-being of the individual and potentially to their community.

Extreme self-neglect can be known as Diogenes syndrome, which is a disorder characterized by extreme self-neglect, domestic squalor, social withdrawal, apathy, compulsive hoarding of garbage, and lack of shame. Sufferers may also display symptoms of catatonia.

An individual may be considered as self-neglecting and therefore maybe at risk of harm when they are:

- Either unable, or unwilling to provide adequate care for themselves.
- Unable to obtain necessary care to meet their needs.
- Unable to make reasonable or informed decisions because of their state of mental health, or because they have a learning disability or acquired brain injury.
- Refusing essential support without which their health and safety needs cannot be met and the individual does not have the insight to recognize this.

What is Hoarding?

Hoarding is the excessive collection and retention of any material to the point that it impedes day to day functioning. 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 2008).

There are 3 Types of Hoarding

- **Inanimate objects -** This is the most common and could consist of one type of object or a collection of a mixture of objects such as old clothes, newspapers, food, containers or papers.
- **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.
- **Data Hoarding** - This could present with the storage of data collection equipment such as computers, electronic storage devices or paper. A need to store copies of emails, and other information in an electronic format.

Other distinctive features include:

- **Fear and anxiety**: may have started as a learnt behavior 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 behavior pattern:** possibly developed over many years or decades of 'buy and drop' and an inability to throw way items without experiencing fear and anxiety.
- **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.
- **Socially isolated:** can include the alienation of family, friends and visitors. Reluctance for home visits from professionals, in favor of office based appointments.
- **Mentally competent**: ability to make decisions that are not related to the hoarding. That said, hoarding is now considered a standalone mental disorder and can also be a symptom of other mental health issues.
- **Extreme clutter**: hoarding behavior may prevent several or all of the rooms being used.
- **Self-care**: may appear to neglect their self-care.

- **Poor insight:** generally see nothing wrong with their behavior and the impact it has on them and others.

Hoarding is now recognised as a distinct mental health difficulty of its own, with specific issues affecting access to services and psychological intervention. Hoarding can have a severe 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.

Information Sharing

Practitioners must understand *when* to share information*; what* information to share; *how much* information to share*; who* to share the information with and *the way in which* the information should be shared. Practitioners must also understand the possible adverse consequences *of not* sharing information.

Practitioners must understand the legislation underpinning information sharing which includes The General Data Protection Regulation (GDPR); The Data Protection Act 2018; The Human Rights Act 1998 and the European Convention on Human Rights (ECHR). **Legislation** *supports* **lawful information sharing and should not be seen as a barrier.**

GDPR is a legal framework that sets out guidelines for the collection and processing (sharing) of personal data (information) and special category data (information) of individuals within the European Union (EU).

GDPR describes the principles which must underpin information sharing practice and the basis (formerly known as conditions) upon which information can be shared. All practitioners must understand the **principles** and **basis** for sharing information.

Practitioners should always refer to and comply with their own service / agency information sharing guidance.

Practitioners should always consider whether or not there is a legal requirement to seek consent to share information.

Toolkit and Resources

This toolkit has been designed to support practitioners within Health and Social Care Partnerships, Police Scotland, NHS Tayside, Housing Services, Substance Use Services and other relevant social care providers to support assessment and intervention with individuals who may self-neglect or hoard.

This toolkit has been produced using a variety of widely available materials, in particular from Scottish Fire and Rescue Service and the National Adult Protection Coordinator.

Practitioners have a legal obligation to:

- Always act in the best interest of individuals and others.
- Not to act or **fail to act** in a way that results in harm.
- Act within your competence and not take on anything you do not believe you can safely do.
- As a practitioner you would owe a duty of care to the people you support, your colleagues, your employer, yourself and the public interest.
- Social Care Institute for Excellence (2012) state that when acting in a person's best interests you must normally do so with their consent unless you have evidence that the person lacks capacity to make that particular decision at the time it needs to be made.

Points to consider:

- Many tools, all assist in thinking about the elements to consider and to record.
- It's the analysis that counts – how do you reach a view about what to do and how to do it?
- Who can you involve?
- Assessment and working with the person will take time but remember the Golden Rule: Clean ups don't work! At best they create a short term fix at worst they severely traumatise the person and create a situation where they will not accept help in the future. However there may be circumstances where there is an urgent need to address health and safety issues.
- Consider how the person processes information (ability to focus on their situation), beliefs (how do they view their situation) and emotions (does change create anxiety, grief etc.) [Orr et al 2017].
- A good assessment may be as far as you get the first time around but it provides invaluable information for future work and a base line for others to note in the future if the service user's level of need is increasing.

