

Self-Neglect Procedures and Best Practice Guidance

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About this document

This document outlines the process for reporting and responding to concerns of self-neglect in relation to adults with care and support needs.

The document also provides best practice guidance in relation to selfneglect.

This document should be read in conjunction with Staffordshire and Stoke-on-Trent's Adult Safeguarding Procedures and the West Midlands Adult Safeguarding Policies and Procedures.

As with all safeguarding concerns, the 6 key principles set out in the Care and Support Statutory Guidance should underpin all work with adults when there are concerns about self-neglect.

These are as follows:

• **Empowerment:** People being supported and encouraged to make their own decisions and informed consent.

"*I* am asked what *I* want as the outcomes from the safeguarding process and these directly inform what happens."

• **Protection:** Support and representation for those in greatest need.

"I get help and support to report abuse and neglect. I get help so that I am able to take part in the safeguarding process to the extent to which I want."

• **Prevention:** It is better to take action before harm occurs.

"I receive clear and simple information about what abuse is, how to recognise the signs and what I can do to seek help."

• **Proportionality:** The least intrusive response appropriate to the risk presented.

"I am sure that the professionals will work in my interest, as I see them and they will only get involved as much as needed."

• **Partnership:** Local solutions through services working with their communities. Communities have a part to play in preventing, detecting and reporting neglect and abuse.

"I know that staff treat any personal and sensitive information in confidence, only sharing what is helpful and necessary. I am confident that professionals will work together and with me to get the best result for me."

• **Accountability:** Accountability and transparency in delivering safeguarding.

"I understand the role of everyone involved in my life and so do they."

Key Contact numbers

Concerns relating to self-neglect should be made to the respective contact centres for Staffordshire County Council and Stoke-on-Trent City Council.

Staffordshire County Council during standard office hours)	Tel: 0345 604 2719 (available
Emergency Duty Service	Tel: 0345 604 2886
Stoke-on-Trent City Council during standard office hours	Tel: 0800 561 0015 (available
Emergency Duty Service	Tel: 01782 238770

Where a child (a person under 18) is identified in a household where there is a concern about an adult's self-neglect, they should be referred to the relevant local authorities Children's Service:

Staffordshire County Council's Children Advice and Support Service – tel: 0300 111 8007 and select option 1.

Stoke-on-Trent City Council Children's Advice and Duty Service tel: 01782 235100

This guidance does not include issues of risk associated with deliberate self-harm. These concerns should be directed to the appropriate mental health services for the area in which the adult lives.

If the adults GP is in:

South Staffordshire

Tel: 0808 196 3002

North Staffordshire (includes Stoke-on-Trent)

Tel: 0800 0328 728 (Option 1)

If the adult has an out of area GP, please refer to relevant mental health services in that area (if known) or seek advice from local services.

In an emergency always call 999.

Introduction

Self-neglect is a complex area of work which can result in significant, or even fatal harm, for the adults concerned.

Self-neglect is a theme which is disproportionately represented in Safeguarding Adult Reviews (SAR's). A recent analysis of SAR's identified self-neglect as a theme in 60% of the SAR's considered (Local Government Association, 2024). Self-neglect has been a theme within 3 local reviews – details of which can be found at the end of this guidance.

Staffordshire and Stoke-On-Trent Adult Safeguarding Partnership Board have also recently completed an audit of self-neglect concerns. This identified the following:

- Not all professionals were confident of how to report concerns about self-neglect.
- A lack of understanding of the self-neglect protocol, guidance and risk matrix.
- Need to identify a lead professional/agency.
- Lack of follow up following referral to other agencies.
- Inconsistency regarding multi-disciplinary team responses.
- Lack of engagement with the adult themselves
- Need for improved use of advocacy services.
- Poor recording of the rationale for decision-making.
- Lack of integrated IT systems

This guidance has therefore been developed to help ensure that all partners have a clear understanding of the processes in place within Staffordshire and Stoke-on-Trent and to help support practitioners when working with adults where there are concerns about self-neglect.

Self-neglect - Mythbusters

Self-neglect is usually a lifestyle choice.

False. Research shows that self-neglect results from a complex interaction between physical, psychological, emotional and social factors in the persons life. Self-neglect is more often a response to trauma and adverse experiences – a coping mechanism to manage fear and insecurity, which then itself produces shame, isolation and further distress.

Self-neglect doesn't always have to be the subject of a safeguarding enquiry

True. The Statutory Guidance to the Care Act states that self-neglect might not always lead to a Section 42 enquiry. A decision has to be made on a case by case basis on whether the person is able to protect themselves by controlling their own behaviour. Situations of high risk arising from self-neglect need to be addressed, whether through safeguarding or other approaches.

If someone who is self-neglecting has mental capacity and refuses to engage in intervention, there is nothing that can be done to impose a solution.

False. Mental capacity is pivotal to determining interventions. If the adult lacks capacity in relation to a particular decision, the Mental Capacity Act 2005 sets out the requirement for those decisions to be made by others, acting in the person's best interests. Wishes, feelings, beliefs and values must still be taken into account.

If the person has been assessed as having capacity and negotiated solutions have not been possible, interventions can be considered under legislation relating to housing, public health or anti-social behaviour. In some circumstances, application can be made to the High Court to take action under its powers on Inherent Jurisdiction.

Making Safeguarding Personal means you can only do what the person will allow you to do. We have to respect autonomy.

