

Self-Neglect and Hoarding Strategy and Pathway

This document sets out the SAEB's multi-agency strategy and guidance for working with people who are experiencing self-neglect and hoarding

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Safeguarding Adults Executive Board Strategic Vision

The Safeguarding Adults Executive Board (SAEB) is a statutory partnership that sets the strategic direction for safeguarding and has responsibility for overseeing and leading on the protection of adults who are experiencing, or who are at risk of abuse or neglect living across the Royal Borough of Kensington and Chelsea and Westminster City Council (referred to as the Bi-Borough).

The SAEB holds strategic responsibility for ensuring that self-neglect and hoarding is taken seriously and responded to effectively on a multi-agency basis. This strategy operates within a shared interagency governance framework informed by the following principles:

- (1) Agencies have a shared understanding and definitions of self-neglect and hoarding.
- (2) Inter-agency coordination and risk management is facilitated by clear referral routes, effective communication and information sharing, and use of shared risk management and decision-making systems.
- (3) Relationship-based and person-centred involvement is accepted as pivotal in achieving long-term and meaningful outcomes.
- (4) Practitioners need to be supported to deal with the ethical challenges relating to supporting adults experiencing self-neglect and hoarding. Training and supervision should support practitioners to increase their knowledge and build practical skills to support effective practice.

(Based on work by Braye et al., 2011; Braye et al., 2014).

This strategy reflects a determined effort across the range of SAEB partner organisations, including social and private housing and voluntary and community sector organisations, to produce a strategy which will make a real difference to how we support adults experiencing self-neglect and/or hoarding.

Within this strategy, the term self-neglect when used here onwards on its own is intended to be considered as an umbrella term which can encompass both self-neglect and hoarding. The SAEB has produced a separate hoarding toolkit, which is linked to this overarching strategy.

1. Introduction

- 1.1 Supporting adults who experience self-neglect is a highly complex area of practice. Practitioners often find work in this area to be personally and professionally difficult, with ethical and legal considerations, including in relation to striking the right balance in protecting adults at risk against their right to self-determination, and where adults have the mental capacity to refuse support. Often people experiencing self-neglect find it difficult to trust and engage with services and services can in turn find it challenging to work and effect changes when working with those who are self-neglecting.
- 1.2 Many Safeguarding Adults Reviews (SARs) have highlighted important learning in relation to self-neglect and a need for:
 - Early and effective information sharing and multi-agency communication and collaboration.
 - Comprehensive and robust risk assessment, planning and management.
 - A clear interface with safeguarding adults' procedures when indicated.
 - Understanding of the application of the Mental Capacity Act (MCA) 2005.
 - A clear understanding of the range of legislative options available to intervene to safeguard a person who is self-neglecting.
 - Effective management oversight and supervision to enable reflection on working with complex cases involving self-neglect.
- 1.3 The <u>Second National Analysis of SARs</u> (April 2019 March 2023) reported the most common type of abuse was self-neglect, which featured in 60% of cases; a marked increase in comparison with 45% in the first national analysis.
- 1.4 This strategy, pathway and accompanying hoarding toolkit sets out the Bi-Borough's approach for collaborative multi-agency working and offers guidance to practitioners and managers from any agency to follow when working with adults who are self-neglecting. It focuses on the importance of early intervention and prevention and working in partnership to manage risks and to empower adults as far as possible to understand the implications of their self-neglecting behaviour.
- 1.5 The aims of this policy and procedures are to:
 - Set out a clear multi-agency self-neglect pathway to follow, whether this falls within a Section 42 safeguarding enquiry or outside of this, with a focus on shared responsibility for assessing and managing risks and working collaboratively and creatively in planning responses and solutions.
 - Utilising a person-centred and strength-based approach to maximise an individual's engagement in addressing concerns relating to self-neglect.
 - Establish best practice and improve knowledge of legislation (including in relation to the application of the MCA) and other routes to support individuals who are experiencing self-neglect.
 - Enable a preventative and proactive approach in which organisations uphold their duties of care.
 - Ensure there is a proportionate response to the levels of risk the adult experiencing self-neglect presents to self and others.

- 1.6 The purpose of this strategy is to foster a consistent approach, that works alongside agencies own self-neglect policies and guidance. It should inform working practices for all agencies based within the Bi-Borough who work with adults experiencing self-neglect. There is an expectation that everyone will engage fully with the principles set out in this document as well as utilise the resources provided within the hoarding toolkit.
- 1.7 This strategy should be read in conjunction with the <u>London Multi-Agency Adult Safeguarding Policy and Procedures</u> and the <u>Care and Support Statutory Guidance</u> which accompanies the Care Act 2014.

2. Self-neglect and hoarding pathway

2.1 The flowchart below provides an overview of the self-neglect pathway in the Bi-Borough. It should be used to help determine what appropriate steps should be taken to best support the adult and reflects the interface between the self-neglect pathway and cases that progress to a Section 42 safeguarding enquiry.

Early intervention and prevention

Many adults with care and support needs will have lower-level issues or concerns linked to self-neglect, and most of these people will not come to the attention of statutory services (nor will want to).

Low Risk

Individual agencies in contact with the adult should remain vigilant in monitoring and offer early help, signposting and support to prevent problems from escalating.

Identifying agency raises a concern

If concerns relating to an adult with care and support needs who is experiencing selfneglect and/or hoarding reach a point where the adult is experiencing harm (and/or presenting a risk to others) and is unable to protect themselves from this, the identifying agency should:

- Contact Adult Social Care (ASC) to raise a safeguarding concern.
- Where possible, have a conversation with the adult beforehand to seek their views and consent to making a referral to ASC. Where consent is not given, but there are concerns that the person is at significant risk to themselves or there is risk to others, professionals can override consent and contact ASC. The reasons for taking this action should be explained to the adult and assurance given that their wishes will be respected as much as possible.
- Consider the person's mental capacity in relation to the risks relating to their self-neglect and/or hoarding behaviour – where necessary seek support from ASC around capacity considerations.

