





Sussex Self-Neglect Practice Guidance for Staff

Don't turn your back on abuse. Speak up and we will listen.



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This guidance provides staff with practice guidance when working with adults who are self-neglecting. It has been created in recognition that in a lot of situations, selfneglect practice sits outside of safeguarding; that is, it does not meet the threshold for a Section 42 safeguarding enquiry under the Care Act 2014.

The guidance does, however, reflect key points on self-neglect from the <u>Sussex</u> <u>Safeguarding Adults Policy and Procedures</u> (2024) and <u>Sussex Safeguarding Thresholds</u> (2023).

What is self-neglect?

Self-neglect can describe a wide range of situations or behaviours experienced by a person. Each circumstance is unique. It could be someone whose personal care or health is deteriorating due to a lack of attention, or where they are not maintaining their home environment for so long that it becomes overly muddle or dirty, and therefore unsafe to their health or the wellbeing of others.

Signs of self-neglect

- Very unclean surroundings, possibly with signs of vermin.
- Neglecting household maintenance, creating fire risks or hazards, e.g. lack of boiler or dangerous electrics.
- Hoarding objects to the level there is an environmental and/or health risk.
- Poor personal hygiene and poor health (caused by untreated health conditions), e.g. unkempt appearance, long fingernails, pressure ulcers, malnutrition or dehydration. Not attending essential health appointments.
- Declining prescribed medication or declining to follow the recommendations of health and/or social care services.
- Living with many animals who are kept in unsafe conditions.
- Financial debt issues, which may lead to rent arrears or eviction.
- Not managing finances, such as prioritising the purchase of alcohol or substances over buying food and paying utility bills.
- Excessively cluttered environment which poses a fire risk and access difficulties.
- Substance and alcohol use to the point of harm or risk of harm.

Please note: This list is not exhaustive.

Important note

Professional curiosity is important when working with someone you suspect is selfneglecting. The term professional curiosity, is used to describe an in-depth interest in the adults you are working with by exploring and understanding what is happening, or may be happening, rather than making assumptions or accepting things at face value.

A person who is self-neglecting may not want others to know what they are experiencing. People may also struggle to admit they are self-neglecting or share the circumstances of the self-neglect, due to shame or stigma. Practicing professional curiosity helps to prevent abuse and neglect from happening or worsening.

Possible reasons for selfneglect

There are a range of explanations and contributing factors which may lead to a person self-neglecting, including:

- Physical or mental health problems, or substance dependency
- Psychological and social factors
- Diminished social networks
- Traumatic histories and life-changing events

Often the reasons for self-neglect are complex, multiple, and varied. It is important that we pay attention to mental, physical, social, and environment factors that may be affecting the situation (Braye, Orr, Preston-Shoot, 2015).

Self-neglect and the Care Act

The Care Act (2014) recognises self-neglect as a category of abuse and emphasises the importance of working with the adult to take preventative actions to minimise risk.

A safeguarding enquiry (Care Act Section 42) may be required when the person meets the safeguarding three key test, which is that the person:

- has needs for care and support (whether or not the local authority is meeting any of those needs), and;
- is experiencing, or is at risk of, abuse or neglect, and;
- as a result of their care and support needs is unable to protect themselves from either the risk of, or the experience of, abuse or neglect.

In order to meet self-neglect safeguarding criteria there may also be risks such as:

- The person is living in squalid or unsanitary conditions that mean life is in danger.
- Extensive structural deterioration or damage in the property causing risk to life.
- Lack of self-care and/or refusal of health or medical treatment, resulting in a significant impact on health and wellbeing.
- High level of clutter/hoarding leading to obstructed access within a property, and fire hazards.
- Behaviours such as substance use that pose risk to self and/or others.
- The individual is not able to accept any support to improve the situation.

Remember, self-neglect is sometimes not obvious; it is not associated with a physical need.

The Guidance (2024) states further that selfneglect may not prompt a Section 42 enquiry. Decisions are made on a case-by-case basis and 'the safeguarding response will depend on whether the adult is able to protect themselves by controlling their own behaviour'.

Adult's situations which do not meet the three key tests might be addressed through other routes, such as:

- a non-statutory safeguarding enquiry
- a Care Act assessment (<u>Care Act 2014,</u> <u>Section 9</u>),
- signposting to alternative services or community resources (<u>Care Act 2014,</u> <u>Section 4</u>),
- arranging for mental health services/support or contact with GP

You should report any concerns which meet the threshold for reporting via safeguarding to the relevant local authority:

- Brighton & Hove Adult Social Care
- <u>East Sussex Adult Social Care</u>
- West Sussex Adult Social Care

Important note

In all cases, when a concern is raised regarding self-neglect, all agencies have a responsibility to consider and act upon the Sussex procedures for supporting adults who are self-neglecting. This is regardless of whether the concern falls within the scope of a Safeguarding Section 42 enquiry, or not.