False. Respect for autonomy has to be balanced with a duty of care. Making Safeguarding Personal involves working with the person to help them develop the ability to see and pursue different options, to live in ways that could be safer and to manage the risks they face. Respecting autonomy does not mean abandonment.

Making Safeguarding Personal takes too long – we don't have time, we need to find quick solutions.

False. Quick solutions that "solve" the immediate risk to health and safety that self-neglect presents van be a false time-economy. Without addressing the underlying influences on the adult's behaviour or establishing a relationship of trust, such solutions are likely to be followed by a reoccurrence of the concern. They can also cause acute and lasting psychological distress, adding a further layer of trauma to the adult's life. Equally, walking away from self-neglect because of lack of time to show professionals curiosity and build relationships may result in far greater costs if risks remain unaddressed, even as far as cost to life.

Adapted from Local Government Association (2024).

What is self-neglect?

The Care and Support Statutory Guidance states that self-neglect "covers a range of behaviour neglecting to care for one's personal hygiene, health or surroundings and includes behaviour such as hoarding. A decision on whether a response is required under safeguarding will depend on the adult's ability to protect themselves by controlling their own behaviour. There may come a point when they are no longer able to do this, without external support."

Concerns relating to self-neglect may include the following:

- Lack of self-care placing the adult's health and well-being at risk
- The adult not attending to their living environment to the extent that it is hazardous to themselves and others (for example, vermin infestations or fire risks)
- The adult refusing services that might alleviate any identified health or care needs.

<u>Indicators</u>

The West Midlands Adult Self-Neglect Best Practice Guidance notes the following indicators of self-neglect. The impact of these factors on the adult's well-being should be considered throughout the safeguarding process:

- Failure to provide care for themselves resulting in a decline in physical or mental well-being.
- Living in very unclean, sometimes verminous, circumstances.
- Neglecting household maintenance, resulting in potentially hazardous living conditions.
- Obsessive hoarding creating potential mobility and fire hazards.
- Animal collecting with potential of insanitary conditions and neglect of the animals needs.
- Poor diet and nutrition.
- Inability to maintain social contacts.
- Inability to manage finances.
- Declining prescribed medication and/or other community healthcare support.
- Declining support from health and/or social care staff in relation to personal hygiene.
- Declining access to other organisations with an interest in the property for example, housing staff, utilities companies.

It is important to acknowledge that poor environmental and personal hygiene may not always be linked to concerns of self-neglect. The adult may not be able to meet their needs in these areas due to cognitive impairment, deteriorating physical health or financial constraints. In addition, people may lack the ability and/or confidence to ask for help. Similarly, they may not have the social networks that could support them in asking for help.

There are also a number of factors that may lead to adults experiencing, or at risk of, self-neglect being over-looked:

- Perception that the presenting circumstances are "a lifestyle choice".
- Poor information sharing and/or multi-agency working.
- Lack of engagement from the adult and/or their representative.
- An individual in the household/social network is incorrectly identified as a carer leading to assumptions that the adult is receiving care and support.
- A de-sensitisation to well-known adults/those with frequent referrals.
- Adult's may be vulnerable to other forms of abuse which are given greater focus at a particular time (for example, cuckooing).

What are the possible causes of self-neglect?

 Bereavement/traumatic event – Research has indicated that the two most common experiences cited in the life stories of adults who self-neglect are psychologically traumatic loss or having experienced physical trauma or sexual abuse (Lien, Rosen, Bloemen, Abrams, Pavlou & Lachs, 2016).

Bereavement and loss have been identified as factors in local Safeguarding Adult Reviews. It should be noted that the loss can be due to a bereavement, but may also be linked to loss of a particular role (employment or caring role) or a loss of independence/particular abilities due to illness of disability.

• Age related changes, in physical or mental health – Research has shown that self-neglect most often occurs with older adults, particularly those over the age of 75 (Lauder & Roxburgh, 2012).

Age related changes that result in functional decline or cognitive impairment can impact on an adult's ability to manage activities of daily living.

• **Chronic mental health needs** – Research frequently highlights mental ill health as a factor when there are concerns relating to self-neglect.

Mental health needs have featured in local Safeguarding Adult Reviews and Learning Reviews.

It should be highlighted that hoarding is now recognised as a mental health disorder – see section on Hoarding for more information.

 Alcohol or drug misuse/dependency – Addiction to alcohol or drugs can lead to adults prioritising access to these above all else. Financial difficulties can occur due expenditure on substance meaning that the adult is unable to meet the costs of basic needs. Substance use can also lead to an increased risk of deteriorating in physical or mental health. There may also be an increased risk of other forms of abuse.

Alcohol use has been identified as significant factor in a number of Safeguarding Adult Reviews, and indeed was a factor in local SARS relating to self-neglect.

For more information please refer to https://alcoholchange.org.uk/publication/learning-from-tragediesan-analysis-of-alcohol-related-safeguarding-adult-reviewspublished-in-2017

- Social isolation Social isolation is where there is an absence of positive or meaningful social relationships. Social isolation can impact on an individual's physical and mental health and can also increase their vulnerability to self-neglect and other forms of abuse. There is also a risk that these adults may be over-looked as there may be no others within their social networks that could identify and raise any concerns.
- **Hopelessness and or helplessness** The adult may feel that that they have little or no control over the circumstances in which they are living and they may also feel shame about how their situation.