Moderate Risk

Implement Self-Neglect and Hoarding (SNAH) pathway

In line with Section 42 of the Care Act, concerns in relation to self-neglect do not necessarily trigger a Section 42 enquiry, and in the first instance the self-neglect and hoarding pathway will be used, in which ASC will:

- Consider the adult's needs for a social care assessment under the Care Act and/or signpost to other relevant services, such as Primary Care or Mental Health support.
- ASC convenes a meeting to confirm who will be the lead agency and is best placed to coordinate the self-neglect process*.

*The lead agency will be the agency best placed to coordinate the self-neglect pathway. This could be because:

- The agency is already involved with the adult.
- The agency has a duty of care towards the adult because of their needs.
- The agency holds significant information relating to the adult.
- The adult has shown a likelihood to engage best with this agency in the past.

Lead agency actions under the SNAH pathway

- Works with the adult and /or their representative to ensure that they are involved throughout the process.
- Coordinates information gathering.
- Undertakes a comprehensive risk assessment.
- Carries out a mental capacity assessment, where required.
- Convenes a multi-agency meeting to consider risks, share information and devise a shared action plan.



Outcomes achieved and risks reduced / addressed:

- Support accepted.
- Ongoing monitoring arrangements.

End of SNAH process



Outcomes not achieved / risks remain:

Refer to step below

Escalation to Section 42 Safeguarding Enquiry

If there is a risk of significant harm (life threatening) or the self-neglect and hoarding pathway has been exhausted and risk to the adult not sufficiently reduced, a Section 42 enquiry should be instigated.

Consideration will also be given to escalation of concerns to senior manager and legal services.

Please also refer to the hoarding flowchart below for specific steps to be taken in hoarding cases.

Moderate Risk

High Risk 2.2 In addition to the flowchart above, the following pathway is adopted specifically in hoarding cases. Refer to the hoarding toolkit for risk assessment, hoarding assessment and Clutter Image Rating (CIR) tool templates.

Hoarding case identified



Conduct an assessment using relevant assessment tools and the Clutter Image Rating (CIR) Tool:

Consider joint assessments – ASC, Housing, Primary Care, Mental Health and Voluntary and Community Sector



Level 1 Low Risk

Early intervention and prevention



Level 2 Moderate Risk

Multi-Agency response via SNAH pathway



Level 3 High Risk

Consider multiagency response under safeguarding procedures

3. Definitions of self-neglect and hoarding

- 3.1 Self-neglect covers a wider range of situations and behaviours, linked to numerous factors including:
 - Changes in physical or mental health, including age-related changes.
 - Impact of trauma, including Adverse Childhood Experiences (ACEs), bereavement, loss and traumatic events.
 - Alcohol or drug misuse or dependency.
 - Diminishing social networks and/or economic resources leading to social isolation.
 - Fear, anxiety or pride in relation to a need to be self-sufficient.
- 3.2 The reasons for self-neglect are complex and varied, and it is important that health and social care practitioners pay attention to mental, physical, social and environmental factors that may be affecting the situation (Braye, Orr and Preston-Shoot, 2015).

What is self-neglect?

- 3.3 The <u>Care and Support Statutory Guidance</u> defines self-neglect as "covering a wide range of behaviours neglecting to care for one's personal hygiene, health or surroundings and includes behaviour such as hoarding".
- 3.4 The following indicators of self-neglect is not an exhaustive list, but it can include:
 - Living in very unclean, sometimes infested and verminous circumstances.
 - Neglecting household maintenance creating fire risks or hazards, e.g. rotten floorboards, lack of boiler, dangerous electrics.
 - Poor personal hygiene and poor health, e.g. unkempt appearance, long finger nails and toe nails, pressure sores, malnutrition and dehydration.
 - Poor diet and nutrition, e.g. little or no fresh food, or mouldy out-of-date food, and there is evidence of significant weight loss.
 - Declining prescribed medication or necessary help from health and/or social care services.
 - Collecting a large number of animals who are kept in inappropriate conditions.
 - Financial debt issues which may lead to rent arrears and the possibility of eviction.
 - Not managing finances, such as prioritising the purchase of alcohol or substances over buying food and paying utility bills.
 - Excessively cluttered environment which poses a fire risk and access difficulties.

What is hoarding?

- 3.5 Hoarding can be described as the excessive collection and retention of any material to the point where it impedes day to day functioning (Frost and Gross, 1993). Those who experience hoarding have a persistent difficulty in discarding or parting with possessions because of a perceived need to save them. Hoarding behaviour can become a concern for others when health and safety is threatened by the nature or number of items accumulating within, and sometimes overflowing from, the property of the person who is hoarding.
- 3.6 Pathological or compulsive hoarding is a specific type of behaviour characterised by:
 - Acquiring and failing to throw out many items that would appear to hold little or no value.
 - Severe cluttering of a person's home (rated 7 9 on the <u>International Clutter Rating</u>) is usually at a point when rooms can no longer be used for their intended purposes.
 - There will be signs of significant distress or impairment of work or social life.
- 3.7 Hoarding was previously considered a form of Obsessive-Compulsive Disorder (OCD) but is now considered a standalone mental disorder and is included in the 5th edition of the <u>Diagnostic and Statistical Manual of Mental Disorders (DSM) 2013</u>. However, hoarding can also be a symptom of other mental disorders. Hoarding disorder 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.
- 3.8 Not everyone who owns lots of possessions exhibits hoarding behaviour and a chronic disorganisation can be caused by numerous factors and a range of conditions, including, for example, autism, acquired or traumatic brain injury, stroke, dementia, post-traumatic stress disorder (PTSD), obsessive compulsive personality disorder, anxiety or depression.
- 3.9 There are several types of hoarding:

Inanimate objects	The most common and may consist of hoarding either one type of object of a mixture: old clothes, newspapers, food, containers etc.
Animal hoarding	This is an increasing area and is often accompanied by the inability to provide minimal standards of care. The person is unable to recognise the animals are at risk and feel that they are saving them. The accumulation of animal faeces and pest or insect infestations is a particular issue.
Data hoarding	This is a relatively new area and may include computers, electronic storage devices, the need to store copies of emails and other information in electronic format.
Diogenes syndrome	Is a disorder characterised by extreme self-neglect, domestic squalor, social withdrawal and apathy. The individual is often an older person and struggles to manage their personal care as well as home environment.

