

Lambeth Adult Safeguarding Board

Self-Neglect

Multi-Agency Practice Guidance

Approval date	13 th October 2020
Planned review date	13 th October 2023

This document is being piloting from October- December 2020.

If there are areas that you feel are confusing or information missing, please email <u>LSABAdmin@lambeth.gov.uk</u> to provide feedback/make a request.

Acknowledgements: This document has taken content from the Wiltshire Safeguarding Adults Board guidance on self-neglect (2019), the Bath and North East Somerset SAB Revised self-neglect policy and best practice guidance (2019), Merseyside Self-neglect tool (2019)

Version Control

Version number	Purpose of the change or details of the change	Person making the change	Date
2020.01	Initial drafting	Ceri Gordon	Jan 2020
2020.02	Amendments/final draft	Mala Karasu/Janna Kay/David Rowley	Sept 2020
2020.03	Approved and adopted by LSAB for trial	LSAB 13 th Oct	Oct 2020

Documents superseded

Reference	Document name
	None

Table of Contents

1.	Key messages	4
2.	Introduction and purpose	5
3.	Lambeth Safeguarding Adults Board Policy on self-neglect	5
4.	What is self-neglect?	7
5.	Hoarding as a form of self-neglect	9
6.	Assessing a person's situation	10
7.	Mental Capacity	11
8.	Assessing Risk	15
9.	Responding to risk:	16
10.	How to approach your interventions	17
11.	Standard multi-agency responses to self-neglect	19
12.	Formal multi-agency responses to complex cases of self-neglect	20
Арре	endix 1: General characteristic of hoarding	22
Арре	endix 2: Mental Capacity Assessment template for self-neglect	23
Арре	endix 3: Risk Assessment guidance	25
Арре	endix 4 Hoarding Assessment form	30
Арре	endix 5 Legal frameworks for responding to self-neglect	32
Арре	endix 6 Case Pathway meeting template	34
Арре	endix 7: Useful resources for professionals and people who self-neglect:	36

Key messages for working with people who self-neglect

All agencies have a role to play in supporting people who self-neglect. This document will help you and your agency to play your part.



Relationship building is crucial. Try to really get to know the person and 'get alongside' them; show interest and concern. Communicate clearly and regularly with the person.

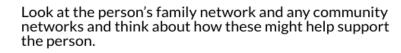


[/] D Risk

Support

Try to find out why the person is self-neglecting – this may be connected with trauma, grief, mental health episodes or other experiences. Don't just look at the current picture; try to piece together the person's life story and find out what is important to them.

Undertake a thorough risk assessment and explain your concerns openly to the person who is self-neglecting.





Be clear about your role and responsibilities and those of others. Think about how to link up with others agencies involved to ensure a joined up approach. Share the risk and ensure that everyone understands that persistence and commitment require time.







Consider mental capacity in relation to the decisions which need to be made – is the person able to understand information / retain it / weigh it / communicate their decision?

Also consider the person's '**executive functioning**' – they may appear to understand but can they / will they see the decision through in action?

Be patient and work at their pace. Be prepared for longterm involvement – self-neglect situations are rarely resolved quickly.

The term 'self-neglect' can be perceived as a very stigmatising and emotive term – be careful how you use it. Don't dismiss self-neglect as a 'lifestyle choice' or take an initial rejection of support as final. Work on shared goals, not goals based on how you think they should live

2. Introduction and purpose

Many professionals working with adults have encountered cases of self-neglect or hoarding. This is a challenging area of work because often there is no simple way to help. This practice guidance has been written to help provide a clear pathway and tools for dealing with people who are self-neglecting or hoarding.

The Care Act 2014 places duties on *all professionals* to respond to people who self-neglect. Where people are placing themselves at serious risk due to their self-neglect, adult safeguarding concerns can be raised with the local authority.

The Lambeth Safeguarding Adults Board (LSAB) recommends that all agencies, both statutory and voluntary, utilise this practice guidance to inform their responses to people with complex needs who self-neglect. This should be used to inform individual agencies' own procedures on Self-Neglect.

This guidance was produced following <u>Safeguarding Adults Review (Martin)</u> where a death occurred. There were multiple agencies involved who struggled to know how to effectively respond to a vulnerable man self-neglecting and refusing help.

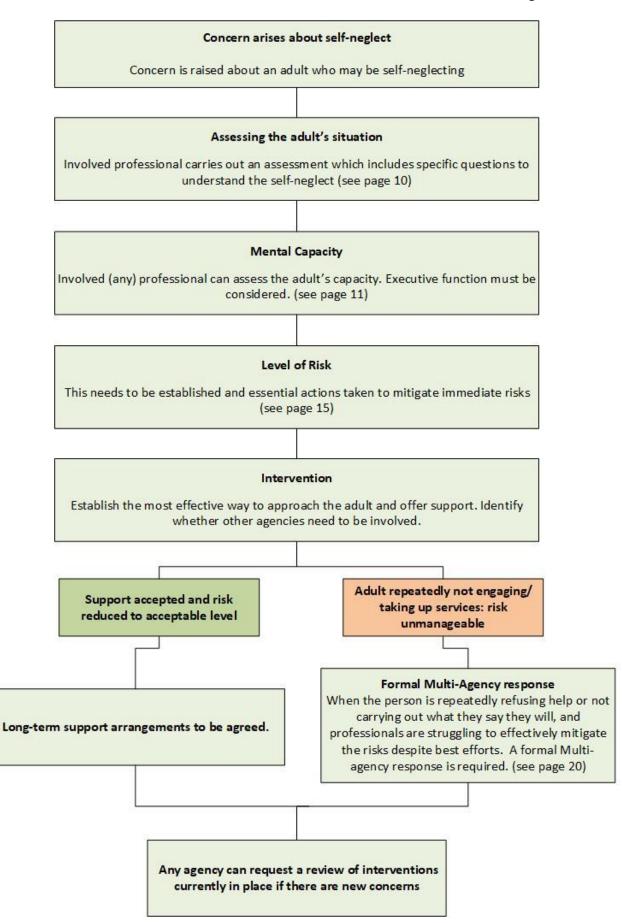
Complex situations such as self-neglect can lead to competing professional values – those of respect for autonomy and self-determination, versus 'duty of care' and promotion of dignity. Finding the right balance is a difficult judgement. Concerns around self-neglect are often best approached by pulling together key elements of the person's personal, social, and professional network to find solutions.

Co-ordinated actions by general practitioners, district nurses, housing officers, mental health services, volunteers, social workers, police and fires services *alongside* the person's family members and friends, have led to improved outcomes for individuals.

3. Lambeth Safeguarding Adults Board Policy on self-neglect

The <u>Lambeth SAB Policy</u> outlines the local policy on adult safeguarding responses to selfneglect. This states that in Lambeth, the starting point will be that an adult safeguarding enquiry <u>is usually not</u> the best response to *a first incident or concern about self-neglect or hoarding*. Any professional who has concerns about someone who is self-neglecting should consider how best to respond. Often this will involve discussing with the adult the concerns and agreeing with the adult, what could happen. Individuals can be offered an assessment and support in the first instance. Where this is taken up, no further protective action is likely to be necessary.

The flowchart below outlines the process for responding to concerns of self-neglect. The details of the different stages are fully explained within this guidance document.