Feelings of hopelessness and or helplessness may also be associated with significant physical or mental health conditions and drug or alcohol dependency.

A useful video has been produced by the North East Safeguarding Adult Review Champions Group:

https://www.youtube.com/watch?v=XDht3RUYZcs

- Poverty Adults with care and support needs may be particularly vulnerable to poverty. Adults living in poverty may, for example, be less able or unable to afford to heat or maintain their home. Poverty may also impact on decisions regarding vital home treatments such as oxygen or dialysis treatments due to the cost of utilities.
- Current/previous abuse or neglect A number of safeguarding Adult Reviews have identified that childhood or adult trauma can have a significant impact on factors such as a person's ability to cope, their sense of self or interpersonal relationships. Practitioners working with adults who are self-neglecting should consider whether the adult is experiencing, or has experienced, other forms of abuse and the impact this has had on them.

The Legal and Policy Framework

The Care Act 2014

The Care Act 2014 places specific duties on Local Authorities in relation to abuse and neglect, including self-neglect.

Assessment:

Section 9 of the Care Act states that where it appears to a Local Authority that an adult may have needs for care and support, the authority must assess:

- a) Whether the adult does have needs for care and support, and
- b) If the adult does, what those needs are.

The duty applies regardless of the authorities view of the level of the adults needs for care and support or the level of the adult's financial resources.

It should also be noted that under Section 11(2) of the Care Act there is a duty to undertake an assessment of the adult's care and support needs despite their refusal in situations where:

- a) They lack capacity to refuse the assessment and it would be in their best interests.
- b) The adult is experiencing, or at risk of, abuse and neglect.

Enquiry:

The Care Act 2014 requires the Local Authority to make enquiries, or cause enquiries to be made, in cases where the Local Authority has reasonable cause to suspect that an adult in its area:

- Has needs for care and support (whether or not the local authority is meeting any of those needs),
- Is experiencing, or at risk of, abuse or neglect (including selfneglect), and
- As a result of those needs is unable to protect themselves from the abuse or neglect or the risk of it.

In accordance with the well-being principle of the Care Act, Local Authorities must put an individual's well-being at the heart of any decisions or the delivery of any care and support functions.

"Well-being" is a broad concept. The Care Act Statutory guidance lists the following areas to be considered:

- Personal dignity (including treatment of the individual with respect)
- Physical and mental health and emotional well-being

- Protection from abuse and neglect
- Control by the individual over day-to-day life
- Participation in work, education, training or recreation
- Social and economic well-being
- Domestic, family and personal
- Suitability of living accommodation
- The individuals contribution to society

There is no hierarchy and all factors should be considered of equal importance when considering the adults well-being.

Duty of Co-operation

Section 6-7 of the Care Act creates a general duty to co-operate between the Local Authority and other organisations which have functions relevant to care and support. This includes a duty on the Local Authority itself to ensure co-operation between its adult care and support, housing, public health and children's services.

Further information on other legal frameworks/interventions is available within the Supporting Documents.

Making Safeguarding Personal

"No decision about me without me"

Making safeguarding Personal (MSP) is an approach to safeguarding that aims to ensure the adult (and/or their advocate) is fully involved in the safeguarding process and working with the adult towards the outcomes they have identified.

"Making Safeguarding Personal means it should be person-led and outcomes focussed. It engages the person in a conversation about how best to respond to their safeguarding situation in a way that enhances involvement, choice and control as well as improving quality of life, wellbeing and safety." (DH, 2018).

MSP is about seeing people as experts in their own lives.

Equity, Equality and diversity

The Equality Act 2010 identifies nine protected characteristics:

- Age,
- Disability,
- Gender reassignment,
- Marriage and civil partnership,
- Pregnancy and maternity,
- Race,
- Religion or belief,
- Sex
- Sexual orientation.

The Equality Act places a duty on public bodies to ensure that they are proactive in eliminating unlawful discrimination, advancing equality of opportunity and fostering good relations. This means that the Local Authority has a duty to consider the diverse needs of the individuals they support, minimising disadvantage and ensuring the inclusion of underrepresented groups.

Self-neglect process in Staffordshire and Stoke-on-Trent

Referral Process:

Concerns relating to self-neglect will be made to the respective Contact Centres for Staffordshire County Council and Stoke-on-Trent City Council.

If the abuse occurred in Stoke-on-Trent – Tel: **0800 561 0015** (available during standard office hours)

If you have a concern about the safety of an adult with care and support needs in Stoke-on-Trent and need to report these concerns overnight, over a weekend or on a Bank Holiday, please contact the Emergency Duty Service on Tel: **01782 238770**

If the abuse occurred in Staffordshire – Tel: 0345 604 2719 (available during standard office hours)

If you have a concern about the safety of an adult with care and support needs in Staffordshire and need to report these concerns overnight, over a weekend or on a Bank Holiday, please contact the Emergency Duty Service on Tel: **0345 604 2886**

<u>Consent</u>

All adults have the right to choice and control in their own lives. As a general principle, no action should be taken for, or on behalf, of an adult without obtaining their consent. However, there will be times when it is necessary to override the adults wishes and raise the concern without their consent. Indeed, consent will need to be considered at all stages of the safeguarding process.

If there is an overriding **public interest** or **vital interest**, or if gaining consent would put the adult at further risk, the concern must be reported.