- 3.10 The impact of hoarding behaviour on the individual and others is significant and can:
 - Make cleaning very difficult, leading to unhygienic conditions prone to rodent or insect infestations.
 - Pose a fire risk and block exits in the event of a fire occurring. Where there is
 excessive accumulation of items, this can further increase risks around fire spreading
 and can lead to access difficulties for firefighters.
 - Restrict access to key parts of the property and cause falls risks.
 - Present risk of injury if large piles of items fall or collapse.
- 3.11 The table below summarises the general characteristics of hoarding:

Fear and anxiety	Compulsive hoarding may have started as a learnt behaviour or following a significant event such as bereavement. The adult may feel that buying or saving things will relieve the anxiety and fear that they feel. The hoarding becomes their comfort blanket.
Excessive attachment to objects	People who hoard may hold a strong emotional attachment to items that can be difficult to understand.
Indecisiveness	People who hoard may struggle with the decision to discard items that are no longer necessary, including items others would consider as waste.
Unrelenting standards	People who hoard may often find fault with others, requiring others to perform to excellence while struggling to organise themselves and complete tasks of daily living.
Social isolation	People who hoard will typically alienate family and friends and may be embarrassed to have visitors. They may refuse home visits from professionals.

Large number of pets	People who hoard may have many animals that can be a source of complaints by neighbours. The adult may have a tendency to 'rescue' strays.	
Mental capacity	People who hoard are typically able to make decisions that are not related to hoarding behaviour.	
Extreme clutter	Hoarding behaviour may be in more than one room, or all rooms, and prevent them from being used for their intended purpose.	
Churning	Hoarding behaviour can include moving items from one part of the property to another without ever discarding them.	
Self-care	A person who hoards may appear unkempt and dishevelled due to a lack of access to bathroom or washing facilities. However, some people who hoard will use public facilities to maintain their personal appearance and hygiene.	
Poor insight	A person who hoards will typically see nothing wrong with their behaviour or the impact of this.	

3.12 The hoarding toolkit should be used in conjunction with this guidance to support the identification of hoarding and to assess the overall level of risk.

4. When is self-neglect a safeguarding issue under the Care Act 2014?

- 4.1 The Care Act 2014 formally recognises self-neglect as a category of abuse and places a duty of cooperation on all agencies to work together to support adults who are self-neglecting and/or hoarding. The Care Act emphasises the importance of early intervention and preventative actions to minimise risk and harm. Central to the Care Act is the wellbeing principle and focusing on decisions which are person-led and outcomes-focussed. The principles are important considerations when responding to cases involving self-neglect.
- 4.2 Under <u>Section 42 of the Care Act</u>, a safeguarding enquiry is required when the person who is self-neglecting meets the statutory criteria below:
 - The adult has needs for care and support (whether or not the local authority is meeting any of those needs), and
 - Is experiencing, or is at risk of abuse or neglect, and
 - As a result of their care and support needs is unable to protect themselves from either the risk of, or the experience of, abuse or neglect.
- 4.3 However, the <u>Care and Support Statutory guidance (14.17)</u> states 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".

- 4.4 This recognises that Section 42 enquiries are primarily aimed at adults who are experiencing abuse or neglect caused by a third party, and a safeguarding response in the first instance may not be the most effective approach to respond to the self-neglect and engage with the adult to facilitate effective and longer-term change.
- 4.5 Decisions are made on a case-by-case basis, but in the first instance the Self-Neglect and Hoarding (SNAH) pathway will be used. Situations which present with a lower level of risk, and can include adults who are not in receipt of health and social care services, and have not been known to ASC previously, are addressed through other pathways, such as:
 - Engaging the adult in a Care Act assessment.
 - Signposting to alternative services or community resources.
 - Arranging for mental health services and support.
 - Contact with community health services, such as GP.
- 4.6 Professional judgement and risk assessment is key in determining the level of intervention required. Any factor or issue may move a lower risk case into a higher threshold which would warrant consideration under safeguarding procedures and/or consideration of other legal remedies. Where there are indicators that the level of risk is likely to change, appropriate action should be taken or planned.
- 4.7 Significant indicators of risk include:
 - History of crisis incidents with life-threatening consequences.
 - Risks to self and/or others relating to substance misuse.
 - Risks of fire to self and/or others associated with hoarding, smoking, use of portable heaters and candles, overloaded electrical sockets, lack of smoke alarms etc.
 - High level of multi-agency referrals received.
 - Risk of domestic violence.
 - Fluctuating capacity.
 - History of safeguarding concerns or the person being vulnerable to exploitation.
 - Financial hardship including risk to tenancy or home security risks.
 - Committing criminal offences, such as public order offences, including anti-social behaviour, hate crime, offences linked to petty crime, etc.
 - Unpredictable or chronic health conditions due to non-compliance with the proposed treatment.
 - History of traumatic and/or unstable life, significant substance misuse or self-harm.
 - Environment presents high risks, such as inadequate plumbing, washing or toileting facilities.
 - Difficulties in professionals being able to effectively engage with the person.
 - Little or no informal support network, socially isolated.
- 4.8 In all cases, when a concern is raised regarding self-neglect all agencies have a responsibility to consider the guidance within this strategy. This is regardless of whether the concern falls within the scope of a Section 42 enquiry or not.
- 4.9 The SAEB has produced <u>Safeguarding Referral Practice Guidance</u>, which provides advice on when safeguarding concerns should be raised, including in relation to self-neglect.
- 4.10 Any safeguarding concerns or requests for care and support assessments under the Care Act should be raised with ASC:

- Kensington and Chelsea on 020 7361 3013 or socialservices@rbkc.gov.uk
- Westminster on 020 7641 2176 or adultsocialcare@westminster.gov.uk

5. Effective engagement

- When working with adults who are self-neglecting, the starting principle must always be the adoption of a person-centred, strengths-based approach. This will ensure the adult's rights to be treated with dignity and respect are upheld, and that they are supported to remain in control of decisions about their lives, as much as possible.
- 5.2 Key principles of effective engagement include:
 - Building a relationship of trust with the person over a period of time and at the person's own pace.
 - Ensuring the adult has access to information in a format they can understand.
 - Finding the whole person and understanding their history.
 - Consider who is best placed to support you to engage with the adult (e.g. family, advocate, other professional). Always involve Lasting Powers of Attorneys or representatives if the adult has one.
 - Taking account of the person's mental capacity to make self-care decisions and to act upon those decisions.
 - Being open and honest about risks, and check that the person understands the options available and consequences of their choices.
 - Working across the safeguarding partnership in a structured approach.
 - Developing creative and flexible interventions. These should include personalised therapeutic and psychological support and not just deep clean or decluttering services in isolation, which on their own are unlikely to lead to long-term and meaningful change and can further impact on the trauma experience by the person.