What have Safeguarding Adult Reviews (SARs) told us?

SARs have told us the importance of:

- Early and ongoing information-sharing and collaborative working, in line with a multi-agency working approach.
- Robust face-to-face assessment, reviews, and risk assessment.
- Understanding of legislation e.g. Mental Capacity Act.
- Challenging and reflecting on practice.
- Robust guidance to assist practitioners, and clear evidence of whether safeguarding procedures were considered and deemed to be necessary or not.
- Assessment processes involving the adult/carers/significant others.

What is the aim of the Sussex self-neglect procedure?

The procedures set out a framework and pathway for collaborative multi-agency working. The procedures ensure:

- Adults are empowered, as far as possible, to understand the implications of their self-neglect.
- A shared, multi-agency understanding, and recognition of the issues involved in working with adults who self-neglect.
- Effective multi-agency working and practice.
- Agencies uphold their duties of care.

Any professional can request or arrange a multi-agency meeting to support an adult who is self-neglecting. If there is a safeguarding enquiry, the lead agency will likely be the local authority. In other cases, you will need to discuss who is best placed to coordinate a multi-agency meeting. When multi-agency meetings are called by any agency, there is an expectation that all agencies will contribute or attend, regardless of whether the concern is managed via safeguarding processes or not.

It is acknowledged that, in some cases, multiagency liaison may be sufficient, in place of a meeting.



What is the self-neglect process in Sussex?

In Sussex we have a five-step process to working with adults who are self-neglecting. These steps are set out in the Pan Sussex Safeguarding Policies and Procedures but are also relevant for self-neglect which sits outside of safeguarding processes. The steps are:

1. Self-neglecting identified

The identifying agency should consider:

- Immediate actions required to minimise risk
- Arranging a multi-agency meeting
- Requesting a social care assessment
- Raising a detailed safeguarding concern with risks clearly documented and narrative on whether an adult is able to protect themselves by managing their behaviour without external support

2. Identify lead agency

If there is a safeguarding enquiry, this will be the local authority. In other cases, this could be another agency because:

- The agency is already involved
- The agency has a duty of care
- The agency holds significant information
- The adult has shown a likelihood to engage with them
- Needs appear to relate to the service provided by that agency

3. Information sharing

It is crucial to share information and determine who takes responsibility for what part of the process. The lead agency should consider the most appropriate actions to address the concerns raised and consider the adult's mental capacity.

4. Multi-agency meeting

The lead agency convenes a meeting to:

- Consider risks and issues of mental capacity
- Share information between agencies
- Devise a shared action plan
- Involve the adult concerned as much as possible and/or their representative or advocate

Multi-agency working is usually needed throughout, whether a meeting is arranged or, not. This means contacts with other agencies involved to share information and assess and decide together on what actions are needed and, as risks change.

Process continued on the next page.

5. Comprehensive assessment of risk

Comprehensive assessment of risk includes considering with all those involved, what the risks are, including any risks to children, other adults, and those with caring responsibilities. Referrals to children's and adult's services should be considered.

The assessment should identify who is taking forward actions, within what time frame, and will either lead to:

- Outcomes being determined, and risk addressed, resulting in:
 - o Support accepted
 - Ongoing monitoring, or:
- Outcomes being determined and risk remaining, resulting in:
 - Escalation to risk panels if available/senior managers/legal services, and ongoing monitoring
 - Repeat multi-agency meetings
 - Safeguarding concern raised where required.

For further information on risk assessment, please see the West Sussex Safeguarding Adults Board (WSSAB) <u>learning resources</u>.

Tips on working with adults who self-neglect

When engaging with an adult who is selfneglecting, and who may lack capacity or have difficulty with their executive functioning (the ability to plan, organise and complete tasks), consider whether:

- Information is in a format the adult understands.
- It is possible to have conversations over a period of time to build-up a relationship.
- There is someone else who can help support you to engage with the adult. (e.g. family, advocate, or other professional).
- The adult understands their options and the consequences of their choices.
- Adults who present with fluctuating capacity, can plan or agree actions or outcomes at a time when they have capacity for that decision.

A frequent challenge for professionals when working with adults who self-neglect is when adults refuse, or are unable, to engage with or accept services. When adults appear not to be engaging, this can present in a variety of ways, including:

- Not attending appointments.
- Not opening the door to professionals.
- Being unable to agree to a plan of support to effect change and minimise risk.
- Being unable to implement recommendations to reduce risk.
- Being affected by substances, compromising the ability to engage in any support.