Please refer to Section 2 of the Adult Safeguarding Procedures for more information on "Mental Capacity and Consent" & "Reporting without Consent".

Decision Making:

The Care and Support Statutory Guidance makes is clear that self-neglect is not necessarily to be considered as a cause for enquiry under Section 42 of the Care Act 2014.

If an assessment has been offered and either the assessment or the proposed care provision has been declined **and** it is considered that the adult remains at risk of harm, then the concerns may be considered under safeguarding processes.

Decision-making as to whether actions are needed under Section 42 of the Care Act will be based on the following:

- The concern relates to a person who is 18 or over;
- The adult has needs for care and support (whether or not these are being met at this time);
- The adult is experiencing, or at risk of abuse, neglect or self-neglect;
- As a result of the adult's care and support needs the adult is unable to protect themselves from the risk of abuse or the experience of abuse or neglect.

Information gathering will take place to identify which of the relevant agencies know the adult or could have information to share as part of the decision-making process.

If it is felt that further actions under Section 42 of the Care Act 2014 are required, the concern will be progressed by the relevant area team irrespective of the level of risk.

Severity Of Impact						
Likelihood		No Impact	Low Impact (A)	Medium Impact (B)	High Impact (C)	
LIK	Unlikely	None 0	Low 2	Low 3	Medium 7	
	Possible	Low 1	Low 2	Medium 6	High 9	
	Likely	Low 1	Medium 4	Medium 7	High 10	
	Certain	Low 1	Medium 5	High 8	High 10	

Please refer to the risk matrix tool and associated Levels of Harm chart:

Levels of Harm:

	Risk Indicators
Low	 Concern about an adult who is beginning to show signs and symptoms
LOW	of self-neglect
	• Property neglected but utilities/appliances work and the adult is not at
	risk of being made homeless as a result of the condition of their property
	 No/low risk or impact to self or others.
	Risks can be managed by current professional oversight, case
	management or universal services
	• Some evidence of hoarding but little/ no impact or risk to own wellbeing
	No/minimal harm has occurred.
	Milere there are according to college and the pattern of concern
	Where there are several low-level concerns or a pattern of concern –
Medium	 consider progressing under safeguarding progresses. Some signs of engagement with professionals but compliancy with
Medium	 Some signs of engagement with professionals but compliancy with treatment and support does not mitigate risk
	 Indication of a lack of insight into neglect
	 Lack of essential amenities/food provision
	Apparent financial deprivation
	Collecting a number of animals which are kept in inappropriate
	conditions.
	Increasing unsanitary environment
	 Non-compliance with medication/treatment/clinical
	investigations/attending health appointments
	The adult has required a period of or repeated periods of treatment or
	care as a result
	 The adult has been impacted by distress/injury Evidence of hoarding beginning to impact on health/safety to the adult
	and others
	 No access to meaningful contact within community.
	 Harm has occurred or risk of harm is present and significant
High	Living in squalid or unsanitary conditions
	Significant structural deterioration/damage in the property causing
	significant risk to health, wellbeing and longevity
	Refusal of health/medical treatment/support that is having a significant
	impact on health/well-being
	 The adult has required a period of/ or repeated periods of treatment or
	care as a result
	 The adult has been impacted by distress/injury High level of clutter/hoarding impacting on health and wellbeing of the
	adult and others including fire hazard
	 Life expectancy could be compromised without immediate intervention
	 Attempts to engage the adult fully have been exhausted and non-
	productive
	• The individual is not accepting any support and has no options for self-
	managing the situation
	 Harm has occurred AND a high risk of harm is present

Enquiry process:

Multi-Agency Planning Meeting

The area team will arrange for a Multi-Agency Planning Meeting (MAPM) to take place within 10 days of the concern being raised (subject to the seriousness of the risk of future harm).

The MAPM will include all relevant agencies and should follow the agenda provided within the Supporting Documents.

The MAPM will enable the sharing of information and will include consideration of the options for intervention and also the legal position.

Possible options for intervention are included within the Supporting Documents.

The enquiry process for self-neglect concerns differs slightly in Staffordshire and Stoke-on-Trent. These are outlined below:

Staffordshire - The MAPM will be chaired by a Managing Officer from the area team for low and medium risk concerns. A Managing Officer from the Adult Safeguarding Enquiry Team will chair the MAPM for high-risk concerns.

No enquiry report will be required for this meeting. Where interventions are required this will be recorded as a safeguarding plan.

The minutes of the MAPM, the safeguarding plan and the minutes of any subsequent Safeguarding Plan Review Meetings will constitute the evidence of the enquiry process.

Stoke-on-Trent – The MAPM will be chaired by the Safeguarding Officer or a Managing Officer, dependent on the level of risk and complexity of the situation.

The Safeguarding Officer is required to complete a safeguarding enquiry report. Where interventions are required this will be recorded as a safeguarding plan.

This, along with the minutes of the MAPM, the safeguarding plan and the minutes of any subsequent Safeguarding Plan Review Meetings will constitute the evidence of the enquiry process.

It is emphasised that **safeguarding is everyone's responsibility.** A collaborative approach is essential if adults are to receive the support they require in a timely way.

Safeguarding Plan

A safeguarding plan is the document that clarifies all the protective or supportive systems that are in place, irrespective of who provides these and sets them out as steps towards a defined outcome.

