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Self-neglect Guidance for Professionals

Introduction

Definition: “Self-neglect is an extreme lack of self-care; it is sometimes associated with hoarding and may be a result of other issues such as addictions” (SCIE 2018).

Building a positive relationship with individuals who self-neglect is critical to achieving change for them and in ensuring their safety and protection.

Promoting a person-centred approach supporting the right of the individual to be treated with respect and dignity, and be in control of, as far as possible their own life. The focus should be on person centred engagement and risk management. All professionals have an equal duty to recognise the significant time investment required to work with the person to achieve a safer life.

This toolkit is designed to support professionals in Wigan Borough in working effectively with adults who self-neglect and as a result are at risk of serious harm or death.

All partner agencies must take all reasonable steps to work with the individual and address the risks when they have been made aware themselves.

Who is it for?
- For all professionals working in complex self-neglect situations.

Who is it not for?
- Individuals whose behaviours are as a result of experiencing a period of mental ill health that may require a consideration for an assessment under the Mental Health Act 1983.
- Individuals who do not have capacity.

When do you use this toolkit?
- When the adult has mental capacity
  - When the adult’s decision making means they are unable to protect themselves from the risk of serious harm from themselves or others
  - When you have exhausted all other available avenues and resources, yet the risk continues to cause significant concerns.

What is it designed to do?
- To support you in evidencing defensible decisions
- To provide suggestions about what you can do in difficult situations that challenge decision making
- To ensure that all possible avenues have been explored
- To support you in understanding the process
• To support you in determining the roles of all professionals in taking a multi-agency approach.

When using the toolkit as lead professional you will need to establish the following:

• Does this risk impact on other people in the community?
• What are the persons views?
• Have they been informed of this process and have they been asked to take part? If not, why not? (Record decision and why it was made)
• How current is your information – How reliable is your information
• When was the person last seen and who by?
• How long has this risk behaviour been occurring?
• What are the current risks, and can they be managed with an alternative response?
• Is this behaviour connected to life history, family or social connections which contribute to the levels and intensity of the associated risk?

Relevant Legislation

• The Care Act 2014: self-neglect is included as a category under adult safeguarding.
• Article 8 of the Human Rights Act 1998: gives people the 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.
• Public Health Act (1984) s.31-32: local authority environmental health could use powers to clean and disinfect premises but only for the prevention of infectious diseases.
• The Housing Act 1988: a landlord may have grounds to evict a tenant due to breaches of the tenancy agreement.
• Common law: including the inherent jurisdiction of the High Court, and common law powers of the police to prevent or deal with a breach of the peace. Common law allows for the intervention, without consent, to save life or avoid serious physical harm based upon the principle that the action is reasonable and can be professionally justified as immediately necessary for the purpose of saving life or preventing serious physical harm. Conversely, not to act in such circumstances of the utmost gravity could be deemed negligent.
• Data Protection 2018 and GDPR 2018: the appropriate use, sharing and storage of personal information. Further information is available on the [Wigan Council website](https://www.wigan.gov.uk/)
Principles underpinning this guidance and the Safeguarding Adults Policy:

- Promoting a person-centred approach that supports the right of the individual to be treated with respect and dignity, and, as far as possible, to be in control of their own life. The emphasis should be on being person centred and risk management. If the individual is more inclined to engage with one organisation over others, then this should be made the most of in working with the person.
- The response needs to be proportionate to the level of risk to the person and others, this guidance can be used to determine the level of risk as low, moderate or high.
- A multi-agency approach is more effective in complex cases of self-neglect and hoarding and each agency needs to take responsibility for their role in supporting the individual. There needs to be a shared understanding that at no point will any agency rely solely on another agency intervening, without following it up.
- Accepting self-neglect as a "lifestyle" choice and closing a case without having assessed the risk and engaged with the adult in a meaningful way is unacceptable, and agencies will be failing in their duty of care.
- Rigid Did Not Attend (DNA) policies that do not take into account reasons for DNA such as literacy, capacity, mental health issues, coercion and control features, should be avoided, and adjustments should be made to allow the individual to attend.

What is self-neglect?

- Lack of self-care to an extent that it threatens personal health and safety
- Not managing one’s personal hygiene
- Not caring for one’s surroundings, this can include behaviour such as hoarding
- Inability to avoid harm as a result of self-neglect
- Not seeking help or accessing services to meet health and social care needs
- Inability or unwillingness to manage one’s personal affairs.

