Barking & Dagenham

Safeguarding Adults Board

Barking & Dagenham

SAB Multi-Agency Policy & Guidance

Part 1: Self-Neglect Policy
Part 2: Hoarding Support

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Introduction

Self-neglect can be a result of a conscious decision to live life in a particular way that may result in having an impact on a person's health, wellbeing and relationships with others. There may also be a negative impact on the living conditions, surrounding environment and health and safety of other people. Often in these circumstances people may be unwilling to acknowledge that there might be a problem or be open to receiving support to improve their circumstances. There are various reasons why people self-neglect.

Some people have insight into their behaviour, while others do not. Some may be experiencing an underlying condition, such as dementia. The person's needs and situation will need to be assessed to establish the facts of the situation, the nature and extent of the concern, and what action, if any, should be taken. Part of the challenge is knowing when and how far to intervene when there are concerns about self-neglect and a person makes a capacitated decision not to acknowledge there is a problem, or to engage in improving the situation. This may involve making individual judgments about what is an acceptable way of living, balanced against the degree of risk to an adult and others.

Managing the balance between protecting adults from self-neglect against their right to self-determination is a serious challenge for public services. Balancing choice, control, independence and wellbeing calls for sensitive and carefully considered decision-making. Dismissing self-neglect as a 'lifestyle' choice is not an acceptable solution in a caring society. On top of this there is the question of whether the adult has the mental capacity to make an informed choice about how they are living and the amount of risk they face. There needs to be consideration of executive mental capacity and the person's ability to improve their situation to keep themselves safe. Assessing that mental capacity and trying to understand what lies behind self-neglect is often complex. It is usually best achieved by working with other organisations and, if they exist, extended family and community networks. Often people who self-neglect do not want help to change, which puts themselves and others at risk, for example through vermin infestations, poor hygiene, or fire risk from hoarding.

However, improvements to health, wellbeing and home conditions can be achieved by spending time building relationships and gaining trust. When people are persuaded to accept help some research has shown that they rarely go back to their old lifestyle, although this sometimes means receiving help over a long period. This may include treatment for medical or mental health conditions or addictions, or it could be practical help with de-cluttering and deep cleaning someone's home.

The Safeguarding Adults Board (SAB)

The Barking and Dagenham Safeguarding Adult Board (SAB) is made up of a number of key partners from across social care, health, the police and the community. The SAB has a statutory duty to ensure that it safeguards people from abuse and neglect. The SAB has

developed this guidance to support professionals across the partnership who work with people who are at high risk of significant harm due to self-neglect. It aims to help professionals identify cases, manage the risks and safeguard people through coordinated multi agency partnership approaches, in a way that supports the person(s) involved.

The Care Act 2014

The Care Act 2014 statutory guidance includes self-neglect and hoarding in the categories of abuse or neglect relevant to safeguarding adults with care and support needs.

The Local Context

This policy will be referred to when an adult at risk is believed to be self-neglecting and should be read in conjunction with the London Multi-Agency Adult Safeguarding Policy and Procedures https://londonadass.org.uk/safeguarding/review-of-the-pan-london-policy-and-procedures/

Many cases of hoarding and self-neglect are referred through our local Safeguarding Adults Complex Cases Group which is a committee of the Barking and Dagenham Safeguarding Adults Board (SAB). This is because these are often some of the most complex cases, with people having a number of different support needs including care and support, mental health and physical health needs along with the mental capacity to make their own decision around their care and support and accommodation. The needs of the person self-neglecting often span across a number of partner organisations, requiring a multi-agency approach to managing and sharing the risks in order to keep the person safe. Local community and voluntary sector organisations can also support the risk management in cases like this. Often the adult lives alone, is elderly and has lived in their own property for many years and they are the owner-occupier. The adult more often than not has mental capacity to make decisions about their housing. Some adults experience poverty and are unable to maintain their homes, other adults have money but due to their age they may consider it pointless to maintain their home given they think about their own mortality and apathy may set in and home falls into disrepair.

Part 1

Self Neglect

1. Self-Neglect

1.1 What is Self-Neglect?

The Care Act 2014 recognises self-neglect as a category of abuse and neglect, which means that people who self-neglect will be supported by safeguarding adults teams, as well as social care support and other health and community support.

Self-neglect involves any failure by an adult to take care of him or herself, which causes or is reasonably likely to cause serious physical, mental or emotional harm or substantial loss of assets. Self-neglect covers a wide range of behaviours where a person neglects to attend to their basic care and support needs, such as personal hygiene, appropriate clothing, feeding or tending appropriately to any medical conditions they may have.

- Lack of self-care to an extent that it threatens personal health and safety
- Neglecting to care for one's personal hygiene, health or surroundings
- Inability to avoid harm as a result of self-neglect
- Failure to seek help or access services to meet health and social care needs
- Inability or unwillingness to manage one's personal affairs.

1.2 Why do people Self-Neglect?

It is not always possible to establish a root cause for self-neglecting behaviours. Self-neglect can be a result of:

Sometimes self-neglect is related to deteriorating health and ability in older age. People with mental health problems may display self-neglecting behaviours. There is often an assumption that self-neglecting behaviours indicate a mental health problem but there is no direct correlation.

Mental health illnesses can include (but not limited to)

- Bereavement
- Depression
- Post traumatic Stress Disorder
- Obsessive compulsive disorder
- Hoarding disorder
- Personality disorder
- Anxiety
- Mood disorder
- Psychotic disorder

Physical illnesses can affect certain abilities (but not limited to)

- Reduced mobility
- Sleep
- Energy levels
- Attention span
- Organisational skills
- Motivation
- Memory
- Confidence
- Decision making
- Side effects of medication e.g. drowsiness etc

1.3 Recognising Self-Neglect

There are many ways that self-neglect can present itself. The indicators below do not include all signs but may help you to identify if an individual is self-neglecting.

Social & Community Factors	Personal Neglect	Neglect in the Home
Declining support from family, professionals or the community	Dirty / inappropriate clothing	Poor maintenance of property
Unwilling to attend appointments including medical or housing appointments	Poor finance management – e.g. bills not being paid leading to utilities being cut off, unexplained money being drawn from bank account	Lack of heating, running water, sanitation, utilities
Situations where there is evidence that a child is suffering or is at risk of suffering significant harm due to self-neglect by an adult	Medical / health needs unmet e.g. diabetes & refusing insulin, treatment of leg ulcers etc	Unsanitary, untidy or dirty conditions, which create a hazardous situation
Eccentric behaviour/lifestyle leading to harm	Alcohol and/or substance misuse	Keeping lots of pets who are poorly cared for
Social isolation	Malnutrition	Hoarding
Lack of interest or concern about life	Poor hygiene	Presence of vermin

2. Supporting People who Self-Neglect

2.1 Building Relationships

Research has shown that those who self-neglect often do not see anything wrong with the way they live and don't wish to accept help or support to address the issues or risks. People may be deeply upset and even traumatised by interventions such as 'deep cleaning'. When developing an approach, it is important to try to understand the individual and what may be driving their behaviour. The person may try to use avoidance tactics when discussing the self-neglect or addressing issues in their home environment. It may take many attempts to talk to someone or it may help for messages to be communicated through a trusted person such as a family member, friend, neighbour or another professional who already has a relationship with the person such as a GP. In some cases, community or voluntary sector organisations can support these relationships, as they are independent from professionals working in health and social care. The Fire Brigade can also assist with offering home fire safety advice and can provide free smoke alarms. People may be more open to speaking with them as, again, they are independent from other professionals. It is important to allow people to have a voice, listen to their opinions, their wants and needs and give people choices at every step of the way. The options they choose, the risks involved and the consequences of their decisions should be communicated with them so that they can make informed choices.

2.2 Professional Curiosity

Professional curiosity is a combination of looking, listening, asking direct questions, checking out and reflecting on information received. It means not taking a single source of information and accepting it at face value. It means testing out your professional assumptions about people and their situations. Being professionally curious enables practitioners to support people and explore vulnerability and risk while maintaining an objective, professional and supportive manner.

