BSAB Self-Neglect and Hoarding Policy and Procedures

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# Policy - Self-neglect

## Introduction

This document outlines the policy for dealing with concerns in relation to self-neglect for adults with care and/or support needs. It should be read alongside the Buckinghamshire Multi-agency Safeguarding Adults Policy and Buckinghamshire Self-neglect Procedures.

Buckinghamshire SAB expects all agencies, both statutory and voluntary, to engage fully with this policy in order to achieve the best outcome for the person. Self-neglect is everyone’s business.

## What is self-neglect?

There is no universally accepted definition of self-neglect but the Care Act Statutory Guidance (updated 2018) defines self-neglect as

‘a wide range of behaviour neglecting to care for one’s personal hygiene, health or surroundings and includes behaviour such as hoarding,’

and states that:

‘where someone demonstrates lack of care for themselves and or their environment and refuses assistance or services. It can be long-standing or recent’ (DH 2018: Annex J).

The research literature suggests that self-neglect is generally made up of three elements:

* Lack of self-care (for example, neglect of personal hygiene, nutrition, hydration and/or health) and/or
* Lack of care of the domestic environment (for example, squalor or hoarding) and/or
* Refusal of services that would mitigate risk to safety and wellbeing.

The person concerned may recognise the term, but may not wish to use it to describe their own situation (Braye, Orr and Preston-Shoot, 2015).

### Models of self-neglect

Research provides a broad consensus on the main characteristics of self-neglect and the approach practitioners should take when working with people who are deemed to be self-neglecting. There is less consensus as to why people self-neglect.

Models of self-neglect encompass a complex interplay between physical, mental, psychological, social and environmental factors.

In some cases, a traumatic experience, such as bereavement, may have triggered the self-neglecting behaviour. Gaining a fuller understanding of a person’s life history and experiences may well help to create a better insight into their behaviour and possible changes that can be affected.

Sometimes self-neglect is related to deteriorating health and ability in older age and the term ‘Diogenes syndrome’ may be used to describe this. People with mental health problems may display self-neglecting behaviours. There is often an assumption that self-neglecting behaviours indicate a mental health problem but there is no direct correlation.

### Indicators of self-neglect

Self-neglect is often defined across three main areas.

**Lack of self-care, including:**

* neglect of personal hygiene
* dirty/inappropriate clothing
* poor hair, oral, skin or nail care
* malnutrition
* poor hydration and/or diet
* unmet medical health needs (e.g. refusing to take insulin for diabetes, refusing treatment for leg ulcers)
* eccentric behaviour leading to harm
* alcohol/substance misuse
* social isolation

**Lack of care of the environment, including:**

* unsanitary, untidy or dirty conditions which create a hazardous situation that could cause serious physical harm to the person or others
* poor maintenance of property / dwelling
* keeping lots of pets who are poorly cared for
* vermin
* lack of heating, running water or sanitation
* poor financial management leading to utilities being cut off etc

**Refusal of services that could alleviate these issues and mitigate against the risk of harm, including:**

* refusing prescribed medications
* declining community health care/support
* refusing help with personal hygiene from social/heath care personnel
* refusing to allow other professionals interested in keeping the environment safe access to the property for appropriate maintenance (e.g. water, gas, electricity)

It is important to understand that poor environmental and personal hygiene may not necessarily be a result of self-neglect. It could arise as a result of cognitive impairment, poor eyesight, functional or financial constraints, or neglect by others. In addition, many people who self-neglect may lack the ability and/or confidence to come forward to ask for help, and may also lack others who can advocate or speak for them.

### Characteristics identified by people considered to self-neglect

Research has identified the following common characteristics in people who are considered to be self-neglecting:

* Fear of losing control
* Pride in self sufficiency
* Sense of connectedness to the places and things in their surroundings
* Mistrust of professionals / people in authority

## Principles

Practitioners should be aware of the six safeguarding principles that underpin the Care Act 2014 and all safeguarding practice in Buckinghamshire, as outlined in the Board’s [Multi-agency Policy and Procedures.](https://www.buckssafeguarding.org.uk/adultsboard/resources/reviews-annual-reports-policies-procedures/)

Below are the principles that are particularly important for self-neglect.

