Swindon Safeguarding Partnership

# Swindon Safeguarding Partnership Multi-Agency Policy and Guidance on Responding to Self-Neglect

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# PART 1 - Self-Neglect Policy

## 1. Introduction

Self-neglect is a spectrum of behaviours, with mental, physical, social and environmental factors interacting and affecting an adult's ability to care for themselves. The adult may initially be fully able to care for themselves, but as problems such as chronic illness develop, the person may gradually lose the ability to perform activities of daily living.

Professionals need to be alert to these changes to fulfil their duty to prevent a situation from escalating and to protect the adult from risk to their life and dignity, but they also have to show respect for the adult's life experience and autonomy. Making decisions based on these competing moral imperatives is not easy and this policy gives practitioners ideas for reflection and tools to make better judgements on how and when to intervene in another person's life.

Professionals should consider their personal biases and the preferences for what constitutes a 'life well lived' will vary between people. Any professional in Adult Health and Social Care in the Swindon Safeguarding Partnership would be expected to show an interest in the person they work with, their life story, the reasons behind their choices and a willingness to explore if an adult's refusal of support is based on an informed choice or an inability to understand risks or put decisions into practice.

Interagency communication, collaboration, and sharing of information has shown to be effective in preventing and addressing risks to adults who are self-neglecting and this policy provides templates which can be adapted in different agencies for this purpose.

**PART 1** of this document focuses mainly on the principles of support that will be offered to those that have reached a stage of self-neglect that can result in significant harm or death. For details on referrals to Adult Social Care and Adult Safeguarding, see **PART 2** of this document.

Reasons for self-neglect are often complex but so is the impact on the adult's life. Self-neglect may impact on a person's health, wellbeing or living conditions and may have a negative impact on other aspects of their life. Without early intervention, existing health problems may worsen. Neglect of personal hygiene (physical factor) may lead to social difficulties and isolation (social factor), or physical/mental health breakdown and cognitive difficulties (mental factors). Dilapidated property or excess rubbish (environmental factor) can become infested and can be a fire risk, which is a risk to the adult, family, neighbours and others.

We hope this guidance will help you to:

- Define different types of self-neglect
- Feel confident in identifying self-neglect
- Know what you can do to support people who self-neglect
- Know your responsibilities when working with someone who self-neglects

The Self-Neglect Risk Assessment and Tool included with this Guidance will be helpful for responding to cases of self-neglect. This approach includes the necessity of placing the Adult at the centre of the enquiry process and enabling their views, wishes and experience to be fully understood.

Several completed Safeguarding Adults Reviews (SARs) in Swindon had self-neglect as a major point of concern. Recommendations from these SARs place an emphasis on the importance of multi-disciplinary risk management and professionals working together at an early stage to support adults experiencing self-neglect.

The SAR reports can be accessed here:
https://safeguardingpartnership.swindon.gov.uk/info/1/swindon_safeguarding_partnership/15/adult_safeguarding/7

A recent National Review of 231 SARs across England identified that 45% of the cases involved self-neglect. Recommendations on a national and local level included improvements in risk assessments, capacity assessments and local self-neglect policies and procedures.

## 2. What is Self-Neglect - a definition

**The Care Act (2014)** Guidance advises that 'self-neglect' covers a wide range of behaviour including neglecting to care for one's personal hygiene, health or surroundings, and includes behaviour such as hoarding.

Partner agencies should think broadly on what may constitute self-neglect and what pathways may be available to address concerns. 'Hoarding' is only one of the behaviours that fall into this category but it is often used almost as a synonym for self-neglect.

Further useful information can be found at Social Care Institute for Excellence (SCIE)
https://www.scie.org.uk/self-neglect/at-a-glance

## 3. Prevention

Self-neglect is one end of a spectrum of a person's ability to care for themselves. Initially, the adult may be living independently and fully able to care for themselves. As time progresses or as a result of key events in their lives (such as the death of significant others) they may develop physical or mental health problems such as chronic illness, restrictions of mobility or a dependence on substances and as a result, lose the ability to care for themselves. This often happens gradually over time, but may happen more quickly.

Professionals may notice the changes as the individual not looking after themselves or their home environment quite as well as they used to. As time moves on, this may lead to a lack of ability to complete basic tasks of self-care and daily living such as personal care, food preparation or care for one's home environment.

All practitioners should be alert to these changes when they see them or visit a person in their home. It is important that professionals remember the principles of Making Every Contact Counts and all professionals should be taking this into their interactions, including carers, district nurses, housing officers, social workers, paramedics etc. Those who are visiting someone more regularly should remind themselves of the value for the person by taking the opportunity to have conversations while the person is not in a crisis, which is often a point when services such as Adult Social Care or hospital staff become involved.

The person's needs can increase to such an extent that they experience or are risk of harm. The earlier the changes are recognised, the sooner professionals are able to support the individual and avoid progression to a stage where they are at risk of significant harm or death before their situation is identified.

Further complicating this picture is that standards for hygiene and tidiness vary for each individual and what one person sees as very messy, or unhygienic, another would see as acceptable. It can also be that the person does not feel comfortable with new people they don't know in their home or have other personal reasons why they are declining extra support. In these situations, prevention of self-neglect may include keeping in touch with the person on a regular basis and building trust between the person and the service. In addition, it may be that the person is afraid that accepting a referral about their care needs could mean that they are not going to be able to remain living in their own home, so a clear message should be given about wanting to help the person to remain as independent as possible.

Where practitioners have identified that the adult's wellbeing is being affected to the point that they may need care and support in their daily life, for example from domiciliary care, a referral to Adult Social Care at Swindon Borough Council for a Care Needs Assessment should be made. The urgency of the referral will depend upon the situation. Further information on what the assessment involves, and the referral process can be found in **PART 2** of this document.

It may be that it is found during a needs assessment that the person requires support from a paid carer, but a person with capacity to make decisions about their care may decline this support. If a professional is in a position where it becomes clear that a person needs domiciliary care but is declining support or there are other reasons why their care needs cannot be met, this is then best discussed in a multi-agency meeting, which includes the person, other professionals and possibly people from their informal support network. The lead professional and MDT should support the person with a Welfare and Safety Plan, where the risks will be documented. Further information on multi agency meetings can be found in **PART 2** of this document.

It is possible that the situation may progress to that of self-neglect. It may also be that the situation of the individual is not recognised by services until the situation has escalated to that of self-neglect.

## 4. Indicators of Self-Neglect and reasons why people may self-neglect

### What are some of the indicators of self-neglect?

- Lack of self-care in relation to daily needs to an extent that it adversely affects well-being, personal health and safety.
- An inability or unwillingness to accept essential care and support, and services, or necessary medical treatment to avoid harm to self. (Missed appointments can be an early sign of self-neglect in regards to medical treatment.)
- A lack of care of the living environment to the extent that this neglect of personal hygiene, health or surroundings may create a public health hazard and /or increased fire risk, or to the adult becoming homeless.
- A lack of management of finances, where for example the individual may fall into debt or is no longer be able to pay for essential items
- A lack of participation in society, where the individual is isolating themselves

### Why do adults neglect themselves?

Sometimes self-neglect results from physical or cognitive difficulties but at times the reasons for it are not clear.

Research suggests that it may also be the result of:

- Physical or mental health deterioration or response to trauma
- Mental illness or problems with mood/behaviour, whereby the adult no longer feels 'worthy' of being seen and connected; this can also contribute to a reluctance or refusal to accept help and is sometimes falsely interpreted by professionals as 'lack of engagement'
- Deterioration in cognitive skills and the level of mental capacity required to understand risks or circumstances of their own behaviours, to make decisions based on this understanding, or to put decisions into practice
- Substance misuse
- Ineffective medication for an existing condition
- Physical or nutritional deterioration
- Personal beliefs and values which may have affected an adult's choices throughout their life but have now become more risky due to physical or mental changes
- A loss of social connections: social networks decreasing naturally due to the death of important 'anchors', or due to the adult's actions, or the person's inability to maintain their social networks.
- Fear of losing control
- A mistrust of professionals/people in authority
- Financial/economic hardship
- Abuse or neglect by others

## 5. What needs to be considered by professionals when working with self-neglect cases?

Self-neglect presents a great challenge for professionals due to its complexity. This guidance recognises the inter-relationship between financial, physical, mental, social, personal and environmental factors in contributing to self-neglect.

Partner agencies therefore have a vital role in the early recognition and prevention of self-neglect and have a responsibility to recognise and act upon the risk factors associated with self-neglect.

Early intervention is the most effective means to prevent a harmful level of self-neglect. Please see **PART 2** to view the early intervention options for those people who become unable to care for themselves.

**Key to effective interventions is building relationships to effectively engage with people without causing distress, reserving the use of legal powers to where they are proportionate and essential.**

## A person centred approach

An initial response should take into account the principles of Making Safeguarding Personal (MSP). More information and the MSP Toolkit is at https://www.local.gov.uk/msp-toolkit. In line with 'Making Safeguarding Personal' principles of good practice, the Adult should be included and involved in the assessment process and in developing a plan to reduce or eliminate identified risks. The person, their advocate, or someone from their personal support network should be invited to attend any meetings and comment on any findings or proposed actions.

Care and action plans are much more likely to succeed if the person at risk has been involved in developing them and if they are in a format that the person and/or their representative can understand and make use of in their daily life.

## Things to consider when working with people who self-neglect:

- Work at an individual's own pace and set achievable goals (smaller steps rather than complete life changes)

- Support the person to be 'in control' of their life and involve them in decisions

- Support autonomous decision making but also consider that to make independent and rational decisions, a person may sometimes need support (this also applies to situations where the person is considered to be capacitated to make decisions)

- Try and view the risk and concerns from the person's perspective:
    - What do they identify as the most pressing concern?
    - Would they benefit from taking actions, which are considered risky?
    - What would their quality of life be if all risk were removed?
    - Is there a way to agree an outcome that addresses the risk with the person still being in control of their life?

- Supporting someone who self-neglects to manage risk to their wellbeing can take a long time, months or sometimes years to address; a short term outlook or plan are unlikely to achieve any change

- Would the person benefit from attending a professionals' meeting, what would a meeting have to look like to support the person to want to engage? How can the person be involved in their action plan and how can this be put into a format that makes sense to the person and/or their representative? Advocacy support may be considered here, and reasonable adjustments should be considered to meet any additional needs that the person may have.