What may cause self-neglect?

It is not always possible to determine the cause for self-neglecting behaviours. However, here are some reasons that may result in self-neglect:

- A person’s brain injury, dementia or other mental disorder
- Obsessive compulsive disorder or hoarding disorder
- Physical illness which impacts on functional abilities, energy levels, attention span, organisational skills or motivation
- Reduced motivation as a side effect of medication
- Addictions, or co-dependence; including pets
- Domestic abuse and other forms of abuse
- Traumatic experiences including from childhood
- Bereavement
- Life change, including change in physical ability.
Sometimes self-neglect is related to deteriorating health and ability in older age and the term ‘Diogenes syndrome’ may be used to describe this. People with mental health problems may display self-neglecting behaviours. There is often an assumption that self-neglecting behaviours indicate a mental health problem but there is no direct correlation.

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 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.

It is important to consider capacity when self-neglect is suspected. However, always remember the MCA principle of assuming capacity. This means there is an expectation for professional curiosity and the testing of executive and functional decision-making capability and capacity for change.

Characteristics identified in people deemed to self-neglect

- Fear of not being in control
- Pride in independence and self sufficiency
- Sense of connectedness and emotional attachment to the environment or belongings
- Distrust of services, professionals and any perceived authority
- Embarrassment of situation or circumstances.

Characteristics of hoarding

Hoarding behaviour is typically manifested in three ways:

- **Acquisition** - compulsive buying and/or the accumulation of items.
- **Saving** – this may be because of emotional attachment, a history of deprivation or of having experienced items forcibly removed from them.
- **Disorganisation** - items of value are mixed in with rubbish and items of no apparent value.

Common responses by people deemed to self-neglect

- I can take care of myself, I don’t need any help
- I do my best to make ends meet
- I prioritise and let other things go
- This is my life and I’ll live it how I want
- I’ve been meaning to do...(it), I’ve just not got around to it.

Best practice when working with people in complex cases of self-neglect

It is important to recognise that research has shown that those who self-neglect may be deeply upset and even traumatised by interventions such as ‘blitzing’ or ‘deep cleaning’. This approach does not address the longer-term issues to promote lasting change.

It may become necessary to seek legal advice regarding applicable enforcement action via environmental health or seeking the inherent jurisdiction of the high court dependant on the
nature of the identified risk – any such consideration will need a robust chronology evidencing extensive multi agency working that has been undertaken in an attempt to minimise the risk.

When planning what needs to happen, it is important to try to understand and work with the individual and what may be driving their behaviour. Remember there may be relevant history and experiences that will impact on the individual’s capacity and motivation to change. No worker should be working in isolation in complex cases of self-neglect, who and what their role is included in this guidance. In all instances there should be a multi-agency approach due to the complex issues of working with someone who is capacitous and self-neglecting. The following list should be taken into consideration when planning what is to happen with the person:

- **Multi-agency** – work with partners to ensure the right approach for each person
- **Person centred** – respect the views and the perspective of the individual, listen to them and work towards the outcomes they want (Making Safeguarding Personal)
- **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** – it is not helpful for practitioners to make judgements about cleanliness or lifestyle; everyone is different
- **Empathy** – it is difficult to empathise with behaviours we cannot understand, but it is helpful to try
- **Patience and time** - short interventions are unlikely to be successful, practitioners should be enabled to take a long-term approach and develop a positive working relationship with the individual
- **Trust** - try to build trust and agree small achievable steps. ‘Quick wins’ can be a motivating factor
- **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 and realistic for the individual
- **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
- **Terminology** - the term ‘self-neglect’ can be perceived as a very stigmatising and emotive term; be considerate and careful how you use it.

Concluding the enquiry may happen at any point within the process triggered for a variety of reasons for example a lack of capacity or access to treatment etc, become unwell, change in mental health.
Mental Capacity Act 2005 – 11 things to think about

Mental capacity involves not only the ability to understand the consequences of a decision, (decisional capacity), but also the ability to execute, or carry out, the decision, (executive capacity). A simple way to demonstrate this is to use ‘tell me/show me’ approaches. Ask the person to ‘tell you’ how they can do something, and ask them to ‘show you’ how they do it.