The following questions may help to start the conversations:

How do you get in and out of your property?	Do you feel safe living here?	Have you ever had an accident, slipped, tripped up or fallen? How did it happen?
How do you move safely around your home?	Are you able to cook and prepare food for yourself?	Do you need help with shopping?
We are concerned about the level of things in your property can place you at risk of fire. Do you need help with clearing out or tidying the property?	Is there hot water, lighting and heating in the property? Do these services work properly?	Are you able to manage your personal care, like washing, showering or bathing yourself?
Do you smoke? Do you drink alcohol?	Do you use substances? How does this affect you and your relationships with others?	If there was to be a fire do you think you would be able to get out of the property easily?
Where do you sleep?	Do you take any prescribed medication? Are you able to get this from the pharmacy yourself?	Are there any obvious major repairs that you think need carrying out at the property?
Have you thought about undertaking repairs or moving?	When did you last go out in the garden?	Do you feel safe to go out on your own?
Are you in agreement for me to share your information with another professional who may be able to help you?	Have you received support from Social Services or any other organisation or group?	Would you like to receive support with anything in particular?
Is there medical oxygen in use at the property	Is there a reason why you may not want support or help?	Has a fire ever started by accident?

2.3 Good Practice

The Self-Neglect Policy and Practice: Key Research Messages, SCIE, 2015 outlines a number of areas of good practice when working with people who self-neglect:

- Adopt a trauma informed and be curious to establish 'what happened' to the person in their life before this point, rather than focusing on 'what's wrong' with them.
- Taking the time to build rapport and a relationship of trust, through persistence, patience and continuity of involvement.
- The theme that emerged most consistently in the research carried out by Braye, Orr and Preston Shoot in 2014 was the importance of establishing a relationship to secure engagement and achieving interventions that could make a difference.
- Trying to find the whole person and to understand the meaning of their self-neglect in the context of their life history, rather than just the particular need that might fit into an organisation's specific role.
- Engaging with the individual's family, friends and/or support network (with the person's consent). Their knowledge and understanding of the person may assist with understanding the reasons for self-neglect and they may be best placed to provide support.
- Working at the individual's pace and being able to spot moments of motivation that could facilitate change, even if the steps towards it are small.
- Offering choices and having respect for the individual's judgements on the most appropriate form of help even when coercive measures are being taken. The degree to which the person is treated with respect can go a long way in creating a beneficial outcome.
- Ensuring an understanding of the nature of the individual's mental capacity in respect of self-care decisions.
- Being honest, open and transparent about risks and options.
- Having in-depth understanding of legal mandates providing options for intervention.
- Making use of creative and flexible interventions, including family members and community resources where appropriate.
- Engaging in effective multi-agency working to ensure inter-disciplinary and specialist perspectives, and co-ordination of work towards shared goals. If there are children living in the home of someone who self-neglects then children's services should be informed and form part of the multi-agency response.

There are some general pointers for an effective approach:

Multi Agency	Work with partners to ensure the right approach for each individual.
Person Centred	Respect the views and the perspective of the individual, listen to them and work towards the outcomes they want.
Acceptance	Good risk management may be the best achievable outcome, it may not be possible to change the person's lifestyle or behaviour.
Analytical	It may be possible to identify underlying causes that help to address the issue.
Non-judgemental	Try not to make judgements about cleanliness or lifestyle, everyone is different.
Empathy	Try to empathise with behaviours even though they are hard to understand.
Trust	Try to build trust and agree small steps.
Reassurance	The person may fear losing control, it is important to allay such fears.
Bargaining	Making agreements to achieve progress can be helpful but it is important that this approach remains respectful.
Patience and time	Short interventions may not be successful, practitioners should be enabled to take a long-term approach.
Exploring alternatives	Fear of change may be an issue so explaining that there are alternative ways forward may encourage the person to engage.
Always go back	Regular, encouraging engagement and gentle persistence may help with progress and risk management.

2.4 Think Family

Self-neglect can often adversely affect whole households. You will need to consider the impact of the persons behaviour has on other family members (including children). Consider whether there are any children or any adults living in the property or regularly visiting, who may be at risk of harm within the current environment. If there are any concerns about a child you must raise a safeguarding concern and Children and Young People's Social Care need to be informed. In order to support families to make changes that are helpful and long lasting, work needs to be done with all the members of the family. Recognising that the needs and desired outcomes of each person in the family affect each other, will support and enable sustainable change. Agencies should ensure that the 'Think Family' approach is embedded not only into every day practice at the front line but is reflected in service design, structure and commissioning. Family means different things to different people. We know that different communities and cultures consider family in different ways and this is not static. The understanding and practice of family changes develops over time and is affected by external circumstances and environments. Risks that have an impact on other people will need to be managed, with or without the cooperation of the person who is self-neglecting and non-engaging. It is still important that all activity is communicated to the person.

Things to consider include:

- What impact is the person's behaviour having on the people around them?
- What impact are other people in the family having on the person self-neglecting?
- Is the person an informal carer and what impact is this having on the person they are providing care to?
- Is there anyone else at risk in the household? If so, then a safeguarding referral must be made to either Children and Young People's Services for a child or Adults Care and Support for an adult with care and support needs.
- Is there domestic abuse occurring? Does a referral need to be made?

2.5 Care Act Assessment

Self-neglect is a complex phenomenon and it's important to elicit the person's unique circumstances and perceptions of their situation as part of assessment and intervention. It is important to consider how to engage the person at the beginning of the assessment. Think carefully about how to word and appointment letter. The usual standard appointment letter is unlikely to be the beginning of a lasting trusting professional relationship if it is perceived as being impersonal and authoritative. Home visits are important and practitioners should not rely on proxy reports. It is important that the practitioner uses their professional skills to be invited into the person's house and observe for themselves the person and the condition of their home environment. Practitioners

should discuss with the person any causes for concern over the person's 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 overall cumulative impact of a series of small decisions and actions as well as the overall impact.

Equally, repeat assessments might be required as well as ensuring that professional curiosity and appropriate challenge is embedded within an assessment. It is important than when undertaking the assessment, the practitioner does not accept the first and potentially superficial response rather than interrogating more deeply into how a person has understood and how this could impact on their situation. A sensitive and comprehensive assessment is important in identifying capabilities and risks. It is important to look further and tease out, through a professional relationships, the possible significance of personal values, past traumas and social networks. Some research has shown that events such as loss of parents as a child, abuse as a child, traumatic wartime experiences and struggles with alcoholism have preceded the person self-neglecting. It is important to collect and share information with a variety of sources, including other agencies, to complete a picture of the extent and impact of the self-neglect and to work together to support the individual and assist them in reducing the impact on their wellbeing and on others. In potentially complex situations or where there is thought to be significant risk to the person's health, wellbeing, environment or to others, consideration should be given to convening a multi-disciplinary and multi-agency meeting to share information and agree an approach to minimising the impact of specific risks and to improve the person's wellbeing. The person themselves should be included in the meeting along with significant others and an independent advocate where appropriate.

It is important to undertake risk appraisal which takes into account individuals' preferences, histories, circumstances and lifestyles to achieve a proportionate and reasonable tolerance of acceptable risks. **The case should not be closed simply because the person refuses an assessment or to accept a plan to minimise the risks associated with the specific behaviours causing concern.**

2.6 Advocacy

Under the Care Act 2014, the role of an independent advocate is to ensure the person's voice is heard and their rights are upheld. They also enable the person to be fully involved in the process and in decision-making. This can include representing someone if they are unable to represent themselves and supporting someone to self-advocate.

There is a legally-binding duty upon the local authority to arrange an independent advocate. You can find out more here about advocacy services in Barking and Dagenham https://www.lbbd.gov.uk/adult-health-and-social-care/getting-someone-speak-my-behalf

This duty applies in cases where, if an independent advocate was not provided, the person would have substantial difficulty in being fully involved and where there is no appropriate individual available who meets the criteria of the Care Act.

The duty applies to both carers and those with care and support needs across different types of care settings.

The duty to arrange an independent advocate applies from first contact onwards, in the care planning process and in a review of arrangements. If the person moves area, the local authority carrying out the assessment, planning or review, is responsible for deciding whether continuity of independent advocacy is desirable.

The Care Act 2014 defines four domains, in any one of which a person might have substantial difficulty in being fully involved:

- understanding relevant information
- retaining information
- using or weighing up information
- communicating their views, wishes and feelings.

Professionals make a judgement as to whether a person has substantial difficulty, they do not have to prove this conclusively.

A carer, friend or family member can be appointed to assist a person's involvement by acting as an 'appropriate individual', instead of appointing an independent advocate. They must meet the criteria of the Care Act and be able to maximise the individual's involvement in the process. There are instances when a person may be judged as not being an appropriate individual or where they may not be able and willing to provide the right support.