4. What is self-neglect?

Self-neglect is extremely difficult to define given it takes several forms. It has sometimes been referred to as 'Diogenes syndrome'. Gibbons (2006) defined it as: "The inability (intentional or non-intentional) to maintain a socially and culturally accepted standard of self-care with the potential for serious consequences to the health and wellbeing of the self-neglecters and perhaps even to their community".

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

- deteriorating physical health
- onset of depression or other mental health needs
- trauma response, and/or neuropsychological impairment
- diminishing social networks and/or economic resources
- personal philosophy and identity

Gaining a fuller understanding of a person's life history and experiences may help to create a better insight into their behaviour and possible changes that can be affected.

Self-neglect can be found in all areas of society and needs to be understood in the context of each individual's life experience. It is more usual for people to start to self-neglect when they become mentally or physically unwell or older and frailer. Those who are homeless or living in temporary accommodation may also be at greater risk. *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).

The signs of self-neglect often include a dirty or squalid home circumstances, poor hygiene, and personal care, dirty, unchanged or inappropriate clothing, signs of weight loss, lack of evidence of food in the house, untreated injuries or skin breakdown, or poor dental care.

Personal care

Very poor personal hygiene and unkempt appearance. They lack essential food, clothing or shelter.

Living conditions

Living in squalid or unsanitary conditions and neglecting household maintenance.





Hoarding

Long-term hoarding behaviours, with an inability to throw away items without experiencing fear and anxiety

Poor health

Unwillingness or inability to take medication or treat illness or injury. Person may be malnourished or dehydrated. and refusing offers of support

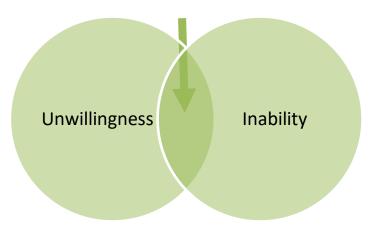
Figure 1; Signs that someone may be self-neglecting

It is important to understand that poor environmental and personal hygiene 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.

It can be helpful to remember that Self-neglect:

- Arises from an unwillingness or inability to care for oneself, or both.
- It is interlinked where inability arises from the care and support needs of the individual.



Research in Practice for Adults (RiPFA)

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

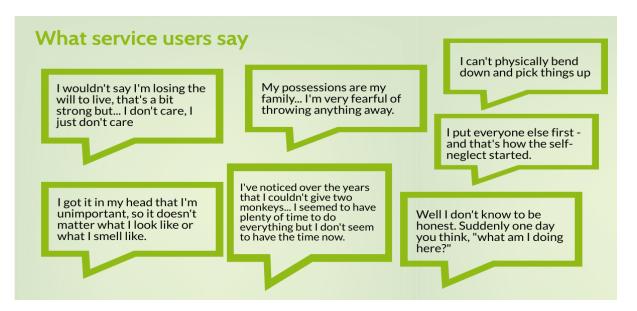


Figure 2: Braye, Orr and Preston-Shoot, 2015.

5. Hoarding as a form of self-neglect

Professionals will come across different types of concerning environments and it is important to fully understand a person's situation first, <u>because people can have cluttered</u> <u>homes without having a hoarding disorder.</u>



Homes can become disorganised and / or squalid due to:

- Psychosis
- Dementia
- Intellectual disability
- Someone 'not coping' through depression or trauma
- Drug or alcohol use

The main difference between a hoarder and a collector is that hoarders have strong emotional attachments to their objects which are well in excess of their real value. <u>Appendix</u> <u>1</u> outlines some of the general characteristics of hoarding.

In 2018, the World Health Organisation included hoarding disorder in the latest edition of its <u>International Classification of Diseases (ICD 11, 6B24)</u> for the first time. The decision was important because it meant that hoarding could be formally recognised and defined as a distinct mental health condition, allowing UK patients to be formally diagnosed by their GPs for the first time.

Definition of Hoarding Disorder (HD):

"Hoarding disorder is characterised by accumulation of possessions due to excessive acquisition of or difficulty discarding possessions, regardless of their actual value... The symptoms result in significant distress or significant impairment in personal, family, social, educational, occupational or other important areas of functioning".

A formal mental health assessment is required by a qualified mental health professional before someone can be diagnosed and treated for Hoarding Disorder.

Most hoarders never seek help. People are referred for other reasons – depression, anxiety, and obsessive-compulsive disorder. People who hoard are often difficult to treat. They may deny that there is a problem, rationalise the situation and/or display a low motivation to change.

6. Assessing a person's situation

Self-neglect is a complex issue and 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 should be given to what it says and whether this is the best way to engage the person. The usual standard appointment letter is unlikely to be the beginning of a trusting professional relationship if it is perceived as being impersonal and authoritative.

Home visits are important. The professional will need to use their skills to be invited into the person's house and observe for themselves the conditions of the person and their home environment. Professionals should discuss with the person any causes for concern about their health and wellbeing and obtain the person's views and understanding of their situation and the concerns of others. The assessment should include the person's understanding of the cumulative impact of a series of small decisions and actions as well as the overall impact.

- What is the person's own view of the self-neglect?
- Is the self-neglect a recent change or a long-standing pattern?
- What motivation for change does the person have?
- Is alcohol consumption or substance misuse related to the self-neglect?
- Does the self-neglect play an important role as a coping mechanism? If so, is there anything else in the person's life that might play this role instead?
- Is the self-neglect important to the person in some way?
- Is the self-neglect intentional or not?
- What strengths does the person have what is he or she managing well and how might this be built on?
- Are there links between the self-neglect and health or disability?
- How might the person's life history, family or social relations be interconnected with the self-neglect?
- Does the person have mental capacity in relation to specific decisions about selfcare and/or acceptance of care and support?

Figure 3: Questions to consider as part of the assessment

Sensitive and comprehensive assessment is important when identifying the person's capabilities and level of risk. When undertaking the assessment, the professional should be cautious not to accept the first, and potentially superficial response given rather than exploring more deeply how a person understands and could act on their situation. It is important to look further and tease out the possible significance of personal values, past traumas, and social networks. **This may require more than one visit**.

In cases of hoarding, professionals can use the <u>clutter image rating scale</u> to determine the level of hoarding in an environment. <u>Appendix 4</u> is a Hoarding assessment template that can be used to support any professional in assessing hoarding.

7. Mental Capacity

All adults should be presumed to have capacity; however there may be cases where a person may demonstrate a lack of understanding and insight into the impact of their actions (or inactions) on themselves or on others.

When an individual's behaviour or circumstances cast doubt as to whether they have capacity to make a decision, then a capacity assessment should be carried out in line with the Mental Capacity Act 2005.

Any capacity assessment in relation to self-neglect or hoarding behaviour must be time specific and relate to a specific intervention or action; they should therefore be considered and/or repeated as risk increases and in relation to each individual risk. Capacity Assessments must be appropriately recorded.

All professionals working with someone who is self-neglecting should know how to carry out a mental capacity assessment. See <u>appendix 2</u> for an MCA template.

Key considerations when assessing capacity on decisions related to self-neglect

♦ Identify the decision

When assessing capacity in relation to self-neglect, the key issue to consider is whether the adult can make decisions about their circumstances, and the potential risks arising from it. It is helpful to phrase the decision from the viewpoint of the person, avoiding any preconceived opinion on what is in the person's best interests' e.g.

Should I maintain my personal hygiene? Should I clean/ maintain my living conditions?

Decision's about self-neglect are not always straightforward to identify, and may be nuanced within, or alongside, decisions related to other capacity assessments being undertaken by services e.g.