### Empowerment

There are various reasons why people self-neglect. Some people may make a conscious decision to live life in a way that may have a negative impact on their health, well-being or living conditions. Often people can be unwilling to acknowledge there may be a problem or to be open to receiving support to change their circumstances.

It is important to understand the person's unique circumstances and their perception of their situation as part of any assessment and intervention.

It is crucial to consider how to engage the person at the beginning of the assessment. If an appointment letter is being sent, careful consideration must be given to what it says and whether this is the best way to engage the person. A letter may not always be the most appropriate form of initial contact, other means of communication that may be better suited to the person must always be considered.

Working with self-neglect is likely to involve making individual judgements about what is an acceptable way of living, balancing this against the degree of risk to the person and/or others.

Managing the balance between protecting adults from self-neglect against their right to self-determination is a serious challenge for both statutory and voluntary services. It calls for sensitive and carefully considered and recorded decision-making. The person should always be at the centre of the decision making and where possible make the relevant decisions.

### Partnership

Assessing mental capacity and reaching an understanding of what lies behind self-neglect is often complex. It is usually best achieved by working with other organisations and, where possible, the person, extended family and community networks. Where possible, look to work in collaboration with agencies already in contact with the individual, as they may have an existing trusting relationship.

### Protection

Dismissing self-neglect as a ‘lifestyle choice’ is not acceptable.

Sometimes people who self-neglect do not want help to change, which puts themselves and others at risk, for example through vermin infestations, poor hygiene, or fire risk from hoarding. Improvements to health, wellbeing and home conditions can be achieved by spending time building relationships and gaining trust.

Physical or mental health conditions or addictions should be reviewed and where relevant treated and then monitored.

Practical help with de-cluttering and deep-cleaning someone's home should be an option offered to the person on more than one occasion.

At the start of an enquiry process, or at any later point, the ability of the adult to understand and engage in the enquiry must be assessed and recorded. If the adult is likely to have 'substantial difficulty' in understanding and engaging in the Care Act Safeguarding Enquiry and/or section 9 care and support needs assessment, it is essential that there is an appropriate person to help them and, if there isn’t, the worker must arrange an independent advocate.

## Legal framework

### Human Rights Act 1998

Public bodies have a positive obligation under the European Convention on Human Rights (ECHR, incorporated into the Human Rights Act 1998 in the UK) to protect the rights of the individual. In cases of self-neglect, Articles 5 (the right to liberty and security) and 8 (the right to private and family life) of the ECHR are of particular importance.

These are not absolute rights: they can be overridden in certain circumstances. However, any infringement of these rights must be lawful and proportionate, which means that all interventions undertaken must take these rights into consideration. For example, any removal of a person from their home which does not follow a legal process (e.g. under the Mental Capacity or Mental Health Acts) is unlawful and would be challengeable in the Courts.

### The Care Act 2014

Under the Care Act 2014, the local authority must undertake a needs assessment, even when the adult refuses, where

1. it appears that the adult may have needs for care and support,
2. and is experiencing, or is at risk of, self-neglect.

This duty applies whether the adult is making a capacitated or incapacitated refusal of assessment.

The local authority must make, or cause to be made, whatever enquiries it thinks necessary to enable it to decide what action should be taken in an adult’s case, when the local authority has reasonable cause to suspect that an adult in its area

1. has needs for care and support,
2. is experiencing, or is at risk of, self-neglect, and
3. as a result of those needs is unable to protect him or herself against self- neglect, or the risk of it.

If the adult has 'substantial difficulty' in understanding and engaging with a safeguarding enquiry, the local authority must ensure that there is an appropriate person to help them and, if there isn’t, arrange an independent advocate.

### Other relevant legislation

**Mental Health Act (2007) s.135** – if a person is believed to have a mental disorder and they are living alone and unable to care for themselves, a magistrate’s court can authorise entry to remove them to a place of safety.

