Self-Neglect Guidance for Professionals

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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 and provides the legal framework to make safeguarding enquiries under S.42.

Human Rights Act 1998: Consideration should be given to Article 3, 5 and 8 with regards to this piece of legislation.

Mental Health Act 1983 amended 2007: If there are concerns about the persons mental health and there is significant risk a Mental Health Act assessment may need to be considered.

Mental Capacity Act (2005): If there are concerns about the persons mental capacity and there are significant risk a Mental Capacity Assessment may need to be considered. Please see page…

Public Health Act (1984): Local authority environmental health officers could use powers to clean and disinfect premises but only for the prevention of infectious diseases.

The Housing Act 1988: Landlords may have grounds to evict a tenant due to breaches of the tenancy agreement. Landlords have legal obligations to ensure properties are kept to a regulated standard and are required to inspect these regularly.

Inherent Jurisdiction of the High Court: Enables the Court to make an order (which could relate to gaining access to an adult) or any remedy which the Court considers appropriate (for example, to facilitate the taking of a decision by an adult with mental capacity free from undue influence, duress or coercion) in any circumstances not governed by specific legislation or rules. Please see page ……

Data Protection 2018 and GDPR 2018: The appropriate use, sharing and storage of personal information. Further information is available on the Wigan Council website

Domestic Abuse Act 2021: Transforms the response to domestic abuse, helping to prevent offending, protect victims and ensure they have the support they need.
https://www.gov.uk/government/publications/domestic-abuse-bill-2020-factsheets/domesticabuse-bill-2020-overarching-factsheet

Serious Crime Act 2015: Provides for the offence of controlling or coercive behaviour, where the perpetrator and the victim are personally connected.

Police and Criminal Evidence Act 1984 (PACE) 1984: Power of the police to enter and arrest a person for an indictable offence.

Common law: Powers of the police to prevent, and deal with, a breach of the peace. Although breach of the peace is not an indictable offence the police have a common law power to enter and arrest a person to prevent a breach of the peace.

Fire Safety Order 2005: Regulatory Reform, this can serve a prohibition or restriction notice to an occupier or owner of a flat where there is a risk to other occupiers/residents; this notice would take

immediate effect. This option does not apply to premises such as detached/semi-detached/town houses or other premises consisting of or comprised in a house which is occupied as a single private dwelling.

For further information about relevant legislation, see Wigan Safeguarding Adults Policy.

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, this may be food that is being consumed although it is past its expiry date
- Not managing one's personal hygiene, an example would be not washing and changing clothes after episodes of incontinence
- Not caring for one's surroundings, this can include behaviour such as hoarding, broken windows and door locks
- Inability to avoid harm because of self-neglect, including inappropriate clothing, bedding or seating
- Not seeking help or accessing services to meet health and social care needs, including dental care
- 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. https://www.wigansafeguardingadults.org/Docs/Guidance/Hoarding-Toolkit.pdf

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 to try 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 with the person what is to happen:

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

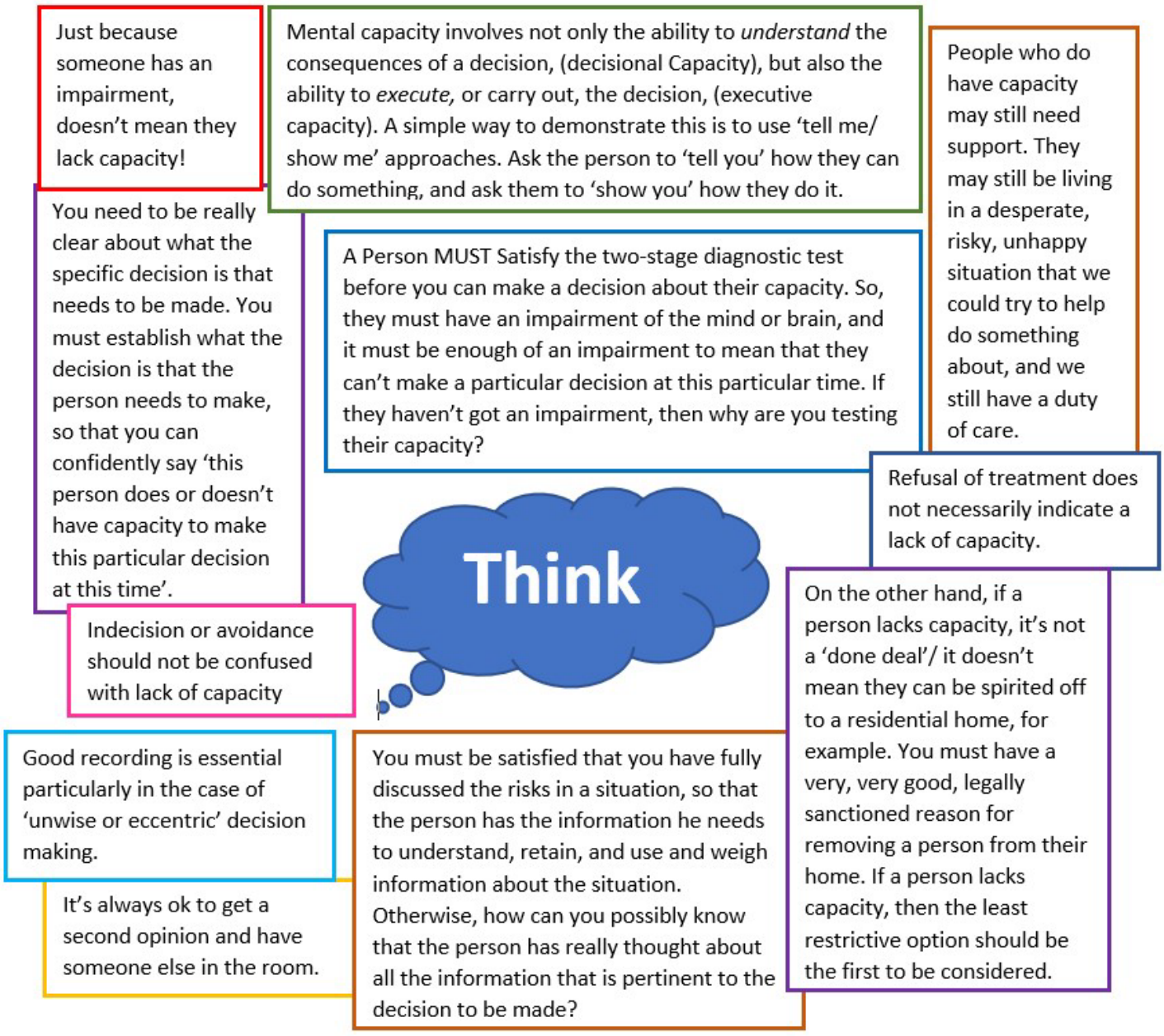
Always go back - regular, encouraging engagement and gentle persistence may help with progress and risk management

Terminology - the term 'self-neglect' can be perceived as a very stigmatising and emotive term; be considerate and careful how you use it.

Trauma responsive - always remember that this person has a history that is likely to have resulted in the way they live their life now and how they understand it. This means that you need to work to the 5 principles of being trauma responsive: safety, trust, choice, empowerment, and collaboration.

Concluding the intervention may happen at any point triggered for a variety of reasons, for example: lack of capacity or access to treatment etc, become unwell, change in mental health.

Mental Capacity Act 2005 – 11 things to think about



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 assessing to 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.

Executive function and mental capacity

An example of executive functioning impairment is when an individual affected by brain injury may have an apparent dissociation between what they say and what they do. They may be able to coherently voice their rationale surrounding a specific decision, however, their actions do not mirror this, being 'unable to give effect to their decision' (MCA Guidance Chapter 4, page 54, point 4.38). It would be a psychologist or doctor who would complete the assessment on executive functioning.

One quick and easy screening test that can be performed is the clock drawing test (Rouleau et al 1992).