Should I receive care/ support/ treatment from (insert as appropriate) service?

♦ The assessment

It is helpful to think of the capacity assessment as simply a conversation between the person and the decision maker. The decision maker needs to take all practicable steps possible to facilitate the conversation, so that the person has the best opportunity to make the decision by themselves

Provide the information

The professional should initially clearly lay out to person relevant information about the decision. This may include information about self-neglect, the reasons why the professional has concerns (including clarifying risks), as well as the options on offer.

♦ <u>The two-stage test</u>

- i) In the first stage of the test, the assessment should consider:
- Understand: Does the adult understand the information provided?
- **Retain:** Is the adult able to retain the information presented for long enough to make a decision?
- Use and weigh: Is the adult able to use and weigh up the options?

Important - This section of the assessment must consider a person's *executive function*, or the ability of the adult to carry out what they say they are going to do.

The concept of executive functioning is particularly relevant with people who selfneglect and where risks are high or increasing *(see below section for further information on executive function)*

Preston-Shoot, Braye & Orr (2014) highlight that professionals assessing capacity in relation to self-neglect must remember that capacity involves not only:

- weighing up information and being able to understand consequences of decisions and actions, but also
- the ability to implement (execute) those actions
- Communicate: Can the adult communicate their decision

If the person is unable to either understand or retain or weigh or communicate factors related to the decision (or more than one of those factors), **and** the reason for this is directly linked to an impairment of the brain or mind, then the person is deemed not to have mental capacity to make that decision

 If you have said no to any of the above, the 2nd stage of the test must then consider whether the person has an impairment or disturbance of the mind or brain.

Vhat happens if the person does not have capacity

When a person is assessed as lacking capacity, a Best Interests Decisions should be made on their behalf, involving other professionals and anyone with an interest in the person's welfare (such as members of the family). <u>The less restrictive response to a person's rights and freedoms option should always be preferred.</u>

In particularly challenging cases it may be necessary to refer to the <u>Court of Protection</u> to make the best interests decision e.g. where someone lacks capacity but is objecting to the intervention or family members are in dispute.

Further information on executive function:

What is executive function? Executive function is a group of cognitive processes that regulate, control, and manage other cognitive processes. It is responsible for a number of key skills including:

- Planning and organisation
- Flexible thinking
- Solving unusual problems
- Motivation
- Initiating appropriate behaviour
- Inhibiting inappropriate behaviour
- Controlling emotions
- Concentrating and taking in information

Practitioners must consider both a person's decisional and executive capacity

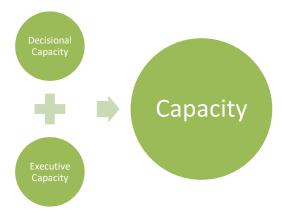


Figure 4: Preston-Shoot, Braye & Orr (2014)

Whilst it may be determined that someone has decisional capacity around their personal welfare or their environment, this may not translate into the person's ability to carry out the actions needed to keep themselves safe or well. This may relate to a deficit in the person's

executive functioning and is a result of their cognitive impairment.

Impairment of executive functioning can make it difficult for a person to initiate appropriate behaviours in the moment; for example, they may recognise the need to eat and drink, but fail to act on that need. (Braye, Orr and Preston-Shoot, 2015).

'Articulate and demonstrate' models of assessment (**tell me, then show me**) can be effective in identifying if the person's executive functioning is impacting their mental capacity.

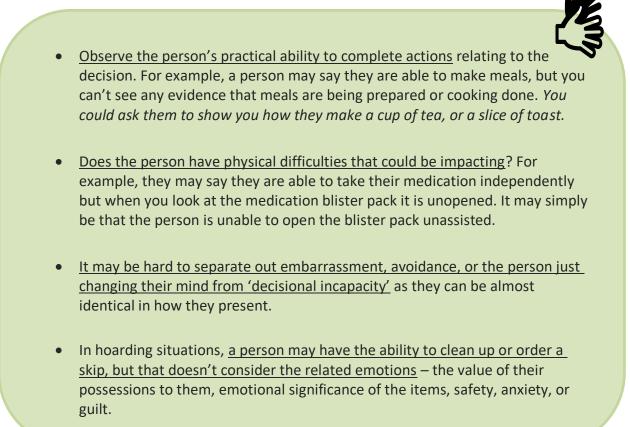


Figure 5: Examples of how you might explore executive function

Section 11 of the Care Act provides local authorities with a legal right to conduct an assessment for someone assessed as having mental capacity to refuse an assessment where that person is subject to a s42 adult safeguarding enquiry. As such, where the safeguarding concern relates to self-neglect and the person is refusing, this piece of legislation enables information gathering and sharing with involved professionals.

8. Assessing Risk

A number of Safeguarding Adults Reviews (SARs) undertaken in relation to self-neglect have highlighted how there were failures by multi-agency professionals to work together to assess and manage risks effectively. This is usually because someone is considered to have capacity to make decisions and so professionals feel unclear as to how to intervene appropriately. A key lesson arising from these SARs in the importance of a person-centred approach and agencies working together.

It is important to undertake a risk assessment which considers an individual's preferences, histories, circumstances, and lifestyle to achieve a proportionate and reasonable tolerance of acceptable risks.

Minimal Risk	Moderate Risk	High/Critical Risk
 Person is accepting support and services Health care is being addressed Person is not losing weight Person accessing services to improve wellbeing There are no carer issues Person has access to social and community activities Person is able to contribute to daily living activities Personal hygiene is good 	 Access to support services is limited Health care and attendance at appointments is sporadic Person is of low weight Persons wellbeing is partially affected Person has limited social interaction Carers are not present Person has limited access to social or community activities Person's ability to contribute toward daily living activities is affected Personal hygiene is becoming an issue 	 The person refuses to engage with necessary services Health care is poor and there is deterioration in health Weight is reducing Wellbeing is affected on a daily basis Person is isolated from family and friends Care is prevented or refused The person does not engage with social or community activities The person does not manage daily living activities Hygiene is poor and causing skin problems Aids and adaptations refused/ not accessed Person's vital interests (life) is at risk due to their level of self-neglect

The below risk assessment can assist you in determining the level of risk for the adult:

For more guidance on assessing risk, please see appendix 3

9. Responding to risk:

There are a number of actions that must be taken as outlined below, in response to managing the risks identified. There are some standard actions recommended for levels 1-3 and additional actions that should be considered for levels 2 and 3.