It is important that you remain nonjudgemental and have a compassionate approach to understanding the complexity of the adult's history, background, and any traumas, and how this has contributed to their current circumstances.

Where an adult appears to refuse support to address their self-neglect, it is important to consider mental capacity and ensure the adult understands the implications, and that this is documented. You should not end your involvement solely on the grounds of an adult not agreeing to support.

Organisations involved in supporting an adult who is self-neglecting may have a nonengagement policy. You must refer to your own organisation's policies in addition to the self-neglect procedures.

More information

For more information on trauma-informed care see <u>Section 1.1.6. Trauma informed</u> <u>practice, care and approaches in adult safeguarding</u> of the Sussex Safeguarding Adults Policy and Procedures (2024).

Tips for effective interventions

The information below is based on work by Braye, Orr, and Preston-Shoot (2014), and explains methods and interventions to support effective practice.

- Take time to get to know the person
- Treat them with respect and non-judgement
- Maintain contact and reliability
- Monitor risk(s) and mental capacity to assess the risks associated
- Look out for motivation for change
- Talk to the adult about their interests and stories to build a relationship
- Be honest about potential consequences of actions and your involvement
- Move slowly without forcing things; focus on continued involvement and improvement over time
- Be proportionate to risk and seek agreement to actions at each stage
- Link to the adults' interests
- Provide small practical help at the outset, for example, household equipment, repairs, benefits, 'life management'
- Link practical help to another element of agreement/bargaining
- Find something to be the basis of the initial agreement that can be built on later
- Encourage safe drinking strategies or agreement to fire safety measures or repairs
- Facilitate doctors' appointments or hospital admissions, providing practical support to attend appointments
- Ensure that options for intervention are rooted in sound understanding of legal powers and duties
- Engage with the person's family, community or social connections
- Consider options for short-term respite if required, for example, to have a 'new start'
- If the adult declines options suggested, consider any other supportive options including for example, mental health or psychotherapy services

Balancing adults' rights and agencies' duties and responsibilities

All adults have the right to take risks and to live their life as they choose.

Agencies must respect this right and be mindful of this right when considering our duties and responsibilities towards an adult who is self-neglecting. This right should only be overridden when it is clear that the consequences of the risks taken would be detrimental to either the adult's, or another person's health or wellbeing.

You must also ensure that you inform adults of their rights and relevant duty of care towards them. This should include the person's right to privacy and informationsharing under the General Data Protection Regulations.

Assessing mental capacity

The Mental Capacity Act (MCA, 2005) is crucial in determining what action may or may not be taken in self-neglect cases. It is designed to protect adults who cannot make decisions for themselves, whilst protecting their human rights. Anyone working with the adult can assess mental capacity, for example, a care worker, a care service manager, a nurse, a doctor or a social worker.

An adult should be presumed to have capacity. However, when an adult's behaviour or circumstances cast doubt as to whether they have capacity to make a decision, then a mental capacity assessment should be carried out, in order to evidence the adult's understanding of risks and consequences. Robust mental capacity assessments are critical in determining the approach to be taken by professionals, either to support the decision-making of an adult with capacity or to intervene to protect the best interests of an adult who lacks capacity. Any mental capacity assessment in relation to self-neglect must be time-specific and relate to a specific intervention or action. The assessment should be carried out by the staff member needing to take action or an intervention, and it needs to be appropriately recorded.

It is important to clearly document how you have maximised an adult's autonomy and involvement within the capacity assessment, ensuring they have been given all practical support to help them reach a decision for themselves.

This will include exploration of their understanding of their behaviours and associated risks, including:

- Can they tell you what the risks are?
- What is their understanding or view of their actions which place them at risk?
- What is their understanding of the consequences of taking these risks?
- If the risk is death, explore what the adult's understanding and beliefs are regarding their death.

Good practice is to record the actual questions as they were asked, and the adult's responses.

In circumstances where there is difficulty engaging the adult, it is important to distinguish between the situation where the person is unwilling to take part in the assessment, and the one where they are unable to take part. The assessor will need to consider and document clearly:

- What steps have been taken to assist the adult to engage, and
- what alternative strategies have been used.

If it has not been possible to engage the adult in an assessment, it is important to consider if you have enough supporting evidence to come to a reasonable belief about capacity or incapacity. If the presenting risk/s are high, to the adult or others, consider an application to the court to decide whether the adult has or lacks the capacity to make the relevant decision.

For further information on how to assess mental capacity, please see the self-neglect section of the <u>Sussex Safeguarding Adults</u> <u>Policy and Procedures</u>, and West Sussex Safeguarding Adults Board's <u>learning</u> <u>resources on mental capacity</u>.

