SELF- NEGLECT (INCLUDING CHRONIC HOARDING) GUIDANCE

LONDON BOROUGH OF CAMDEN

ADULT SOCIAL CARE

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1. Introduction

"***Self-neglect covers a wide range of behaviour - neglecting to care for one's personal hygiene, health or surroundings and includes behaviour such as hoarding."***
(Department of Health, 2014)

Self-neglect often involves interplay between mental health problems (diagnosed or undiagnosed) and physical, social and environmental factors. Other key triggers can include:

- substance misuse/dependency issues
- cognitive impairments or other anti-social behaviours, disability, poverty and/or lack of physical space in the home
- inequalities in terms of access to health and social care services.

There is no clear point at which lifestyle patterns become self-neglect, and the term can apply to a wide range of behaviours and different degrees of self-neglect.

Sometimes professional concerns do not match the individual's own perception of their situation. Adults that self-neglect usually have longstanding, recurring, complex needs and/or present with particular behaviours that mean they are difficult to work with.

Working with adults who self-neglect can be very time consuming and stressful for staff as there are no straightforward and proven approaches available to follow. In most instances of self-neglect the person is assessed as having the mental capacity to make relevant decisions in relation to their self-neglect. However, their behaviour may include not wishing to engage with services to make any changes to their situation. Risks as a result of this lack of engagement include: social isolation, verbal abuse, homelessness and a risk to health and wellbeing.

The Care Act 2014 formally recognised self-neglect as a category of abuse and neglect, however this does not mean that the safeguarding process will need to be followed in every case of self-neglect and may be suitably managed via a mainstream social work response. Research (*Self-neglect and adult safeguarding: findings from research, SCIE report 46, 2011)* suggests that a multi-agency, multi-professional and multi-disciplinary approach to self-neglect is the most effective one.

This guidance is outcome focused and outlines who is best placed to engage with the vulnerable person who self-neglects and how a coordinated multi-agency/multi-disciplinary/multi-professional approach should assist in achieving the best possible result.

2. Key Principles of the guidance

1. the most effective approach to self-neglect is to use consensual and relationship-based approaches. These may be more effective if carried out by, or in partnership with, non-statutory parties including family members, friends, housing officers, charities and voluntary sector organisations

2. the rights of individuals under the Human Rights Act (1998) should be supported and consensual, least restrictive interventions should be made unless there is evidence that a clear risk of significant harm exists to the person or others, which may require a non-consensual intervention

3. given the subjective nature of clutter, disarray and the value of possessions and life-styles, it is necessary to use an objective rating scale to assist communication and

understanding of the level and impact of hoarding (see resources at end of document for the objective rating scale)

4. risk of harm should always be considered in terms of harm to the individual and of harm to other people, for instance, neighbours

5. because of the diverse nature of hoarding and self-neglect, it is necessary to co-ordinate interventions across multiple organisations when concerns of risk of harm arise and to do this, a lead organisation has to be identified

6. particularly high risk is present where:
    a. multiple organisations are involved, but their actions are not coordinated and there is no clear oversight and direction

    b. a person who hoards or self-harms is of concern to numerous different organisations but does not meet their threshold criteria.

3. Sharing information

Due to the complex and diverse nature of self-neglect responses by a range of organisations, a multi-agency response is likely to be more effective than a single agency response. Sharing information between organisations will usually require the person's consent and each organisation must consider when it is appropriate to share information without the person's consent, for example, if there is a public or vital interest.