Level 1 **Discuss concerns** with individual and obtain their views of their Level 3 situation Refer to landlord: if resident is a tenant and landlord needs to be **Discuss with NOK/Family/Carer** aware of risk to others Refer to landlord: who should wherever possible and Assistive Technology: Consider • Carry out their own inspection of appropriate how this can be used to increase property **Fire Services Home Safety** safety e.g. more smoke detectors Consider what tenancy conditions in the property Check: Agree with individual relating to resident's that a referral will be made for responsibilities will be enforced Animal welfare referral to (where this • Work collaboratively with agencies appropriate): consent not involved to achieve the best required who should: Assessment of needs (if outcome •Visit property to undertake required): discuss a referral to Safeguarding Adults: raise a concern wellbeing check on animals Social Care if person has no insight into risk and •Remove animals (if required) to a is not engaging or accepting **GP notification:** refer where safe environment assistance (a multi-agency response appropriate and consented • Educate client regarding animal is likely required) welfare (if appropriate) Signpost for emotional and Environmental Health: Refer to if • Take legal action for animal practical support: Provide resident is a private tenant or owner cruelty if appropriate details of supports available e.g. occupier (and risk to others • Provide advice/assistance with charities/voluntary established) re-homing animals organisations e.g. Samaritans Environmental Health to assess and Environmental Health: Refer to if consider serving notices under: **Tenancy support:** including resident is a private tenant or owner occupier (and risk to others helping to ensure rent and Environmental Protection Act 1990 established) utilities are maintained • Prevention of Damage by Pests Act 1949 Information sharing with other Finance check: Provide details agencies to ensure a collaborative Housing Act 2004 on debt or benefit advice (if response (consent must be Mental Health services: this level of appropriate) and options for obtained) hoarding indicates the person likely appointeeship requires support from MH services. Safeguarding Adults: raise a Risk to adults: Assess and take concern if person has no insight • If the person already has a MH into risk and is not engaging or action if required diagnosis but is not known to a accepting assistance (consent not CMHT, referral should be made to Risk to children: Assess and essential) Mental Health Single Point of take action if required Access (SPA) • If no diagnosis known, referral to GP should be made for MH input

e.g. assessment and treatment for

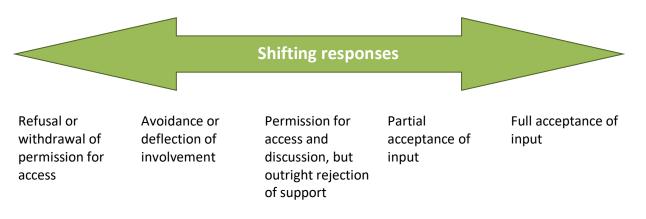
hoarding disorder through

secondary services

10. How to approach your interventions

The risk assessment described above helps to inform whether there are immediate actions that need to be taken i.e. where someone's life is at risk. The starting point however for most interventions should be to encourage the person to do things for themselves. This approach should be revisited regularly throughout the period of the engagement. All efforts and the responses of the person to this approach should be recorded fully.

It is important to understand that people who self-neglect often have shifting responses - Braye et al. (2005) outline this below to highlight the difficulty professionals will encounter with trying to work with the person.



Efforts should be made to build and maintain supportive relationships through which the take up of support or services by the person, is negotiated over time. This involves a person-centred approach that listens to the person's views of their circumstances and seeks informed consent where possible before any intervention. Figure 5 (below) provides tips on how to effectively engage someone. A **gradual approach** to gaining improvements in a person's health, wellbeing and home conditions **is more likely to be successful** than an attempt to achieve considerable change all at once.

For example, forcible clearing away of possessions is rarely a successful approach with hoarders, as discarded items are usually replaced. The process of forcible clearing can also be a very traumatic experience and detrimental to a person's wellbeing. Any clearing process should take place as part of an integrated, multi-agency long-term plan.

As self-neglect is often linked to disability and poor physical functioning, a key area for intervention is often around assistance with activities of daily living, from preparing and eating food to using toilet facilities. The <u>range of interventions</u> can include adult occupational therapy, domiciliary care, housing and environmental health services and welfare benefit advice.

Home fire safety visits

Where a person's home environment becomes cluttered through the excessive hoarding of items, the risk of a fire occurring increases, and it is more difficult for adult's living within the property to evacuate safely. With the consent of the adult, the London Fire Brigade will undertake a home safety visit and provide the necessary guidance and advice regarding fire safety, and also where necessary will install smoke alarms and / or other specialist equipment. Any individual or partner agency can make a referral for a home safety visit by contacting the London Fire Brigade. The adult, or a friend or family member, may also make a self-referral. The London Fire Brigade also have some useful tips for carers and support workers.

- **Building rapport**; taking the time to get to know the person, refusing to be shocked
- Moving from rapport to relationship; avoiding kneejerk responses to selfneglect, talking through interests, history and stories
- **Finding the right tone**; being honest while also being non-judgmental, separating the person from the behaviour
- **Going at the individual's pace**; moving slowly and not forcing things; continued involvement over time
- Agreeing a plan; making clear what is going to happen; a weekly visit might be the initial plan
- Finding something that motivates the individual, linking to interests (e.g. hoarding for environmental reasons, link into recycling initiatives)
- **Starting with practicalities**; providing small practical help at the outset may help build trust
- **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
- Keeping company; being available and spending time to build up trust
- Straight talking; being honest about potential consequences
- Finding the right person; working with someone who is well placed to get engagement
- External levers; recognising and working with the possibility of enforcement action

Figure 6: Tip for engaging with person as suggested by Braye et al (2015)

When professionals are unable to engage the person and obtain their acceptance of the support offered, the person, carer or advocate should be fully informed of the support or services offered and the reasons why the services were not implemented. The professional should make it clear that the person can make contact at any time in the future for services (if this is possible) or advise them who they can contact in the future.

Where the conditions of the individual's wellbeing or their environment are such that they appear to pose a serious risk to the adult's health, or their living conditions are becoming a nuisance to neighbours/affecting their enjoyment of their property, advice from Environmental Health should be sought and joint working should take place.

There will be times when the impact of the self-neglect on the person's health and well-being or their home conditions or neighbours' environmental conditions are of such serious concern that practitioners may need to consider what <u>legislative action (appendix 5</u>) can be taken to improve the situation when persuasion and efforts of engagement have failed. Such considerations should be taken as a result of a **multi-disciplinary, multi-agency intervention plan with appropriate legal advice.**

11. Standard multi-agency responses to self-neglect

Any professional who is working with an individual who is self-neglecting should consider engaging with other involved agencies where relevant, to optimise the responses to managing the risk. For example, with the consent of the adult, the London Fire Brigade will undertake a home safety visit and provide the necessary guidance and advice regarding fire safety, install smoke alarms or other specialist equipment (see appendix x).

Case example

Arlene's story provides an example of how different services can come together to support a person who is self-neglecting:

Arlene is in her 70s and lives alone in her privately owned property. Arlene's neighbour tells the housing officer she is worried that Arlene may be self-neglecting. Her flat is completely full of hoarded items, papers, old clothes and a strong smell coming from the property. Arlene's boiler is broken, and she has been using an electric heater to keep warm; it is not clear how long this has been the case. Arlene is also spending a lot of time sat in one spot.

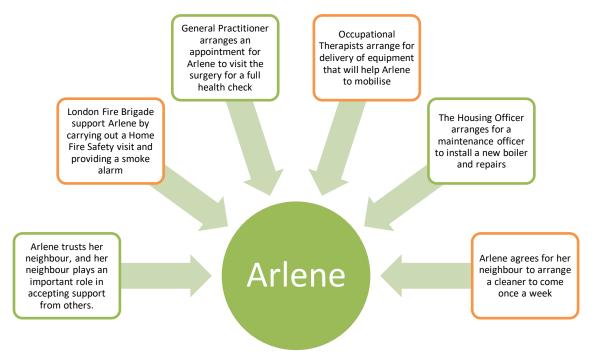


Figure 7: Example of the different roles partner agencies play in responding to self-neglect

The above shows how different agencies play their role in responding to the concerns about Arlene's selfneglect. The Housing Officer and Neighbour play an important role in ensuring the areas of risk are addressed.