**Mental Capacity Act (2005) s.16(2)(a)** – the Court of Protection has the power to make an order regarding a decision on behalf of an individual. The court’s decision about the welfare of an individual who is self-neglecting may include allowing access to assess capacity.

**Public Health Act (1984) s.31-32** – local authority environmental health could use powers to clean and disinfect premises but only for the prevention of infectious diseases.

**The Housing Act 1988** – a landlord may have grounds to evict a tenant due to breaches of the tenancy agreement.

### Data protection

Good information sharing is essential in working with people who self-neglect.

The Data Protection Act 2018 contains GDPR and retains much of the 1998 Act relating to information sharing.

However, while the GDPR places greater emphasis on the need to justify the rationale for retaining personal information, organisations will remain compliant as long as they are able to demonstrate why it is necessary to keep this information for safeguarding purposes as long as the lawful basis for holding this information remains.

Under Article 23, sharing data is permissible ‘if there is a risk to an individual, or society, of […] not sharing the information’, but only ‘where the restriction respects the essence of the individual’s fundamental rights and freedoms and is a necessary and proportionate measure in a democratic society to safeguard the protection of the individual, or the rights and freedoms of others.’

# Policy - Hoarding

Hoarding is one common aspect of self-neglect and typically involves the excessive collection and retention of any material to the point that this has a significant negative impact on the wellbeing of the person.

Hoarding is recognised as a mental disorder and is defined as involving a persistent difficulty discarding or parting with possessions because of a perceived need to save them. A person with hoarding disorder experiences distress at the thought of getting rid of the items. Hoarding involves the accumulation of items, regardless of actual value.

Hoarding often creates such cramped living conditions that homes may be filled to capacity, with only narrow pathways winding through stacks of clutter. Countertops, sinks, stoves, desks, stairways and virtually all other surfaces may be piled up with stuff. The clutter may spread to the garage, vehicles, garden and other storage facilities.

Hoarding ranges from mild to severe. In some cases, hoarding may not have much impact on a person’s life, while in other cases it seriously affects their functioning on a daily basis.

People with hoarding disorder may not see it as a problem, making intervention challenging.

## Signs and symptoms of hoarding

The first signs and symptoms of hoarding disorder often occur during the teenage to early adult years. Problems with hoarding gradually develop over time and, often, significant clutter has developed by the time it reaches the attention of others.

Signs and symptoms may include:

* Excessively acquiring items that are not needed or for which there is no space
* Persistent difficulty throwing out or parting with your things, regardless of actual value
* Feeling a need to save these items, and being upset by the thought of discarding them
* Building up of clutter to the point where rooms become unusable
* Having a tendency toward indecisiveness, perfectionism, avoidance, procrastination, and problems with planning and organising.

Excessive acquiring and refusing to discard items results in:

* Disorganised piles or stacks of items, such as newspapers, clothes, paperwork, books or sentimental items
* Possessions that crowd and clutter walking spaces and living areas and make the space unusable for their intended purpose, such as not being able to cook in the kitchen or use the bathroom to bathe
* Build-up of food or rubbish to excessive, unsanitary levels
* Significant distress or problems functioning or keeping the person and others safe in their home
* Conflict with others who try to reduce or remove clutter from your home
* Difficulty organising items, sometimes losing important items in the clutter

## Reasons for hoarding

People with hoarding disorder typically save items because:

* They believe these items are unique or will be needed at some point in the future
* The items have important emotional significance - serving as a reminder of happier times or representing beloved people or pets
* They feel safer when surrounded by the things they save
* They don't want to waste anything

Hoarding disorder is different from collecting. People who have collections, such as stamps or model cars, deliberately search out specific items, categorize them and carefully display their collections. Although collections can be large, they aren't usually cluttered and they don't cause the distress and impairments that are part of hoarding disorder.