4. Presenting problems of self-neglect

The presenting problems related to self-neglect can be wide ranging. Examples include:

- a person 'hoards' excessively and this impacts on the living environment causing health and safety concerns for themselves and for their neighbours

- signs of serious self-neglect are regularly reported by the public or other agencies but there is no change in the person's circumstances

- a person's actions/inactions indicate a high risk of fire

- a person's personal or domestic hygiene exacerbates a medical condition and could lead to a serious health problem

- the accommodation becomes filthy (including problems associated with cats/dogs and their excrement) and verminous causing a health risk or possible eviction
- the person has no heating or water and refuses to move to alternative accommodation

- the person appears unkempt and/or exhibits extreme weight loss

- there are structural problems with the property and the person cannot afford repairs or refuses to consider alternative accommodation

- financial debt issues which may lead to rent arrears and the possibility of eviction

- there are health and safety issues around gas or electricity and the person refuses or cannot afford to get the appliances repaired

- anti-social behaviour intimidates neighbours and causes social isolation

- the conditions in the property cause a potential risk to people providing support or services e.g. paid or unpaid carers.

This list is not exhaustive and there may be other areas of concern or a mixture of the above that highlight a difficulty for the vulnerable adult and those trying to assist them. It is important to recognise that assessments of self-neglect are grounded in, and influenced by, personal, social and cultural values and practitioners should always reflect on how their own values might affect their own judgements.

5. Hoarding

Hoarding is considered as an element of self – neglect. Hoarding refers to the acquisition of items with an associated inability to discard things that appear to others to have little or no monetary value, to the point where it interferes with use of their living space or activities of daily living. Hoarding can include new items that are purchased and hoarded. It can also include food items, items of no monetary value, refuse and animals.

Hoarding Disorder has now been identified as a distinct diagnosis in the DSM 5 (American Psychiatric Association, 2013) but does not appear in the ICD 10 (World Health Organisation, 2010). Individuals may benefit from mental health intervention and should be encouraged to accept referral by their GP to psychological therapies or other relevant secondary mental health professionals for support.

Signs of hoarding

Conditions of extreme clutter, especially where bathroom facilities, food storage, oven, heating sources, and entry and exits are blocked, inability to throw things away that may seem to be, or actually are, rubbish, empty food containers, or papers stacked up in the living space.

6. Reasons for self–neglecting behaviour

There are a range of explanations for self-neglect (*Self-neglect and adult safeguarding: findings from research, SCIE report 46, 2011)* and a reluctance to accept intervention, including:

- psychiatric history
- underlying personality disorder, depression, dementia, obsessive-compulsive disorder, trauma response, severe mental distress
- diminishing social networks and/or economic resources
- attempts to maintain continuity and control
- physical and nutritional deterioration
- personal philosophy such as pride in self-sufficiency
- a sense of connectedness to place and possessions
- in some cases, shame and efforts to hide state of residence from others.

Unpaid carers may self-neglect as a result of their caring responsibilities and workers should be aware of the impact that caring for a vulnerable person might have on the carer and ensure that a carer's assessment is carried out and appropriate support offered.

7. Working with those who self-neglect

Challenges to practitioners working with self – neglect issues include:

- divergent agency thresholds for triggering concern and involvement
- competing value perspectives e.g. duty of care versus choice and control
- understanding complex family relationships
- dealing with the emotional effect of self-neglect on those experiencing it
- care management workflow arrangements
- care management models that do not recognise the amount of time required to build relationships and engage in what are often long, slow negotiations
- the need for legal literacy (knowledge of all relevant legislation, including the Mental Capacity Act 2005 and the Mental Health Act 1983)
- the need for creative interventions which are flexible, negotiated and proportionate.

8. Mental Capacity and self-neglect

If concerns are raised by anyone about self-neglect, the statutory agency must be clear about the person's mental capacity in respect to the key decisions that may require intervention.

If there are any doubts about the person's capacity especially with regard to their ability to 'choose' their living conditions or refuse support, then where possible a mental capacity assessment should be undertaken.

There may be circumstances in which it is useful to involve therapists in capacity assessments, for example, where the decision is around managing the home environment or where the person has communication difficulties and speech and language therapists could be helpful.