12. Formal multi-agency responses to complex cases of self-neglect

SAR Martin highlighted the need for professionals to recognise an individual's 'vital interests'. Vital interests covers interests that are essential for someone's life- to prevent death (ICO, 2020). "If someone's vital interests are at risk, a case should <u>not</u> be closed simply because the person refuses an assessment or refuses to accept a plan to minimise the risks associated with the specific behaviour(s) causing serious concern."

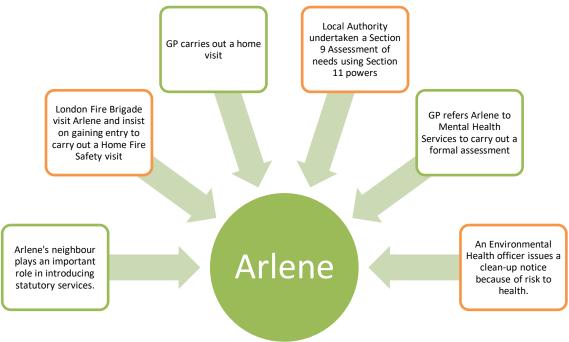
As outlined in section 2, there will be **certain situations when the person's needs are extremely complex, and professionals are struggling to effectively mitigate the risks** *despite best efforts*. In these situations, a multi-agency risk management meeting should be arranged.

The use of either the complex case pathway or adult safeguarding enquiry process is required for complex cases of self-neglect of hoarding. Conditions that would warrant this include:

- Person is repeatedly refusing care, support, essential medical treatment services or frequently engages but does not take forward what is agreed, and this is placing their life at risk (vital interests) **and/or**
- Person repeatedly refuses to engage with necessary services or frequently engages but does not take forward what is agreed and there is a significant risk of fire and/or public interests' risk and/or
- Person lacks mental capacity to decide about how to manage their situation and the state of their environment is causing chronic health and safety risks or pending enforcement action (placing them at risk of homelessness)

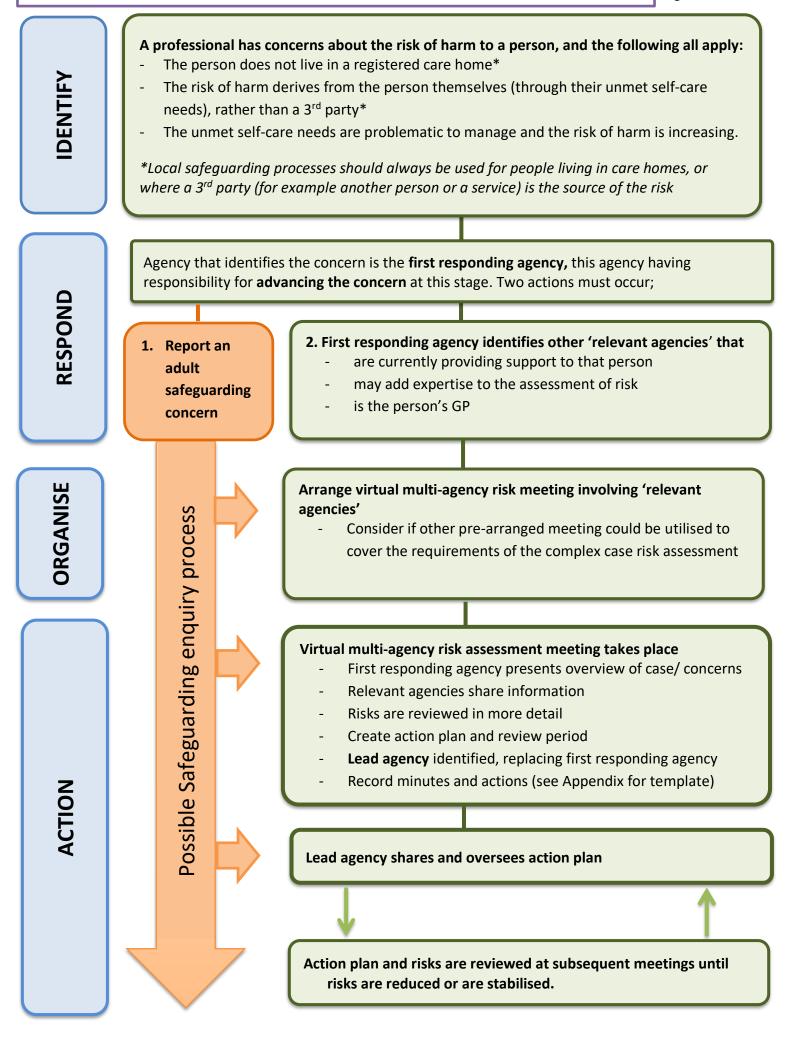
Any professional who has involvement (*more than one off*) is in a position to initiate a multi-agency meeting. Section 13 outlines what the process might look like. <u>Appendix 6</u> provides a meeting template.

Figure 7 below demonstrates the possible actions agreed following a multi-agency meeting to the case example of Arlene - in the circumstances where *she is repeatedly refusing the support offered and those involved are worried about her vital interests.*



13. Complex Case Pathway – Access further guidance on using this tool here.

Page **21** of **36**



Appendix 1:

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 person hoarding believes buying or saving things will relieve the anxiety and fear they feel. The hoarding effectively becomes their comfort blanket.
- Any attempt to discard hoarded items can induce feelings varying from mild anxiety to a full panic attack with sweats and palpitations.
- Long term behaviour pattern: possibly developed over many years, or decades, of "buy and drop".
 Collecting and saving, with an inability to throw away items without experiencing fear and anxiety.
- *Excessive attachment to possessions*: People who hoard may hold an inappropriate emotional attachment to items.
- Indecisiveness: people who hoard struggle with the decision to discard items that are no longer necessary, including rubbish.
- Unrelenting standards: People who Hoarder will often find faults with others, require others to
 perform to excellence while struggling to organise themselves and complete daily living tasks.
- Socially isolated: people who hoard will typically alienate family & friends and may be embarrassed to have visitors. They may refuse home visits from professionals, in favour of office based appointments.
- Large number of pets: people who hoard may have a large number of animals that can be a source of complaints by neighbours. They may be a self-confessed "rescuer of strays"
- Mentally competent: People who hoard are typically able to make decisions that are not related to the hoarding.
- *Extreme clutter*: hoarding behaviour may prevent several or all the rooms of a person property from being used for its intended purpose. Churning: hoarding behaviour can involve moving items from one part a person's property to another, without ever discarding anything.
- Self-Care: a person who hoards may appear unkempt and dishevelled, due to lack of toileting or washing facilities in their home. However, some people who hoard will use public facilities, in order to maintain their personal hygiene and appearance.
- Poor insight: a person who hoards will typically see nothing wrong with their behaviour and the impact it has on them and others.

Appendix 2:

Mental capacity assessment template for Self-Neglect:

Mental Capacity Assessment record

1.1 Person's details					
Name:	Name: Date of Birth:				
Case/Ref:					
Present Address/Location:					
Home Address (if Different):					
1.2 Details of person carrying out this assessment		2 			
Name:		- -			
Role: Organ	isation:				
Tel:	Email:				
1.3 What is the specific decision relevant to this ca	pacity assessment? (Suggest	this is written in 1 st person)			
 Should I be admitted to hospital? Should I take my x (e.g. diabetes) medication? Should I receive care/treatment for my pressure areas? Should I receive support to change/ modify/ clean my living environment? 1.4 Have you been supported to carry out the capacity assessment by another person or professional?					
□ Yes	No (Ifyes, give d	etails of person/s below)			
Name Profession	Relationship to Person	Contact details			
1.5 Identify any legally appointed Decision Maker:					
Is there Power of Attorney or Court appointed deputy in place with authority to make this decision?					
□ Yes Details:					
1.6 MCA Principles:					
\Box I have provided all the information the person needs to make an informed decision, incl. all options available.					
□ The decision cannot be delayed, and I have chosen the best time for the person to engage in the assessment.					