The safeguarding plan will clearly identify what the objectives and safety goals are, who will be responsible for each aspect, who will co-ordinate the plan, communication arrangements and when it will be reviewed.

Safeguarding Plan Review Meetings should take place in all cases where there have been agreed safeguarding actions to ensure that there is multi-agency accountability and that safeguarding measures are adequate. The Safeguarding Plan Review Meeting should review the level of risk and identify any further actions needed.

The need to engage with the adult and to work in a person-centred and outcome-based manner is as important in cases of self-neglect as it is in cases of other types of abuse. In many cases the adult will have mental capacity to consent to interventions and support measures and therefore their participation and agreement will be of utmost importance.

In a small number of situations where it is believed that the adult is acting under undue influence or is otherwise prevented from protecting themselves, there may be a need to complete a safeguarding plan without the adult's consent. Furthermore, there may need to be consideration of an application to the High Court to use it Inherent Jurisdiction to determine or enforce any necessary protective measures.

Please see the Guidance note: using the Inherent Jurisdiction in Relation to Adults <u>Mental-Capacity-Guidance-Note-Inherent-Jurisdiction-</u> <u>November-2020.pdf (39essex.com)</u>

Resolving disagreements

A frequent learning point from Safeguarding Adult Reviews is the failure to raise and escalate concerns about a course of action taken, or not taken, to safeguard an adult with care and support needs. The escalation of concerns is important, and often vital, both within and between organisations. It is essential that disagreements are resolved professionally through constructive dialogue and a willingness to consider other points of view. The outcome of these discussions should be recorded in line with each agencies individual processes.

The Staffordshire and Stoke-on-Trent Adult Safeguarding Partnership Board (SSASPB) has also produced an Escalation Procedure for resolution of inter-agency difficulties <u>Escalation policy (ssaspb.org.uk)</u>.

Learning from Local SARS

The Care Act states that Safeguarding Adults Boards must arrange a Safeguarding Adult Review (SAR) when an adult in its area dies as a result of abuse or neglect, whether known or suspected, and there is concern that partner agencies could have worked together more effectively to protect the adult.

The SARs below both related to concerns about self-neglect. For more information please follow the associated links:

Andrew (2022) - <u>https://www.ssaspb.org.uk/About-us/Andrew-SAR-</u> <u>Report-Final.pdf</u>

Gillian (2024) - <u>https://www.ssaspb.org.uk/About-us/GILLIAN-FINAL-</u> May-2024.pdf

A learning review was also completed for **David (2017)** – a 50 year old man who died with self-neglect contributing to his death.

To read the full review please use the following link:

https://www.ssaspb.org.uk/About-us/David.aspx

Any SAR's that have been completed following publication of this guidance can be accessed via the following link: <u>https://www.ssaspb.org.uk/About-us/Safeguarding-Adult-Reviews.aspx</u>

Best Practice Guidance

Mental Capacity & Self-Neglect

The essential principles of any mental capacity assessment are set out in the Mental Capacity Act 2005 and the associated Code of Practice.

Mental Capacity Act 2005 – 5 principles

- 1. A presumption of capacity
- Start by thinking I can make a decision
- 2. Individuals supported to make their own decisions

 Do all you can to help me make a decision
- 3. Unwise decisions
 - You must not say I lack capacity just because my decision seems unwise
- 4. Best interests
 - Use a best interest checklist for me if I can't make a decision
- 5. Less restrictive option
 - Check the decision made does not stop my freedom more than needed



When should a capacity assessment be completed?

It is important to carry out an assessment when an adult's capacity is in doubt.

The Mental Capacity Act Code of Practice (para. 4.35) identifies a number of reasons why people may question a person's capacity to make a specific decision:

- The person's behaviour or circumstances cause doubt as to whether they have capacity to make a decision.
- Somebody else says they are concerned about the person's capacity, or
- The person has previously been diagnosed with an impairment or disturbance which that affect the way their mind or brain works, and it has already been shown that they lack capacity to make other decisions in their life.

Practitioners should consider an adult's capacity to make decision relating to the self-neglect concerns throughout the safeguarding process.

Who should assess capacity?

This will depend on the type of decision that needs to be made.

Different professionals may be involved in assessing the persons capacity to make different decisions at different times.

If a doctor or healthcare professional proposes treatment or some form of health care intervention, they must assess the persons capacity to consent. Where necessary, this might require the involvement of a multidisciplinary team. However, the Code of Practice makes it clear that it is the responsibility of the professional responsible for the treatment to make sure that capacity has been assessed.

What should the capacity assessment cover?

Capacity is decision specific – before starting any assessment you will need to define the decision that needs to be made.

For example, if the adult is declining health interventions for a pressure wound, the decision is whether they have capacity to consent to the treatment or interventions proposed.