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 evidenced and explained.

The duty of care in relation to decisions made will be considered to be met where:

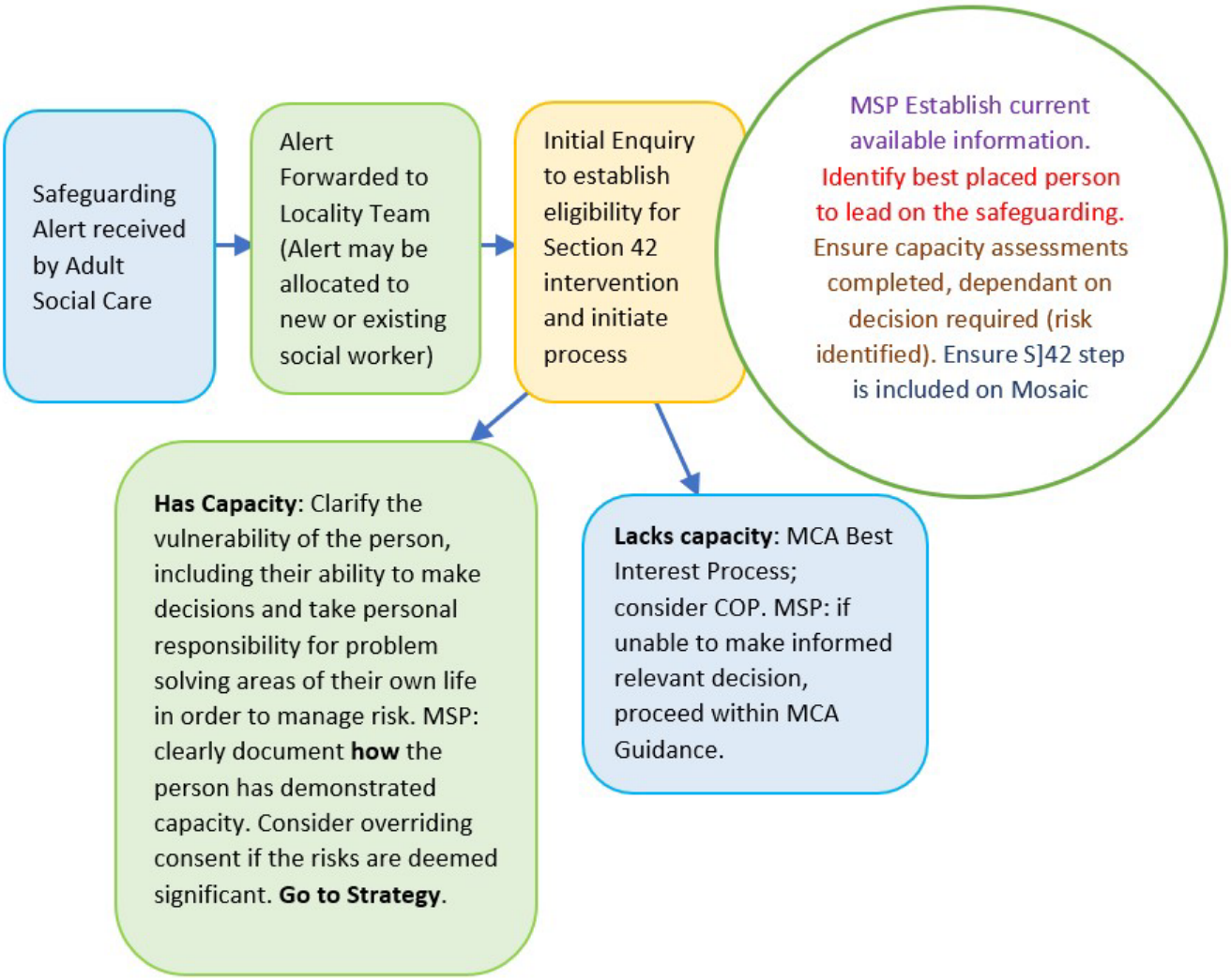
- Clear records of all decisions and why they were made is maintained
- All reasonable steps have been taken
- All relevant agencies have been involved
- Reliable assessment methods have been used
- Information has been collated and thoroughly evaluated
- Policies (including the Safeguarding Adults Policy), 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.
- Resolution policy