- The action plan should be reviewed to assess whether outcomes are being met.

Balancing autonomy and protection is important. An assessment of a person's mental state is important and mental capacity assessments are key in professional decision making. A person with mental capacity has the right to make decisions even if they threaten their health or safety; however, a capacitated decision alone does not mean that the professional can cease engagement/close a case/walk away if the person still remains at significant risk of harm or is experiencing harm. The onus is on the professional to look for other ways to engage the individual, and consider alternative legal powers if necessary and proportionate. For those

who lack the capacity to make a specific decision, a decision will need to be made in their best interests.

**A capacitated decision alone does not mean that the professional can cease engagement.**

## Person Centred Assessment of Risk

A person centred risk assessment should be completed using the Welfare and Safety Plan Tool at **Appendix 1**, or the professional's own agency Safety Plan. Experts by experience have told us that using the term 'risk assessment' has heightened anxiety and they co-produced the name Welfare and Safety Plan.

When completing a Welfare and Safety Plan, consideration should be given to the following aspects of the adult's life in order to establish a holistic view of the person's situation:

- Presentations of self-neglect and the home situation
- The individual's perception of their situation
- Underlying mental health conditions
- Functional and cognitive abilities of the person
- Underlying medical conditions
- Engagement in activities of daily living
- Family and social support networks, and the lack of these
- Substance or alcohol misuse issues
- Environmental factors, including fire risks
- Domiciliary care and other services offered/in place and whether living conditions are preventing necessary care being provided
- Environmental health monitoring
- Money management and budgeting
- Risks to others
- Other people posing risks

A multi-agency partnership approach is the most effective in gathering information regarding the extent of the risk and identifying an appropriate person or agency to take the lead in coordinating a person centred, outcome focused response. This plan should be completed in partnership with the person where possible, this supports principle 2 of the Mental Capacity Act 2005, 'Taking all Practical steps to support this person to understand/make the decision themselves'. It is important that the person understands that this is a part of assessing what the person understands about the risks and the impact on their health and wellbeing. It is also important that a date is set to review the Welfare and Safety Plan; this also supports any possible Mental Capacity assessments as how the person has used this information will support the understanding of executive functioning. For example, has the person been able to use the information and actions as they said they would? What has been the impact of this on the person's welfare, wellbeing and safety?

Professionals must consider whether anyone else is at risk as a result of the individual's self-neglect. This may include children or other adults with care and support needs. Professionals from all organisations have a responsibility to take action to safeguard others. Children's Multi-Agency Safeguarding Hub (MASH) referral information is in PART 2.

## Assessing Mental Capacity

Understanding and assessing mental capacity is crucial when working with people who self-neglect.
The principles of the **Mental Capacity Act 2005** should be applied where there is a reason to believe an adult lacks the capacity to make specific decisions because of an impairment of, or disturbance of, their mind or brain. No formal diagnosis of a cognitive impairment is required, but for the adult to be found to lack capacity, the inability to make the specific decision needs to be causally related to the functioning of the brain ('because of').

Establishing whether someone has the mental capacity to make decisions relating to their self-neglect can be challenging. It may be difficult to distinguish whether a person is making a personal choice to live in a certain way which others may consider unwise, or whether the person lacks the mental capacity to make a decision.

This brings into focus the dilemma that exists between the duty of care that professionals have to the individual - the impact that severe self-neglect can have in compromising human dignity and wellbeing, and the individual's right to make their own choices.

Key to addressing this dilemma is to take all practicable steps to support the adult with decision making. Under the Care Act 2014, the adult also has the right to an advocate if they have *substantial difficulties* with making decisions. All efforts should be made to help the adult participate in making decisions.

A person is considered unable to make a decision for themselves if they are unable to:

- Understand the information relevant to the decision
- Retain that information
- Use or weigh that information as part of the process of making the decision
- Communicate their decision whether by talking, using sign language or any other means.

There should be an accurate record of how the relevant factors for a decision were explained to the person. What steps have been taken to encourage and support the person, consideration of how and whether the person understood these, as well as the consequences of not making a decision, and how the inability to make a decision is related to the adult's impairment of, or disturbance of the mind.

**Mental capacity involves the ability to understand and reason through the elements of the decision (decisional capacity) and the ability to realise when that decision needs to be put into practice and execute it at the appropriate moment (executive capacity).**

This part is often confused by practitioners who may determine that someone has decisional capacity around their personal welfare or their environment, without considering if the person can carry out the actions needed to keep themselves safe or well. Professionals should consider the person's ability to implement a decision in practice and implement a point of review of the persons capacity, have they been able to use the information and decision as

they indicated? It is important that practitioners remember to review capacity at appropriate intervals, has the person acted in the way they stated they would?

**A person assessed to have capacity and making 'unwise' decisions, does not mean we can walk away. It is still vital that practitioners continue to use Strengths Based and Trauma Informed Approaches to engage and support the person towards greater safety.**

A person with impaired executive function (frontal lobe damage) may have difficulty understanding, retaining, using and weighing relevant information, as well as planning, problem solving and enacting a decision in the moment. Where the adult refuses assistance and they have been assessed as having the mental capacity to understand the consequences of such actions, this should be fully recorded.

Practitioners should also include a record of the efforts and actions taken by all agencies involved to provide support and confirmation that they have considered alternative means to meet any duty of care owed to the person or others affected by the self-neglect.

Some conditions may cause fluctuating capacity. A Mental Capacity Act assessment assesses a person's capacity to make a specific decision at a specific time, so it may be necessary to return for another visit, or gather more information, before completing a Mental Capacity Assessment. Practitioners 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, how the risks change when someone is under the influence of alcohol.

Where it is assessed that an adult does not have the mental capacity to make a specific decision, this does not mean that they are no longer involved in decisions. The Best Interests process ensures that the adult is consulted.

A Deprivation of Liberty Safeguards (DoLS) authorisation may be necessary if an adult lives or needs to live in a care home, or is staying in hospital. Where a person is living in a community setting, a Community DoL application may need to be made. In circumstances where a person is objecting to being removed from their home, a referral to the Court of Protection may be needed in order to remove someone from their home under the Mental Capacity Act (2005). Legal advice should be sought about whether the Mental Health Act (1983) is appropriate.

## Professional Curiosity

Learning points from SARs across the country tell us that professionals could and should have been more professionally curious when working with self-neglect cases.

Professional Curiosity is the open mind and readiness to explore a situation in full, instead of accepting it 'at face value'. Natural curiosity can be supressed by competing commitments and biases. Professionals are naturally curious but also have a tendency to think that 'what they see is all there is'.

Professional curiosity tries to reach beyond the patterns of first impressions and assumptions. It requires practitioners to ask questions about themselves and their beliefs as much as of the people they encounter in a professional situation.

Curious professionals:

- Appreciate people's lived experience as much as the situation they currently find themselves in
- Are respectfully quizzical about people's lives and get an understanding of individuals' and their families' past history
- Look, listen, and ask direct questions but generally communicate and engage in ways that work for the person
- Triangulate information from different sources to gain a better understanding of individuals and their networks
- Check and test their professional hypotheses

Professional curiosity involves keeping an open mind and applying critical evaluation to any information received, whilst maintaining an open and honest relationship with the individual. It requires holistic thinking, looking at how all factors in a person's life impact on each other, and not thinking in a way that is restricted to your professional role.

The Swindon Safeguarding Partnership 7 Minute Briefing/Resource Pack on Professional Curiosity can be accessed here: resource_pack_-_professional_curiosity

## Engaging with people who self-neglect

Key to effective interventions is building relationships to effectively engage with people without causing distress and reserving use of legal Powers to where they are proportionate and essential.

Safeguarding processes may be required when working with people that self-neglect, but much of the work is long-term work, which happens under other frameworks. This 3 minute animation video https://www.youtube.com/watch?v=ZEXrczADeKo from Lambeth SAB highlights the challenges faced.

The nature of self-neglect cases means there is an increased likelihood that the person may refuse support when it is first offered. In conjunction with being flexible, patient and creative, professionals have to be gently persuasive and persistent in working with a person to reduce risks. Professionals may consider if there are alternative agencies that may be able to joint work to assist engagement with the person. Working creatively with other agencies supports the person and professionals in sharing the risk and finding alternative ways to support the person to engage in support.

Initial non-engagement should **not result in no further action**. Support could be offered again later, particularly where risks may have changed, or referral made to other agencies clearly indicating why the referrer thinks these agencies may be best placed to try and engage the person. If you are faced with repeated low-level concerns over a short period, this could mean the situation is more serious than it initially appears. Consider whether more support is needed to get a wider picture of the adult's situation on a daily basis.

Consider different ways to engage the person:

- Go on a joint visit with someone that the individual knows, trusts and feels comfortable with. This could be a family member, friend or another professional.
- Contact other professionals who are in contact with the person (GP, day centre workers, cleaners, etc.). They may have suggestions about how best to engage with the individual.
- Discuss whether the person would engage with a fire safety assessment from the fire brigadethat you could go along to.
- Take something as a positive introduction. For example, an Occupational Therapist may take a piece of equipment, which could make the person's life easier and may be accepted. If the individual has meals delivered, you could go along at the same time as the delivery.
- Ask others about the individual's interests and hobbies to find something that might engage them, think creatively about how this could be incorporated into your work, or the work of other agencies.
- Consideration should also be given to things that you know have succeeded in the past with this individual, as this may have the same outcome if tried again.

If there are significant concerns, professionals may need to visit someone with a police escort. Local PCSOs often have a good relationship with the community and may know the person. The police can also gain entry if there are risks to the person's life, in line with Police and Criminal Evidence Act legislation.

The various options for referral are described fully in **PART 2**

**In all cases, where potential harm of any level could occur, professionals need to work collaboratively, communicate well, and share information with other agencies.**

Multi-agency meetings can be the best way to do this, especially when there is risk of significant harm. Meeting or discussions will usually be coordinated by the agency, which is most involved in the main area of the person's self-neglecting behaviour. For example, if an assessment under the Care Act 2014 is required, the meeting should be organised by an Adult Social Care team. If health or primary medical needs are the main concern, they should be organised by the relevant health organisation. If a section 42 Enquiry is under way, the meeting should be organised by the Adult Safeguarding team as part of the safeguarding process, including where the self-neglect is health related.

