

Supporting Adults with Hoarding and Self-neglecting behaviours Protocol

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Supporting Adults with Hoarding and Self-neglecting behaviours Protocol

City of Edinburgh Council

NHS Lothian

Health & Social Care Partnership

Scottish Fire Service

Police Scotland

Registered Social Landlords

Voluntary Sector partners

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1. Purpose of Protocol

The purpose of this protocol is to enable services to respond effectively to adults who display hoarding and self-neglecting behaviours. The protocol will introduce standardised tools and assessment guidance to assess levels of risk for all partners to direct how services respond.

There is a difference between adults who:

- a) lack the skills and motivation to manage a tenancy of their own
- b) those who have cognitive processing issues – learning disability, acquired brain injury, ADHD, Autism, etc
- c) adults who are physically frail due to an impairment/decline in functionality
- d) and those who have an emotional attachment to the items they collect, i.e. hoarding and unable to disregard. These are the adults who require a specialist hoarding informed approach

A different response is required for each of the above. Partners are to use the Clutter Image Rating Scale (CIR) to assess the level of risk in each situation to determine the course of action.

Definitions:

Hoarding

The International Classification of Diseases (ICD) defines as hoarding as:

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.

Difficulty discarding is due to a perceived need to save items, and distress associated with discarding them.

Hoarding behaviour is sufficiently severe to result in significant distress or significant impairment in personal, family, social, educational, occupational or other important areas of functioning.

It is important to distinguish between **overcrowding and hoarding**. The impact of overcrowding in a small living space may appear to workers as a hoarding issue when it is in fact a lack of living space for necessary possessions which is the presenting issue.

Self-neglect:

Self-neglect can be associated with a range of social, psychological and health issues. These impact on the individual, or groups ability to maintain standards of care and hygiene which are safe or acceptable. Intervention needs to be sensitively managed and one-off interventions are seldomly effective.

Extreme self-neglect can be known as Diogenes syndrome, a disorder characterised by domestic squalor, social withdrawal, apathy and/or compulsive hoarding of rubbish and lack of shame. Hoarding and self-neglect do not always appear together, and one does not necessarily cause the other.

Self-neglect is usually a symptom of other problems such as:

- deteriorating physical health
- onset of depression or other mental health needs
- Trauma response, and/or neuropsychological impairment
- Diminishing social networks and/or economic resources
- Personal philosophy and identity

Health implications can be:

- Living in squalid conditions, infestations and associated diseases;
- Limited cooking, bathing, heating. Sometimes without connected utilities
- Self-neglect, leading to other medical complications;
- Lack of mental capacity leading to unwise decision-making;
- Anxiety and depression; and
- Serious risk to life

Characteristics and behaviours of hoarders

It can be difficult to identify a person who hoards as the indicators are not always clear and not all adults who hoard carry the same characteristics. Like most people, adults who hoard may accumulate items for:

- **Sentimental value** - emotional attachment or to remember an important life event.
- **Utility value** - the item is or could be useful in the present or future.
- **Visual value** - the item is considered to be attractive or beautiful.
- **Instrumental saving:** saves to use in the future
- **Fear of losing information:** has to read all printed material
- **Indecisiveness:** not always purely related to decisions about their belongings
- **Fear of making a mistake:** fear they'll feel awful later because of a 'wrong decision' if they throw items away.
- **Inability to prioritise:** adult applies same level of importance to all objects, regardless of worth
- **Fear of loss:** disproportionate fear of discarding, anxiety provoking.

- **Lack of organisation:** become overwhelmed as more “stuff” is acquired and not discarded

These are some of the standard behaviours you will be presented with when working with an adult who is on the clutter/hoarding scale.

Behaviours:

- **Disorganisation:** as a result of difficulties with processing information
- **Over-focus on details:** unable to create large categories
- **Memory:** rely on visual clues, hence keeping everything out on show to stop OOSOOM (out of sight, out of mind)
- **Decision-making** due to applying equal weight to all objects regardless
- **Distractibility:** start but don't finish; flashbacks –memory lane, flitting to another task and forget to go back
- **Unrealistic** value, opportunity or responsibility for possessions
- **Churning:** most common source of frustration and decreases motivation
- **Procrastination:** some people say that *avoidance* is the compulsion of hoarding

Other types of hoarding

- **Animal hoarding** – obsessive collection of animals, often with an inability to provide the minimum 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 animals are often unable to take care of themselves.
- **Data hoarding** – This is a relatively new phenomenon and relates to the hoarding and storage of data collection equipment such a computers and other electrical storage devices or paper.

Aims & Objectives of Protocol

- To improve the management of adults who self-neglect and/or hoard through evidence-based practice
- To facilitate people to remain in their own homes
- To engage with, and support, those in the local community such as friends, relatives and neighbours who are often best placed to work with the person who is self-neglecting/hoarding
- To improve the co-ordination of services between agencies in taking responsibility for the management and support of adults who self-neglect/hoard
- To establish best practice guidance

Scope:

Who does this Protocol apply to:

- City of Edinburgh Council
- NHS Lothian
- Health & Social Care Partnership
- Scottish Fire Service
- Police Scotland
- Registered Social Landlords
- Voluntary Sector partners

Response

Some risk for people described in this protocol will be managed at a first level response i.e the worker who first comes across the person who is hoarding such as a Family and Household Support officer, Social Worker, Housing Officer, Health Worker, etc.

This requires the worker and their line manager to identify the risk and implement an agreed Action Plan to manage or minimise the risk.

Services must use **the Clutter Image Rating Scale** to initially assess the level of clutter in each situation and refer to the **Assessment Tool Guidance and Actions**. These tools will provide a comprehensive overview of what the level of risks are and the proposed/suggested interventions.

Where the tenant is already engaging with a support service, you should work alongside this arrangement and factor this into the Action Plan. This is important where the adult already has an established relationship, as adults who hoard can be mistrustful of new services.

Where a first level respondent is unable to support or carry out the actions outlined in Level's one and two and the risks persist or escalate then they should contact Social Care Direct for assistance.

Who can help and how to refer?

Social Care Direct
0131 200 2324
socialcaredirect@edinburgh.gov.uk