Challenges of non-engagement

- 5.3 A frequent challenge encountered by professionals when working with adults who are experiencing self-neglect is when adults refuse or are unable to engage with and accept services to support them. There will often be competing demands between demonstrating respect for the adult's autonomy and self-determination and the need to protect the adult and or others from harm.
- 5.4 Ineffective agency engagement can present in a variety of ways, including:
 - The adult may forget or need support to attend appointments.
 - The adult may have had previous negative experiences with services and is hesitant to work with services again.
 - The adult may have difficulty agreeing a plan of support or implementing actions.
 - The adult declines to engage with support and/or provide access to the property.
 - The adult fails to respond to telephone calls and/or letters from the agency.
- As set out at 3.2, self-neglect is a complex interplay between physical, mental, social, personal and environmental factors. It is likely that self-neglect is the result of some incident or trauma experienced by the adult, for example childhood trauma, bereavement or abuse. The impact of this trauma can lead to a person becoming demotivated and developing a poor self-image and

- self-esteem. The person may feel embarrassment, shame, guilt, and anxiety, which can impact on their ability to engage with professional support. Positive outcomes can be achieved by thorough approaches which are trauma-informed, non-judgemental and compassionate.
- 5.6 Accepting self-neglect as a 'lifestyle' choice and closing a case without having assessed the risk and engaged with the adult in a meaningful way is unacceptable, as this exposes the adult to on-going or increased harm or risk and leads to organisations failing in their duty of care. Cases involving moderate or high risk should not be closed simply because an individual has difficulty engaging with support, without ensuring that a multi-agency meeting has taken place to discuss the implications of this decision.
- 5.7 Part of the challenge is knowing when and how far to intervene where there are concerns about self-neglect when a person makes a capacitated decision not to acknowledge there is a problem or to engage in improving their situation. This involves making professional judgements about what is an acceptable way of living, balanced against the degree of risk to the adult and/or others. Multi-agency meetings should always be held, with agreement as to which organisation will maintain contact in an effort to engage the individual and monitor/reduce the risks. This may require agencies to be flexible about their use of criteria to access services when they appear best placed to lead and coordinate the care and support.

Person-centred approaches

- 5.8 Effective multi-agency working requires consideration of who is best placed to work creatively and proactively with the adult who is self-neglecting and who can build a relationship of trust that is more likely to enable the person to accept support. For example, the person may have already established a positive working relationship with another professional, such as a worker from a care agency, voluntary agency, mental health services or housing department.
- 5.9 It is important to seek to understand self-neglect from the adult's perspective and to work collaboratively to seek solutions. This includes ensuring that appropriate and sensitive language is used. For example, adults may prefer the term 'collecting' rather than 'hoarding', and the word 'rubbish' has a tendency to demean the items which may be important to the person. The use of phrases such as 'losing control of your home environment' rather than hoarding for example, has been identified as a feature of successful interventions and encouraging people in a positive manner to accept care and support.
- 5.10 Finding the right approach to working with an adult who is experiencing self-neglect is critical in achieving the best outcomes. It involves seeking to understand the meaning and significance of that self-neglect for that person. Research by Braye, Orr and Preston-Shoot (2015, updated 2020) outlines how practice in this area is a complex balance of knowing, being and doing:

Knowing	in the sense of understanding the person, their history and the significance of their self-neglect, along with all the knowledge resources that underpin professional practice.
Being	in the sense of showing personal and professional qualities of respect, empathy, honesty, reliability, care, being present, staying alongside and keeping company.

Doing	in the sense of balancing hands-on and hand-off approaches, seeking the		
	tiny opportunity for agreement, doing things that will make a small difference		
	while negotiating for bigger things, and deciding with others when the risks		
	are so great that some intervention must take place.		

5.11 Appendix 1 provides details of various approaches and interventions to support effective practice in working with adults who are self-neglecting. Practitioners should also refer to the additional guidance contained in the hoarding toolkit around effective engagement.

6. Self-neglect and mental capacity

- When concerns about self-neglect are raised, there is a need to be clear about the person's mental capacity in respect to key decisions to the proposed interventions. If there are any doubts about the person's mental capacity, especially regarding their ability to 'choose' their living conditions or refuse support, then where possible a mental capacity assessment should be undertaken.
- The MCA Code of Practice states that one of the reasons why people may question a person's capacity to make a specific decision is "the person's behaviour or circumstances cause doubt as to whether they have capacity to make a decision" (4.35, MCA Code of Practice, page 52). In extreme cases of self-neglect, the very nature of the environment should lead professionals to question whether the adult has capacity to consent to the proposed action(s) and trigger an assessment of that person's mental capacity.

Assessing mental capacity

- 6.3 Understanding and assessing mental capacity in individuals who self-neglect is complex. It is often best achieved collaboratively with other organisations, as well as with family or community networks where available. Consider the option to undertake joint assessments where indicated, such as working with an Occupational Therapist to support an assessment of a person's executive functioning (see section below).
- Robust mental capacity assessments are critical in determining the approach to be taken by professionals, either to support the decision-making of an adult with capacity or to intervene to protect the best interests of an adult who lacks capacity. Any mental capacity assessment in relation to self-neglect must be time-specific and relate to a specific intervention or action.
- 6.5 It is important to clearly document how a worker has maximised an adult's autonomy and involvement within the capacity assessment, ensuring they have been given all practical support to help them reach a decision for themselves.
- 6.6 Since self-neglect encompasses such a wide range of behaviours, the relevant information that a person needs to understand, retain and use or weigh, will vary from case to case. However, it will include exploration of the adult's understanding of their behaviours and associated risks, including:
 - Can they report back to you what the risks are (e.g. around a lack of self-care, malnutrition/dehydration, environmental neglect, fire risks, falls risks, infection risks, hoarding, risk of enforcement action being taken etc)?