# PART 2 - Guidance on Responding to Self-Neglect Cases

## 1. Pathways for Self-Neglect

**Multi-Agency Self-Neglect Meetings**
Multi-agency working is key to supporting people who are Self Neglecting. Multi agency meetings can be held at any time and further information can be found in the section below.

**Referral to Adult Social Care**
Where care needs are identified by a professional, a referral to Adult Social Care should be made to enable an assessment of these needs so that appropriate care can be put into place.

**Referral to Adult Safeguarding**
Where a person has been identified as having care and support needs under the Care Act, and is at risk of harm, self-neglect or abuse, a referral should be made to Adult Safeguarding.

**Referral to Children's Safeguarding (MASH)**
If there is concern for the safety and wellbeing of a child or young person who may be at risk, a referral to the MASH must be considered.

Further information for each pathway option is outlined in more detail below.

The response to self-neglect, as any other professional response, needs to be proportionate. Some situations may be best addressed by advice and information to the person or their representative, or by some support or assessment by a single person or agency who the person is most familiar with.

From a certain risk level (see Risk Assessment at Appendix 1) however, responses need to be coordinated between agencies in order to protect the person better and to manage risk appropriately.

Where there is evidence that an individual may be at significant risk from self-neglect, a referral should be made to Adult Safeguarding and a social work assessment visit must take place within 24 hours to assess the level of risk. Where a person is an inpatient this will likely be managing the initial presenting self-neglect concerns for the duration of their stay.

Professional judgement will need to be applied when deciding on the most appropriate pathway to secure professional multi-agency collaboration and appropriate risk management.

Multi-agency collaboration is the starting point and referrals to Safeguarding can be made alongside this if the specified criteria are met.

Multi-Agency meetings can be organised and led by one agency. They will likely address the concerns if the risk is low or moderate; if the risk is higher, they will be useful in making the referral to Adult Safeguarding more comprehensive.

Professionals can make a referral to Adult Social Care if it is considered that an assessment of the adult's needs for care and support (section 9-10 Care Act) or a detailed consideration of their ability to protect themselves from risk (under MCA and/or section 42 Care Act), procedures may be the best route to provide an appropriate intervention in situations of hoarding or self-neglect. The referral information is detailed in the below.

Seeking legal advice as early as possible may help to identify other legal frameworks. Using two examples relating to Local Authorities: if the alleged behaviour is anti-social, it may be that the Council can use its various anti-social behaviour management powers to deal with it and this may present a more effective and efficient remedy. Likewise, it may be that where the person is a Council tenant, actions relating to the management of the tenancy agreement and enforcing the terms of this agreement might be more appropriate.

## Multi-Agency Meetings

Agencies have a duty to respond to abuse and neglect under the Care Act 2014. Key professionals from any agency or organisation can call Multi-Agency meetings for a person who self-neglects and who they are concerned about in their service.

The purpose of the Multi-Agency meeting is to discuss risks, identify the most appropriate lead, and implement a plan, which provides the most appropriate person-centred response to manage risk to the person. This can include professionals across health, social care, housing, environmental health, and the voluntary sector. For example, a GP practice may include district nurse, community navigator, social prescriber, pharmacist, and any carer or care coordinator in their meeting (the list is not exhaustive).

In the meeting, professionals can share their concerns associated with the adult's risk behaviours so that decisions are made based on all available evidence, and to allow a more complete picture of the situation, and to develop a plan. This can be a formal risk management plan if deemed appropriate by the agency.

Following the meeting, a risk management plan should be circulated to all attendees and reviewed by the lead agency, to ensure that actions have been completed and the risks are mitigated. When the risk can be managed without the plan being monitored, the plan can be closed.

Actions set in a Multi-Agency meeting should be based on the person-centred risk assessment and contribution from all key professionals.

One professional or agency will take responsibility for risk assessment and for scheduling the Multi-Agency meeting, and for sharing and coordinating the actions that are set in the meeting; this would normally be the agency which is most involved in the main area of the person's self-neglecting behaviour e.g. Health. The key factor for deciding who should take the lead in the Multi-Agency meeting should be what is best for the adult at risk.

The agency organising the meeting should invite any professional that they know is currently working with the adult or that they feel would be relevant.

A proposed Agenda template for a Multi-Agency meeting is at **Appendix 3.**

Decisions on actions and rationale for decisions should be recorded and recording should include for example:

- What options have been considered and how has the appropriate action pathway been decided on?
- Have issues been explored with professional curiosity?
- Who was invited to a Multi-Agency meeting?
- Who else was consulted and what information was gathered/evaluated?
- What actions were set/for whom/with what date for completion. Note that in most cases this will include a conversation with the person at risk and/or other assessments?
- Who will monitor completion of the tasks set and whether there will need to be another meeting?
- How has any immediate risk been addressed? Have long-term risk considerations been shared and what actions have been taken to address the risk?
- How have decisions were shared and communicated to referrers
- What legal frameworks have been considered (for example Mental Capacity Act 2005)
- Date and time of visits, calls and decisions
- Who reported which piece of information
- Professional opinion clearly shown as such

Timely and appropriate information sharing is at the core of this process and professionals need to refer both to the SSP Information Sharing Agreement as well as their own agency's information governance policies and guidance. Swindon Safeguarding Information Sharing arrangements are at https://safeguardingpartnership.swindon.gov.uk/info/12/about/80/information_sharing_agreement

Professionals should consider their own agency's Self-Neglect policy if applicable.

## Referral to Adult Social Care

If you think that the adult has care and support needs, a referral to Adult Social Care at Swindon Borough Council for a Care Needs Assessment should be made. As part of the assessment or review, the worker will discuss the situation with the individual and explore the best options for supporting them in their day to day living, as well as to help them achieve their desired outcomes. This may include community resources, informal support from the person's own network as well as statutory services (such as the provision of domiciliary care or residential care). Where the person is entitled to such services under the Care Act, these services would be subject to an individual financial assessment (to establish if there is a contribution charge to the person and how much this will be).

Ideally, the person should always be aware of the referral and have given their consent. If the person lacks capacity to give their consent, or declines to do so, a referral can still be made where necessary in the vital interests of the individual or the public interest.

To refer someone to Adult Social Care, there are several options.

**Non-Urgent**

For all referrals call Swindon Borough Council on: 01793 463333. This phone number should be used to refer for a Care Act assessment to assess or re-assess a person's care needs, for carer support services, or Occupational Therapy.

More information on support available can be found using the following link: Refer yourself or another person to Adult Social Care | Swindon Borough Council.

**Urgent**

If you feel that a same day response is required and care may need to be arranged urgently, please telephone to speak to the Initial Contact Team (ICT) directly as follows:

- Monday to Friday 9am-5pm: 01793 463333 and select option 2. This will take you through to the Initial Contact Team. Please ensure that you make it known to the ICT if you are enquiring an urgent same day assessment.

- Monday to Friday after 5pm, and before 9am and all weekend: 01793 436699. This will take you through to the Emergency Duty Team who can if necessary arrange urgent support out of hours.

## Referral to Adult Safeguarding

Report a safeguarding concern about an adult at risk of, or experiencing, harm | Swindon Borough Council

Self-Neglect may trigger a Safeguarding concern where the person who self-neglects has needs for care and support and is experiencing, or at risk of, abuse or neglect (including self-neglect). It may also be necessary to raise a safeguarding concern if the adult who is self-neglecting is a carer for an adult at risk. Think family - is anyone else at risk because of the self-neglect?

The SSP Threshold e-guidance should be used and is at:
https://safeguardingpartnership.swindon.gov.uk/downloads/file/307/threshold_framework_document

Note that self-neglect may not prompt an Adult Safeguarding section 42 enquiry.

An assessment should be made on a case by case basis, and advice can be provided by the Adult Safeguarding Team.

A Care Act section 42 Safeguarding referral should be considered and applied where necessary. This would be the case where single agency and inter-agency collaboration under this policy has failed to address identified risk around self-neglect.

This may be because:

- The person is persistently refusing care and support and professionals and family members struggle with the complexity of statutory duties and legal powers which could possibly be used to improve the individual's situation
- Other approaches have failed and the risk remains high
- Agencies refuse to cooperate under this Policy and Guidance (Escalation should also be used in this instance)
- Despite appropriate resources (available to the individual or being formally provided), the individual cannot protect themselves by controlling their behaviour

## Referral to Children's Safeguarding (MASH)

Professionals must consider whether anyone else is at risk as a result of the individual's self-neglect. This may include children or other adults with care and support needs. Professionals from all organisations have a responsibility to take action to safeguard others.

If you are working with an adult who self-neglects, consider if there is a child within the person's household, family or network and follow your agency's safeguarding procedures around children. If you feel that a child may be at risk of serious harm, contact:

Swindon Children's Multi-Agency Safeguarding Hub at: swindonmash@swindon.gov.uk or telephone 01793 466903.

Further information at:
https://www.swindon.gov.uk/info/20043/child_protection/929/report_suspected_child_abuse_or_exploitation/1

## Escalation

Where professionals disagree about the approach to a self-neglect case, and where this cannot be resolved, the Swindon Safeguarding Partnership Escalation Policy should be used: https://safeguardingpartnership.swindon.gov.uk/downloads/file/1072/adults_escalation_policy

## 2. Key Agencies and Their Responsibilities

It is fundamental that a partnership approach is adopted when responding to, and managing Self-Neglect referrals and enquiries.

### Swindon Borough Housing Services

Where an adult is at risk of homelessness as a result of self-neglect or hoarding behaviour, the Housing Service will offer advice and assistance to individuals and practitioners involved in their care to minimise any risk of homelessness. Early involvement from Housing, particularly when considering alternative temporary or permanent accommodation options, is therefore essential.

### Swindon Borough Council Adult Social Care Services

As detailed above, an assessment of the adult's needs for care and support or a detailed consideration of their ability to protect themselves from risk can be the best route to provide an appropriate intervention in situations of hoarding or self-neglect. The Adult Social Care referral information is detailed in the section above

### Other Adult Social Care services:

For information and advice please direct individuals to the Councils Local Offer page, which, contains information on Adult Social Care services, services within the community and voluntary organisations:
https://localoffer.swindon.gov.uk/content/adult-social-care/landing-pages/adult-social-care/

### Health Services

The key role for Health services will be to raise concerns and provide information to discussions and continue to meet need in accordance with their professional standard and duty of care. Where a patient is assessed as lacking mental capacity, a decision will be made in that patient's best interests as to how to support their medical needs, as per the law on best interest decisions for patients.