A Person MUST Satisfy the two-stage diagnostic test before you can make a decision about their capacity. So, they must have an impairment of the mind or brain, and it must be enough of an impairment to mean that they can’t make a particular decision at this particular time. If they haven’t got an impairment, then why are you testing their capacity?

You need to be really clear about what the specific decision is that needs to be made. You must establish what the decision is that the person needs to make, so that you can confidently say ‘this person does or doesn’t have capacity to make this particular decision at this time’.

Indecision or avoidance should not be confused with lack of capacity.

People who do have capacity may still need support. They may still be living in a desperate, risky, unhappy situation that we could try to help do something about, and we still have a duty of care.

Just because someone has an impairment, doesn’t mean they lack capacity!

You must be satisfied that you have fully discussed the risks in a situation, so that the person has the information he needs to understand, retain, and use and weigh information about the situation. Otherwise, how can you possibly know that the person has really thought about all the information that is pertinent to the decision to be made?

On the other hand, if a person lacks capacity, it’s not a ‘done deal’/ it doesn’t mean they can be spirited off to a residential home, for example. You must have a very, very good, legally sanctioned reason for removing a person from their home. If a person lacks capacity, then the least restrictive option should be the first to be considered.

Good recording is essential particularly in the case of ‘unwise or eccentric’ decision making.

It’s always ok to get a second opinion and have someone else in the room.

Self-neglect and mental capacity

Where there is a belief that the adult may not have the relevant mental capacity, they should be assessed under the Mental Capacity Act, making sure that sufficient information is provided to the adult to enable informed decision making. There should be proper assessment of capacity, including enabling the adult to demonstrate understanding, the weighing of potential risks, benefits and solutions, and making a choice including the ability to put decisions into effect.

Best practice guidance encourages professionals to consider utilising the ‘Articulate-Demonstrate’ method (Naik et al, 2008) of assessing as it helps identify when capacity to make a decision is present, but the ability to carry out that decision is not.
It is also important to understand the decision specific nature of capacity, so that the apparent capacity to make simple decisions is not assumed automatically in relation to more complex ones.

Where an adult has fluctuating capacity, it may be possible to establish a plan when they are capacitated which determines what they want to happen when they lack capacity. It is important to make every effort to ‘enhance’ the person's capacity through the timing of discussions and assessment processes.

Assessing risk where someone has fluctuating capacity

Some conditions mean that certain individuals can present with fluctuating capacity. A Mental Capacity Act assessment must only examine a person’s capacity to make a specific decision at a specific time. It may be possible to put off the decision until the person has the capacity to make it. Professionals may also wish to complete a risk assessment with individuals when they have capacity, looking at what the risks are when they lack capacity. For example, when someone is under the influence of alcohol, how do the risks change? This will help all agencies better manage risk at those times when the individual lacks capacity.

Defensible and evidenced decision making

Defensible decision making is making sure that the reasons for decisions, as well as the decision itself, have been thought through, recorded and can be explained. The duty of care in relation to decisions made will be considered to be met where:

- Clear records of all decisions and why they were made is maintained
- All reasonable steps have been taken
- All relevant agencies have been involved
- Reliable assessment methods have been used
- Information has been collated and thoroughly evaluated
- Policies (including the Safeguarding Adults Policy), procedures and guidance have been followed
- Professionals and their managers adopt a person centred and investigative approach and are proactive.

Practitioners should challenge views including, but not limited to:

- Perceiving / expressing that this is a lifestyle choice.
- Relying on previous assessments or decisions about eligibility, engagement, risk or capacity.
- The need for multi-agency work and information sharing.
- Challenges from the individual or their family for interventions that reduce risk.
- Attempts to disengage whilst still at risk of significant harm
- The perception that this behaviour is normal for the individual
- Record all decisions made and why.
The Process for working with those who self-neglect

Initial Enquiry

- Safeguarding Alert received by adult social care
- Alert Forwarded to Locality Team (Alert may be allocated to new or existing social worker)

MSP Establish current available information. Identify best placed person to lead on the safeguarding. Ensure capacity assessments completed, dependant on decision required (risk identified). Ensure Sec 42 step is included on Mosaic.