## Clutter Image Rating Tool

In cases of hoarding, practitioners should consult the [Clutter Image Rating Tool](https://www.buckssafeguarding.org.uk/adultsboard/information-for-professionals/) to assess the level that the hoarding has reached and determine the next course of action. It has been developed in partnership with Buckinghamshire Fire and Rescue Service to be used by practitioners. Images are rated from 1 to 9 for level of seriousness. However, this Tool should be used as a guide only and should not replace professional decision making.

## Fire risks

If the practitioner has assessed that a person’s hoarding is impinging on their own life and wellbeing, they should consider referring to the Buckinghamshire Fire and Rescue Service, via their [Fire and Wellness Visits](https://bucksfire.gov.uk/service/fire-and-wellness-visits/).

While a person’s consent to involve the Fire Service should always be sought, it may be necessary to override their wishes if they are at risk of serious injury or death should a fire occur. Properties with large amounts of hoarded items also present a risk to neighbours and any fire fighters called to attend an incident.

To arrange for a Fire and Wellness Visit, the practitioner should email their name, address, phone number and concern to centraladmin@bucksfire.gov.uk or phone 01296 744477. It is important to include the contact details of the adult at risk and whether they have provided consent.

## Hoarding and animals

People who hoard animals may collect dozens or even hundreds of pets. Animals may be confined inside or outside. Because of the large numbers, these animals often aren't cared for properly. The health and safety of the person and the animals are at risk because of unsanitary conditions.

The Animal Welfare Act 2006 places a duty of care on the person to look after an animal’s welfare as well as ensure that it does not suffer. This applies to all animals. If there is a concern, report it to the [RSPCA](https://www.rspca.org.uk/utilities/contactus/reportcruelty/crueltychecklist) on 0300 1234 999.

If children are involved in environments where animals are being hoarded and are at risk of being harmed as a result, a referral to Children’s Services is required.

# Procedures

## Identifying self-neglect concerns

Where concerns of self-neglect are established, the practitioner should focus on building a relationship with the adult to identify proportionate options that would improve their health, wellbeing and living conditions, and to support them in the implementation of those options.

The aim should be:

* To understand from the person how the situation has been triggered and developed.
* To empower the person who is neglecting him/herself as far as possible to understand the implications of their actions.
* To help the person, both individually and collectively with others (e.g. family, friends, other professionals and agencies) without colluding with the person or seeking to avoid the issues presented.
* To avert the potential need for statutory intervention wherever possible. This may be achieved by providing some form of low level monitoring.

The practitioner should refer to the [Self-Neglect and Hoarding Risk Assessment Tool](https://www.buckssafeguarding.org.uk/adultsboard/information-for-professionals/) to assess the level of risk involved in the person’s situation.

Whether or not the adult has capacity to give consent, action may need to be taken if others are or will be put at risk if nothing is done or where it is in the public interest to take action. Wishes need to be balanced alongside wider considerations such as level of risk or risk to others, including any children who could be affected. The person still needs to be involved and kept informed of any actions to be taken.

## Multi-agency meetings

If the risks relating to a person’s self-neglect appear low, the usual adult support services will be the most proportionate and least intrusive way of addressing the risk of self-neglect, although it is important to monitor the situation and identify any escalation of risks.

Where higher-risk self-neglect concerns are apparent, it is the responsibility of the agency/individual providing on-going support to arrange an initial Multi- Agency Meeting, involving all the relevant agencies, the person themselves (wherever possible) and other members of the person’s network as appropriate.

### Purpose of the meeting

The purpose of the meeting will be to identify and consider options to support the person to make changes, taking account of their views, capacity assessments, risk assessments, public safety and health.

### Attendance, roles and responsibilities

The meeting must be convened by, and chaired by, the agency most closely involved with the person, which has identified the issue of self-neglect.

The adult should always be informed of the multi-agency meeting and invited to attend, or have the opportunity to have their wishes and views shared at the meeting.

It is essential that all relevant agencies are aware of and involved in the case, and that information is being shared appropriately and plans are being agreed. Any concerns about lack of involvement by a particular agency or individual should be recorded and escalated through senior managers. If there is a significant lack of co-operation which cannot be resolved, this should be escalated to the Council’s Head of Safeguarding.