A patient who has mental capacity may make a fully informed decision to decline a medication or treatment option and the health practitioner should support them in this decision.

Such decisions must be re-visited often to ensure the decision remains a capacitated one, and to afford patients the opportunity to say they have changed their minds. Should the health practitioner feel alternative pathways/options may improve the health of that person they should work with them over time to ensure that the patient continues to make fully informed decisions about their health.

On a case-by-case basis, taking into account other contextual factors in that person's life, if the person is not able to look after themselves and this is having an impact on their health and (for example) their ability or motivation to take their medication or repeatedly decline opportunities to engage with recommended care plans, this may suggest self-neglect and as such should be discussed with the service safeguarding lead.

If agencies other than health agencies have a concern about health in the risk matrix, please refer to the adult's GP or other health practitioner.

### Swindon Borough Council Environmental Health Service

Environmental Health can assist where a person is exposed to a public health risks or hazards in the home that affect their health safety and welfare. This applies to private rented accommodation and where the property is owner occupied. The Environmental Health team have powers to take enforcement action and subsequent works in default to clear a hoarded property where the hoard consists of putrescible waste and/or where there is evidence of vermin (rats/mice). The team can also assist where the property is in a poor condition and that condition is affecting the health safety and welfare of the occupier. The team also administer disabled facilities grants and work with the Occupational Therapy team to enable adaptions to homes for access into and out of the home and access to amenities in the home.

If the property is owned and managed by the Council, the Neighbourhood Housing Officer will assist with all of the above matters as the property is council owned.

### RSPCA

If an animal/s are being neglected by the individual, a referral may need to be made to the RSPCA.

### Wiltshire Police

Self-neglect is a form of vulnerability. Vulnerability is a priority for Wiltshire Police, and this is reflected in the Chief Constable's force priorities around safer public spaces and violence and the Police and Crime Commissioner's Plan.

Police are called to addresses for a variety of reasons such as when a crime is committed, Anti-Social Behaviour is reported or there is concern for the occupant's welfare. There is a policy in place which governs how staff should deal with vulnerability which is split into three strands; Strand 1 - Adult concern for safety. Strand 2 - Crime or ASB against vulnerable adult. Strand 3 - Adult at risk the adult is in need or receipt of community care of services and the victim is at risk of suffering abuse or neglect (including self-neglect). As a result of their needs they are unable to protect themselves against abuse or neglect.

Strand 2 cases require the attending officer to complete a vulnerability risk assessment and complete an action plan. This is then owned and progressed by the relevant Neighbourhood Policing Team. For a strand 3 case a PPN will be completed in all cases for this information to be shared with the Adult MASH and then Adult Social care. For strands 1 and 2 direct contact will be made via phone or e-mail and the attending officer will use their professional judgement to decide if the level of threat, harm and risk justifies a PPN submission. Wiltshire Police play a key role in information sharing and working with partner agencies around vulnerability the vulnerability process is designed to be robust and ensure intelligence is accurate and the right support is in place for each individual.

### Swindon Advocacy Movement (SAM)

An Independent Advocate is an advocate working independently of the Local Authority and appointed under the Care Act. The role of an Independent Advocate is different to the role of a general Advocate because they are not just supporting the person to have a voice, but to facilitate and maximise their involvement in a whole range of adult Care and Support processes.

There is a duty to make advocacy available under 2 sections of the Care Act-section 67 and section 68. An advocate may be referred to as a section 67 or 68 advocate so it is important to know the distinction.

Section 67: An advocate to support a Care and Support process not related to safeguarding;

Section 68: An advocate to support a safeguarding process.

Under the Care Act, the Local Authority must arrange for an Independent Advocate to be available to represent and support the person (or carer) if:

a. There is no appropriate other person to support and represent them; and
b. They feel that the person (or carer) would experience substantial difficulty being fully involved in the Care and Support process without support.

Substantial difficulty applies to one or more of the following areas:

a. Understanding relevant information relating to the process or function taking place;
b. Retaining that information;
c. Using or weighing up that information as part of the process of being involved; or
d. Communicating their views, wishes or feelings (whether by talking, using sign language or any other means).

Under the Care Act, consideration of an advocate should be made at the first point of contact with the person or carer. The Care Act is clear that this is the stage where the assessment begins as information starts to be gathered, and it is therefore where the duty to make independent advocacy available also begins. Where the need for an Independent Advocate has been identified, the Care and Support process should not start before the advocate has been allocated.

Where the person does not have capacity, or is not able to communicate their views, wishes or feelings, the Independent Advocate must do so to the extent that they can ascertain them. Where the person does not have capacity, or is not able to challenge a decision made by the Local Authority in relation to the Care and Support function the Independent Advocate must challenge the decision if they consider the Local Authority to be in breach of their general responsibility to promote individual Wellbeing

Swindon Advocacy are at https://www.swindonadvocacy.org.uk/

## Commissioners

Commissioners will be made aware of this policy statement to consider it in future planning for services.

A directory of contacts is available at **Appendix 4.**

## Appendices:

Appendix 1A: Risk Assessment Tool

Appendix 1B: Further information for health

Appendix 2: Legal Frameworks for partner agencies in relation to Self-Neglect

Appendix 3: Proposed Agenda Template for Professionals Self-Neglect meeting

Appendix 4: Directory / useful contacts

Appendix 5: Clutter Scale Rating

Appendix 6: Other resources to inform working on self-neglect cases

Appendix 7: Self-Neglect Case Law

Appendix 8: Self-Neglect - Swindon case study stories

## Appendix 1: Multi-Agency Self-Neglect and Hoarding Risk Assessment Tool

| Swindon Self-Neglect and Hoarding Risk Assessment | | |
|---|---|---|
| Name: | | |
| NHS number: | RIO number: | Eclipse number: |

Include the adult and persons close to them as much as possible, but also show your consideration of:

- Human Rights Act, Article 2 (protection and right to life) and 3 (protection from inhuman or degrading treatment or punishment) and the right to make autonomous decisions
- The Mental Capacity Act 2005 (the person's right to have their decisions respected but also the right to be supported with decision making and to assessment where there is reasonable belief that the person lacks the relevant capacity)
- The Care Act 2014 (the person's right to be supported in making decisions where they have substantial difficulty)
- The Mental Health Act 1983 (the legal rights for people with a mental disorder; the person can be admitted to, detained and treated in hospital for their disorder without their consent only when it is absolutely essential to ensure their mental well-being or safety, or for the protection of other people)

**Reach across your agency's boundaries to collect information and collect information from various sources to inform your assessment of risk. This assessment is to be used as a guide.**

| Minor | Moderate | High/Critical |
|---|---|---|
| Report of some risky behaviours where the adult has lost control over some aspects of daily living.<br><br>Consultation with the adult AND people interested in the adult's welfare, and/or review of relevant records, show that these can be managed with signposting, advice, or minimal, occasional, informal or formal support.<br><br>The likelihood of an effect on the adult's wellbeing is minimal because advice was provided. | Some risky behaviours with significant impact on the adult's wellbeing. The person may be accepting of full or limited support.<br><br>A face-to-face visit and wider consultation is required; these show that some regular formal support, care planning and monitoring will resolve the issues.<br><br>There is a moderate likelihood that the behaviour will re-occur and potentially escalate; the situation needs to be monitored. | Reports of serious concerns about the individual's ability to manage activities of daily living, with significant risk to their wellbeing.<br><br>Self-neglect significantly impacts on health, quality of life, inclusion, and independence.<br><br>The adult is likely to or has refused support. Face-to-face visits, wider consultation and ongoing support is required.<br><br>There is a high likelihood that the behaviour will continue and severely affect the adult's wellbeing. |

| For environmental risk: Level 1 – 3 on Clutter Scale at **Appendix 7** | For environmental risk: Level 4 – 6 on Clutter Scale at **Appendix 7** | For environmental risk: Level 7 – 9 on Clutter Scale at **Appendix 7** |
|---|---|---|

**Guidance notes**

- This tool is designed to be used in conjunction with Swindon Safeguarding Adults Board Self-Neglect Policy and Guidance
- It is designed to help practitioners and managers determine the extent to which an individual is at risk due to their self-neglecting behaviours and prompt appropriate action.
- The guidance table below can be used to remind you of some helpful things to consider when trying to assess a person's risk level.
- It should be noted that this is not an exhaustive list of the different self-neglecting behaviours and their associated risks. This document is intended to be **indicative**, rather than **definitive.**

**Agencies should always refer to their own safeguarding policies and procedures, as well as practitioners' own professional judgement.**

**What helps achieve positive outcomes:**

Practitioners

- Time to build a relationship, to 'find the person', to understand the meaning of their self-neglect in the context of their life history
- Collaborative work, multi-agency involvement and systems for securing it.
- Finding value in small achievements, recognising what is being given up.