Capacity assessments should take full account of the complex nature of capacity. *Self-neglect and adult safeguarding: findings from research, SCIE report 46* highlights the difference between capacity to make a decision (decisional capacity) and capacity to actually carry out the decision (executive capacity). However, this distinction does not currently exist in policy or guidance. Good practice should involve considering whether the person has the capacity to act on a decision that they have made (executive capacity).

Strong emphasis needs to be placed by practitioners on the importance of inter-agency communication, collaboration and the sharing of risk. The autonomy of an adult with capacity should be respected including their right to make what others might consider to be an "unwise decision". However, this does not mean that no further action regarding the self-neglect is required. Efforts should be directed to building and maintaining supportive relationships through which services can in time be negotiated.

If the person is assessed as not having capacity to make decisions in relation to their self-neglect, then any decisions should be made following the best interests process, which includes taking into account the person's views and taking the least restrictive action. Additionally, consideration should be given as to whether an Independent Mental Capacity Advocate (IMCA) should be instructed. IMCAs may be instructed in Safeguarding regardless of the level of involvement of family or friends.

9. Good practice

Good practice when working with self-neglect *(Self-neglect policy and practice: key research messages, SCIE, 2015)* is:

- 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

- engaging with the individual's family/friends/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 coordination 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.

In order for good practice to occur there is a need for:

- flexibility (to fit individual circumstances)
- negotiation (of what the individual might tolerate)
- proportionality (to act only to contain risk, rather than to remove it altogether, in a way that preserves respect for autonomy).

The worker should:

- be honest
- show empathy
- demonstrate patience
- work at the individual's own pace.

10. Autonomy versus a duty of care

There is often a difficult balance to be struck between respecting an individual's autonomy and having a duty of care.

Balancing choice, control, independence and wellbeing calls for sensitive and carefully thought through decision-making. It is important to understand each individual's situation and to try and find a way of working effectively with them. Both the Care Act and Making Safeguarding Personal emphasise the importance of involving the person in decision making and focusing on the outcomes that the person wants to achieve.

Where the individual has capacity but there are concerns about the impact of their decisions on health and well-being then professionals should continue to try and work with them and people close to them (with their consent) to negotiate creative solutions. This requires appropriate and sensitive engagement by those involved with the person. Consideration should be given as to whether the person meets the requirement for a Care Act Advocate.

If there is an assessed risk of significant harm then the professional's duty of care may require them to override the individual's right to exercise choice and control. Any restrictions imposed must be necessary to prevent harm, and proportionate to the risk of that harm. Any restrictions imposed for the protection of others must have the proper authorisation, e.g. the decision of a police officer or a court order. The individual and their supporter/advocate should be kept informed of any decisions made and actions to be taken and solutions acceptable to the person sought wherever possible.

11. Key agencies and their roles

Environmental health service (EHS)

The EHS has a range of powers to intervene where a property is in a condition that is prejudicial to health, or where the premise is materially affecting neighbouring premises. EHS is a frontline agency in raising alerts and early identification of cases of self-neglect and hoarding. Where properties are verminous or pose a statutory nuisance EHS will take a leading role in case managing the necessary investigations and determining the most effective means of intervention.

Where the individual is residing in conditions that only pose a threat to their own welfare, the powers available to EHS may have limited or no effect. In cases involving persistent hoarders the powers may only temporarily address and/or contain the problem. Therefore utilising powers under public health legislation in isolation may not be the most effective use of resources, particularly where a coordinated approach could provide immediate protection of the individual and others and also promote a long term solution.

Housing department

Under Part 1 of the Housing Act 2004, the housing department has powers to take enforcement action where there is any risk of harm to the health or safety of an actual or potential occupier of a dwelling or house of multiple occupation which arises from a deficiency in the dwelling or house of multiple occupation or in any building or land in the vicinity (whether the deficiency arises as a result of the construction of any building, an absence of maintenance or repair, or otherwise). The housing department can require access to residential premises in their district to assess if such a hazard exists.