At different stages in the process:

- An appropriate adult can replace an independent advocate
- An independent advocate can replace an appropriate individual
- An independent advocate can support the involvement of two people from the same household, as long as there is no conflict of interest.

Being an independent advocate means maximising the individual's involvement, supporting and representing the person to:

- understand key care and support or safeguarding processes, communicate views, wishes and feelings, and self-advocate where possible
- understand and uphold their rights
- understand how their needs can be met in the local context
- make decisions and challenge decisions where the advocate believes that they don't fulfil the local authority's duty to promote individual wellbeing.

An independent advocate must have appropriate experience and training and display integrity, competence and good character, be able to work independently and be regularly supervised. The local authority is expected to recognise the independent advocate's duty and the importance of their service, including ensuring there is sufficient provision of independent advocates in their area and that identification and referral is working effectively.

The main interfaces of Care Act 2014 advocacy are with the Mental Capacity Act 2005 and Mental Health Act 1983 (as amended in 2007). Some people qualifying for independent advocacy under the Care Act 2014 will also qualify for advocacy under the Mental Capacity Act 2005. The same advocate can provide support under both acts if they meet the appropriate requirements. The provision of independent advocacy also applies to those people being jointly assessed by the NHS and the local authority, or where a package of support is planned, commissioned or funded by both a local authority and a Clinical Commissioning Group.

3. Safeguarding

3.1 Safeguarding Concerns

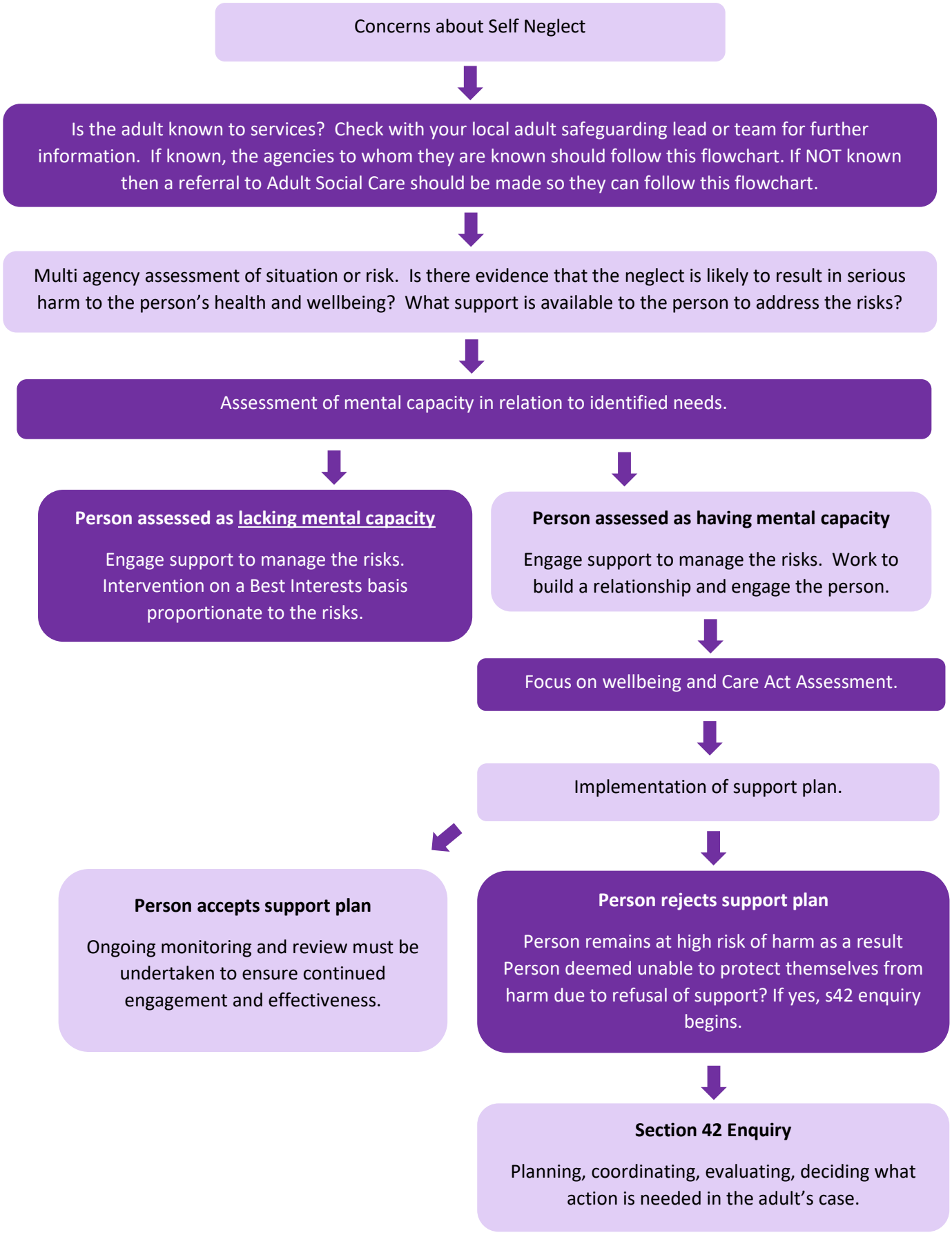
The London Multi Agency Adult Safeguarding Policies and Procedures state that an adult safeguarding concern is any concern about an adult (aged 18 or over) who has or appears to have care and support needs, that they may be subject to, or may be at risk of, abuse and neglect and may be unable to protect themselves against this. The adult does not need to be already in receipt of care and support. A concern may be raised by anyone, and can be:

- An active disclosure of abuse by the adult, where the adult tells a member of staff that they are experiencing abuse and/or neglect.
- A passive disclosure of abuse where someone has noticed signs of abuse or neglect, for example, clinical staff who notice unexplained injuries.
- An allegation of abuse by a third party, for example, a family, friend or neighbour who have observed abuse or neglect or have been told of it by the adult.
- A complaint or concern raised by an adult or a third party who doesn't perceive that it is abuse or neglect. Complaint officers should consider whether there are safeguarding matters.
- A concern raised by staff or volunteers, others using the service, a carer or a member of the public.
- An observation of the behaviour of the adult at risk.
- An observation of the behaviour of another.
- Patterns of concerns or risks that emerge through reviews, audits and complaints or regulatory inspections or monitoring visits.

Concerns can be raised in person, by telephone, email or letter. They may also be raised through specific organisation processes for example London Ambulance Notifications and police Merlin Adult Come to Notice (ACN) reports. Merlin ACNs are reports completed by operational police officers and sent to local authorities where they have concerns about people who may be adults at risk, whether they are a victim, witness, suspect or member of the public. The police will make a decision about whether to refer to the Local Authority, using their operational toolkit. Some concerns may not sit under adult safeguarding processes but remain concerns that may require other action.

Making Safeguarding Personal necessitates a conversation with the adult about the concern to gain their consent, however, professionals will consider vital or public interest if the risks are high or put other adults at risk. This means that information may need to be shared without the consent of the adult in order to safeguard others.