Service Users

- Practical input, household equipment, benefits, advocacy, re-housing
- Promoting choice where possible
- Access to psychological and mental health services to tackle deep-rooted issues.

| | **Examples of concerns that do not require formal safeguarding procedures and can be dealt with by agencies' own safeguarding policies or by multi-agency working.** | **The below are risk indicators that someone could be in need of support such as a multi-agency meeting.**<br>**If there is any immediate danger to an individual, consider calling 999, or address the risk with the most appropriate action.**<br>**Consider escalation where other agencies are not engaging, or, depending on the circumstances (see Self-Neglect Policy and Guidance for more information), a referral to Adult Safeguarding.** |
|---|---|---|

| Home Environment | Minimal | Moderate | High / Critical |
|---|---|---|---|
| • Condition of accommodation<br>• Shelter<br>• Animals<br>• Utilities | Maintenance issues are minimal (e.g. broken lightbulb) but individual needs prompting to address them.<br><br>Individual is homeless but engages with support to look after their personal wellbeing and safety.<br><br>Individual has pets but they appear mostly well cared for, and this does not significantly prevent them from caring for themselves.<br><br>Person usually addresses their housing needs, but requires support from specialist services or their support networks.<br><br>Early signs of vermin or infestations are visible and are addressed by the individual, but only with prompting.<br><br>There are some signs of hoarding but these are addressed by the individual when prompted.<br><br>Level 1 – 3 on Clutter Scale at **Appendix 7** | Maintenance issues are more significant (e.g. cracked window pane, broken boiler) and individual has made minimal attempts to address them, despite prompting.<br><br>Individual is homeless but does not consistently engage with services to keep themselves safe, or look after their health and/or personal wellbeing. This contributes to their homelessness.<br><br>Individual has pets which are not all cared for appropriately, or doing so causes harm to the person (e.g. walking dogs makes individual's severe arthritis flare up, then requiring intervention).<br><br>Person admits to needing support in addressing their housing needs but does not consistently seek or follow this information and advice.<br><br>Vermin and infestations are visible, but limited to one area in the home, and individual requires significant encouragement to address this.<br><br>Initial prompts to address signs of hoarding are largely ignored, but this is addressed by the individual with more intensive support<br><br>Level 4 - 6 on Clutter Scale at **Appendix 7** | Maintenance issues are a significant threat to safety (e.g. floorboards missing, broken external doors). Individual has made no attempt to address them, or obstructs attempts to do so.<br><br>Individual is rough sleeping and not engaging with any support services to keep safe. Or individual has a safe property to stay in, but chooses not to use it.<br><br>The number of pets in the property is unmanageable and makes the living environment dangerous for the individual.<br><br>Individual refuses specialist support to address their housing needs, putting them at risk of imminent homelessness.<br><br>Vermin and infestations are rife and individual does not cooperate with attempts to address this.<br><br>There are clear signs of hoarding that may cause harm to the person e.g. blocked exits. The individual is unwilling to address this, with or without support.<br><br>Level 7 – 9 on Clutter Scale at **Appendix 7** |

| **Personal Care and Wellbeing** | **Minimal** | **Moderate** | **High / Critical** |
|---|---|---|---|
| • Engagement with services<br>• Social isolation<br>• Clothing<br>• Hygiene<br>• Presentation | Person has engaged with an assessment and will follow most of the recommendations, but not all.<br><br>Self-neglecting behaviours (e.g. unpleasant odours from lack of self-care) has a small impact on their access to community facilities (e.g. groups, cafes) but the person seeks support to address this.<br><br>Individual can sometimes appear dishevelled or unkempt (e.g. clothes buttoned up incorrectly, wearing items backwards) but not consistently, and generally washes themselves.<br><br>There is sometimes a discernible unpleasant smell but the person addresses this when prompted.<br><br>Person presents well (mood, behaviours, and physical appearance) most of the time, but not always, and they require low level prompts which are generally responded to.<br><br>Person generally appears to have an awareness of their dignity but they require and engage with support to maintain this (e.g. requires help to do buttons but still takes pride in choosing clothes). | Person engages with the assessment stage but does not follow any of the recommendations.<br><br>Self-neglect impacts on access to some key community facilities (e.g. shops, buses) and/or their support network and the person does not seek support for this, but will reluctantly engage when offered.<br><br>Individual often appears unkempt and there are minimal signs that the person washes regularly (e.g. greasy hair, wearing the same clothes repeatedly).<br><br>There is often a discernible unpleasant smell and the person does not consistently address this, despite repeated prompting.<br><br>Person's presentation often causes some concern but more so lately (low mood, erratic behaviours, dishevelled appearance), signifying a slow deterioration.<br><br>Person needs support to maintain their dignity (e.g. used to be house-proud but now needs a cleaner due to ill-health) but individual has inconsistent engagement with this, which may cause harm to their health e.g. unhygienic bathroom and kitchen areas). | Person refuses to engage in an assessment, and doesn't follow any other associated advice and guidance.<br><br>Self-neglect has caused significant estrangement with essential services (e.g. food shops) and/or their support network, and person makes no attempt to address this.<br><br>Individual has major infestations due to lack of washing (scabies, nits, headlice), that result in secondary conditions such as sepsis. Person may refuse support to address this.<br><br>Person has a strong and distinct odour without seeming to notice or be willing to address.<br><br>There is a rapid deterioration in the individual's presentation over a short period of time.<br><br>Individual's sense of dignity has decreased severely. They do not engage with support to maintain their dignity, appearing not to care, and this is a rapid deterioration. |
| **Nutrition** | **Minimal** | **Moderate** | **High / Critical** |
| • Weight (loss or gain)<br>• Food preparation | Lots of the individual's food is out of date by up to a week but there is some food still in date. | Most of the food is out of date by up to a week and there is little evidence of attempts to get more. | All the food is severely out of date (over two weeks) and this is what the individual has been consuming. |

| | | | |
|---|---|---|---|
| • Food choices<br>• Access to food | Individual is over or underweight but this is not likely to cause them significant harm now, and they are generally engaging in support to manage their weight.<br><br>Food is generally stored in an appropriate place, but not always (e.g. meat not always put in the fridge quickly enough).<br><br>The individual eats and drinks regularly, and prepares meals. | Individual is noticeably under/overweight and requires specialist support to manage this. Engagement with the support is inconsistent and person requires a lot of encouragement.<br><br>Food is stored inappropriately and person requires support with this, which they reluctantly engage with, needing frequent encouragement and repeated advice. | Individual makes informed choices not to spend money on food leading to significant and dangerous weight loss. Or individual appears to have only one food-type (e.g. fast food, biscuits, sweets), which causes them to become dangerously overweight.<br><br>Food is stored in a way which is likely to cause significant harm to the individual if consumed (e.g. uncovered raw meat stored on top of cooked meat, and the individual plans to consume this).<br><br>The individual does not eat or drink regularly, and does not prepare meals for themselves. |
| **Finance** | **Minimal** | **Moderate** | **High / Critical** |
| • Access to money<br>• Management of money<br>• Self-funding | The person may have limited finances due to unemployment, not claiming all benefits, or debt, which they may need support to address.<br><br>Person is self-funded and pays for essential services that will keep them safer, but only after much advice and guidance from their support network.<br><br>Person often makes decisions around their finances which could put them at risk of harm (e.g. not leaving enough money to buy adequate food, or not prioritising money to pay for utilities) but is working with agencies to address this. | The person may have very limited access to money (due to financial exploitation, benefit error, lack of support networks), and does not engage with support to address this.<br><br>Person is self-funded and often chooses not to pay for essential services that will keep them safer, but pays for some.<br><br>Person's financial decisions frequently put them at great risk of significant harm (e.g. regularly not prioritising paying for essential utilities and so is temporarily cut off), and person is reluctant to engage with support for this, requiring extensive intervention before risk is reduced. | The person has no access to money at all or is in serious debt, due to their self-neglect (e.g. not applying for benefits, not opening a bank account or setting up payment plans for essential services) and needs immediate support to address this, including emergency financial aid.<br><br>Person is self-funded and doesn't pay for essential services that will keep them safe, through a seeming absence of awareness about their responsibility for their own safety and does not see this as a financial priority.<br><br>Person consistently makes financial decisions which put them at immediate and significant risk of harm e.g. refusing to pay utility bills. |

| | | | |
|---|---|---|---|
| **Original section on Health in risk assessment** | | | |
| **Health** | **Minimal** | **Moderate** | **High / Critical** |
| • Physical and mental health<br>• Engagement with universal health services (e.g. GP)<br>• Engagement with<br>• Specialist health services (e.g. Diabetes service, drug, alcohol, counselling)<br>• Compliance with medication Medical advice<br>• Supportive equipment | Individual sometimes engages with universal and/or specialist physical/mental health services, but only after prompting or with support.<br><br>Individual doesn't always take prescribed medication as advised, but this is unlikely to result in significant harm.<br><br>Individual generally seeks medical support, but not straightaway and not always from the most appropriate agency.<br><br>Individual only uses any physical aids and equipment sometimes, and requires prompting, but this is not likely to cause significant harm to their health. | Inconsistent engagement with universal and/or specialist physical/mental health services, despite prompting and support. This is likely to result in significant harm to their health over time.<br><br>Individual doesn't take prescribed medication consistently, which is likely to cause a significant deterioration in health over time.<br><br>Individual needs a lot of prompting to seek medical help, which might cause damage to their health over time.<br><br>Individual only uses physical aids or equipment with extensive prompting, and this is likely to cause significant harm to their health over time. | Individual doesn't engage with any physical/mental health service, universal or specialist. This is likely to result in immediate and significant harm to their health.<br><br>Individual consistently doesn't take life-sustaining medication (e.g. insulin), contrary to medical advice, which will result in an immediate threat to their life.<br><br>Individual fails to consistently seek medical advice for conditions that put their life at imminent risk.<br><br>Individual refuses to use, or does not see the need to obtain, physical aids or equipment that are vital to enabling daily life e.g. a ventilator. This puts their life and/or personal wellbeing at immediate risk.<br><br>The person's mental health is not controlled with medication and support, psychosis is not managed or monitored. |
| **Self-Neglect and Hoarding Risk Assessment – for completion by practitioner** | | | |

| History and current position (Background to person's self- neglect and impact of self-neglect on the individual and on others) | Provide information and complete referral or other action as appropriate |
|---|---|
| Speak to the person and their representatives. What are their strengths and skills, and is support already available to address some or all of the above risks? (Provide detail on who does what) | |
| Functioning of mind or brain impairing decision making? (add diagnosis if known) Is psychosis distracting the person from or influencing their decision making? | |
| Are critical life events or experiences causing e.g. grief, or trauma affecting person's feelings about themselves? Is decision making delayed or influenced by these feelings to a degree that causes substantial difficulty? | |
| Is a chronic health condition or disability affecting a person's ability to care for themselves? | |
| What is the impact on others from the person's self-neglect? How are other people in or outside the family circle/or animals affected by the person's self-neglect? | |
| Is the self-neglect caused by abuse/crime/neglect from others? | |
| Does the adult understand and acknowledge the consequences of their behaviours but refuse support? What could be the reason? | |