1.7 Stage 1: Assessment process

 \Box Can the person understand relevant information to the decision? YES/ NO

□ Can the person retain relevant information to the decision for long enough to make the decision? YES/ NO

□ Can the person use or weigh the relevant information/options to make this decision (Please consider executive functioning within this factor)? YES/ NO

 \Box Can the person communicate this decision YES/ NO

If the answer to all four factors in YES – person has capacity and assessment is complete If the answer to any of one or more than one the above factors is NO – please continue to Stage 2

1.8 Stage 2 Assessment process

□ The person is considered to have an impairment/disturbance in the functioning of the mind/brain. Please state what this is:

1.9 Causative Nexus: How does the identified impairment or disturbance in Stage 2 is affect the service user's ability to make the decision in Stage 1:

2. Best Interests Decision Making

□ I have consulted with all those involved with the person incl. family/friends/person themselves

□ The decision taken is one that is the less restrictive and determined to be in their best interests

2.1 Please outline what action has been agreed

Date:

Signed:

Appendix 3: Risk Assessment guidance

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	Minimal Risk	Moderate Risk	High/Critical Risk
Health Physical and mental health Engagement with universal health services (e.g. GP) Engagement with specialist health services (e.g. drug, alcohol, counselling), Compliance with medication Medical advice	 Minimal Risk Individual sometimes engages with universal and/or specialist physical/mental health services, but only after prompting or with support. Individual doesn't always take prescribed medication as advised, but this is unlikely to result in significant harm. Individual generally seeks medical support, but not straight away and not always from the most appropriate agency. Individual only uses any physical aids and equipment sometimes, and requires prompting, but this is not likely to cause significant harm to their health. 	Noderate Risk Inconsistent engagement with universal and/or specialist physical/mental health services, despite prompting and support. This is likely to result in significant harm to their health over time. Individual doesn't take prescribed medication consistently, which is likely to cause a significant deterioration in health over time. Individual needs a lot of prompting to seek medical help, which might cause damage to their health over time. Individual only uses physical aids or equipment with extensive prompting, and this is likely to cause significant harm to their health over time. Some evidence of untreated skin conditions such as ulcers, skin sores etc. which is having a negative impact on their health and wellbeing	High/Critical Risk Individual doesn't engage with any physical/mental health service, universal or specialist or Individual says they will but never do. This is likely to result in immediate and significant harm to their health. Individual consistently doesn't take life-sustaining medication (e.g. insulin), or Individual says they will but never do. This is then contrary to medical advice, and resulting in an immediate threat to their life. Individual fails to consistently seek medical advice for conditions that put their life at imminent risk. Individual refuses to use, or does not see the need to obtain, physical aids or equipment that are vital to enabling daily life e.g. a ventilator. This puts their life and/or personal wellbeing at immediate risk Evidence of untreated skin conditions such as ulcers, skin sores etc. which is compromising and impacting on their health and wellbeing and resulting in significant or life-threatening harm
Home Environment Condition of accommodation Shelter Animals Utilities	Maintenance issues are minimal (e.g. broken lightbulb) but individual needs prompting to address them. Individual is homeless but engages with support to look after their personal wellbeing and safety.	Maintenance issues are more significant (e.g. cracked windowpane, broken boiler) and individual has made minimal attempts to address them, despite prompting. Individual is homeless but does not consistently engage with services to keep	Maintenance issues are a significant threat to safety (e.g. floorboards missing, broken external doors). Individual has made no attempt to address them or obstructs attempts to do so. Individual is rough sleeping and not engaging with any support services to keep safe. Or individual has a safe property to stay in but chooses not to use it.

Individual has note but		
Individual has pets but	themselves safe or look	The number of pets in the property
they appear mostly well	after their health and/or	is unmanageable and makes the
cared for, and this does	personal wellbeing. This	living environment dangerous for
not significantly prevent	contributes to their	the individual.
them from caring for	homelessness.	
themselves.		Individual refuses specialist
	Individual has pets	support to address their housing
Person usually	which are not all cared	needs, putting them at risk of
addresses their	for appropriately or	imminent homelessness.
housing needs but	doing so causes harm	
requires support from	to the person (e.g.	Vermin and infestations are rife,
specialist services or	walking dogs makes	and individual does not co-operate
their support networks.	individual's severe	with attempts to address this.
	arthritis flare up, then	•
Early signs of vermin or	requiring intervention).	There are clear signs of hoarding
infestations are visible	· · · · · · · · · · · · · · · · · · ·	that may cause harm to the
and are addressed by	Person admits to	person e.g. blocked exits. The
the individual, but only	needing support in	individual is unwilling to address
with prompting.	addressing their	this with or without support.
with prompting.	housing needs but does	and war of warloat support.
There are some signs	not consistently seek or	Incorrect use of items within the
of hoarding, but these	follow this information	house which could lead to serious
are addressed by the	and advice.	and immediate harm e.g. lighter
individual.		
individual.	Vermin and infestations	fluid to light internal fire.
		Individual bas no sofety systems
Items within the house	are visible, but limited to	Individual has no safety systems
are not used for their	one area in the home,	or makes no attempt to maintain
intended purpose but	and individual requires	systems, coupled with behaviours
this is unlikely to cause	significant	that make them more necessary
immediate harm e.g.	encouragement to	(e.g. no smoke detector, heavy
significantly	address this.	smoker and lack of fire escape).
overloading plug		
sockets.	Initial prompts to	There is no working toilet and
	address signs of	individual uses other receptacles,
Individual has some	hoarding are largely	without proper waste disposal.
safety systems (e.g.	ignored, but this is	
basic smoke detector,	addressed by the	There is no supply of basic utilities
lockable external	individual with more	to the house nor is the individual
doors) but needs	intensive support	seeking alternatives, and
support to fit or		individual is therefore lacking heat
maintain them.	Items within the house	and / or access to clean water.
	are sometimes used in	This is likely to cause immediate
There is a working	a way that may cause	harm to their health.
toilet, but it requires	harm (e.g. lighting gas	
fixing and individual is	hob to keep warm) and	
using makeshift	person doesn't always	
repairs.	respond to safety advice.	
Dronorty has basis	auvice.	
Property has basic	Individual bas four	
utilities (heating,	Individual has few	
access to clean water)	safety systems and	
but individual	makes little attempt to	
sometimes needs	maintain them or allow	
prompting or support to	others to do so (e.g.	
use, or minor	broken front door	
maintenance is needed	locks).	
which support is		
needed for (e.g.	Property has a toilet	
bleeding radiators).	and sewage system but	
	significant repairs are	
	needed, with little effort	