A ‘Lead Agency’ should be agreed at the multi-agency meeting – this should be the most appropriate agency involved with the person, e.g. Social Care, a GP, the Police, a Housing agency or any other organisation involved with the person, either statutory or voluntary.

It will also agree a ‘Lead Worker’ to co-ordinate actions, and will set a date for a review meeting.

The Lead Agency and Lead Worker role may change at any time if this is required in response to the situation, but this decision should be clearly recorded and communicated to all those involved.

The multi-agency meeting will keep the person at the centre and consider any risk assessments in line with their goals and identified needs. Any options identified will be discussed with the person to then agree further action.

### Decisions

A Self-Neglect Risk Plan to address the issues raised must be agreed. This plan should be clear about the roles and responsibilities of the various professionals involved and include timescales for actions to be completed. A date should be set for a Review Meeting.

Where the person appears to have a need for care and support, a referral for a Care Act assessment should also be made and this should be undertaken by Adult Social Care within 28 days. The Agency carrying out a Care Act assessment or Section 42 Enquiry must consider whether a multi-agency meeting needs to be convened before the outcome of the assessment/enquiry is known and the reasons for the decision here recorded in full.

Similarly, where the person appears to have health needs, a referral must be made to the appropriate health professional(s) for relevant assessments to be undertaken. The agency/individual identifying the self-neglect concern must, wherever possible, make the person aware that they are referring them for the health or social care assessment. Any reason for the person not being aware of the referral needs to be included in the referral information.

An immediate Safeguarding Adults referral must be made if the risks are considered high or very high or where there appear to have been acts of neglect or abuse by a third party. Where this is not the case, these Self Neglect procedures should be followed. The Safeguarding Adults referral option should be a standard agenda item for discussion at review meetings.

### Progressing actions

A record of the meeting will be made and distributed as soon as possible after the meeting takes place.

A review meeting will be set at each multi-agency meeting until the situation has been resolved.

At the point of closure, a plan should be drawn up, ideally with the person, to establish ongoing arrangements for monitoring the situation. The person and their network must have information about how to report concerns if the situation is deteriorating.

## Assessing mental capacity

A proper understanding of mental capacity is a crucial aspect of working with people who self-neglect. Practitioners should be familiar with the Mental Capacity Act 2005 and its Code of Practice, [which can be found on the government website](https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice).

It is important to assess whether people who self-neglect can:

* Understand, retain, use and weigh relevant information, including information about the consequences of any decision (mental capacity) and
* Implement their actions (executive capacity).

The assessment should consider:

* Does the adult understand they have a problem with self-neglect and the risks associated with this?
* Does the adult understand the impact their self-neglect may be having on others, e.g. children?
* Can the adult retain the information given to them?
* Is the adult able to weigh up the alternative options? e.g. being able to move around their accommodation unhindered, being able to sleep in their bed, cook in their kitchen?
* Can the adult communicate their decision?

Assessment should consider whether there are any concerns about possible duress and whether the individual is being influenced or exploited by others who may not have their best interests at heart.

Practitioners should remember the empowering principles of the MCA. It is essential that all capacity assessment is clearly documented in case records.

Where the individual has mental capacity but is not able to exercise choice as a result of duress or exploitation, legal advice should be sought regarding an inherent jurisdiction application to the High Court.

When a person is assessed as lacking capacity, a Best Interests decision should be made on their behalf and the least restrictive option should always be preferred. The person remains involved as far as possible.

Mental capacity assessments are both time and decision specific and should be considered and/or repeated as risk changes and in relation to each individual decision/risk.

The person should be supported to make an informed decision. This means that professionals will need to take time explaining the likely consequences of all courses of action.

### Deprivation of Liberty Safeguards

The Mental Capacity Act allows for a person, who lacks mental capacity to make relevant decisions, to be deprived of their liberty under the Deprivation of Liberty Safeguards (DoLS) for the purposes of care and treatment.