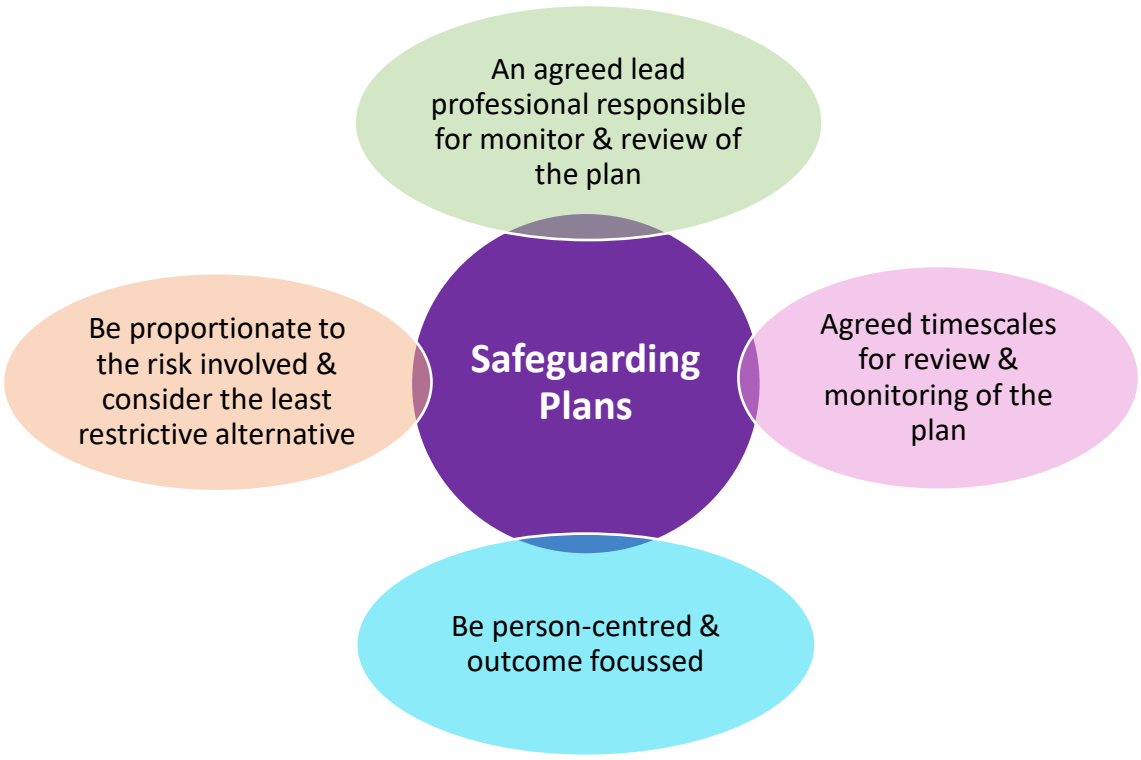
3.2 Safeguarding Concerns Flow Chart



3.3 Safeguarding Plans

In some cases, following a self-neglect enquiry, it will be necessary to have a safeguarding plan. This will usually be in circumstances where the risk cannot adequately be managed or monitored through other processes. Safeguarding plans will not always be required, for example, in circumstances where the risk to the adult can be managed adequately through ongoing assessment and support planning input, through Care Programme Approach by mental health services or through a positive risk taking and management plan approach. In other circumstances, for example, where the adult has been assessed as having mental capacity to make informed decisions about their care and support needs and has been given all reasonable support and encouragement to accept support to meet those needs, however still chooses to refuse support, it may be decided that the action required is to provide information and advice including how to get in touch with the Council, and no ongoing safeguarding plan would be appropriate.

However, in other circumstances, particularly where the risks to independence and wellbeing are severe (e.g. risk to life or others) and cannot adequately be managed or monitored through other processes, it will be necessary to have a safeguarding plan to monitor the risk in conjunction with other agencies. In self-neglect cases this would usually involve health service colleagues, but other agencies may well need to retain ongoing oversight and involvement (e.g. Environmental Services and Housing Services). If the plan is still rejected and the risks remain high, the meeting should reconvene to discuss a review plan. **The case should not be closed just because the adult is refusing to accept the plan.** Legal advice should be sought in these circumstances. All professionals involved should be clear about their roles and actions.



3.4 Multi Agency Working and Managing the Risks

When there is a safeguarding concern about an adult that is self-neglecting it is advisable to discuss it with the adult in terms of Making Safeguarding Personal, with a view to convening a safeguarding meeting with others that may be known or could be a source of support to the adult. Various professionals may have information about the adult and some may already have a strong relationship with them. Multi-agency meetings enable information to be shared and decisions to be made about how best to support the person. It also allows the risks to be shared and managed across agencies. It is important to record the information shared and the decisions made, together with the agreed actions. If necessary, consider getting legal advice. As far as possible always inform the adult of any planned meetings, explain why the meeting is necessary and invite them to attend.

Possible areas for exploration		
Does the individual have mental capacity to make an informed decision about risks they are placing themselves in, and whether or not they need support?	How should mental capacity be assessed?	Who should undertake the assessment?
Explore the risks / likely harm of non-intervention with the person in their home.	What are their views about the additional risks you have pointed out to them?	Document all views, decision making and record whether or not the professionals present feel that the circumstances require consideration under safeguarding protocols.
Are there children at risk?	Are there any other vulnerable adults at risk?	

3.5 The Safeguarding Adults Complex Cases Group (SACCG)

The Barking and Dagenham Safeguarding Adults Complex Cases Group (SACCG) is sub-committee of the Safeguarding Adults Board (SAB). It is a meeting where information is shared on cases presenting with the highest risk and complexity. When an adult's circumstances have been discussed at multi-agency level and the risks have not reduced and where they remain high, it is best to refer such cases to the SACCG. The group is made up of representatives of the Local Authority, the Police, Mental Health services, Housing Services, safeguarding officers, officers from the Fire Service, and other professionals as and when

required. The case can therefore be discussed at a higher management level to support and share the risks within and across organisations.

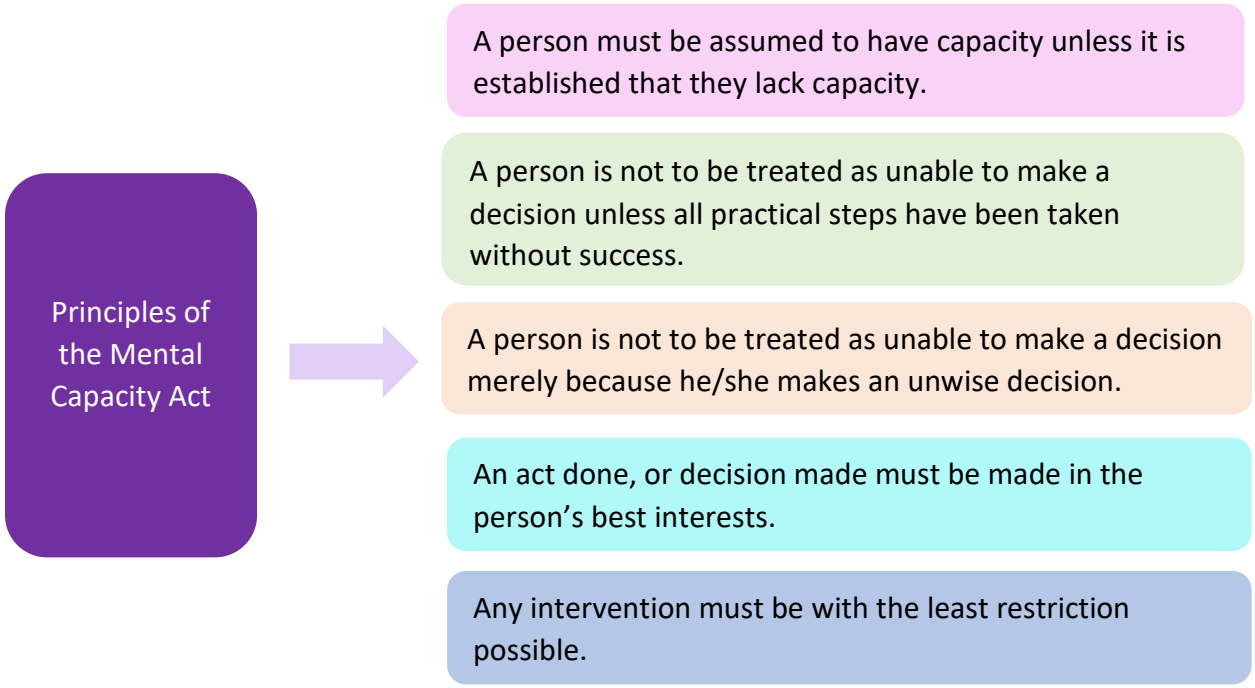
The SACCG considers new cases to support the identification of high risks that need to be shared across agencies. Cases are also brought for discussion to monitor and review those risks. Every case represents a safeguarding concern for an adult that requires multi agency communication and approach to addressing risks adequately. The SACCG will consider cases in respect of adults aged 18 years and over, as well as transitional cases of people aged 17 years and over to ensure well-managed transitioning into adult services where care and support needs are likely under the Care Act 2014. This will be where existing mechanisms within agencies, for resolving or minimising risk, have not achieved this outcome.

A number of cases of hoarding and self-neglect have been presented at the Safeguarding Adults Complex Cases Group and the risks are managed across the agencies.

More information about the Safeguarding Adults Complex Cases Group can be found here https://www.lbbd.gov.uk/adult-social-care/barking-and-dagenham-safeguarding-adults-board/safeguarding-adults-complex-cases

3.6 Mental Capacity

The Mental Capacity Act 2005 provides a statutory framework for people who lack capacity to make decisions for themselves.