		Property has an inconsistent supply of basic utilities, due to individual neglecting to maintain systems (e.g. broken radiators, blocked drainage) but individual is using alternatives (electric heater, bottled water). Reluctant engagement with attempts to fix broken systems.	
Personal care and well- being Engagement with	Person has engaged with an assessment and will follow most of the recommendations, but not all.	Person engages with the assessment stage but does not follow any of the recommendations.	Person repeatedly refuses to engage in an assessment and doesn't follow any other associated advice and guidance. Self-neglect has caused significant estrangement with essential
services Social isolation	Self-neglecting behaviours (e.g. unpleasant odours from lack of self-care) has a small impact on	Self-neglect impacts on access to some key community facilities (e.g. shops, buses) and/or their support	services (e.g. food shops) and/or their support network, and person makes no attempt to address this.
Clothing Hygiene	their access to community facilities (e.g. groups, cafes) but the person seeks support to address this.	network and the person does not seek support for this but will reluctantly engage when offered.	Individual has major infestations due to lack of washing (scabies, nits, headlice), that result in secondary conditions such as sepsis. Person may refuse support
Presentation	Individual can sometimes appear dishevelled or unkempt (e.g. clothes buttoned up incorrectly, wearing items backwards) but not consistently, and generally washes themselves. There is sometimes a discernible unpleasant smell but the person addresses this when prompted. Person presents well (mood, behaviours, and physical appearance) most of the time, but not always, and they require low level prompts which are generally responded to. Person generally appears to have an awareness of their	 Individual often appears unkempt and there are minimal signs that the person washes regularly (e.g. greasy hair, wearing the same clothes repeatedly). There is often a discernible unpleasant smell and the person does not consistently address this, despite repeated prompting. Person's presentation often causes some concern but more so lately (low mood, erratic behaviours, dishevelled appearance), signifying a slow deterioration. Person needs support to maintain their dignity (e.g. used to be house- proud but now needs a 	 Sepsis Person may relase support to address this. Person has a strong and distinct odour without seeming to notice or be willing to address. There is a rapid deterioration in the individual's presentation over a short period of time. Evidence of skin breakdown which is compromising and impacting on their health and wellbeing and resulting in significant or life-threatening harm Evidence of faecal matter and urine which is compromising and resulting in significant or life-threatening harm No usable bath/bathroom appliances which is compromising and impacting on their health and wellbeing harm

	dignity but they require and engage with	cleaner due to ill-health) but individual has	
	support to maintain this (e.g. requires help to do buttons but still takes pride in choosing clothes).	inconsistent engagement with this, which may cause harm to their health e.g. unhygienic bathroom and kitchen areas).	
Nutrition Weight (loss or gain) Food preparation Food choices Access to food	Lots of the individual's food is out of date by up to a week but there is some food still in date. Individual is over or underweight, but this is not likely to cause them significant harm now, and they are generally engaging in support to manage their weight. Food is generally stored in an appropriate place, but not always (e.g. meat not always put in the fridge quickly enough).	Most of the food is out of date by up to a week and there is little evidence of attempts to get more. Individual is noticeably under/overweight and requires specialist support to manage this. Engagement with the support is inconsistent and person requires a lot of encouragement. Food is stored inappropriately, and person requires support with this, which they reluctantly engage with, needing frequent encouragement and repeated advice.	No evidence of food in the property or evidence of mouldy and out of date food items which is compromising and impacting on their health and wellbeing and resulting in Individual makes informed choices not to spend money on food leading to significant and dangerous weight loss. Or individual appears to have only one food-type (e.g. fast food, biscuits, sweets), which causes them to become dangerously overweight. Evidence that food and drink is not a priority which is leading to concerns such as dehydration/malnutrition/significant weight loss etc. which is compromising and impacting on their health and wellbeing and resulting in significant or life- threatening harm
Finance Access to money Management of money Self-funding	The person may have limited finances due to unemployment, not claiming all benefits, or debt, which they may need support to address. Person is self-funded and pays for essential services that will keep them safer, but only after much advice and guidance from their support network.	Person may have very limited access to money (due to financial exploitation, benefit error, lack of support networks), and does not engage with support to address this. Person is self-funded and often chooses not to pay for essential services that will keep them safer but pays for some.	The person has no access to money at all or is in serious debt, due to their self-neglect (e.g. not applying for benefits, not opening a bank account or setting up payment plans for essential services) and needs immediate support Person is self-funded and doesn't pay for essential services that will keep them safe, through a seeming absence of awareness about their responsibility for their own safety and does not see this as a financial priority.
	Person often makes decisions around their finances which could put them at risk of harm (e.g. not leaving enough money to buy	Person's financial decisions frequently put them at great risk of significant harm (e.g. regularly not prioritising paying for essential	Person consistently makes financial decisions which put them at immediate and significant risk of harm e.g. refusing to pay utility bills.

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Appendix 4

Hoarding Assessment form (for multi-agency use):

This assessment should be completed using the information within this guidance document. Complete this review away from the adult's property and in conjunction with the clutter image rating scale tool and guidance.

Date of				
assessment				
Name of ad	ult			
Date of Birth	า			
Address				
Contact deta	ails			
Type of dwe	lling			
Freeholder		If adult is a tenant: Name & address of landlord		
		Name	Relationship	DOB
Household N	vlembers			
Does the p	erson		I	1
appear to h				
physical/m impairme				
Agencies cu involved wi and contact	th adult			
Other pers informal sup and cont details	oport act			
Adult's view own enviro				



	Ple	ease indicate if	present at the prop	erty		
Structural damage to property	Insect of rodent infestat		Large number animals	of	Clutter	outside
Rotten food	Animal in hous		Concerns over the cleanliness the property	of	Visible h faeces	numan
Concern of self- neglect	Concer childrei propert	n at the	Concerned for other adults at the			
Using	g the Clutter	Image scale p	lease score the each	of the roo	ms below	
Bedroom 1		Bedroom 4		Separa	te toilet	
Bedroom 2		Kitchen		Lounge	5	
Bedroom 3		Bathroom		Dining	Room	
animal waste, rodents	or insects, ro	otting food, are	•		-	
animal waste, rodents with blocked exits, are Please conduct yo	or insects, ro there combu pur assessme	otting food, are ustibles, is there ont using the cl	utilities operational, e a fire risk? etc.) utter image rating s	structural	damage, nd then re	problems efer to the
animal waste, rodents with blocked exits, are Please conduct yo	or insects, ro there combu pur assessme	otting food, are ustibles, is there ont using the cl his document	e utilities operational, e a fire risk? etc.)	structural	damage, nd then re	problems efer to the aded?
animal waste, rodents with blocked exits, are Please conduct yo essential actions g	or insects, ro there combu our assessme guidance in t	otting food, are ustibles, is there ont using the cl his document	e utilities operational, e a fire risk? etc.) utter image rating so Based on this, what	cale tool a	damage, nd then re our case gra	problems efer to the aded?
animal waste, rodents with blocked exits, are Please conduct yo essential actions g Level 1- Green Name of the profess undertaking this	or insects, ro there combu our assessme guidance in t	otting food, are ustibles, is there ont using the cl his document	e utilities operational, e a fire risk? etc.) utter image rating so Based on this, what	cale tool a	damage, nd then re our case gra	problems efer to the aded?
animal waste, rodents with blocked exits, are Please conduct yo essential actions g Level 1- Green Name of the profess undertaking this assessment:	or insects, ro there combu our assessme guidance in t sional	otting food, are ustibles, is there ont using the cl his document	e utilities operational, e a fire risk? etc.) utter image rating so Based on this, what	cale tool a	damage, nd then re our case gra	problems efer to the aded?
animal waste, rodents with blocked exits, are Please conduct yo essential actions g Level 1- Green Name of the profess undertaking this assessment: Name of Organi	or insects, ro there combu our assessme guidance in t sional sisation ails:	otting food, are ustibles, is there ont using the cl his document	e utilities operational, e a fire risk? etc.) utter image rating so Based on this, what	cale tool a	damage, nd then re our case gra	problems efer to the aded?