Assessing capacity in the setting of self-neglect:

- In self-neglect the assessment of the ability of the person to make informed choices requires the assessing worker to gather evidence and input from as many sources as possible. The individuals circumstances including age, physical and mental health, family, social and community contacts, their attitudes towards societal and establishment norms must be taken in to account when making a decision on how to engage or what action should or should not be taken.
- Assessment of capacity does not negate duty of care. No case should be closed until a multi-agency meeting has been held to explore options for intervention that will improve outcomes.

What does Self-neglect look like?

- Poor personal hygiene
- Mental state; cognition, delusions, ability to respond to an emergency
- Medical needs e.g. untreated medical needs
- Domestic squalor
- Hoarding
- Public safety
- Requires an interdisciplinary, multidimensional intervention placement
- Condition of the home – inside and outside
- Duration of issue

Self-neglect policy and practice: research messages for practitioners – SCIE (2015):

- Building a relationship is important – demonstrate your compassion, reliability, empathy, patience, honesty and preparedness to work at their pace.
- Understand their life history and current circumstances and how they connect to self-neglect; loss, grief, harm, depression, cognitive impairment.
- Understand the legal responsibilities and tools.
- Be creative; flexible approach, negotiate the level of intervention they can tolerate, aim to contain rather than remove risk.
- Accept a reduction in neglect as a good outcome as opposed to complete cessation of self-neglect.
- What can others offer – fire service, safe drinking programmes, aids and adaptions?
- Negotiating for and with service users, coordinate with them, reassure them and others, containing anxiety of others, be the bridge, maintain contact, friendship and influence – who can be a positive influence without being overbearing.

Hoarding Good Practice Principles:

- Forced cleanup is not an optimal response and rarely works in the longer term.
- Meaningful engagement is the most effective tool - trusted person to engage with to affect change.
- Where animal hoarding is involved, psychiatric assessment is usually needed.
- Diogenes syndrome is linked to brain injury, anxiety and depression so assessment needs to be thorough.
- Recognition of impact on other people.
- Multi-agency response required and appropriate sharing of information.
- Do not touch or remove anything without the express permission of the person and don't do it when they are not there.
- Offer advice but DO NOT make the decisions on what stays and goes.
- Maintain the plan on what is stored, displayed and sold/disposed.
- Focus on sorting objects first as opposed to paper as filing paper is more complex as we all know!
- As they sort ask the service user to think aloud so you can consider their thought processes and offer advice.
- One touch chess – try to encourage the service user to only touch something once to avoid moving things around and confusion.
- Be flexible and innovative e.g. locating storage space.
- Deciding how to dispose of items is important – remember no matter your view the item is important to the service user.

Clutter Image Rating Scale

The clutter Image Rating Scale should be used to determine the level of risk and action required. This will aid assessment, however professional judgment and analysis will also be required. It can also be used to facilitate a discussion and aid assessment as to the level of insight.

Unless the property consists only of one room, a single room should not be used in isolation to assess hoarding behavior and the level of clutter throughout the entire home should be taken into account. The general state or repair of the house should also be considered, as should any signs that the utilities to the home have been disconnected or are unusable, i.e. alternative methods of lighting, cooking, heating and sanitation in use.

Hoarding behaviours alone may not automatically require referral to health and social care agencies and will be dependent upon the specific circumstances and risks. However, where you believe a person is at risk of harm (as defined above) due to hoarding or self-neglecting behaviours, it may be appropriate to refer under Adult Support and Protection.

Legally, a person is presumed to have the mental capacity to make their own decisions, unless proven otherwise. You may encounter situations where the risk is significant but the person refuses such consent. However, where you believe they are unable to provide informed consent or are being unduly influenced or pressurized to withhold consent, you must take advice from your line manager.

A referral to health and social care agencies can be made whether or not you believe the adult is at risk of harm in terms of the Adult Support and Protection (Scotland) Act 2007. Assessments may also be undertaken under community care, mental health or adults with incapacity legislation. Contact details are noted at the end of this document.