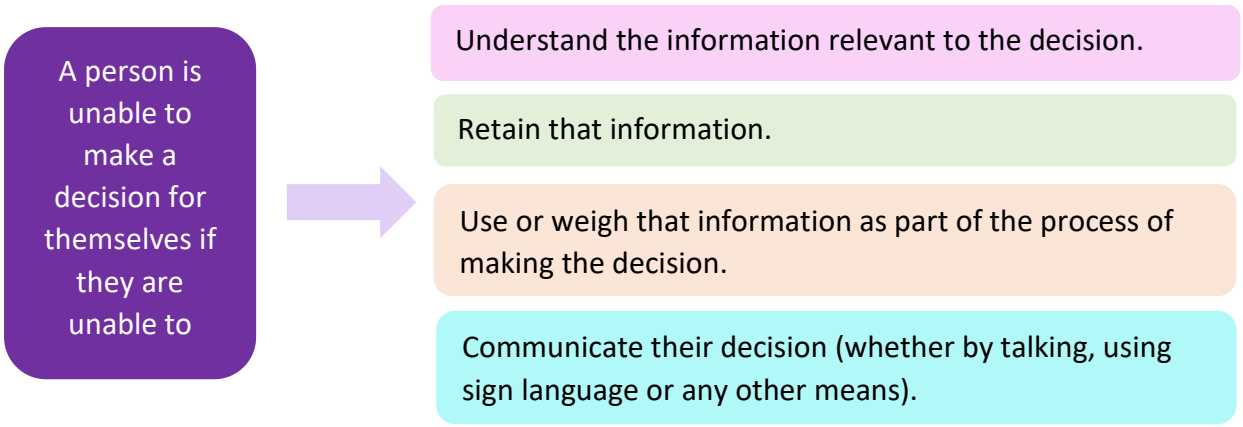
When a person's self-neglecting and hoarding behaviour poses a serious risk to their health and safety, interventions from professionals may be required using a multi-agency

approach. The Act provides protection from liability for actions taken, as long as actions taken are in the individual's best interests as per the terms of the Act. The seriousness of any decision made and actions undertaken increase the need for very clear documentation as well as the need to alert others to the situation. A decision to intervene in the individual's best interests may need to be in line with following up through safeguarding adults' procedures.

For more information on the Mental Capacity Act, see the associated Code of Practice https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice

3.7 Assessing Mental Capacity When Adults Self-Neglect

Guidance for assessing mental capacity is provided through the Mental Capacity Act 2005 (MCA) which states that:



Mental Capacity Assessments, Choice & Control

Establishing whether a person has the mental capacity to make a decision with regard to their self-neglect is often a challenging exercise for many professionals. The Mental Capacity Act 2005 is clear on the presumption of mental capacity and the rights of individuals to make unwise or eccentric choices. However, it is difficult to accept that some individuals would seriously neglect themselves to the extent of threat to life and refuses to engage and that this is a choice. It is often difficult understand how anyone would not want to follow the norms of society to ensure their own safety and wellbeing. However, the Mental Capacity Act reminds us that a person is not to be regarded as unable to understand the information relevant to a decision, if the person is able to understand an explanation of it given to them in a way that is appropriate to their circumstances (using simple language, visual aids or any other means).

Often as a result of trauma someone may self-neglect despite being very aware of the risks of their behaviour and the negative impact it would imminently, or eventually have on their health or wellbeing. There are a number of other reasons where it may influence the

person to make unwise decisions. Self-determination, the right to control one's life and need for independence can often drive someone to make a particular choice.

Exploring Matters with the Adult

What is of critical importance is that social workers and practitioners need to explore with the adult their reasons for not taking particular action to better support their health and wellbeing. Where there are risks these needs to be assessed with the adult and get their views on these. These should then be well recorded, ideally verbatim.

The First Principle is not Designed to be the First Hurdle to Enable Support to the Adult

The Mental Capacity requirement to assume capacity, is sometimes used by a practitioners or social workers faced with a person who is self-neglecting and refusing to engage with support. The practitioner may reach a superficial conclusion that the person has mental capacity, meanwhile the supporting evidence of degree of harm that is occurring may indicate a need for a closer look. The MCA Code of Practice says that, if a person repeatedly makes unwise decisions that put them at significant risk of harm or exploitation or they make a particular unwise decision that is obviously irrational or out of character, although this may not necessarily mean that the person lacks capacity, there might be need for further investigation, taking into account the person's past decisions and choices.

For example:

Have they developed a medical condition or disorder that is affecting their capacity to make particular decisions?

Are they easily influenced by undue pressure?

Do they need more information to help them understand the consequences of the decision they are making?

In cases of self-neglect it is essential that a person's mental capacity, to make informed choices about their personal and domestic care, is assessed carefully. Mental capacity is a complex attribute, involving not only the ability to understand the consequences of a decision but also the ability to execute the decision. It is often here that a person would require some support to arrange services to address the problem, for example arranging a tradespersons to carry out work on their property or support to clean their home environment, if this is their only need.

Executive Mental Capacity (ability to act on the issue)

The meta-analysis undertaken by Braye, Orr and Preston-Shoot (2011), has proposed that mental capacity consists of two distinct components, which have come to be labelled:

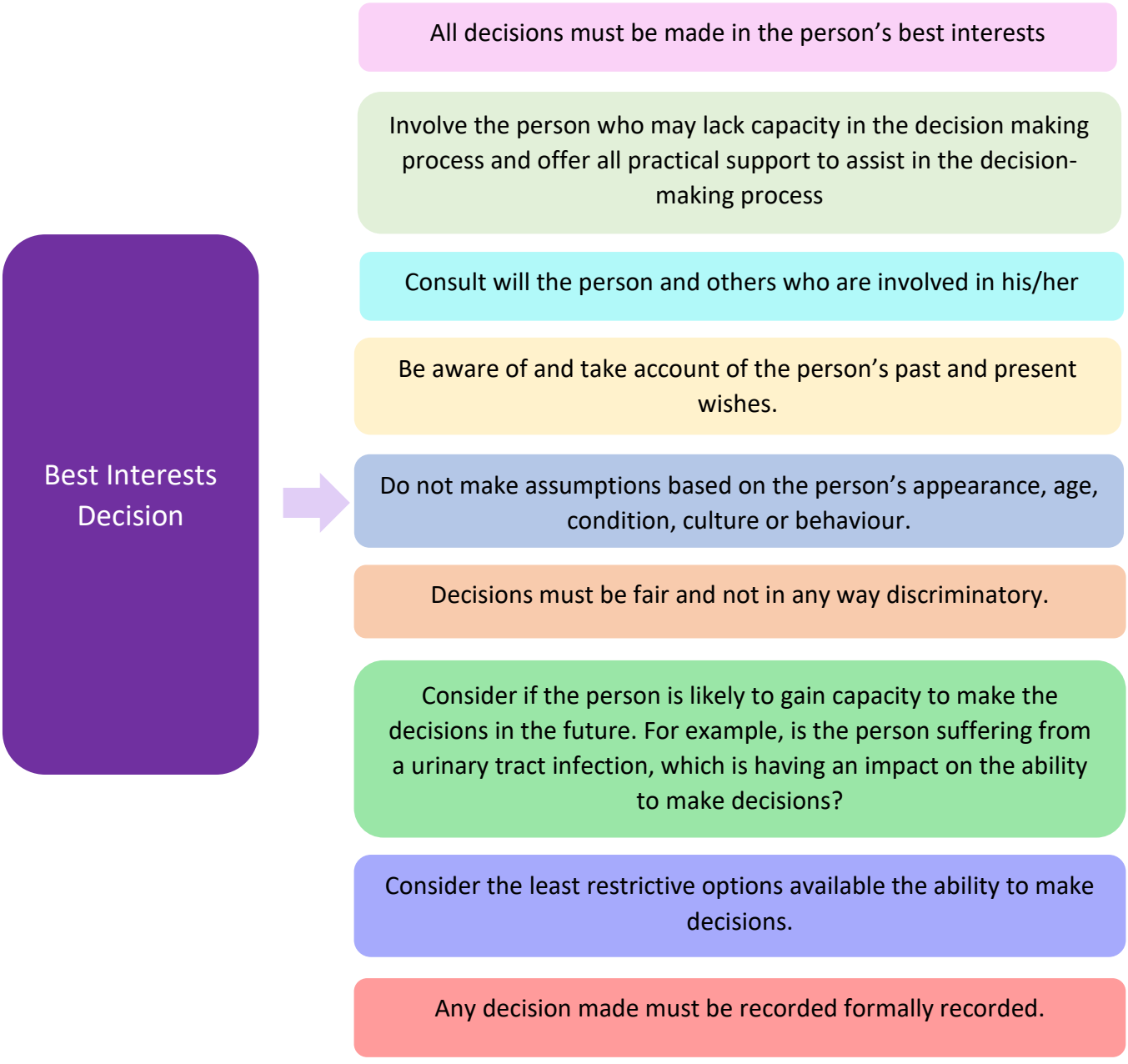
- Decisional Capacity
- Executive Capacity

The use of an 'articulate-demonstrate' model may be helpful. Here the person is first asked questions (as part of an assessment under the MCA) and then asked to show how they would actually implement their decision, or specific components of this decision. In the case of self-neglect and hoarding this might include showing how they would get a drink or prepare food, or exit the property quickly if there was a fire. It might involve obtaining reports from others who might have witnessed these actions. Where decisional capacity is not accompanied by executive capacity and thus overall mental capacity for autonomous action is impaired, 'best interests' intervention by professionals to safeguard wellbeing may be legitimate.