- Can they report back to you that they know their behaviour places them at risk?
- Can they report back to you the consequences of taking these risks?
- If the risk is death, explore what the adult's understanding and beliefs are regarding their death.
- 6.7 Good practice is to record the actual questions as they were asked, and the responses provided by the adult.

Fluctuating capacity

- 6.8 Some people's ability to make decisions fluctuates because of the nature of a condition that they have. This is particularly common in situations involving self-neglect. This fluctuation can take place either over a matter of days or weeks (for instance where a person has bipolar disorder) or over the course of the day (for instance a person with dementia whose cognitive abilities are significantly less impaired at the start of the day than they are towards the end). Consideration should be given to undertaking the mental capacity assessment at a time when the adult is at their optimum level of functioning.
- 6.9 For adults who have ongoing fluctuating capacity, the approach is to keep the person's decision-making ability under review and reassess where relevant. 39 Essex Chambers have produced useful guidance on <u>Fluctuating Capacity in Context</u>.

Decisional and executive capacity

- 6.10 Another common area of difficulty is related to the distinction between the capacity to make a decision (decisional capacity) and the ability to actually carry out the decision (executive capacity). Whilst the MCA does not explicitly address executive capacity, it should be considered as part of the functional tests that form the capacity assessment.
- 6.11 Where decisional capacity is not accompanied by the ability to carry out the decision, overall capacity is impaired and interventions by professionals to reduce risk and safeguard wellbeing may be legitimate.
- 6.12 Integrating a 'pyramid model' to mental capacity assessments in relation to self-neglect helps to assess not just the person's factual understanding in relation to their self-neglecting behaviours, but their deeper levels of awareness and executive function. The pyramid model of awareness includes the following levels:
 - (1) Basic Awareness: The person recognises basic facts or risks.
 - (2) **Situational Awareness:** The person is aware of how their behaviour could contribute to those risks in specific situations.
 - (3) **Executive Awareness:** The person can plan or modify their behaviour based on this knowledge.

Best interests decision-making

6.12 If an adult is assessed to lack capacity to make decisions in relation to their self-neglect, any subsequent decisions and actions should be made in the adult's best interests. Any best interests decisions should be taken formally and involve relevant professionals and anyone

with an interest in the adult's welfare, such as family and members of their informal support network.

- 6.13 Best interests must be determined by what the person would want were they to have capacity "Lacking capacity is not a switch off for freedoms" (Wye Valley NHS Trust v Mr B, 2015, EWCOP 60). Therefore, in situations where an adult has experienced self-neglect over a long period of time and then loses capacity, previous behaviours must be considered when looking at the less restrictive options to keep the person as safe as possible.
- 6.14 If there are difficulties in making a best interests decision, it may be necessary to seek legal advice. In particularly challenging and complex cases, it may be necessary to make a referral to the Court of Protection. Where the person has been assessed to lack mental capacity to make specific decisions about the impact of their self-neglect on their health and wellbeing, in urgent cases, where the home situation required urgent intervention, the Court of Protection can make an interim order and allow intervention to take place. The court will, however, expect to see evidence of professional decision-making and what attempts have been made to engage and/or support change in behaviour.

Advocacy

6.15 Where individuals are likely to face substantial difficulties in participating in mental capacity assessments and subsequent support processes, the local authority must facilitate their involvement. If a suitable friend or family member is unavailable, an independent advocate should be arranged.

Individuals with capacity choosing to decline support

- 6.16 Principle 3 of the MCA enshrines a person's right to their own values, beliefs, preferences and attitudes. Where an adult has capacity to make decisions but may be making what others consider to be an 'unwise decision', this does not mean that no further action regarding their self-neglect is necessary, especially when the risk of harm is deemed to be serious or critical.
- 6.17 The duty of care includes gathering comprehensive information to conduct a thorough risk assessment. While there may ultimately be no legal grounds for intervention, it is essential to demonstrate that risks and potential actions have been carefully considered on a multi-agency basis.
- 6.18 A case should never be closed solely based on an individual's refusal to accept support. Highrisk cases will require legal advice and consideration of a range of other options, including potential consideration of using the inherent jurisdiction of the High Court – see appendix 2 legal remedies. Continued engagement and risk monitoring are essential using the principles set out in this strategy.

7. Risk enablement and risk assessment

7.1 It is important to be mindful that organisational and professional risk aversion and defensive practice (rather than *defensible* decision making) can hinder choice, control and independent living. This can create challenges for practitioners in balancing risk enablement with their professional duty of care to keep people safe. Risk enablement should always be a core part of placing people at the centre of decisions about their own care and support. Providing real choice and control is about adopting a positive approach to risk taking and enabling people to

be autonomous in taking the risks that they choose whilst balancing safeguarding risk considerations.

- 7.2 Defensible decision making is about ensuring the reasons for decisions, as well as the decision itself, have been comprehensively considered, recorded and can be explained. The duty of care in relation to decisions made will be considered to be met where:
 - All reasonable steps have been taken.
 - Reliable assessment methods have been used.
 - Information has been collated and thoroughly evaluated.
 - Policies and procedures have been followed.
- 7.3 Risk assessment and risk management are an essential part of responding effectively to self-neglect. Risk assessments should be robust and holistic, with risks considered individually and collectively. Assessments should be evidence-based and not rely solely on an individual's self-reporting. The approach should be multi-agency, culminating in risk management plans that include consideration of all legal options. Decisions and the reasons behind them should be clearly documented, with multi-agency meetings re-convened to consider progress and review the plan. Cases should not be closed without prior discussion and agreement between agencies.
- 7.4 Key components of the comprehensive risk assessment should include:
 - Risks identified (to the individual and others), including the likelihood and severity.
 - The adult's views and wishes, and where appropriate views of others, such as family members
 - How risks will be mitigated and managed, including the adult's protective factors.
 - Who is responsible for each action and timescales should be clearly recorded.
 - Ongoing monitoring arrangements and who is responsible for this.
 - Contingency plan if risk increases, including when to seek legal advice and the escalation process.
- 7.5 The lead agency is responsible for collating and sharing risk assessments and management plans, which should be shared with the adult and all relevant professionals so that everyone has a clear understanding of what the issues are, how risks are to be managed and who is responsible for specific areas.
- 7.6 The hoarding toolkit contains risk assessment and hoarding assessment templates along with the Clutter Image Rating (CIR) tool. The CIR tool includes accompanying guidance which guides professional responses in accordance with the CIR score.