**Risk Matrix**

Use the examples above to inform risk category. Note that the examples are a prompt; you should include other information that impacts on the risk to the person where appropriate. Consider the likelihood of the risky behaviour to happen or continue and the possible consequences

| | Minimal | Moderate | High / Critical |
|---|---|---|---|
| Home Environment | | | |
| Personal Care and Wellbeing | | | |
| Nutrition | | | |
| Finance | | | |

| | | | |
|---|---|---|---|
| | | | |
| Health | | | |
| **Outcome of Risk Assessment for Self Neglect**<br>Take appropriate action according to the outcome of your risk assessment | | | |
| | **Minimal** | **Moderate** | **High / Critical** |
| | **Single agency response possible.**<br><br>Consider the adult's strengths and informal circle of support when determining what support is needed but do corroborate information with other sources.<br><br>Talk to the person involved about your concerns. Provide information and advice about what the risks are, and how they could be reduced.<br><br>Promote self-help e.g. mechanisms for keeping appointments, encouragement to ask for help.<br><br>Signpost to universal services e.g. GP, fire service, libraries, leisure services. Consider housing support services if a change in accommodation may be required, as a preventative measure. | **Single or multi-agency response. If multi-agency, arrange multi agency planning meeting and establish lead.**<br><br>Regular support and secure protective arrangements must be considered with the adult for all activities of daily living (include management of personal finances).<br><br>Evidence your actions well in recording. | **Multi-agency response**<br><br>Depending on severity of risk, complete first response on same day.<br>Call emergency services if there is an immediate and serious risk of harm.<br><br>Complete face-to-face visit on same or next day, with prompt protective arrangements put in place considering legal pathways.<br><br>Complete multi-agency planning meeting or discussion, and consider referral to Adult Safeguarding or referral to Risk Enablement Panel.<br><br>Regular support and secure protective arrangements for all activities of daily living must be considered (work with the adult but also consider best interests decisions and applications to court.) |

| | | | |
|---|---|---|---|
| | Identify a lead worker to ensure liaison with other agencies to gather and share information on risk. | | |

## Appendix 2: Legal Frameworks for partner agencies in relation to self-neglect

There may be times when practitioners must consider the use of legal interventions to safeguard a person, if the impact of their self-neglect puts them at serious risk of harm. This may be the case where persistent efforts to engage with someone have failed and the concern is still very high, or where all other actions taken to improve the situation have been exhausted.

The most important legal frameworks to consider in all cases of self-neglect are: the Care Act 2014, the Human Rights Act 1998, and the Mental Capacity Act 2005.

The following laws may also be useful to be aware of when working with people who are self-neglecting. Please note that this is not an exhaustive list.

| **Environmental Health** |
|---|
| Environmental Health services have power of entry under the following laws, with Police presence:<br><br>**Environmental Protection Act 1990:** used where a person is self-neglecting behaviours (e.g. hoarding) have begun to affect other people's environment or communal or public areas.<br><br>**Prevention of Damage by Pests Act 1949:** used where the person is self-neglecting behaviours result in household conditions in which there is evidence of pests (e.g. rats, mice).<br><br>**Public Health Act 1936:** used to gain entry where the person is not engaging with services, to carry out or examine necessary work to a property relating to public health. Can also be used to deliver Enforcement Notices, requiring an individual to comply. |
| **Police** |
| **Police and Criminal Evidence Act:** enables the police to gain power of entry to a property if they have information that someone inside the premises is ill or in danger, and is not responding to outside contact. |
| **Housing** |
| **Anti-Social Behaviour, Crime and Policing Act 2014:** used where the person's self-neglecting behaviours amount to Anti-Social Behaviour e.g. repeatedly preventing gas inspections. There Act can also be used to require individuals to co-operate with a support service to address the underlying reasons behind their behaviour.<br><br>**Housing Act 2004**<br><br>**Environmental Protection Act 1990:** see above.<br><br>**Animal Welfare Act 2006:** used where there is concern about the welfare of animals in a property, and the owner is not responding to advice to improve this. |

The Care Act 2014 guidance [paragraph.14.14] advises a 'broad community approach' to Safeguarding responsibilities, so it is vital that statutory agencies understand the full extent of statutory powers for intervention when living conditions pose risk to an adult at risk to themselves or others.

The Care Act sets out six Making Safeguarding Personal principles to guide professionals when engaging with individuals who may self-neglect. These are:

| | |
|---|---|
| **Empowerment** | People being supported and encouraged to make their own decisions and have informed consent. |
| **Prevention** | Taking action before harm occurs. |
| **Proportionality** | Using the least intrusive and most appropriate response to the risk presented. |
| **Protection** | Support and representation for those in greatest need. |
| **Partnership** | Using local solutions through services using their communities. Communities have a key part to play in preventing, detecting and reporting self-neglect. |
| **Accountability** | Accountability and transparency in delivering safeguarding. |

## Legal options for gaining access / entry to a property where an adult may be self-neglecting:

- **The Court of Protection:** The Court of Protection can make any decision on behalf of a person who lacks capacity that the person could have made themselves. This therefore includes decisions as to who to permit to enter any property owned or controlled by the person and decisions as to where they should reside. This general power is contained within Section 16 of the Mental Capacity Act 2005.

- **Section 115 of the Mental Health Act 1983:** An Approved Mental Health Practitioner (AMHP) may at all reasonable times enter and inspect any premises (other than a hospital) in which a mentally disordered patient is living, if he has reasonable cause to believe that the patient is not under proper care. This does not permit the AMHP practitioner to use force and it may be an offence, under Section 129 of the Act, to obstruct an AMHP in relation to Section 115

- **Section 135 of the Mental Health Act 1983:** An AMHP may apply to the Magistrates Court for a warrant where someone who is suffering from a mental disorder is being or has been ill-treated, neglected, or not kept under proper control, or is living alone and unable to care for themselves. The warrant permits a police constable (in the company of an AMHP and a registered medical practitioner) to enter the property, by force if required, in order to transport the person to a place of safety.

- **Common law powers:** There may exist a number of common law powers, such as a landlords' power to force entry to a property in an emergency situation or applications under the inherent jurisdiction of the High Court, that would help facilitate entry to an adult who may be self-neglecting.

The decision as to which route to take will depend on an assessment of the facts in each case. Legal advice should be sought at the earliest opportunity when it becomes clear that entry to a property may be required and that entry is against the will of the person(s) occupying the property.

**The Human Rights Act (1998)** is a key piece of legislation for safeguarding adults, as it addresses the issue of a person's right to make choices about their life versus professionals' duty to keep them safe. The following articles of the Act state**:**

| | |
|---|---|
| **Article 2:** | The right to life must be protected by law. |
| **Article 3:** | The absolute right to be free of torture or to be subjected to treatment or punishment that is inhumane and/or degrading. |
| **Article 5:** | The right not to be deprived of their liberty, except in limited cases specified within the Article. |
| **Article 8:** | The right to respect their private and family life, their home and their correspondence. |
| **Article 14:** | The right not to be treated differently because of their race, religion, gender, political views or any other protected characteristic unless there is an 'objective justification' for the difference. |
| **Article 1:** | The right to a 'peaceful enjoyment' of their property. |

The Mental Capacity Act says an individual has these rights: You'll be assumed to have capacity, unless you've had an assessment showing that you don't. All decisions made for you when you've lost capacity should be made in your best interests. Your liberty can only be taken away from you in very specific situations.

- Principle 1 – A presumption of capacity.
- Principle 2 – The right to be supported when making decisions.
- Principle 3 – An unwise decision cannot be seen as a wrong decision.
- Principle 4 – Best interests must be at the heart of all decision making.
- Principle 5 – Any intervention must be with the least restriction possible.

The principles of the Mental Capacity Act 2005 should be applied where there is a reason to believe an adult lacks the capacity to make specific decisions because of an impairment of, or disturbance of, their mind or brain. No formal diagnosis of a cognitive impairment is required, but for the adult to be found to lack capacity, the inability to make the specific decision needs to be causally related to the functioning of the brain ('because of'). More detailed guidance on application of the Mental Capacity Act 2005 is in Section 5 of this Guidance.

## Appendix 3 - Proposed Agenda Template for Professionals Self Neglect Meeting

# Professionals Self-Neglect Meeting - AGENDA

- All information shared at this meeting is confidential and privileged and is not shared outside of this meeting without the permission of the chair and the agency that provided the information.
- Timely and appropriate information sharing is at the core of this process and professionals need to refer both to the SSP Information Sharing Framework as well as their own agency's information governance policies and guidance.
- There may be occasions when there are differing perspectives and judgements amongst professionals. When disagreements cannot be resolved, professionals should refer to the Swindon Safeguarding Partnership Escalation Policy

| | |
|---|---|
| **Date** | |
| **Time** | |
| **Chair** | |
| **Organisation** | |
| **Role** | |
| **1. Introduction** | |
| • Chair's Welcome<br>• Introductions<br>• Apologies | |
| **2. Current Situation** | |
| • Summary of any intervention offered, care and support that has been offered or is in place<br>• Individual agency perspectives of the concerns and risks to the adult/others<br>• The individual's views and wishes and how they wish to be involved<br>• The individual's strengths and assets including family and wider social network | |
| **3. Mental Capacity** | |
| • Consideration of the individual's mental capacity around the areas of unmanaged risk | |
| **4. Assessment of Risk** | |

- Collaborative and holistic assessment of presenting risks

**5. Discussion**

- Legal powers and remedies in use or potentially available
- Rationale for using/not using powers and remedies available
- Lead coordinating professional for the process
- Individual named workers for each agency where more than one agency involved
- Information sharing arrangements (with the adult's permission, where possible)
- Contingency and escalation plan