The Process for working with those who self-neglect

Initial Enquiry



Strategy meeting/discussion

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

- Agree and record interventions that have been tried in the past.
- Agree and record actions / decision making and time scales. Clear identification of professionals responsible for specific actions needs to be recorded. This may include different

assessments to identify level of risk e.g., tissue viability, medication, mobility, mental capacity, executive functioning, financial, occupational therapy.

- Agree and record which professional is most appropriate to be the lead enquiry officer.

Risk Management Response (RMR)

RMR meeting	Risk Management Plan (RMP) evidenced and recorded	Risk Management Response (RMR) timescales	Case closure / RMR review / Self-Neglect Panel Meeting
What has/has not worked? Are all risks and decisions clearly recorded to establish chronology? MSP: evidence of involvement of the person /advocate improved, audit records robustly	If plan has been tried and tested and if risks are reduced, agree next steps i.e., safeguarding closure / agree appropriate agencies to monitor the risks and refer again if appropriate. RMP to be recognised on the Mosaic summary screen if appropriate to do so.	If risks remain; timescales for review under the risk management response needs to be agreed. RMP is required to be adapted and monitored in accordance with the risks	Either conclude the intervention at this point or commence to Self-Neglect Panel Meeting: • Please refer to the criteria prior to progression to self-neglect panel https://www.wigansafeguardingadults.org/Docs/Guidance/Self-neglect-criteria-fact-sheet.pdf Self-Neglect Panel Review meetings to take place on a regular basis.

Appendix 1 Screening Tool to evidence decision making

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

Domains of self-care and self-protection	Appreciation of problems	Consequential problem solving	Executive decision-making (Verification of task performance)
Personal needs and hygiene: Bathing, dressing, toileting, and mobility in home	Has it been difficult, or do you need assistance, to wash and dry your body or take a bath?	If you had trouble getting into the bath, how could you continue to bathe regularly without falling?	Physical examination of hair, skin, and nails. Gait evaluation and screening for balance problems and recent falls.
Condition of home environment: Basic repairs/maintenance of living area and avoidance of safety risks	Do you have any trouble getting around your home due to clutter, furniture, or other items? It is important to make basic repairs to one's home; do any parts of your home need repairs?	What if your boiler / heating stopped working; how would you fix the problem?	Professional / certified reports of the home environment or a home safety evaluation performed by an occupational therapist.
Activities for independent living: Shopping and meal preparation, laundry, and cleaning, using telephone, and transportation	Going to the shop is important for buying food and clothing for everyday life. Do you have any problems going to the shop regularly?	If you needed to call a friend, a taxi or other service to take you to the shop, how would you do that?	Ask individual to use the phone to call a friend or other service and ask for a lift. The person should demonstrate all steps for making a call and getting information.
Medical self-care: Sticks to medication routine, wound care, and appropriate self-monitoring	People who forget to take their medications may end up having a worse health condition or need to see the doctor more often. Do you have problems remembering to take medications?	Consider if you had to have someone give your medications to you and watch you take them. How would this affect your everyday life?	Ask individual to bring all medication bottles from home, even empty ones. Review medication fill and refill dates and pill counts or have a District Nurse do a home medication assessment.
Financial affairs: Managing bank card, paying monthly bills, and entering binding contracts	What difficulties do you have in paying your monthly bills on time? Who can assist you with paying your monthly bills or managing your finances?	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?	Proxy reports of bank statements, unpaid debts, or bills. Professionals can formally assess performance with routine financial tasks, such as 1 or 3 item transactions, including making changes or conducting a payment simulation using a bank card and register.

Adapted from: Assessing capacity in suspected cases of self-neglect; Naik et al 2008