Clutter Image Rating: Bedroom

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

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

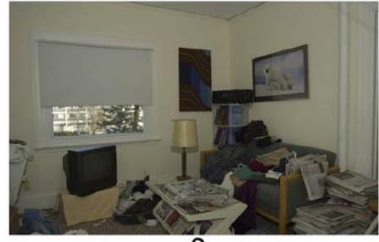
5

6

7

8

9

Clutter Image Rating: 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

Level 1 Characteristics

Level 1 Clutter Image Rating 1-3	Household environment is considered standard, no specialised assistance needed. Appropriate referrals can be made if the tenant requires some assistance with home care of housing support, subject to age and circumstances.
1. Property Structure, Services and Garden Area	• All entrances and exits, stairways, roof space and windows accessible • Smoke alarms fitted and functional otherwise refer to Repairs Call Centre • All services functional and in good working order • Garden is accessible, tidy and maintained
2. Household Function	• No excessive clutter, all rooms can be safely used for their intended purpose. • All rooms rated 0 – 3 on the Clutter Image Rating Scale (CIRS) • No additional unused household appliances appear in the property • Property is maintained
3. Health and Safety	• Property is clean with no odours (pet or other) • No rotting food • No concerns about candles • No concerns about flies • Tenant/s manages personal care/may require some assistance for health reasons
4. Safeguard of Children and Family Members	• No concerns for household members
5. Animals and Pests	• Any pets are well cared for • No pests or infestations at the property
6. Personal Protective Equipment (PPE)	• No PPE required

Actions

Level 1 is Clutter Image Rating 1-3. This may result in a single agency response or referral to another agency or service. Services involved should follow their own single agency guidance on appropriate actions to be taken to provide support and early intervention.   If there is no significant identified risk to adults or children living in the property then a coordinated multi-agency Adult Protection or Child Protection response is unlikely to be required at this stage.

Level 2 Characteristics

Level 2 Clutter Image Rating 4–6	Household environment requires assistance to resolve the clutter and the maintenance issues in the property.
2. Household Function	• The only major exit is blocked • Concerns that services are not well maintained • Smoke alarms are not installed or not working • Garden is not accessible due to clutter or is not maintained • Evidence of indoor items stored outside • Evidence of light structural damage including damp • Interior doors missing or blocked open
3. Health and Safety	• Kitchen and bathroom are difficult to utilise and access • Offensive odour in the property • Tenant is not maintaining a safe cooking environment • Some concern with the quantity of medication, or its storage/expiry dates • Tenant trying to manage personal care but struggling • Tenant has good fire safety awareness with little risk of ignition • No risk to the structure of the property
4. Protection Concerns	• Properties with adults/children presenting care and support needs should be referred to Adult/Child Protection
5. Animals and Pests	• Animals at the property at risk due to the level of clutter in the property • Animals living area is not maintained and smells • Visible rodent infestation
6. Personal Protective Equipment (PPE)	• Is PPE required? • Latex gloves, boots or needle stick safe shoes, face mask, hand sanitizer, insect repellent

Actions

Level 2 is Clutter Image Rating 4-6 and is likely to result in a multi-agency response. Consider the need for a referral to Adult and/or Child Protection. Provide relevant information regarding circumstances of individuals at risk, the degree of risk, actions already taken etc. Support any inquiries or investigations, contribute to protection planning and follow-up actions.

Level Three Characteristics

Level 3 Clutter Image Rating 7–9	Household environment will require intervention with a collaborative multi-agency approach and the involvement of a wide range of professionals. This level of hoarding constitutes a Safeguarding alert due to the significant risk to the health of the householders, surrounding properties and residents.
1. Property Structure, Services and Garden Area	• Limited access to the property due to extreme clutter • Extreme clutter may be seen at windows • Extreme clutter may be seen outside the property • Garden not accessible and extensively overgrown • Services not connected or functioning properly • The property lacks ventilation due to clutter • Evidence of structural damage or outstanding repairs including damp • Interior doors missing or blocked open • Evidence of indoor items stored outside
2. Household Functions	• Clutter is obstructing the living spaces and is preventing the use of the rooms for their intended purpose • Room(s) scores 7 – 9 on the Clutter Image Rating Scale (CIRS) • Beds inaccessible or unusable due to clutter or infestation • Entrances, hallways and stairs blocked or difficult to pass • Toilets, sinks not functioning or not in use • Tenant at risk due to the living environment • Household appliances not functioning or inaccessible • The tenant has no safe cooking environment • Tenant is using candles • Evidence of outdoor clutter being stored indoors • No evidence of housekeeping being undertaken • Broken household items not discarded, e.g. broken glass • Property is not maintained to the Council's standard

3. Health and Safety	• Human urine and excrement may be present • Excessive odour in the property may also be evident from the outside • Rotting food may be present • Evidence may be seen of unclean, unused and/or buried plates & dishes • Broken household items not discarded, e.g. broken glass or plates • Inappropriate quantities of medication • Concern with the integrity of the electrics • Inappropriate use of electrical extension cables or evidence of unqualified works to electrics • Concern for declining mental health
4. Protection Services	• Properties with adults/children presenting care and support needs should be referred to Adult/Child Protection
5. Animal Welfare	• Animals at the property at risk due to the level of clutter in the property • The tenant may not be able to control the animals • Animals living area is not maintained and smells • Animals appear to be undernourished or overfed • Hoarding of animals at the property • Heavy insect infestation (bed bugs, lice, fleas, cockroaches, ants, silverfish, etc.) • Visible rodent infestation
6. Personal Protective Equipment (PPE)	• Latex gloves, boots or needle stick safe shoes, face mask, hand sanitizer, insect repellent • Joint visits if required

Actions

Due to the significant level of risk present, this level will require a multi-agency coordinated protection response. All services should make Adult/Child Protection referrals. Provide relevant information regarding circumstances of individuals at risk, the degree of risk, actions already taken etc. Collaborate with colleagues in key meetings that follow.