Appendix 5

Legal Frameworks for responding to self-neglect

Legal processes can be implemented via a single agency and do not have to be under safeguarding adults' procedures or using the complex case pathway. Legal processes are used to compel an individual to remove risk and or permit service access. This is again where there is a very fine balance between the rights of the individuals and the rights of others who have be affected by the behaviour, particularly in cases of hoarding. Agencies should work together to determine and agree the best legal options to pursue.

In brief some of the legal options may include:

- i. **The Care Act 2014,** Section 42: Adult Safeguarding enquiries, Section 11: Right to carry out an Assessment even if person capacitated and refusing, Section 9: Assessment of needs
- ii. **Mental Capacity Act 2010**: Where an individual who is self-neglecting is unable to agree to have their needs met because they are assessed as lacking mental capacity to make specific decisions in relation to this, then the principles of the Best Interests process must be followed in line with the Mental Capacity Act.
- iii. Human Rights Act 1998: In cases of self-neglect, articles 5 (the right to liberty and security) and 8 (the right to private and family life) 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.
- iv. **The Housing Act 2004:** Allows Local Authorities to carry out a risk assessment of residential premises to identify any hazards that would likely cause harm and to take enforcement action where necessary to reduce the risk to harm. Provide grounds for eviction of a tenant in certain circumstances
- v. **Public Health Act 1936 and 1961**, Section 79: Power to require removal of noxious matter by occupier of premises
- vi. Public Health Act 1936 and 1961, Section 83: Cleansing of filthy or verminous premises
- vii. **Public Health Act 1936 and 1961**, Section 84: Cleansing or destruction of filthy or verminous articles
- viii. **Prevention of Damage by Pests Act 1949**, Section 4: Power of LA to require action to prevent or treat rats and mice
- ix. **Environmental Protection Act 1990**, Section 80: Gives the local authority a power of entry to deal with a statutory nuisance.
- x. Mental Health Act 1983 and 2007, Section 2 & 3: for health and safety and protection of others
- xi. Mental Health Act 1983 and 2007, Section 135: removal of person to place of safety for assessment to take place
- xii. **Anti-Social Behaviour, Crime and Policing Act 2014:** Introduced Injunctions to Prevent Nuisance and Annoyance (IPNA) and Community Protection Notices.

- xiii. **Anti-Social Behaviour Orders** where there is persistent conduct which causes alarm, distress, or harassment (through Police/anti-social behaviour Officer)
- xiv. **Building Act 1984:** Gives the Local Authority powers to undertake works in certain circumstances.
- xv. Animal Welfare Act 2006: Makes it an offence to cause an animal to suffer where that suffering is unnecessary, and also places a duty on people to meet the welfare needs of animals that they are responsible for.
- xvi. **Misuse of Drugs Act 1971 Section 8:** A person commits an offence if, being the occupier or concerned in the management of the premises, he/she knowingly permits or allows production or supply of illegal drugs on their premises.
- xvii. **Court of Protection:** The Court of Protection can be asked to determine whether the person has the mental capacity to make a decision on a specific matter, and/or where they lack capacity, to decide what is in the individual's best interests.
- xviii. **Inherent Jurisdiction of the High Court:** The inherent jurisdiction of the High Court can be used to protect people who have the mental capacity to make decisions but cannot exercise that capacity freely.
 - xix. **Protection of Property (Section 47 Care act 2014):** The Local Authority has a duty to protect the property of adults where A) the adult is being cared for during periods of admission to hospital or residential care and B) it appears to a local authority that there is a danger of loss or damage to movable property of the adult's in the authority's area because i) the adult is unable (whether permanently or temporarily) to protect or deal with the property and ii) no suitable arrangements have been or are being made
 - **XX. Powers of Entry:** Powers of entry are available to the police, to Approved Mental Health Professionals (AMHPs) and to the Local Authority in specific situations.

Appendix 6

Complex Case Pathway Meeting

Venue, date and time of meeting: Initials of adult:

Date:

1. Introductions, roles of attendees and apologies: ensure contact details are shared for future communication/follow up 2. Purpose of the meeting This meeting is convened under the Complex Case Pathway guidance to bring together all relevant and/or involved agencies to identify and agree actions to mitigate risks. 3. Confidentiality and information sharing issues 4. Background of adult and summary of concerns 5. Details of each agency's involvement/concerns Confirm whether there is any agency no longer involved due to services being refused. What has been tried already by each involved agency? What was the outcome? Step 2: Where are we now? (10 minutes) 6. What is the adult's perspective of the situation and their wishes? Where possible, try to facilitate person attending the meeting- what support would be required? If the adult is not attending, ensure that their views are sought prior to the meeting. 7. Details of mental capacity to make a decision regarding ability to prevent harm and self-neglect: Decision(s) and associated risks and consequences against which mental capacity (including 'executive functioning') has been assessed. How capacity assessment was carried out, when and by whom. Is a legal view required? 8. Assessment of risk: Agree severity of risks identified Step 3: Problem Prioritisation (5 minutes) 9. Which of the above issues will be of the most benefit to focus on first? Consider who these will be of most benefit to? 10. What is working well at the moment? Identify strengths of the adult and i	Step 1: Multi-agency involvement (15 min)							
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Step 5: Closure and future follow up								

12. Who will send out a copy of the minutes and plan?

13. Is a further meeting required?

Note: Any agency can re-initiate the complex case pathway meeting if the circumstances change following the implementation of the above agreed action plan and new risks are presented that cannot be managed through existing arrangements.

Appendix 7: Useful resources for professionals and people who self-neglect:

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Lambeth Fire Services Provide an essential response to ensure hoarders reduce fire risks by installing smoke alarms etc. Fire safety check: Send Referral form LFB Hoarding policy	Environmental Health Referrals should be made when there are concerns about a private tenant or owner occupier who is hoarding. EH can also support landlords experiencing difficulties with their tenants. E. pse@lambeth.gov.uk T: 0207 926 4444 For concerns relating specifically to pests you can contact: 020 7926 8860 or You can make a referral through the website to Arrange a pest control visit
Hoarding UK: Provides information, support for hoarders and agencies, including local support groups. T: 020 3239 1600 M: 07444 791 500 E: info@hoardinguk.org	Animal Welfare Service If you are concerned for the welfare of a dog, they will endeavour to visit the address and assess the situation and act accordingly. T: 020 7926 8860 E: animalwelfare@lambeth.gov.uk Alternatively you can contact the RSPCA on: 0300 1234 999.
Carer's Hub We offer advice, information, emotional support, signposting, peer support groups and events T: 020 7346 6800 E. connect@carershub.org.uk	Help for Hoarders Provides information, support and advice for hoarders and their families, including online support forums. www.helpforhoarders.co.uk
Samaritans Samaritans is a confidential emotional support service for people who are experiencing feelings of distress or despair, including those which may lead to suicide. T: 08457 90 90 90 (price of a local call)	Compulsive Hoarding Website based service which provides a resource of up-to-date information about compulsive hoarding, its diagnosis, research, treatment and the available support. www.compulsive-hoarding.org/index.html