Functional Test – The Mental Capacity Act states that a person does not have capacity to make a decision if they cannot do one or more of the following

- Understand information relevant to the decision that needs to be made
- Retain the information for long enough to make the decision
- Use and weigh the available information to make the decision
- Communicate their decision by any means

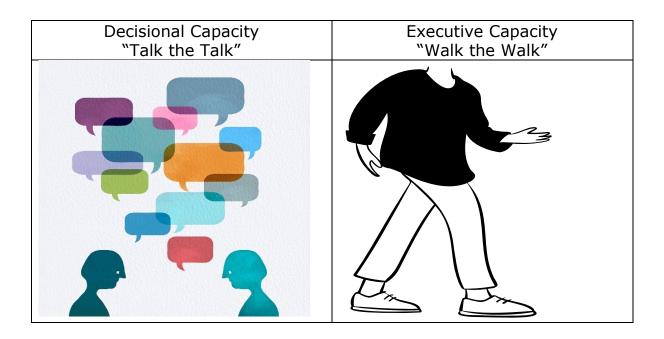
Diagnostic test - Does the adult have an impairment of the mind or brain, or is there some sort of disturbance affecting the way their mind or brain works (this impairment or disturbance can be temporary or permanent)?

Does the impairment or disturbance mean that the adult is unable to make the decision in question at the time it needs to be made? (**Causal nexus**).

This is a complex area of practice and decisions should not be made in isolation. Any decisions should be made in the adult's best interests with the involvement of all involved in the adult's welfare and care provision.

It may also be beneficial to seek the involvement of appropriate professionals.

Practitioners must assess both an adult's decisional and executive capacity. Executive capacity describes where an adult may appear able to weigh information whilst discussing the situation but if they do not apply their reported knowledge and understanding to real life situations, they may lack mental capacity.



Professionals must take all practicable steps to help the adult before concluding that the adult is not able to make the decision in question.

Practicable steps could include:

- Making sure the adult has all of the relevant information they need to make the decision
- Making sure that the adult knows about all of the available options (if there are a range of choices)
- Explaining or providing information in the way that is easiest for the adult to understand (e.g. verbally, in writing or in pictorial form).
- Communicating with the adult in the way that works best for them.
- Considering the best time of day to complete the assessment.
- Considering the best location to complete the assessment.
- Would it benefit the adult to have another person present who could support them?
- Can the assessment be completed over a number of visits to give the adult time to consider the information or build rapport with the assessor?

What if the adult's ability to make a decision fluctuates?

Some people's ability to make a decision may fluctuate because of the nature of their condition. The 39 Essex Street (2023) guidance highlights that the fluctuation can take place over a matter of days or weeks (for example, where a person has bipolar disorder) or over the course a day (for example, an adult with dementia may experience "sundowning" and their cognitive abilities may be more impaired towards the end of the day).

Sometimes if may be possible to delay the decision and complete the capacity assessment when the adult's decision making abilities are not (or less) impacted by their condition. However, for other adults the assessment of capacity may not be a single event and may need to be considered over a period of time.

https://www.39essex.com/sites/default/files/Mental-Capacity-Guidance-Note-Fluctuating-Capacity-in-Context-December-2021.pdf

Refusal of medical treatment

It must be emphasized that refusal of a type of medical treatment is not itself an indication of self-neglect.

A person needs to give their consent for any type of medical treatment, test or examination.

For consent to be valid, the person must have capacity to give consent.

The decision should also be:

Voluntary – the decision to either consent or not to consent to the treatment/intervention must be made by the adult, and must not be influenced by pressure from medical staff, family or friends

Informed – the person must be given all of the information about what the treatment/intervention involves, including the benefits and risks, whether there are reasonable alternative treatments, and what will happen if the treatment/intervention does not go ahead.

An adult with capacity has the right to refuse any medical treatment/intervention.

Unwise decisions or lack of capacity?

The Mental Capacity Act makes it clear that "a person is not to be treated as unable to make a decision merely because s/he makes an unwise decision" (Section 1(4)).

However, a series of unwise decisions may give cause for professionals to complete an assessment of capacity in relation to a defined decision.

Professionals should clearly record both the grounds for completing a capacity assessment or the decision not to complete one when there are concerns that the person could not make the relevant decision.

What if the adult refuses to engage with the capacity assessment?

It is important to distinguish between a situation when the adult is **unwilling** to engage in an assessment and where they are **unable** to.

"... assessments of capacity can undoubtedly be rendered more difficult where the patient deliberately avoids engaging or co-operating with the process...it seems to me that a patients lack of engagement ...may contribute in itself to a conclusion that [they are] unable to understand ...and/or...unable...to use or weigh the information as part of the process." (Cobb, J. in Re P [2014] EWHC119 (COP); para 26)

Professionals should 1) consider what steps could be taken to assist the person to engage in the process and 2) record what steps were taken and what alternative strategies have been used.

If there is reason to believe that the adult's non-engagement is due to undue influence or control from another person, it may be necessary to consider the legal interventions available through either the High Court or the Court of Protection.

As noted within the guidance produced by 39 Essex Chambers "Ultimately, ... it is not possible to force a person to undergo a capacity assessment. It will therefore be necessary to consider whether there is enough surrounding evidence to come to a reasonable belief that the person lacks capacity, if steps are going to be taken on the basis of s.5 MCA 2005. If the stakes are high, for the person or others, then it will be necessary to make an application to court to decide whether the person has or lacks the capacity to make the relevant decision".

Self-neglect and advocacy

Section 68 of the Care Act places a duty on the Local Authority to arrange for an independent advocate to represent an adult who is involved with a safeguarding enquiry or Safeguarding Adult Review where the adult has "substantial difficulty" in understanding or participating in the process.