8. Collaborative multi-agency working and information sharing

Lead coordinating agency

- 8.1 Any professional can request and convene a multi-agency meeting in relation to concerns about an adult who is experiencing self-neglect. It is important to recognise that not all cases may be eligible for ASC support or funding and whilst it is most often the case for the Local Authority (whether that be from ASC or Housing) to lead on coordinating responses to self-neglect, it is important to note that discussions should take place between all agencies involved to agree who is best placed to take on the role of lead coordinating agency. Advice may be sought from agencies who are not involved in the case. The guiding principles in considering who should be the lead agency include that:
 - The agency is already involved in working with the adult.

- The agency has a duty of care towards the adult because of their needs.
- The agency holds significant information about the adult.
- The adult has shown a likelihood to engage best with this agency in the past.
- The adult's primary needs appear to relate to the service provided by the agency.
- 8.2 ASC will always be the lead coordinating agency where the self-neglect concerns are being responded to via a Section 42(2) safeguarding enquiry.
- 8.3 The lead coordinating agency for managing self-neglect cases will have responsibility to:
 - Coordinate information gathering in relation to the initial concerns about self-neglect, including around mental capacity.
 - Ensure the engagement of all relevant agencies in responding to the initial concerns and ongoing work.
 - Provide support to enable the adult's involvement throughout the process, including their attendance at multi-agency meetings should they wish.
 - Lead and facilitate any multi-agency meetings and being responsible for making arrangements such as online meetings or in person and minute taking.
 - Ensure a comprehensive multi-agency risk assessment and management plan is in place and shared with all relevant partner agencies.
 - In collaboration with relevant agencies, plan and coordinate actions to respond to and mitigate risks, including cleaning, repairs, support with re-housing or temporary accommodation options.
 - Seek legal advice where necessary to support appropriate courses of action.
 - Where necessary escalate cases where risks remain significant to the relevant level of senior management to support decision making.

Multi-agency meetings

- 8.4 Given the complex and challenging nature of self-neglect, responses by a range of organisations are likely to be more effective than a single agency response, and a coordinated approach is therefore essential. Multi-agency meetings are often the best way to ensure effective information sharing and communication, and a shared responsibility for assessing risks and agreeing an action plan.
- 8.5 Good practice is to convene a multi-agency planning meeting promptly with the right organisations around the table when the initial concerns are raised. The purpose of this meeting is to:
 - Share the adult's views and wishes as far as they are known.
 - Consider risks and issues of mental capacity.
 - Share information between agencies and consider if any other agency should be involved.
 - Devise a shared action plan, with contingency and escalation arrangements.
 - Agree monitoring and review arrangements.
- 8.6 Wherever possible the individual should be fully involved and attend meetings. However, it is acknowledged that in many situations where there are concerns about the adult's lack of engagement with formal services, ability to involve individuals may be limited. Practitioners should ensure that the adult is provided with accessible information and access to advocacy

- support where appropriate, and that the pace and location of any meetings are guided by the adult's needs and circumstances.
- 8.7 It is expected that all agencies involved will adopt a shared responsibility for managing risks and taking forward actions. Meeting attendees should come prepared with required information to update on actions completed and be able to take responsibility for making any contacts or taking additional actions forward.
- 8.8 In accordance with the safeguarding principle of no delay, actions to respond to concerns about self-neglect, including convening meetings should be undertaken in a timely manner. However, it is acknowledged that concerns about self-neglect often require a more in-depth, longer-term response to build trusted relationships with the adult and agree actions at a pace that is acceptable to the adult. Timescales for achieving actions should be agreed at the meeting and be clearly documented within the shared action plan. Dates should also be considered for review meetings to monitor actions completed and outcomes of these in mitigating risks.
- 8.9 Where significant and ongoing risks remain, it may be necessary to convene further multiagency meetings until there is agreement that the situation has become stable, and the risk of harm reduced to an agreed acceptable level. Cases in which the shared multi-agency approach has not been able to mitigate the risk of significant harm should be escalated to the relevant level of senior management.

Information sharing

- 8.10 The Data Protection Act (DPA) 2018 which sits alongside the General Data Protection Regulation (GDPR) sets out the legal framework which governs information sharing. These place greater emphasis on organisations to be transparent and accountable in relation to their use of data.
- 8.11 Given self-neglect can pose a serious risk to health and safety, interventions across a range of professionals is likely to be required, which necessitates the sharing of information between professionals and organisations. In working in partnership with people using a Making Safeguarding Personal approach, consent should always be sought in relation to information sharing. However, self-neglect and hoarding are complex, and consent may not be given for a range of reasons.
- 8.12 The right to confidentiality is not absolute. If an adult refuses to share information, their wishes should be respected (if they have mental capacity to make that decision), but there are instances where the sharing of information can still legally take place when it is necessary to do so. In the context of self-neglect, where a person is at risk of significant harm because of their self-neglecting behaviour it may be necessary to override their consent in the person's vital interests. Similarly, if other people are at risk, it may be necessary to share information even without the person's consent. Good practice is to clearly explain your grounds and legal basis for sharing information and offer assurance that the person's choice and wishes will be respected as far as possible.
- 8.13 In situations where the person who is self-neglecting lacks the mental capacity to give consent to the sharing of information, then a best interests decision should be made in line with the MCA see 6.12 6.14.