Support any inquiries or investigations, contribute to protection planning and follow-up actions. If at time there are protection concerns for children, adults and/or animals then appropriate referrals should be undertaken immediately.

Contact Details

Adult Services

Any identified adult protection concerns at any level should be shared with the local team in your area.

Angus	Dundee	Perth and Kinross
ACCESSline Tel: 03452 777 778 Web: https://www.angus.gov.uk/social_care_and_health/protect_someone_from_harm/adult_protection_in_angus/what_to_do_if_you_are/concern	First Contact Team Tel: 01382 434019 Web: http://www.dundeecity.gov.uk/socialwork/protecting/	Access Team Tel: 0345 3011120 Web: www.pkc.gov.uk/article/3576/Adult-support-and-protection
Out of Hours Service Dundee and Angus		**Out of Hours Service for Perth & Kinross**
(17:00 – 08:45, Weekends & Public Holidays) 01382 307964		0345 30 111 20

Children's Services

Any identified child protection concerns at any level should be shared with the local team in your area.

Angus	Dundee	Perth and Kinross
Children, Families and Justice Investigations Team ACCESSLine: Telephone: 03452 777 778	Children & Family Service (CFS): based at Seymour House MASH Telephone: 01382 307940	Child Protection (CP) and Duty Team Telephone: 01738 476768
Out of Hours Service Dundee and Angus		**Out of Hours Service for Perth & Kinross**
(17:00 – 08:45, Weekends & Public Holidays) 01382 307964		*(17:00 – 08:45, Weekends & Public Holidays)* 01738 476768

Police Scotland Number: 101
Or 999 in an emergency

Scottish Fire and Rescue
To request a fire safety visit: https://www.firescotland.gov.uk/your-safety.aspx

Scottish Society for the Prevention of Cruelty to Animals (SSPCA)
Evidence of animal hoarding at any level should be reported to the SSPCA. The SSPCA helpline is open 7am to 11pm **(03000 999 999).** Calls are in strict confidence and can be made anonymously if necessary. Please **do not** email concerns about an animal at risk as this information may not be received immediately. https://www.scottishspca.org/

Further Information And Resources

Life Pod
Tel: 07421 329380
Email: linda@life-pod.co.uk
www.life-pod.co.uk

The Hoarding Rating Scale-Interview

Homes Multi-disciplinary Hoarding Risk Assessment

References

Kelly, A et al (2008) Exploring Self-neglect in Older Adults: Preliminary Findings of the Self-Neglect Severity Scale and Next Steps

Orr, Braye and Preston-Shoot (2017) Working with people who hoard, Dartington (ripfa)

Braye, S., Orr, D. and Preston-Shoot, M. (2014) Self Neglect Policy and Practice: Building an Evidence Base for Adult Social Care, SCIE, Report 69, ISBN 978-1-904812-56-2

https://www.scie.org.uk/self-neglect/policy-practice/research-messages-practitioners (2015)

Social Care Institute for Excellence (2012) – needs reference

Appendix 1

Room	Can the room be used for its purpose?		Are there any health and safety concerns?		Clutter rating 1 - 3		
	Yes	No	Yes	No	1	2	3
Kitchen							
Bathroom							
Separate w.c. (if appropriate)							
Lounge							
Bedroom 1							
Bedroom 2							
Bedroom 3							
Dining room (if appropriate)							
Access from the front door							
Access from the back door							
Stairs (if appropriate)							
Loft space (only where specific)							

Additional information	
Any imminent fire risks? Consider: flammable materials, working smoke alarms, any evidence of previous fire/smoke damage e.g. candles	
Are there pet/pest control issues?	
Is hoarding spilling over into the garden/ communal areas?	
Is there an overuse of electric extension cables?	
Any apparent repair issues to address? e.g. mould growth, leaks, electrical etc.	
Do the occupants smoke?	
Do the occupants have known alcohol or substance misuse issues?	
What type of heating is in the property?	
Does the tenant use portable heaters?	
Does the tenant(s) receive housing support or known to any external agency e.g. Wellbeing?	