The Care Act sets out four areas where an adult might experience "*substantial difficulty*" in understanding or participating in a safeguarding enquiry.

understanding relevant information

 Many people can be supported to understand relevant information, if it is presented appropriately and if time is taken to explain it.

 retaining that information

 If a person is unable to retain information long enough to be able to weigh up options, and make decisions, then they are likely to have substantial difficulty in participating.

 using or weighing that information as part of the process of being involved

 A person must be able to weigh up information, in order to participate fully and express preferences for or choose between options.

 communicating their views, wishes or feelings

A person must be able to communicate their views, wishes and feelings whether by talking, writing, signing or any other means, to aid the decision process and to make priorities clear.

Where an adult has "*substantial difficulty*" being involved in the safeguarding enquiry, the Safeguarding Officer must consider and decide whether there is an appropriate person to represent them. This would be a person who knows the adult well, and could be, for example, a spouse, family member, friend, informal carer, neighbour or Deputy/Power of Attorney. The identified person will need to be willing and able to represent the adult. It will need to be considered whether the identified person has conflicting views on the matter which would impact on their ability to represent the adult's own views.

An appropriate person to represent the adult cannot be a person who is involved in their care or treatment in a professional or paid capacity.

Where an adult has "*substantial difficulty*" being involved in the safeguarding enquiry, and where there is no other appropriate person to

represent them, the Safeguarding Officer must identify the need (and arrange where appropriate) for an independent advocate to support and represent the adult. The Care and Support Statutory Guidance states that where the need for an independent advocate has been identified, the Local Authority must arrange for one to be provided.

Findings from research

Research has shown an effective way of working with adults who selfneglect combines aspects of Knowing, Being and Doing.

Knowing – Understanding the person, their history and the significance of their self-neglect, along with all the knowledge of resources that underpin professional practice.

Being – Showing personal and professional qualities of respect, empathy, honesty and reliability, care, being present, staying alongside and keeping company.

Doing – Balancing hands-off and hands on approaches, seeking the tiny element of latitude for agreement, doing things that will make a small difference whilst negotiation for the bigger things, and deciding with others when enforced intervention becomes necessary.

Understanding the individual's experience of self-neglect

Professionals are unlikely to develop a good rapport and support the adult to achieve a positive outcome if they have not been able to gain an understanding of the adult's perception of the concerns that have been identified. This highlights the importance of professional curiosity. Similarly, the Making Safeguarding Personal Agenda emphasis the need to see people as experts in their own lives and identify the outcomes they want to achieve.

Professional Curiosity is where a practitioner explores and proactively tried to understand what is happening for the person, rather than making assumptions or accepting information at face value.

For more information, please visit: <u>https://www.researchinpractice.org.uk/media/z5nl0yiw/adults_profes</u> <u>sional_curiosity_sb_web.pdf</u> The Research in Practice (2020) guidance provides some key areas to consider when working with adults where there are concerns of self-neglect:

- What is the adult's own view of the self-neglect?
- Is the self-neglect important to the adult in some way?
- Is the self-neglect intentional, or an unintended consequence of something else?
- Is the self-neglect a recent change or a long-standing pattern/ Does the person have mental capacity in relation to specific decisions about self-care and/or acceptance of care and support?
- What strengths does the adult have what are they managing well and how might this be built on? What motivation for change does the adult have?
- Have there been recent changes of experience, attitude or behaviour that might provide a window of opportunity for change?
- Are there links between the self-neglect and health or disability?
- Is alcohol consumption or substance misuse related to the selfneglect?
- How might the adult's life history, family or social relationships be interconnected with the self-neglect?
- Does the self-neglect play an important role as a coping mechanism? If so, is there anything else in the adult's life that might play this role instead?

A strengths-based approach explores the adult's abilities and their circumstances rather than making the deficit the focus of the intervention. To gather a holistic picture of the adult life it is important to engage and work with others, including the adult's own social network (with their consent) and any other agencies involved in their support.

Every person is unique and as such any interventions will need to consider the adults individuals needs and circumstances.

The following table from taken from Research in Practice (2020) includes some suggestions of approaches or actions to consider:

The approach	Examples of what this might mean in practice
Building rapport	Taking the time to get to know the person; refusing to be shocked.
Moving from rapport to relationship	Be considered and thoughtful in reactions to self- neglect; talking through with the person their interests, history and services.
Finding the right tone	Being honest whilst also being non-judgmental; expressing concern about self-neglect, whilst separating the person from the behaviour.
Going at the individual's pace	Moving slowly and not forcing things; showing concern and interest through continued involvement over time
Finding something that motivates the individual	Linking to the person's interests
Starting with practicalities	Providing small practical help at the outset may help build trust
Negotiating reciprocal actions	Linking practical help to another element of agreement (for example, I'll bring round a replacement for your heater, then shall we go and see the doctor?)
Focussing on what can be agreed	Finding something to be the basis of initial agreement, than can be built on later
Keeping company	Being available and spending time to build up trust
Straight talking	Being honest about potential consequences
Finding the right person	Working with someone who is well-placed to get engagement – another professional or a member of the person's network.
External levers	Recognising and working with the possibility of enforcement action.

Refer to the Supporting Documents for further actions that can be considered in response to any self-neglect concerns.

Risk assessment & multi-agency working

It is important to recognise that risk is a normal everyday experience and therefore the Safeguarding Principles must be applied in a manner that promotes empowerment and proportionality as well as prevention.

To complete a thorough risk assessment, conversations will need to take place both with the adult and involved professionals to gain a clear understanding of any identified risks and the impact on the adult and/or others.