The duty to inspect the property is restricted to where there is an official complaint made either to the Justice of the Peace or local council. However, where there is evidence that there is imminent risk of serious harm to the health and safety of the occupier, the local authority has emergency power to serve a remedial action notice or emergency probation notice prohibiting the use of the property.

There are also powers to serve a deferred action notice and take emergency remedial action. There is no requirement that the property is owned by the local authority, nor is the capacity

of the inhabitant relevant to the exercise of these powers. However, use of these powers in isolation will have limited effect on those who have persistent behaviours. The Housing Act powers cannot be used to remove hoarded items or address any health and safety problems that are the result of the owner's actions.

Private landlords/housing associations/registered social landlords
Private landlords/housing associations and registered social landlords have an obligation to ensure that their properties are in a good state of repair and are fit for human habitation. Where the tenant is responsible for the disrepair the landlord has a right of action, including ultimately seeking possession of the premises. The role of the landlord/housing association and powers afforded to them means that they have a key role in alerting the statutory authorities to particular cases and that consideration should always be given to their inclusion within multi-agency discussions.

Adult social care
Adult social care will initially co-ordinate the multi-agency approach. In the majority of cases the usual Care Act assessment procedures will be the best route to provide an appropriate intervention. If assessed as having mental capacity to make informed decisions on the issues raised, then the person has the right to make their own choices. However, the assessor must ensure that the person has fully understood the risk and likely consequences if they refuse services. Involvement with the person should not stop at this point and efforts should be made to engage the person in the management of risks and to form a relationship with them to do this.

If the person is assessed as not having capacity to make the relevant decisions then care should be provided in line with "best interest" principles (s.4 MCA). If any proposed care package might amount to a deprivation of liberty, consideration must be given as to whether it would be necessary to obtain authorisation under the DoLS procedure or an order from the Court of Protection. Assessment of self-neglect should include assessment of any health issues such as impaired sight and mobility, pain issues, or long term conditions that may be contributing towards the self-neglect.

Mental health services
Mental health services will be the lead agency where the individual is eligible or believed to be eligible for mental health services. Mental health services will also have a crucial role within many investigations under this protocol as for many individuals hoarding or self-neglect are the manifestations of an underlying mental health condition. Powers conferred by the Mental Health Act 1983 (MHA) to Approved Mental Health Professionals (AMHP) enable the mental health service to take such steps as they consider necessary and proportionate to protect a person form the immediate risk of significant harm.

Police
The police have powers of entry and so may be pivotal in gaining access to conduct assessments if all else fails. Under section 17 (1) (a) of the Police and Criminal Evidence Act 1984, the police have the power to enter without a warrant if required to save life or limb; or prevent serious damage to property; or to recapture a person who is unlawfully at large whilst liable to be detained.

Primary health services
In some cases of chronic or persistent self-neglect individuals who are reluctant to engage with adult social care may engage with primary health care services such as their GP, district nursing service etc. GPs and district nurses carry out home visits to vulnerable older people and may be the first people to notice a change in the person's home environment. Alternatively, failure to keep health appointments or to comply with medication may indicate

self-neglect. As well as raising alerts and providing information, primary health services can be very effective in forming a relationship with the person and in addressing underlying concerns.

Primary health services should monitor those individuals who are engaged with their service and show signs of self-neglect or hoarding. Monitoring might include a regular check in with, and offer of intervention to, someone who is reluctant to engage. If deterioration is such that risks to the person or to others are assessed as high by the health professional then a multi-agency response will be required.

Acute and community health services
Therapists who work in acute wards may observe hoarding and other self-neglect related behaviours when undertaking access visits or home visits to help inform the discharge planning process. Community based therapists and nursing staff are often the first people to observe hoarding and self-neglect related problems. These professionals are key to identifying triggers and changes in behaviour which are then fed into the multi-disciplinary team. Therapists can assess and report on how a client's self-neglect or environment impacts on their overall ability to be safe at home and help determine the level of risk posed to the client and others (family members, neighbours etc).