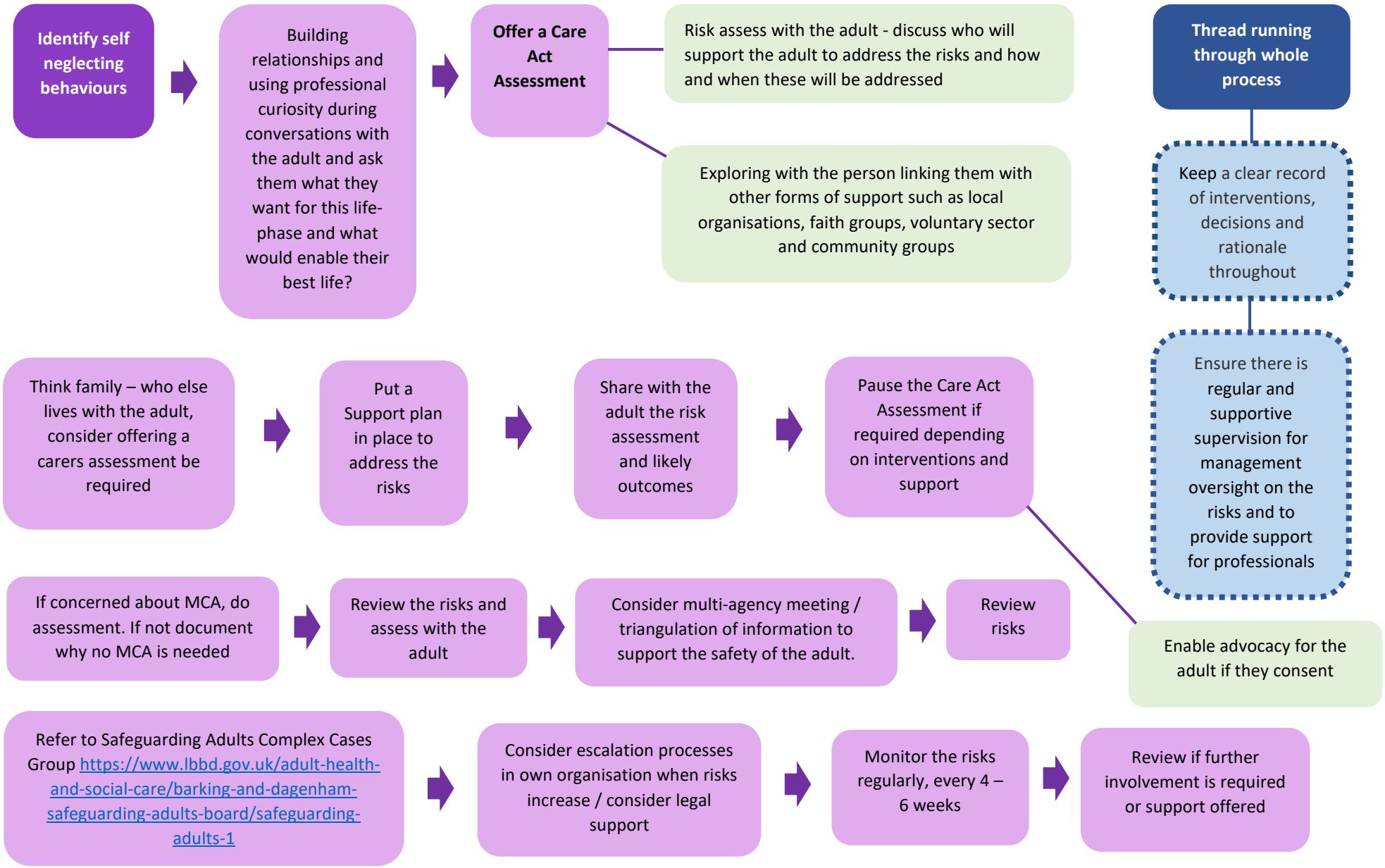
Too often executive mental capacity does not routinely feature in mental capacity assessments and it needs to be included. To understand a person's functioning regarding executive mental capacity it may be necessary to make repeat visits to try to establish a relationship with the person, in order to engage their trust and continue the assessment. Without more in-depth assessment of mental capacity, there is a risk that the absence of executive functioning may not be recognised and the person may be deemed to be making a capacitated choice when in reality they are not able to carry through the necessary actions to keep themselves safe. With regard to people who hoard there may be underlying mental health disorders such as obsessive-compulsive disorders which impact on their decision-making ability with respect to the hoarding. There is a concern too that mental capacity assessments may overlook the decision specific nature of capacity, with the result that apparent capacity to make simple decisions is assumed in relation to more complex ones.

3.8 Best Interests Decisions

A Best Interests decision is a decision made by applying the Best Interest principle, as set out in the Mental Capacity Act 2005. A Best Interests decision is a decision made for and on behalf of a person who lacks capacity to make their own decision. Best interests decisions must be made when there is no one else to decide and the person has been assessed as lacking mental capacity to make the relevant decision themselves. Legal powers are required before making best interest decisions about a person who has dementia, with regards to their money or property. Professionals should check whether there is someone with the appropriate authority to make the relevant decision for the adult, for example, a valid Advanced Decision, Court Order or Lasting Power of Attorney.



3.9 Self Neglect Flow Chart



Part 2

Hoarding Support

4. Hoarding

4.1 What is Hoarding?

Hoarding is now widely considered as a mental health disorder and appears in the US 'Diagnostic and statistical manual of mental disorders' (5th Edition). Hoarding is the excessive collection and retention of any material to the point that it impedes day to day functioning (Frost & Gross, 1993)

Hoarding is the persistent difficulty in discarding or parting with possessions, regardless of their actual value. The behaviour usually has deleterious effects - emotional, physical, social, financial and even legal, for a hoarder and family members. For those who hoard, the quantity of their collected items sets them apart from other people. Commonly hoarded items may be newspapers, magazines, paper, plastic bags, cardboard boxes, photographs, household supplies, food, clothing as well as collections of items have that got out of hand and take over the living space.

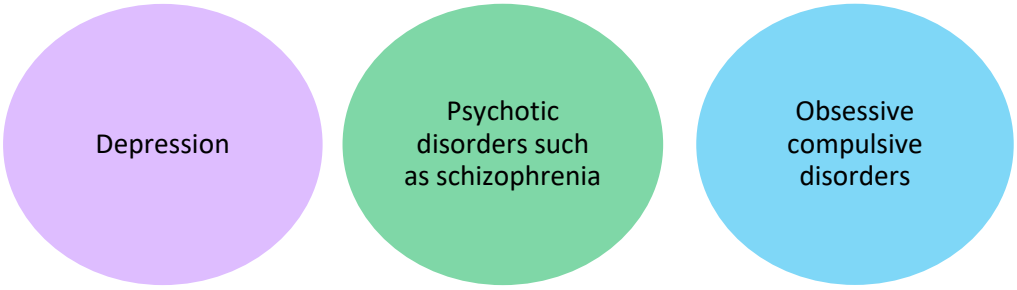
Hoarding can sometimes relate to obsessive compulsive disorder but hoarding and self-neglect do not always appear together and one does not necessarily cause the other.