Fluctuating capacity

Some adults may have fluctuating capacity. This is particularly common in situations of self-neglect. It may occur as a result of their circumstances or behaviour, and lead to making an unwise decision, for example:

- An adult may decline treatment for an overdose when under the influence of alcohol.
- An adult may prioritise a substance over a serious health need.
- An adult experiencing very high levels of distress and making unwise decisions such as those with emotionally unstable personality disorder.

This fluctuation can take place over days or weeks, or over the course of a day. Temporary impairment of decision-making ability may be down to an acute infection. It is best practice to undertake the mental capacity assessment at a time when the adult is at their highest level of functioning.

For adults who have ongoing fluctuating capacity, the approach taken will depend on the 'cycle' of the fluctuation in terms of its length and severity. It may be necessary to review the capacity assessments over a period of time. In complex cases, you should seek legal advice.

Decisional capacity and executive functioning

There is a difference between capacity to make a decision (decisional capacity) and capacity to actually carry out the decision (executive functioning).

Where decisional capacity is not accompanied by executive functioning, overall capacity is impaired and interventions by professionals to reduce risk and safeguard wellbeing may be legitimate.

Decisional capacity and executive functioning may be impacted by, for example, acquired brain injury or prolonged alcohol dependency, and can also be indicated when an adult consistently disregards high levels of risks to themselves or others.

Unwise decisions

If an adult has capacity and is making what others consider to be an 'unwise decision', it does not mean that no further action regarding the self-neglect is required.

You must gather all the necessary information to inform a comprehensive risk assessment. You may determine that there are no legal powers to intervene, but you must demonstrate that the risks, and possible actions, have been fully considered on a multi-agency basis. An ongoing reviewing system may need to be considered, as the adult, at a future date may decide to accept support or may lose capacity relating to their care. As part of the reviewing system, the adult may consent to an agency speaking with a friend or neighbour (who is able to monitor the adult's wellbeing) to request they contact the relevant agency if the adult's condition deteriorates in the future.

Multi-Agency Risk Management meetings

In West Sussex and East Sussex there are Multi-agency Risk Management (MARM) protocols that should be considered when working with adults with multiple compound needs, who remain at high risk of harm despite previous interventions.

For further information on MARMs please go to either the West Sussex SAB or East Sussex SAB website:

- Home | East Sussex SAB
- Home | West Sussex SAB

Inherent jurisdiction

Taking a case to the High Court for a decision regarding interventions can be considered in extreme cases of self-neglect, i.e. where a person with capacity is not consenting to interventions and is:

- at risk of serious harm or death, and;
- refuses all offers of support or interventions, or;
- is unduly influenced by someone else.

The High Court has powers to intervene in such cases, although the presumption is always to protect the adult's human rights. Legal advice should be sought before taking this option.

Best interests decisionmaking

If an adult is assessed as not having capacity to make decisions in relation to their selfneglect, any subsequent decisions or acts should be made in the adult's best interests.

Any best interests decisions should be taken formally and involve relevant professionals, as well as anyone with an interest in the adult's welfare, such as their family. Consideration should also be given as to whether an Independent Mental Capacity Advocate (IMCA) should be instructed.

Best interests must be determined by what the person would want were they to have capacity; "Lacking capacity is not an off switch for freedoms" (Wye Valley NHS Trust v Mr B, 2015, EWOCP 60).

In particularly challenging and complex cases, it may be necessary to make a referral to the Court of Protection for a best interests decision. Any referral to the Court of Protection should be discussed with your Legal Services.

References and further resources

- Braye, Orr, and Preston-Shoot (2015) *Learning lesson about self-neglect? An analysis of serious case reviews,* The Journal of Adult Protection
- Braye, Orr, and Preston-Shoot (2014) <u>Self-neglect policy and practice: early research</u> <u>evidence about good practice (PDF, 2.2MB)</u> Social Care Institute for Excellence (SCIE)
- Braye and Preston-Shoot (2020) <u>Working with people who self-neglect: Practice Tool</u>, Research in Practice

Court of Protection (2015) Wye Valley NHS Trust v Mr B (PDF, 187KB)

Department of Health & Social Care (2024) Care and support statutory guidance

Legislation.gov.uk (2014) Care Act

- Legislation.gov.uk (2005) Mental Capacity Act
- Sussex Safeguarding Adults Boards (2023) <u>Safeguarding Adults Thresholds: Guidance for</u> <u>Professionals</u> (PDF, 456KB)
- Sussex Safeguarding Adults Boards (2024) <u>Sussex Safeguarding Adults Policy and</u> <u>Procedures</u>

Ward and Preston-Shoot (2020) Safeguarding Vulnerable Dependant Drinkers (PDF, 648KB)