In urgent situations, where it is believed that an adult lacks mental capacity (but it has not yet been possible to satisfactorily assess them), and the home situation requires urgent intervention, the Court of Protection can make an interim order to allow intervention to take place.

The Court will however expect to see evidence of professional action planning, decision-making and recording.

Legal advice should be sought at the earliest opportunity to enable applications for authorisation to be made without delay.

## Care Act assessments

In some cases, a Care Act assessment or Carer’s assessment should be undertaken and, if the person is found to be eligible, appropriate services offered. If any agency needs to take such steps, the reasons for doing so should be clearly documented.

The lead worker will ensure that, where the person has capacity to decline intervention after all reasonable efforts have been made to engage them, and the risk is considered acceptable by the professionals involved in the multi-agency review, the person knows how to easily get back in touch with the team, as do all significant others involved.

Just because the person has declined support before does not mean they will in future, and support should continue to be offered as appropriate.

Any attempts to engage the person should be clearly recorded to support any future attempted assessments.

### Undertaking assessments where the person refuses an assessment

As a matter of practice, it will always be difficult to carry out an assessment fully where an adult with mental capacity is refusing to be involved. Practitioners should record fully all steps that have been taken to carry out a needs assessment, including what steps have been taken to involve the person and any carer, and assessing the person’s desired outcomes for their day to day life. They should also record whether the provision of care and support would contribute to the achievement of these outcomes.

In the case of an adult’s repeated refusal, it may not be possible to carry out a full needs assessment or provide any care and support. Case recording should evidence that all necessary steps have been taken to carry out the assessment and that these were necessary and proportionate. It should also evidence that appropriate information and advice has been provided to the adult, including how to access care and support in the future.

If the adult has refused an assessment or services and remains at high risk of serious harm, practitioners must make a referral to the High Risk Complex Case Panel.

## Safeguarding enquiries

The aims of statutory Care Act (s.42) safeguarding enquiries in self-neglect cases are to:

* establish facts and provide a description of the self-neglect
* ascertain the adult’s views and wishes
* assess the needs of the adult for protection and support and how those needs might be met
* protect and support the adult from self-neglect in accordance with the wishes of the adult, and in line with their mental capacity to make relevant decisions about their care and support needs
* promote the wellbeing and safety of the adult through a supportive and empowering process

Any safeguarding enquiries or assessments that are made will need to be appropriate and proportionate to the individual circumstances of the case. These must be formulated and agreed between the practitioner and the Team/Service Manager who chairs the case. Making Safeguarding Personal principles should always be applied, see the Board’s [Multi-agency Policy and Procedures](https://www.buckssafeguarding.org.uk/adultsboard/resources/reviews-annual-reports-policies-procedures/) section on principles for more information.

Any enquiries or assessments made, and actions taken, must be lawful and proportionate to the level of risk involved.

### When to prompt an enquiry

The Care Act Statutory Guidance (2018) states: “It should be noted that self-neglect may not prompt a section 42 enquiry. An assessment should be made on a case by case basis. A decision on whether a response is required under safeguarding will depend on the adult’s ability to protect themselves by controlling their own behaviour. There may come a point when they are no longer able to do this, without external support.”

Where an adult is engaging with and accepting assessment or services that will meet their care and support needs (including those relating to self-neglect), they are not demonstrating that they are ‘unable to protect themselves’ as set out in the criteria for a section 42 safeguarding response.

However, where there is reasonable cause to suspect that the adult is unable to protect him or herself from self-neglect or the risk of it as a result of their care and support needs, and the risk is high or very high, a safeguarding concern should immediately be triggered. This will also be the case where previous attempts to work in a multi-agency way (as set out above) have failed to produce a reduction in risk.

Any agency or individual that is concerned that the Self-Neglect Plan is not reducing risks to an acceptable level should raise a safeguarding concern.

The s.42 enquiry process will determine what action is needed. See the Board’s [Multi-agency Policy and Procedures](https://www.buckssafeguarding.org.uk/adultsboard/resources/reviews-annual-reports-policies-procedures/) for more on the s. 42 process.