Attempts to discard things often bring up very strong emotions that can feel overwhelming, so the person hoarding often tends to put off or avoid making decisions about what can be thrown out. Many of the things kept are of little or no monetary value and may be what most people would consider rubbish. The person may keep the items for reasons that are not obvious to other people, such as for sentimental reasons, or feeling the objects appear beautiful or useful. Most people with a hoarding disorder have a very strong emotional attachment to the objects.

4.2 Why do People Hoard?

The NHS website states that the reasons why someone begins hoarding are not fully understood. It can be a symptom of another condition. For example, someone with mobility problems may be physically unable to clear the huge amounts of clutter they have acquired and people with learning disabilities or people with developing dementia may be unable to categorise and dispose of items.

Mental Health problems associated with hoarding include:



In some cases, hoarding is a condition in itself and often associated with self-neglect. These people are more likely to:

- live alone
- have had a deprived childhood, with either a lack of material objects or a poor relationship with other members of their family
- have a family history of hoarding
- have grown up in a cluttered home and never learned to prioritise and sort items.

4.3 Recognising Hoarding

There are many ways that hoarding can present itself. The indicators below do not include all signs but may help you to identify if an individual is 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 hoard will often find faults with others, require others to perform to a certain standard 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 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.

4.4 Clutter Image Ratings

Research undertaken by the International OCD Foundation has found that people have very different ideas about what it means to have a cluttered home. For some, a small pile of things in the corner of an otherwise well-ordered room constitutes serious clutter. For others, only when the narrow pathways make it hard to get through a room does the clutter register. To make sure people are able to measure the level of clutter in a home the Clutter Image Ratings were created and the full document can be accessed here

https://hoardingdisordersuk.org/wp-content/uploads/2014/01/clutter-image-ratings.pdf

These are a series of pictures of rooms in various stages of clutter, from completely clutter-free to very severely cluttered. People 'rate' the level of clutter in each room of a property based on the pictures. This is really helpful tool to support professionals when recording and sharing information about someone's home. It can help to show if issues with clutter and hoarding are worsening or improving over time. It is also useful to ask the person themselves to rate their own home based on the clutter, to assess the insight they have in terms of the clutter they have accumulated. As we know, no two people's circumstances or homes are the same but in general, clutter that reaches the level of picture number 4 on the scale or higher will impact enough on a person's life and living situation that we would encourage them to get support to address the issue.

4.5 The Hoarding Pathway

The Hoarding Pathway is a support service to empower and reduce risks to those residing within Barking and Dagenham who show hoarding tendency behaviour. It aims to provide support to people in a person-centred way as opposed to solely focussing on the hoarding behaviour itself. The service area is manged within the London Borough of Barking and Dagenham Adults Care and Support. The flow chart below sets out how a referral for support within the hoarding pathway can be made.

Social Workers, Mind Organisation and other partner agencies can refer clients into the Hoarding Pathway.

The following criteria will need to be met:

- Risks clearly identified
- Photographs of the hoarding relating to the Clutter Image Rating scale (refer to page 31)
- Hoarding rating of scale 5 or above on the Clutter Image Rating
- Distinct clarification that this is a hoarding difficulty and not self-neglect
- History of trauma linked to hoarding difficulties.

The referral **must** come to LBBD Adult Social Care. A Social Worker or other professional can complete the referral form and attend a referral meeting to discuss the case.

If the case meets the criteria, it will be discussed at the Hoarding Panel meeting.

Once allocated to the Hoarding Pathway Co-ordinator a meeting will be arranged with the service user and Hoarding Co-ordinator outside of the service user's home.

The Social Worker will consult with the Hoarding Pathway Coordinator and commission the care package for deep cleaning.

The Hoarding Co-ordinator will develop a care plan with the service user to provide 6/8 sessions of support.
Weekly monitoring calls will be undertaken, signposting to further services where appropriate and assisted participation in local resilience building and community connecting initiatives.

The Social Worker, Care Coordinator and Hoarding Pathway Co-ordinator will to jointly review the risks and care plan fortnightly and update line manager of progress.

4.6 Fire Safety and Hoarding

Hoarding increases the risk of a fire occurring and makes it more difficult for people living within a property to evacuate safely in an emergency. Fire can also spread to neighbouring properties if the level of hoarding is severe or if flammable items such as gas containers, paper and plastics are being stored. Hoarded properties also pose a high risk to fire fighters when attending the scene. The sharing of information is extremely important for operational firefighter crew safety. The London Fire Brigade is required to be compliant with the Fire Services Act, 2004, Regulation 7.2d to make arrangements for obtaining information needed for the purpose of extinguishing fires and protecting life and property in their area. The multi-agency approach to sharing information about hoarding enables compliance with the Act and also strengthens the operational risk assessment when dealing with incidents and fires where hoarding is present.

Where information around the risks are shared, the London Fire Brigade are able to flag on their system if a particular property is at higher risk of fire and if there are vulnerable people living there. To help prevent accidents and keep you safe in your home the London Fire Brigade provide a free home fire safety visit service. They can fit free smoke alarms and specialist alarms for people with visual or hearing impairments. Our local London Fire Brigade representatives work in partnership with other key professionals through the Safeguarding Adults Board and have also provided fire retardant bedding where the Safeguarding Adults Complex Cases Group have identified specific risks, that needed to be mitigated.

4.7 Possible Legal Options

There are a number of legal options to take into consideration.

The Care Act (2014) Statutory Guidance – self-neglect is included as a category under adult safeguarding.

Article 8 of the Human Rights Act 1998 gives us a right to respect for private and family life. However, this is not an absolute right and there may be justification to override it, for example, protection of health, prevention of crime, protection of the rights and freedoms of others.

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

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

Where the person's housing and living environment are impacted it is important to discuss options with the relevant housing department withing the Local Authority.

Agency	Legal Power and Action	Circumstances requiring intervention
Private Sector Housing Enforcement Team	**Housing Act 2004** There are powers under this Act to enter the property to determine if there hazards that might require an Improvement Notice or Prohibition Order. These notices are served on the owner or the person responsible and the Council charge a minimum of £570 (as of June 2023) for their service. The notices require works to be carried out to remedy those hazards and if not complied with the owner or person responsible can be prosecuted or fined up to £30K.	A person who is self-neglecting or hoarding is suffering from a mental-health disorder. If they are refusing to engage with supporting services, these powers under the Housing Act would not be appropriate under any circumstances unless to support an application to the Court of Protection as evidence that someone lacks capacity to manage their finances or property – with the sole aim to safeguard the vulnerable individual.
Private Sector Housing Enforcement Team	**Public Health Act 1936 s.83** A notice under this section requires the owner or occupier to clean and disinfect the premises and destroy vermin. This would result in a criminal conviction and fine against the person responsible. If not complied with the Council can use these powers to carry out the work in their default, and bear the cost in so doing which may include costs of providing temporary shelter for the occupier. The costs are likely to be substantial and they will be passed onto the person responsible who will be legally required to repay.	A person who is self-neglecting or hoarding is suffering from a mental-health disorder. The use of these powers would be extremely stressful to the person responsible and it would never be appropriate to use these powers under this policy.

4.9 Case Studies

Case Study 1 - Older person with home in disrepair

Mrs Smith is 75 years old and she lives in her three-bedroom owner occupied home. The house has fallen into serious disrepair and in the past twenty-five years she had not carried out any works or renovations on it. There is no running water and her toilet is broken with sewage leaking all over the top floor as a consequence. Mrs Smith is quite unkempt and it looks like she doesn't change her clothes that often. Mrs Smith has a small dog that she takes for grooming every two weeks. A number of professionals are concerned that she is not able to make decisions about her home environment and fully understand the risks of self-neglect. Mrs Smith recently had to attend hospital following a fall and the Ambulance Service raised a safeguarding concern about her. She has disengaged from the support her social worker was trying to offer her. Mrs Smith's GP confirmed that she does not have any underlying medical or health condition impacting on her brain or mind which would impair her ability to make decisions about her housing and safety.

Meetings were set up to discuss the safeguarding concerns raised with her and she attended, after she was served an eviction notice to manage the environmental risks to her and her neighbours. Much discussion took place between professionals about her mental capacity, but it was agreed that she was aware of the risks involved in staying in her home. After a lot of contact and a person-centred focus of strength-based practice by her social worker, Mrs Smith agreed to move to a sheltered accommodation block with her dog for a period of time whilst she considered the repairs on her house. Since she has been staying in new accommodation Mrs Smith has made arrangements for her house to be sold to developers. Professionals agree that her wellbeing has improved since she has lived in more suitable accommodation that supports her with her needs and frailty. Her dog and trusted friend has brought much happiness to those around them where they now live.