Initial Enquiry to establish eligibility for Section 42 intervention and initiate process

- Has Capacity: Clarify the vulnerability of the person, including their ability to make decisions and take personal responsibility for problem solving areas of their own life in order to manage risk. MSP: clearly document how the person has demonstrated capacity. Go to Strategy.
- Lacks capacity: MCA Best Interest Process; consider COP. MSP: if unable to make informed relevant decision proceed within MCA Guidance.

What other approaches should be considered? Referral to other agencies, placed based colleagues?

- Agree and record approaches considered and/or rejected and why
- Agree and record decision making and time scales and why
- MSP: Strategy box in Mosaic: Use documentation in Mosaic to record strategy meeting; recording clear actions and timescales and individuals tasked with specific actions.
- Agree and record date for self-neglect review

Strategy meeting/discussion
Self-neglect review

**Feedback:** what has/has not worked? Are all risks and decisions clearly recorded to establish chronology.

MSP: evidence improved, audit records robustly

**Improvement evidenced and recorded:** Agree timescale for review under Risk Management.

MSP: report will contain info from sec 4+5 of strategy (sec 6 enquiry report) with social worker’s analysis and conclusion (sec 8) regarding risks for panel to consider urgently

**No Improvement evidenced and recorded:**

Prepare S42 Safeguarding Enquiry report (inclusive of full protection plan and contingency plan) and request safeguarding team arrange Self-Neglect Conference.

Provide invite list to Safeguarding Team

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**Risk Management Review**

**Self-Neglect Conference**
## Decision Making Assessment Tool

**Articulate Demonstrate method:** screening questions to assess **functional domains** of capacity for self-care and self-protection

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<th>Domains of self-care and self-protection</th>
<th>Decisional capacity</th>
<th>Executive capacity (verification of task performance)</th>
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<tbody>
<tr>
<td><strong>Personal needs and hygiene:</strong> Bathing, dressing, toileting, and ambulation in home</td>
<td>Appreciation of problems</td>
<td>Consequential problem solving</td>
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<td>Has it been difficult, or do you need assistance, to wash and dry your body or take a bath?</td>
<td>If you had trouble getting into the bathtub, how could you continue to bathe regularly without falling?</td>
<td>Physical examination of hair, skin, and nails. Gait evaluation and screening for balance problems and recent falls.</td>
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<td><strong>Condition of home environment:</strong> Basic repairs/maintenance of living area and avoidance of safety risks</td>
<td>Do you have any trouble getting around your home due to clutter, furniture, or other items?</td>
<td>What if your air conditioner / heating stopped working; how would you fix the problem?</td>
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<tr>
<td>It is important to make basic repairs to one’s home; do any parts of your home need repairs?</td>
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<td>Proxy reports of the home environment or a home safety evaluation performed by an occupational therapist or home health service.</td>
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<td><strong>Activities for independent living:</strong> Shopping and meal preparation, laundry and cleaning, using telephone, and transportation</td>
<td>Going to the shop is important for buying food and clothing for everyday life. Do you have any problems going to the shop regularly?</td>
<td>If you needed to call a friend, a taxi or other service to take you to the shop, how would you do that?</td>
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<td>Ask individual to use the clinic’s phone and call a friend or other service to ask for a lift. The person should demonstrate all steps for making a call and getting information.</td>
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<td><strong>Medical self-care:</strong> Medication</td>
<td>People who forget to take their medications</td>
<td>Consider if you had to have someone</td>
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<td></td>
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<td>Ask individual to bring all medication</td>
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<td>adherence, wound care, and appropriate self-monitoring</td>
<td>may end up having a worse health condition or need to see the doctor more often. Do you have problems remembering to take medications?</td>
<td>give your medications to you and watch you take them. How would this affect your everyday life?</td>
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<td><strong>Financial affairs:</strong> Managing cheque book, paying monthly bills, and entering binding contracts</td>
<td>What difficulties do you have paying your monthly bills on time? Who can assist you with paying your monthly bills or managing your finances?</td>
<td>How could asking [cite individual] to help you with paying your bills be better than managing your monthly income and paying bills by yourself? Are there any reasons why asking [cite individual] to manage your income might not help or might make things worse for you?</td>
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Adapted from: [Assessing capacity in suspected cases of self-neglect; Naik et al 2008](#)