**6. Shared Risk Management Plan**

- Risk management plan
- Confirm who will share the plan with the individual
- How the individual will be involved and kept up to date
- Monitoring and review arrangements

| Appendix 4: Relevant Agencies and Responses (1) | |
|---|---|
| **Organisation** | **Contact Details** |
| **Emergency services and social care** | |
| Wiltshire Police | 999 for emergencies 101 for non-emergencies<br>https://www.wiltshire.police.uk/article/604/Contact |
| Dorset and Wiltshire Fire and Rescue Service | 999 for emergencies<br>01722 691000 - general enquiries<br>Safe and Well visits -<br>https://www.dwfire.org.uk/safe-and-well-visits/ |
| Adult Social Care | 01793 463333 (option 2)<br>https://www.swindon.gov.uk/info/20011/adult_social_care_and_support |
| Children's Social Care | 01793 466903<br>Out of hours: 01793 466900<br>Swindonmash@swindon.gov.uk |
| **Animals** | |
| Pest Control | https://www.swindon.gov.uk/info/20096/environmental_health/483/get_ |
| Domestic Animal Welfare | https://www.swindon.gov.uk/info/20091/animal_welfare |
| RSPCA | 01793 640136<br>https://www.rspca.org.uk/local/north-wiltshire-ranch/aboutus/contactus |
| Environmental Health | 01793 445500<br>Healthyneighbourhoods@swindon.gov.uk |
| **Housing** | |
| Stonewater Housing | 01202 319 119<br>allocations.south@stonewater.org |
| MHA Housing Association | 01332 29620<br>enquiries@mha.org.uk |
| Green Square Housing | 01249 465465<br>info@greensquaregroup.com |
| Sanctuary Housing | 0800 131 3348<br>ContactUs@sanctuary-housing.co.uk |
| Aster Housing Association | 0333 4008222<br>https://www.aster.co.uk/contact-us |
| Housing Options Swindon Borough Council | https://www.swindon.gov.uk/info/20151/council_housing<br><br>https://www.swindon.gov.uk/downloads/file/4630/housing_association_directory |
| **Mental Health and Substance Misuse** | |
| Avon and Wiltshire Mental Health | 01225 325680<br>http://www.awp.nhs.uk/ |

| | |
|---|---|
| Partnership (AWP) | |
| Individual Access to Psychological Therapies | 01793 836836<br>https://www.awp.nhs.uk/our-services/talking-therapies |
| Richmond Fellowship | 01793 433571<br>http://www.richmondfellowship.org.uk/wiltshire/ |
| Change Grow Live (CGL) | 01793 328150<br>https://www.changegrowlive.org/drug-and-alcohol-service-swindon |
| **Other services** | |
| Live Well | 01793 465513<br>https://www.swindon.gov.uk/info/20139/Live_Well_Swindon_Hub |
| Swindon Advocacy Movement (SAM) | 01793 542575<br>https://www.swindonadvocacy.org.uk/ |
| Age UK Wiltshire | 0808 196 2424<br>https://www.ageuk.org.uk/wiltshire |
| Citizens' Advice Swindon | 0808 2787813<br>https://www.citizensadviceswindon.org.uk/ |

## Appendix 4: Relevant Agencies and Responses (2)

| | |
|---|---|
| **Fire Service** | • Install interlinked smoke alarms in each accessible room<br>• Gives Fire safety advice particularly on electrical, kitchen, candles, electric blankets, fires and heaters |
| **Environmental Health** | • Will consider serving notices under Public Health Act 1936, Environmental Protection Act 1990, Prevention of Damage By Pests Act 1949 or Housing Act 2004<br>• Will consider 'Works in Default' if notices not complied with by occupier |
| **Social Landlord** | • Visit person to inspect the property and assess support needs<br>• Referral to local Floating Support Service to assist in the restoration of services to the property where appropriate.<br>• Ensure person is maintaining tenancy conditions<br>• Enforce tenancy conditions relating to tenant responsibilities<br>• If person refuses to engage serve Notice of Seeking Possession under Ground 13 to Schedule 2 of the Housing Act 1988 |
| **Private landlord** | • Inform Housing Advice Team at the Borough Council if a private landlord has a tenant with hoarding behaviour and is not aware of it. Housing advice teams have the knowledge and ability to challenge any unlawful evictions that might result from hoarding behaviour. |
| **Voluntary agencies** | • Offer debt advice<br>• Support for person who is self-neglecting |
| **GP** | • Visit person - carry out assessment and refer to appropriate mental health teams - consider mental health crisis concordat |
| **Police** | • Complete and submit MASH 101 form or protocol referral form<br>• Consider legal action |
| **Ambulance service** | • Complete and submit MASH 101 form or protocol referral form |
| **Animal Welfare RSPCA** | • Visit property to undertake a wellbeing check on animals at the property<br>• Educate person regarding animal welfare if appropriate<br>• Provide advice / assistance with re-homing animals<br>• Consider removal of animals to a safe environment<br>• Take legal action for animal cruelty if appropriate |
| **Safeguarding Adults and Safeguarding Children and young people** | • In the case of concerns about abuse or neglect, make a safeguarding referral as appropriate to the adult or children safeguarding team |
| **Swindon Advocacy Movement** | • Provide independent advocacy for adults who are at risk of abuse or neglect |

## Appendix 5: Clutter Index Rating

Please see the clutter image rating to assess the level or hoarding for the room/s. This was developed by Hoarding Disorders UK and can be found here: https://hoardingdisordersuk.org/clutter-image-ratings/.

### Clutter Scale Rating: BEDROOM

Please select the photo that most accurately reflects the amount of clutter in the bedroom(s)

1

2

3

4

5

6

7

8

9

## Clutter Scale Rating: LIVING ROOM / LOUNGE

Please select the photo that most accurately reflects the amount of clutter in the living room/lounge


1


2


3


4


5


6


7


8

9

## Clutter Scale Rating: KITCHEN

Please select the photo that most accurately reflects the amount of clutter in the kitchen


1


2


3


4


5


6


7


8


9

**Please complete clutter score for all additional rooms:**

| Room Name | Clutter Score |
|---|---|
| | |
| | |
| | |
| | |
| | |
| | |

Using the clutter image, assess the level of the hoarding. The assessed level is:

**Image 1-3** - Indicate level 1

**Image 4-6** - Indicate level 2

**Image 7-9** - Indicate level 3

Please see tables below for detail and actions:

| Level 1: Clutter Image Rating 1-3 | **Household environment is considered standard. No specialist assistance is needed. If the resident would like some assistance with general housework or feels they are declining towards a higher clutter scale, appropriate referrals can be made.**<br><br>**Follow Self Neglect Policy in relation to Multi Agency Self-Neglect Meeting** |
|---|---|
| **Property, structure, services & garden area** | • All entrances and exits, stairways, roof space and windows accessible.<br>• Smoke alarms fitted and functional or referrals made to fire brigade to visit and install.<br>• All services functional and maintained in good working order.<br>• Garden is accessible, tidy and maintained |
| **Household functions** | • No excessive clutter, all rooms can be safely used for their intended purpose.<br>• All rooms are rated 0-3 on the Clutter Rating Scale<br>• No additional unused household appliances appear in unusual locations around the property<br>• Property is maintained within terms of any lease or tenancy agreements where appropriate.<br>• Property is not at risk of action by Environmental Health |
| **Health and Safety** | • Property is clean with no odours, (pet or other)<br>• No rotting food<br>• No concerning use of candles<br>• No concern over flies<br>• Residents managing personal care<br>• No writing on the walls<br>• Quantities of medication are within appropriate limits, in date and stored appropriately |
| **Safeguarding of children & family members** | • No Concerns for household members |
| **Animals and pets** | • Any pets at the property are well cared for<br>• No pets or infestations at the property |
| **Personal Protective Equipment (PPE)** | • No PPE Required<br>• No visit in pairs required |

| Level 1 | Action |
|---|---|
| **Actions to take** | • Discuss concerns with resident<br>• Raise a request to the fire service to provide fire safety advice<br>• Refer for support assessment if appropriate<br>• Refer to GP if appropriate. |

| Level 2: Clutter Image Rating 4-6 | Household environment requires professional assistance to resolve the clutter and the maintenance issues in the property. |
|---|---|
| **Property structure, services and garden area** | • Only major exit is blocked<br>• Only one of the services is not fully functional<br>• Concern that services are not well maintained<br>• Smoke alarms are not installed or not functioning<br>• Garden is not accessible due to clutter, or is not maintained<br>• Evidence of indoor items stored outside<br>• Evidence of light structural damage including damp<br>• Interior doors missing or blocked open |
| **Household functions** | • Clutter is causing congestion between the rooms and entrances.<br>• Clutter is causing congestion in the living spaces and is impacting on the use of the rooms for their intended purpose<br>• Room(s) score between 4-5 on the clutter scale<br>• Inconsistent levels of housekeeping throughout the property<br>• Some household appliances are not functioning properly and there may<br>• be additional units in unusual places<br>• Property is not maintained within terms of lease or tenancy<br>• agreement where applicable<br>• Evidence of outdoor items being stored inside |
| **Health & Safety** | • Kitchen and bathroom are not kept clean<br>• Offensive odour in the property<br>• Resident is not maintaining safe cooking environment<br>• Some concern with the quantity of medication, or its storage or expiry dates.<br>• No rotting food<br>• No concerning use of candles<br>• Resident trying to manage personal care but struggling<br>• No writing on the walls |
| **Safeguarding of children and family members** | • Consider a referral to Adult Safeguarding or to the Children's MASH<br>• Please note all additional concerns for householders<br>• Properties with children or vulnerable residents with additional support needs may trigger a Safeguarding Alert under a different risk |
| **Animals and pets** | • Pets at the property are not well cared for<br>• Resident is not unable to control the animals<br>• Animal's living area is not maintained and smells<br>• Animals appear to be under nourished or over fed<br>• Sound of mice heard at the property<br>• Spider webs in house<br>• Light insect infestation (bed bugs, lice, fleas, cockroaches, ants, etc.) |
| **Personal Protective Equipment (PPE)** | • Latex Gloves, boots or needle stick safe shoes, face mask, hand sanitiser, insect repellent.<br>• PPE required. |

| Level 2 | Action |
|---|---|
| **Actions to take** | • Refer to landlord if resident is a tenant<br>• Refer to Environmental Health if resident is a freeholder<br>• Raise a request to the Fire Service to provide fire prevention advice<br>• Provide details of garden services<br>• Refer for support assessment<br>• Referral to GP<br>• Referral to debt advice if appropriate<br>• Refer to Animal welfare if there are animals at the property.<br>• Ensure information sharing with all agencies involved to ensure a collaborative approach and a sustainable resolution |