9. 'Think Family' and safeguarding children

- 9.1 In line with a Think Family approach, it's important to consider whether there are any other dependent or vulnerable adults or children living in the same household, who may be at risk from the behaviours of the person who is self-neglecting.
- 9.2 Where there are concerns for a child in the context of an adult experiencing self-neglect, in line with the <u>London Safeguarding Children Procedures and Practice Guidance</u>, Children's Services should be contacted:
 - Kensington and Chelsea on 020 7361 3013 or socialservices@rbkc.gov.uk
 - Westminster on 020 7641 4000 or accesstochildrensservices@westminster.gov.uk
- 9.3 If it is identified that another adult in the household may have needs for care and support, consideration should be given as to whether they require an assessment in their own right under the Care Act. Where an unpaid carer is supporting someone who self-neglects, it is important to ensure that consideration is given as to whether a carer's assessment is required, to establish the carer's need for support and the sustainability of the caring role itself.

10. Fire safety

- 10.1 Self-neglect and hoarding can pose a significant risk to both the people living in the property where the self-neglect is taking place, as well as to neighbouring occupants. Self-neglect increases fire risks due to a variety of reasons, such as unsafe cooking when flammable items are stored near hobs or ovens, portable heating units may be too close to things that can burn, electrical wiring may be old or chewed on by pets / rodent infestations, the use of open flames or candles in homes with excess clutter and clutter creating blocked exits from the home.
- 10.2 Where an affected property is identified, adults should always be advised of the increased risks and discussions should take place around the need to refer to London Fire Brigade (LFB) for a Home Fire Safety Visit (HFSV).
- 10.3 To request a Home Fire Safety Visit, practitioners should complete LFBs online Home Fire Safety Checker. Where feasible it is good practice to complete this with the adult, for example during a home visit. This supports effective engagement with the adult but also ensures a prompt referral is made where high risk is identified. Practitioners can follow up on the progress and outcome of referrals by contacting LFB via email at SWCFSHFSV@london-fire.gov.uk
- 10.4 Given the complex nature of self-neglect cases, consideration should be given to the lead agency carrying out a joint visit with LFB, particularly where the adult requires encouragement and support to engage with a HFSV.
- 10.5 The <u>SAEB Multi-Agency Fire Safety Framework</u> contains further guidance around fire safety considerations. The LFB website also contains general advice on <u>fire safety within the home</u>.

11. Legal remedies

- 11.1 There are many legislative responsibilities placed on agencies to intervene in or be involved with the care and welfare of adults who are at risk in relation to self-neglect. It is important that everyone involved is proactive in exploring all potential options.
- 11.2 Appendix 2 provides a summary of a range of legal powers and duties which may be relevant when supporting adults experiencing self-neglect, in addition to the content within this strategy covering the Care Act 2014 and MCA 2005. It is not an exhaustive list, and in all complex cases, legal advice should be sought as appropriate.

12. Useful resources

- 12.1 The following resources provide additional guidance and information in relation to self-neglect:
 - Research in Practice: Working with people who self-neglect
 - Social Care Institute for Excellence (SCIE): Self-neglect at a glance
 - SCIE: Self-neglect policy and practice: Early research evidence about good practice
- 12.2 Practitioners should also refer to the additional resources contained within the hoarding toolkit.

Appendix 1: Approaches and interventions to support effective practice in working with adults experiencing self-neglect

The following table is based on work by <u>Braye</u>, <u>Orr and Preston-Shoot (2015, updated 2020)</u> and covers themes of effective engagement alongside examples of what this looks like in practice.

Theme	Examples
Building rapport and being there	Taking time to get to know the person; treating the person with respect; refusing to be shocked; maintaining contact and reliability; monitoring risk or capacity; spotting motivation for change
Moving from rapport to relationship	Avoiding kneejerk responses; talking through the person's interests, histories and stories
Finding the right tone and straight talking	Being honest about potential consequences while also being non-judgemental; separating the person from the behaviour
Going at the adult's pace	Moving slowly and not forcing things; continued involvement over time; showing flexibility and responsiveness; small beginnings to build trust
Agreeing a plan	Making clear what is going to happen, for example, a weekly visit might be the initial plan; offering choices; having respect for the person's judgement
Cleaning or clearing	Being proportionate to risk; seeking agreement to actions at each stage
Finding something that motivates the adult	Linking to interests, for example, hoarding for environmental reasons or linking to recycling initiatives
Starting with practicalities	Providing small practical help at the outset may help to build trust, for example, household equipment, repairs, benefits, 'life management'
Bartering	Linking practical help to another element of agreement - bargaining
Focusing on what can be agreed	Finding something to be the basis of the initial agreement that can be built on later
Risk limitation	Communicating about risks and options with honesty and openness; encouraging safe drinking strategies or agreement to fire safety measures or repairs
Health concerns	Facilitating or coordinating doctor's appointments or hospital admissions; providing practical support to attend appointments
External levellers / enforced action	Ensuring that options for intervention are rooted in sound understanding of legal powers and duties; setting boundaries

	on risk to self and others; recognising and working with the possibility of enforced action
Networks	Engaging with the person's family, community or social connections
Change of environment	Considering options for short term respite if required, for example, to have a 'new start'
Therapeutic input	Replacing what is relinquished, for example, through psychotherapy or mental health services e.g. bereavement support or trauma informed interventions. This could either be structured through regular psychotherapeutic interventions or it could be through wellbeing interventions delivered by voluntary sector organisations

Appendix 2: Legal options relevant to self-neglect

Please note these legal actions are not a fully exhaustive list and are not in any hierarchical order.