London fire brigade (LFB)
LFB is best placed to work with individuals to assess and address any unacceptable fire risk and to develop strategies to minimise significant harm caused by potential fire risks. LFB will also raise alerts when called to addresses repeatedly or where homes have significant damage because of a fire and the individual continues to live at that address. LFB will raise alerts, carry out fire risk assessments and offer advice to individuals assuring them of the necessity of fire protection and prevention. LFB may gain entry where home access is refused to other services.

Utility companies/building and maintenance workers
Utility companies/ building and maintenance workers have an important role in the identification of hoarding and self -neglect as they visit people's homes to read meters, carry out inspections or carry out building/maintenance work. Engagement of utility companies and other companies/workers who enter peoples' homes is therefore important so that reports of hording and self-neglect can be received and appropriate action taken.

Domiciliary care providers
Care agencies are commissioned to provide support to people in their own homes and are also commissioned directly by people who fund their own care. They have a role in both identifying people who self-neglect and hoard and in working with them.

12. Self – neglect and risk

Low level risk
It is vital that low level risk is addressed in order to ensure that self-neglect does not escalate and result in high level risk. At a low level of risk the most effective approaches to self-neglect are based on a long-term approach. This involves developing a relationship with the person who hoards or self-neglects, sensitively raising the problems their behaviour causes for them or for others and working with them to find solutions and providing assistance to put these into action. It may include working with someone close to the person who is able to assist the person to achieve change due to a long standing relationship with them.

Low-key monitoring of wellbeing may be the only form of assistance that is acceptable to the person. This may involve community-based voluntary organisations providing specific services such as visiting, floating support, befriending or support in managing finances, and

will often involve members of the individual's social network. Interventions may include de-cluttering or cleaning, although any changes are likely to be temporary unless carried out in conjunction with other interventions such as relationship building with a worker from an appropriate agency e.g. floating support, or specialist psychological intervention.

Such approaches respect the legal right of people with mental capacity to have their autonomy respected, while still taking steps to assist with their safety and wellbeing. Actions to help with daily living may help to build up relationships of trust. These actions might involve the provision of key items of furniture, or white goods such as fridges and microwaves. Ensuring that the person has medical attention to deal with specific health conditions is another way to build trust while acting to address concerns about wellbeing.

It is important to put a plan into place so that change can be maintained. This might be involvement in meaningful activity that could replace but serve the same purpose as the person's previous lifestyle. For example, people who hoard could be linked into workshops or groups that make use of the hobbies or collecting passions that had led them to hoard in the first place. Recognition should be given to the attachment that people often have to their possessions or surroundings, and the need to replace what is being given up with forward-looking interventions focusing on lifestyle, companionship and activities.

During any intervention, it is essential that those involved remain alert to risk factors, especially fire. A referral should always be made for a fire safety check. If the person persistently self - neglects/hoards and, whilst current living conditions may not be posing a significant risk, they would do if left unaddressed, then environmental health services (or the landlord if appropriate) should be involved.

Some situations deteriorate rapidly and may require urgent escalation. If the person's self-neglect does not pose a statutory nuisance and the risk of harm is low, then the key agencies that need to be involved with the individual should be notified of the concerns and requested to monitor or signpost to relevant support.

It is important that approaches are coordinated to avoid situations where activity takes place without any specific aim, or actually conflicts with the interventions of other organisations and so it is important that a lead agency is identified to ensure coordination. The lead agency will not necessarily be responsible for implementing action or interventions but will monitor the actions and interventions of the agencies involved. The lead agency in Camden is Camden adult social care

Significant risk
Where significant risks of harm have been identified at the point of referral or when low level risk has increased following failed interventions from a single agency, a multi-agency response is required. Options should be explored at a multi-agency meeting and a plan of action agreed specifying what will be done, by whom and by when. If positive outcomes are not reached following this input, then a referral should be made to the high risk panel.