Key points from the input of Safeguarding Partners:

- **The Social Worker worked closely with Mrs Smith to consider what she wanted acknowledging that having her dog by her side was very important to her.**
- **An eviction notice supported the legal action needed for her to agree a move to another property for a period of time.**
- **With the right support she took action to sell her property and her wellbeing has improved since she moved to sheltered accommodation.**

Case Study 2 - Hoarding Pathway

Mrs Olu lives in a two bedroom terraced house, which she owns with her son who now permanently resides in Nigeria. She lives with another son in his twenties, but he mainly spends the weekends at his girlfriend's property. Mrs Olu has lived in the UK for 26 years and she has not legalised her stay here. She has a mental health problem, and has recently developed diabetes. She has a mental health nurse who supports her as a care coordinator and who comes to provide her with a depo injection with her medication every fortnight. Mrs Olu had some periods of assessment and treatment in hospital, but that was two years ago. Her mental health has been stable since. She walks around half naked in her home and has been hoarding many items including bottles with urine and bags with excrement that are buried in heaps of old clothes. The Fire Brigade and Ambulance Service have made 36 visits to her in the past four years and her social worker is most concerned about her safety. She has recently been referred through the hoarding pathway and one worker is supporting her with a therapeutic relationship to understand why she has hoarded items in her home to the level of clutter rating 8. The worker is taking a trauma-informed approach in social care practice. An assessment has now started and interventions will be planned with Mrs Olu and she has been referred to a immigration charity that has supported her to apply to remain in the UK which has since been granted. Her mental and physical wellbeing has improved somewhat. As she does not get along well with her son it is recommended that she has a Care Act Advocate to support her during the assessment and ensure her rights are fully considered. Mrs Olu smokes and has caused a small fire on her bed previously. Following a fire safety visit the Fire Brigade has fitted smoke alarms due the risks of fire in her home. They have also provided her with fire-retardant bedding. The hoarding pathway worker meets with Mrs Olu every two weeks at her home. After several weeks they have managed to clear a few items from her home so that her bed is clear and she can sleep more comfortably. The risks of trips and falls were reduced through these actions. The worker will continue to support Mrs Olu over the next few months.

Key points from the input of Safeguarding Partners:

- **The Hoarding Pathway has supported Mrs Olu over a substantial period of time and through trauma-informed approach and reduces the risks of trips and falls in her home.**
- **She had a Care Act Advocate and a Care Act Assessment. This and the fact that her immigration status has now been permitted in the UK has supported her physical and mental health wellbeing.**

Case Study 3 - Safeguarding Concern

Florin Botezatu is 65 years old and he lives in a house he bought when he first came to London. He was badly affected by Covid and experienced an eye stroke as a result. He regularly engages in gambling and has admitted to his friends that he is struggling with the cost of living crisis and is not heating his house regularly due to the expense of it. Lately he has become more isolated as many of his friends have retired and returned to Romania during the pandemic. His front and back garden is very overgrown and there are birds flying in and out of a gap on a top floor window. A housing officer has referred him to the Safeguarding Adults Complex Cases Group. The Safeguarding Adults Cases Group has not accepted the referral because the adult has not been approached about the matter and risks have not been explored at a lower multi-agency level. Instead, they have encouraged the housing officer to raise a safeguarding concern to the Adult Intake Team for consideration of a Section 42 Safeguarding Enquiry. A multi-agency meeting would be prompted with those involved, or those who could offer him the support he needs. When Mr Botezatu says he has no family or friends in the UK he is asked about how he would identify himself in terms of protected characteristics and he confirmed he practices Islam. He is in the process of changing his name to Mr Florin Ali. Mr Ali has stopped engaging with his social worker, but he mentioned that he goes to the mosque on Fridays and he has now asked the faith organisation to support him at the meeting. Six weeks later Mr Ali had his home repossessed and is now being supported by the homelessness services in Barking and Dagenham.

Key points from the input of Safeguarding Partners:

- **The first port of call for Safeguarding Concerns is the Adult Intake Team. Only when a multi-agency meeting and safeguarding processes has been exhausted and risks still remain high will the case be suitable for a referral to the Safeguarding Adults Complex Cases Group.**
- **Faith organisations can support adults as well as other departments such as the money hub and housing services, which can increase a person's wellbeing during difficult times.**

Case Study 4 – Community Support

Mrs Spice is 62 years of age and she lives as a transgendered, lesbian woman. She is known in the community as a harmful drinker. Having lived in her council flat it is her responsibly to report repairs and enable those to take place, but she has not done this for the past three years. The housing department received some complaints that there are many people coming in and out of the property at all hours of the morning, hanging outside the flat smoking and making noise and playing loud music. There is a water leak that has developed into the property on the lower floor which now needs to be repaired, but when Mrs Spice has been approached she has not engaged. A Merlin, which is a safeguarding report from the Police, was received by Adults Intake recently. The Police attended the property and they are worried that Mrs Spice was looking unkempt and when they discussed the concerns with her she seemed quite confused. There were lots of people at the property and they had to move the people on when they became aggressive.

Since a fire was started by burning candles last week, the case was escalated to the Safeguarding Adults Complex Cases Group as the multi-agency meeting has not been able to mitigate the risks at a lower multi-agency level and the risks needed to be shared at a more senior level within the Safeguarding Adults Board Partnership. The Housing Officer has confirmed that Mrs Spice is the only person's name on the tenancy agreement.

Mrs Smith is now connected with someone from a private organisation that supports the LGBTQ+ community and they have accompanied her to access the memory clinic. She was assessed as having Care Act needs and now has a Direct Payment and goes out with a Personal Assistant regularly. Her wellbeing has improved, albeit that a recent scan confirmed she has cognitive impairment.

Key points from the input of Safeguarding Partners:

- **Through an inclusive approach and standing together against discrimination of gender and sexual orientation, organisations in the community can help keep people safe from exploitation and enable them to access support that helps them to live a life free from abuse.**
- **The Police, the local authority and community groups all work together to support the safety and wellbeing of adults.**
- **A direct payment supported this person and will continue to help her as her needs may change over a period of time with regular care reviews.**

Part 3

Support for Professionals

5. Support for Professionals

5.1 Wellbeing at Work

Organisations are aware of the emotional demands inherent in working with adults with care and support needs. This may be more intense when working with someone with complex needs who is also self neglecting or has hoarding behaviours. When professionals work with these people on a regular basis it can effect your wellbeing. It is important to create and encourage a culture of support and self-care.

Please refer to your own organisations' wellbeing resources and supervision policies and support arrangements.

For workers in health and social care we recommend that you use the following types to support for your wellbeing.

5.2 Specialist Support

If a professional's emotional, physical and/or mental wellbeing is at risk please seek further help and advice. For access to more specialist support, a conversation may be required with your line manger to arrange additional input through an occupational health referral or other support available within your organisation or employer. There are some specify 'keeping well' resources available. Here are a few examples, which you can use or share:

Tools to think about response to the current situation

Circle of control during Covid

Feelings wheel

Emotional resilience in times of crisis

Self-care cards

6. Appendices

6.1 RIPFA Working with People who Self Neglect
https://www.researchinpractice.org.uk/adults/publications/2020/december/working-with-people-who-self-neglect-practice-tool-updated-2016/

6.2 Self Nelglect at a Glance
Self-neglect: At a glance | SCIE

6.3 Safeguarding Adults Complex Cases Group
https://www.lbbd.gov.uk/adult-social-care/barking-and-dagenham-safeguarding-adults-board/safeguarding-adults-complex-cases

6.3 Clutter Image Ratings
https://hoardingdisordersuk.org/wp-content/uploads/2014/01/clutter-image-ratings.pdf

6.4 Hoarding UK Website
https://hoardinguk.org/

6.5 Hoarding UK – Overcoming Hoarding: The Basics
https://hoardinguk.org/wp-content/uploads/2019/08/The-Basics-Hoarding-v12.pdf

6.6 Hoarding a Report into Best Practice
https://booklets.foundations.uk.com/hoarding#page=1

6.7 Chartered Institute of Environmental Health – Hoarding and how to Approach It
https://www.cieh.org/media/1248/hoarding-and-how-to-approach-it-guidance-for-environmental-health-officers-and-others.pdf

7. Version Control

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