Risk assessment is a continuous process and must be considered throughout the assessment and safeguarding process.

Different professions and agencies may each have their own risk assessment documentation. All risk assessments should be recorded in line with individual agencies own processes.

Concerns relating to self-neglect may be complex and require the involvement and collaboration of several different agencies.

To ensure effective multi-agency working, consider the following:

- Is there involvement from all professionals, agencies & networks that could make contribution to the adults care and support?
- Are all involved parties clear on their own, and each others, roles and responsibilities?
- Is there a lead professional co-ordinating the process?
- Is there appropriate communication and information sharing in a timely way?

Safeguarding Adult Reviews have frequently identified that failings in multi-agency co-ordination have contributed to negative outcomes for the adult's concerned.

Research in Practice (2020) identified that remedies to non-co-operation could include explicit reference the Care Act duties of co-operations (sections 6 and 7) or escalation of concerns though operational management routes.

Staffordshire and Stoke-on-Trent Safeguarding Adults Board also have an escalation policy which can be referred to when necessary https://www.ssaspb.org.uk/Guidance/Escalation-policy.aspx

Legal Interventions

It is essential that practitioners have knowledge of the legal framework outlined earlier in this document.

This is important because:

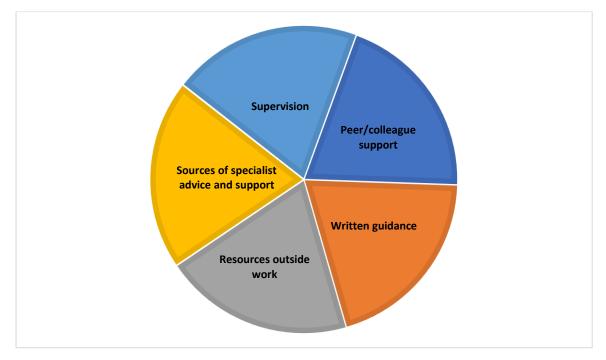
- It gives practitioners the authority to assess the persons needs and determine whether any support is needed.
- It enables practitioners to secure funding for care provision where necessary and appropriate.
- Setting out the legal framework in reports can make it clear to the reader what authority you have and what duties you have to meet.

There are a range of legal interventions that can be considered by individual organisations in relation to concerns of self-neglect (refer to Supporting Documents for more information). Practitioners should seek advice from their line manager regarding access to legal advice/support.

Supervision and support

It is recognised that working with individuals who self-neglect can have a significant impact on practitioners.

The Research in Practice (2020) guidance details a number of mechanisms that can provide the necessary support.



Supervision – Research has highlighted the importance of effective supervision to support practitioners to consider the ethical challenges, legal options and skills involved with self-neglect practice (Braye et al., 2011; Braye at al., 2014). Supervision can also help to ensure practitioners feel confident in their roles and responsibilities and have access to the support they need to manage challenging and complex situations.

Peer/Colleague Support – Informal support from other team members can provide opportunities for reflection and to consideration of different practice approaches.

Written guidance – Practitioners should be aware of the policies, procedures and guidance available which provide the framework for their practice.

Sources of specialist advice and support – Access to specialist advice can help inform the multi-disciplinary team throughout the safeguarding process. This could include input from health colleagues, drug and alcohol services or legal support.

Resources outside of work – Individuals can also consider what sources of support they have available to them outside of the work context.

Self-neglect and deceased adults

Where an adult has died and it is known or suspected that the death resulted from self-neglect, consideration should be given as to whether a Safeguarding Adult Review under Section 44 of the Care Act 2014 needs to be completed by the Safeguarding Adults Board.

The Safeguarding Adult Review process will only be applicable where:

 there is reasonable cause for concern about how the SSASPB or a member of it or any other person involved in the adult's care worked together to effectively protect the adult;

and

 there are clearly identified areas of learning and practice improvement or service development that have the potential to significantly improve the way in which adults are safeguarded in the future. Please refer to the Staffordshire and Stoke-on-Trent Adult Safeguarding Partnership Board Website for more guidance on Safeguarding Adult Reviews <u>Safeguarding Adult Reviews (SARs) (ssaspb.org.uk)</u>

Resources:

https://www.researchinpractice.org.uk/media/xqqlavsi/working with peo ple who self-neglect pt web.pdf

https://www.local.gov.uk/our-support/partners-care-and-health/careand-health-improvement/safeguarding-resources/self-neglect-worbook

https://openjusticecourtofprotection.org/2024/01/17/an-awful-state-selfneglect-and-mental-capacity/

Learning from Tragedies: An analysis of alcohol-related Safeguarding Adult Reviews published on 2017.

References:

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Lien, C., Rosen, T., Blomen, E.M., Abrams, R.C., Pavlou, M. & Lachsm M.S (2016). 'Narratives of Self-Neglect: Patterns of Traumatic Personal Experiences and Maladaptive Behaviors in Cognitively Intact Older Adults'. *Journal of the American Geriatrics Society*, 64 (11), pp 195-200. Available from

https://agsjournals.onlinelibrary.wiley.com/doi/10.1111/jgs.14524 (accessed 01/07/2024)

Supporting Documents:

- 1. Multi-Agency Planning Meeting Agenda
- 2. Possible responses to concerns of self-neglect
- 3. Legal interventions & associated case law
- 4. Directory of resources