Agency	Legal Power and Action	Circumstances requiring intervention
Community Protection	Enforcement Notice (S83 – 85 Public Health Act 1936) The local authority can serve a legal notice requiring the owner/occupier to cleanse the property and/or eradicate any pests on site. If the owner/occupier fails to comply the local authority can carry out the work in default and recover all costs incurred.	Filthy or unwholesome condition of premises (cleanliness not structural concerns), infestation of premises by pests, cleansing or destruction of filthy or verminous articles, cleansing of verminous persons and their clothing.
Community Protection	Power of entry/warrant (S287 Public Health Act 1936) Gain entry for examination/execution of necessary work required under Public Health Act. Police attendance required for forced entry.	Applies to all tenure including Leaseholders/Freeholders.
Community Protection	Authorised officers of the local authority can through the service of statutory notices on owners and occupiers of property require the abatement of a range of problems, including 'any premises in such a state as to be prejudicial to health or a nuisance' and 'any accumulation or deposit' which meets the same test. 'Premises' includes open land such as a garden.	
Community Protection	Prevention of Damage by Pests Act 1949 Local authorities can through service of a statutory notice require steps (such as the removal of materials providing food or harbourage) to be taken by occupiers to keep land clear of rats and mice. Whereas Public Health Act powers teds to be used for internal clearance, the 1949 Act tends to be used for clearing gardens or external areas.	
Police	Power of Entry (S17 Police and Criminal Evidence Act 1984) Person inside the property is not responding to outside contact and there is evidence of danger.	Information that someone was inside the premises was ill or injured and the Police would need to gain entry to save life and limb.

Community Protection / Housing / Provider Service	Anti-Social Behaviour (Crime and Policing Act 2014) S1/5/6 A civil injunction can be obtained some the County Court if the court is satisfied that the person against whom the injunction is sought has engaged or threatens to engage in antisocial behaviour, or if the court considers it just and convenient to grant the injunction for the purpose of preventing the person from engaging in anti-social behaviour. S43 Community Protection warnings and notices can be issued where the conduct of an individual is having a detrimental effect, of a persistent or continuing nature, on the quality of life of those in the locality, and the conduct is unreasonable. The warnings and notices can require a behaviour stops or can require a different type of behaviour to occur i.e. stop collecting waste, do engage with local charities or organisations that can provide support as regards to hoarding behaviour or social isolation. Injunctions are a more significant step or escalation if the behaviour continues and cannot be controlled in	Conduct by the tenant which is capable of causing housing-related nuisance or annoyance of any person. "Housing-related" means directly or indirectly relating to the housing management functions of a housing provider or local authority housing.
	any other way and possible final step before eviction proceedings.	
Housing	Allows Local Authority Housing (LAH) to carry out risk assessment of any residential premises to identify any hazards that would likely cause harm and to take enforcement action where necessary to reduce the risk to harm. If the hazard is a category 1 there is a duty by the LAH to take action. If the hazard is a category 2 then there is a power to take action. However, an appeal is possible to the Residential Property Tribunal within 21 days. A LAH can prosecute for non-compliance.	
Private Sector Housing (Housing Standards)	Housing Act 2004 Introduced the Housing Health and Safety Rating System which is concerned with the assessment of deficiencies in the design, construction and maintenance of dwellings, but	

	does not cover the behaviour of occupiers. Hoarders may nevertheless live in properties which are in disrepair, sometimes extreme disrepair (and poor electrical wiring may exacerbate fire risk). This can prompt action by the local housing authority, usually in the forms of improvement or Prohibition Notices and where there is an imminent risk of serious harm, their emergency variants.	
Planning	Town and Country Planning Act 1990 S215	
	Provides a power to require the owner or occupier of land which is adversely affecting the amenity of an area to return it to an appropriate condition. These powers deal with situations where the material is visible to neighbours or other persons living in the community and which is harmful to the amenity or quality of the environment.	
Environmental Health and	Part 2A Orders	
Public Health	A local authority can apply to a Justice of the Peace (JP) for a Part 2 Order if it considers it necessary to deal with a threat to human health from infection or contamination that presents, or could present, significant harm. It is for the JO to decide whether an order is necessary. If the JP is satisfied by the local authority's case, an order can be made.	
	This power is considered a last resort when other interventions have either failed or are not suitable/	
	A Part 2A Order can be made in relation to:	
	 A person (or persons) A 'thing' (or things) A body or human remains Premises To require a person to give information about a 'related party', 'related person' or 'related thing' as relevant to a particular case. 	
Animal Welfare	Animal Welfare Act 2006	Cases of animal
Agencies, such as RSPCA, the	Offences (Improvement Notice)	mistreatment/neglect. The Act makes it not only against the law to be cruel to

Local Authority,	Education for owner a preferred initial step, improvement notice issued and monitored, if not	an animal, but that a person must ensure that the welfare
Environmental Health	complied can lead to a fine or imprisonment.	needs of the animals are met.
Mental Health	Mental Health Act 1983 S135(1) Provides for a police officer to enter a private premises, if need be, by force, to search for an, if thought fit, remove a person to a place of safety if certain grounds are met. The police officer must be accompanied by an Approved Mental Health Professional (AMHP) and a doctor. Note: Place of safety is usually a mental health unit but can be the A&E department of a general hospital, or anywhere willing to act as such.	Evidence must be laid before a magistrate by an AMHP that there is reasonable cause to believe that a person is suffering from mental disorder, and is being: • Ill treated • Neglected • Being kept other than under proper control • If living alone, is unable to care for self, and that the action is a proportionate response to the risks involved.
All Local Authority	Mental Capacity Act (MCA) 2005 A decision can be made about what is in the best interests of a mentally incapacitated person by an appropriate decision-maker under the MCA. It is important to follow the empowering principles of the Act and ensure that any actions taken in a person's best interests are the less restrictive option available. Note: Where the decision is that the person needs to be deprived of their liberty in their best interests in a care home or hospital, a Deprivation of Liberty Safeguards (DoLS) authorisation may be required. In circumstances where a person is objecting to being removed from their home, or to any DoLS authorisation, referral to the Court of Protection may be needed and legal advice should be sought.	A person who lacks mental capacity to make decisions about their care and where they should live, is refusing intervention and is at high risk of serious harm as a result.
All	Inherent Jurisdiction of the High Court	In extreme cases of self- neglect, hoarding where a person with capacity is at risk of serious harm or death, and refuses all offers of support, interventions or is unduly influenced by someone else, application to the High Court for a decision could be considered. The High Court

	has powers to intervene in
	such cases, although the
	presumption is always to
	protect the individual's human
	rights. Legal advice should be
	sought before taking this
	option.