If there are any risks related to fire risk (such as incidents where there have been "near misses") and you do not feel that the risks have been sufficiently mitigated even with LFB involvement then you should consider referring to the high risk panel.

High level risk
If there is a high risk of serious harm then a referral should be made to the high risk panel. This panel meets on a monthly basis. Options should be explored and a plan of action agreed specifying what will be done, by whom and by when. Statutory interventions may include, but

are not limited to, using Public Health legislation, sectioning or removing the person to a place of safety under the Mental Health Act or obtaining Court of Protection approval to remove someone from their home under the Mental Capacity Act.

Potential triggers of referral to the high risk panel are:

1. repeated problems of self – neglect. When an agency's usual way of engaging with a vulnerable person has not worked and
    (a) no other options appear available, or
    (b) enforcement is being considered using statutory powers

2. serious concerns for health and wellbeing (of the person or others) that require an immediate response, for example, domestic abuse of a vulnerable person

3. fire risk, including "near miss" scenarios.

The high risk panel will consider and agree:

- whether or not urgent action needs to be taken and by whom (each agency representative can inform the panel of what their agency is able to do)
- whether or not a consensual approach is possible
- the legal remedies that are available
- timescales for action
- monitoring arrangements.

13. Process for practitioners

Assessment

Sensitive and comprehensive assessment is of critical importance and should include an accurate assessment of the individual's mental and physical health status, family dynamics and family coping patterns and cultural beliefs.

The practitioner carrying out the assessment should:

1. ensure that the assessment is multi-agency/ multi-disciplinary and includes:
    - a detailed social and medical history
    - whether the presenting issue is self-neglect or is the result of underlying illness/disease
    - a historical perspective of the person and the situation
    - the person's perception of the situation, willingness to accept support, observation and self-reporting
    - liaison with family members and people in the individual's network such as friends and neighbours

2. carry out a risk assessment to determine the level of seriousness of each identified risk. This should include observation of the individual and the home, activities of daily living, functional and cognitive abilities, nutrition, social supports and the environment

3. share information with other relevant professionals who may have a contribution to make in managing or monitoring the risks

4. use the “assessment tool guidelines” and the clutter image scale guidelines to explore the extent and the impact of the presenting problem (see resources at bottom of document)

5. carry out a Mental Capacity Act assessment, if justified under the Mental Capacity Act. This will inform any actions taken

6. make a decision in liaison with the Safeguarding Adults Manager (SAM) as to whether a safeguarding enquiry is required.

7. Operationally, there is a need for flexibility and proportionality in the allocation of self-neglect cases to adult social care or specialist teams. Also, in deciding whether or not to follow the safeguarding process. Decisions will depend on the complexity of the case and the nature of the self-neglect or other risk taking behaviour being presented.

Where an individual is already in receipt of adult social care, known to the service or appears eligible for adult social care support the relevant social work team manager will ensure an allocated social worker is assigned to complete necessary assessments, including of the individual’s mental capacity, community care or health needs. The allocated worker will act as lead in co-ordinating any plan for intervention.

Financial considerations

The financial implications of any agreed actions should not be a factor at the high risk panel in order to focus on the best outcome for the person at risk. Debates and disputes around funding should be resolved outside of the meeting.

14. Additional information and review

Practitioners are encouraged to discuss any cases regarding self-neglect with their line manager and should refer to the guidance for further information. The self-neglect guidance will be reviewed annually or earlier in accordance with relevant changes in legislation, regulations or guidance. Any major changes to this guidance will be subject to consultation.

A Care Act Practice Guide has been developed to support Camden adult social care practitioners understand and deliver their duties in line with the legal requirements outlined in the Care Act 2014.

The Care Act Practice Guide can be found here.

A number of resources to assist practitioners when working on cases of self-neglect and hoarding can be found here.