| | |
|---|---|
| **Level 3: Clutter Image Rating 7-9** | **Household environment will require intervention with a collaborative multi-agency approach with the involvement from a wide range of professionals. This level of hoarding constitutes a Safeguarding alert due to the significant risk to health of the householders, surrounding properties and residents. Residents are often unaware of the implication of their hoarding actions and oblivious to the risk it poses.**<br><br>**Follow Self Neglect Policy in relation to Multi Agency Self-Neglect Meeting and Referral to Adult Safeguarding** |
| **Property structure, services and garden area** | • Limited access to the property due to extreme clutter<br>• Evidence may be seen of extreme clutter seen at windows<br>• Evidence may be seen of extreme clutter outside the property<br>• Garden not accessible and extensively overgrown<br>• Services not connected or not functioning properly<br>• Smoke alarms not fitted or not functioning<br>• Property lacks ventilation due to clutter<br>• Evidence of structural damage or outstanding repairs including damp<br>• Interior doors missing or blocked open<br>• Evidence of indoor items stored outside |
| **Household functions** | • Clutter is obstructing the living spaces and is preventing the use of the rooms for their intended purpose<br>• Room(s) scores 7 - 9 on the clutter image scale<br>• Rooms not used for intended purposes or very limited<br>• Beds inaccessible or unusable due to clutter or infestation<br>• Entrances, hallways and stairs blocked or difficult to pass<br>• Toilets, sinks not functioning or not in use<br>• Resident at risk due to living environment<br>• Household appliances are not functioning or inaccessible<br>• Resident has no safe cooking environment<br>• Resident is using candles<br>• Evidence of outdoor clutter being stored indoors<br>• No evidence of housekeeping being undertaken<br>• Broken household items not discarded e.g. broken glass or plates<br>• Concern for declining mental health<br>• Property is not maintained within terms of lease or tenancy agreement where applicable<br>• Property is at risk of notice being served by Environmental Health |
| **Health & Safety** | • Human urine and or excrement may be present<br>• Excessive odour in the property, may also be evident from the outside<br>• Rotting food may be present<br>• Evidence may be seen of unclean, unused and or buried plates & dishes<br>• Broken household items not discarded e.g. broken glass or plates<br>• Inappropriate quantities or storage of medication<br>• Pungent odour can be smelt inside the property and possibly from outside<br>• Concern with the integrity of the electrics<br>• Inappropriate use of electrical extension cords or evidence of unqualified work to the electrics<br>• Concern for declining mental health |
| **Safeguarding of children and family members** | • Hoarding on clutter scale 7-9 may require a referral to Adult Safeguarding and/or Children's MASH<br>• Please note all additional concerns for householders |
| **Animals and pets** | • Animals at the property at risk due the level of clutter in the property<br>• Resident may not able to control the animals at the property<br>• Animal's living area is not maintained and smells |

| | |
|---|---|
| | • Animals appear to be under nourished or over fed<br>• Hoarding of animals at the property<br>• Heavy insect infestation (bed bugs, lice, fleas, cockroaches, ants, silverfish etc.)<br>• Visible rodent infestation |
| **Personal Protective Equipment (PPE)** | • Latex Gloves, boots or needle stick safe shoes, face mask, hand sanitizer, insect repellent<br>• Visit in pairs required |

| **Level 3** | **Action** |
|---|---|
| **Actions to take** | • Conduct a multi-agency meeting<br>• Raise a request to the Fire Brigade within 24 hours to provide fire prevention advice<br>• Referral to Adult Safeguarding |

## Appendix 6: Other resources to inform working on self-neglect cases

Engaging and intervening with people who self neglect: messages from research, Suzy Braye, Emerita Professor of Social Work, University of Sussex. Independent Consultant in Adult Safeguarding Hampshire, 15th May 2019

Research in Practice, Working with people who self-neglect

SCIE report: Gaining access to an adult suspected to be at risk of neglect or abuse: a guide for social workers and their managers in England

SCIE self-neglect at a glance at: https://www.scie.org.uk/self-neglect/at-a-glance

Community Care article: When mental capacity assessments must delve beneath what people say to what they do (2020): https://www.communitycare.co.uk/2020/10/28/mental-capacity-assessments-must-delve-beneath-people-say/

Swindon Self Neglect 7 minute briefing
https://safeguardingpartnership.swindon.gov.uk/downloads/file/620/7_minute_brief_self-neglect

Age UK Leaflet: https://www.ageuk.org.uk/globalassets/age-uk/documents/factsheets/fs78_safeguarding_older_people_from_abuse_fcs.pdf

Strengths Based Approach: Practice Framework and Practice Handbook:
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/778134/strengths-based-approach-practice-framework-and-handbook.pdf

## Appendix 7: Case law relating to hoarding behaviour

When working with those who experience hoarding behaviour there is case law that may support the work we do and sets out what may be considered Salient Factors under the Care Act 2014. The summary can be found here: https://www.39essex.com/information-hub/case/ac-and-gc-capacity-hoarding-best-interests

Re: AC and GC (Capacity: Hoarding: Best Interests) [2022] EWCOP 30

First reported case regarding hoarding. The case involved AC, a 92-year-old woman with Alzheimer's and alcohol related brain damage. She lived with her son GC who had autism, anxiety & OCD. He had given up work to move in and care for his mother. During proceedings, both were diagnosed with hoarding disorder.

Following a hospital admission, AC was admitted to a care home in her best interests and made subject to a standard DoLS authorisation. She objected and her son wanted her to return home.

The local authority was opposed to AC returning home due to the high risk of failure. The judge ultimately concluded that a trial at home (10-weeks) with a package of care/support from son was a manageable risk.

Her Honour Judge Clayton: 'A trial of care at home is not without risk but, on the evidence before me, it is a manageable risk and one which should be taken to try to afford AC the opportunity of returning to her home, in improved circumstances, and with the hope and expectation that it will continue to improve in the coming weeks and months...It is to her benefit to keep the placement open for the duration of the trial period as, is in the event of a breakdown, the risk of distress to her would be significantly lessened if she were to be returning to the care home and to an environment with which she is familiar, with staff who are now known to her.'

The judge also appointed a deputy for property & financial affairs for AC (solicitor) with 'authority to remove items from the property whether they belong to AC or GC as it is AC's home.'

One of the issues to be determined was whether GC & AC had capacity to make decisions about their hoarding BUT what is the decision? What is the relevant information?

The judge concluded that the correct formulation of the 'matter' was management of items and belongings. The relevant information includes:

1. Volume of belongings and impact on use of rooms – the degree to which they impair the usual function of the important rooms in the property.

2. Safe access and use – the extent to which the residents can safely access and use the living areas.

3. Creation of hazards – the impact on the functioning; maintenance and safety of utilities; hygiene (toilets, food storage and preparation); fire risk etc.

4. Safety of building – the extent to which accumulated clutter and inaccessibility could compromise the structural integrity and safety of the building.

5. Removal/ disposal of hazardous levels of belongings – that safe and effective removal and/or disposal of hazardous levels of accumulated possessions is possible and desirable.

## Appendix 8: Swindon Case Study Stories (names have been changed)

*'Empathy is remembering that everybody has a story. Multiple stories. And remembering to make space to hear someone else's story before immediately telling your own.' Kae Tempest in: 'On Connection'*

### Working with self-neglect - Report and Case Studies by Kati Wood (Live Well)

In terms of self-neglect, the largest number of referrals that come to the Live Well involve hoarding behaviour. I have a good relationship with Jo Cooke, founder of Hoarding Disorders UK. https://hoardingdisordersuk.org/. She has delivered training for the Community Navigators, colleagues across the community and voluntary sector and colleagues in Swindon Borough Council Adult Social Care, Housing, Environmental Health and Children's Services. Jo has redesigned her courses so that they can be delivered online.

With the support of Jo and her colleague Paul, we started a support group last year which quickly established an anonymous membership of more than 20 individuals. This has been put on hold due to the Coronavirus pandemic, but we will look to reinstate the group as soon as possible. In the interim, Jo has been facilitating conference call support groups and Swindon support group attendees that have come forward have been signposted to these groups - for direct support with hoarding behaviour.

The courses that Jo has developed and delivered have shaped our understanding of, and approach to hoarding disorders. Support groups are beneficial to the participant in a number of ways. They provide suggestions, motivation, techniques, understanding and peer support, acceptance and the reduction of feelings of hopelessness and stigma.

That labelling of people as "hoarders" is not helpful; it's better to label the behaviour - "People with hoarding behaviour". More often than not, hoarding behaviour is intrinsically linked to trauma and loss. Therapies such as Cognitive Behaviour Therapy, Emotional Freedom Techniques and talking therapies have shown to have a positive effect for some people with hoarding behaviour.

Collaboration and partnership working between agencies and organisations is essential for positive outcomes for an individual. One to one work with people with hoarding behaviour takes time, compassion and patience.

In 2020, we developed a bid with partners from across SBC and partner agencies to develop a system wide approach to supporting change for people with hoarding disorders. We got through to the second round but no further. There were many people connected to the bid, including Jo Cooke and Paul Cooper from Hoarding Disorders UK, the Fire Service, BSW CCG, Swindon Safeguarding Partnership and others. There was a consensus that even if the bid was not successful, there was a desire to work together to create an approach to supporting people with hoarding behaviour.

The Community Health and Wellbeing service is currently is made up of three areas: **Active and Inclusive:** Physical activity for people furthest away from participation **The Live Well:** the first point of contact for anyone wanting to use our services **Healthy Communities:** includes Community Response, Community Participation and Community Navigators

## Live Well case studies

## Sarah

**Referral Route:** Came to the Hoarding Support Group after referral from her Social Prescriber

Sarah came to the Hoarding Support Group for the last meeting before Covid national lockdown. She found it tricky to engage and didn't share her details. We didn't meet again but she emailed in October 2020.

Sarah is an intelligent and articulate woman who was in crisis when she joined. Her home was full of leaks and she had no hot water as her boiler was broken. She had been furloughed and was having difficult relationships at work, was going through a grievance procedure and was anticipating being made redundant. Her mother, who lives overseas, was critically ill.

She emailed in a desperate state in October 2020 (I gave my email address as a contact to the Hoarding Support Group). This was her first email:

*'I am reaching out to you because I do not know where to turn. As I do not want to lay it all out in an email without knowing whether you are still offering support in this area, or if you know of any place that does offer support, I will sum it up. I currently have no heat or hot water and am in a position where I am facing redundancy. Between hoarding and finance, I am struggling to solve the critical issue about the lack of heat. Do you know of anywhere I can get some kind of assistance? I don't even mean financial, as, even if I had the finances to deal with it, I am mortified about bringing a repair person in. Things are feeling grim right now. I would be grateful for a response either way.'*

Over a number of weeks, we communicated via email. Sarah wouldn't tell me where she lived. We have a compassionate and sympathetic volunteer, Emily, who is also a professional plumber. I suggested that I could introduce Sarah to Emily, explaining that Emily is non-judgemental and supportive. Numerous plans were postponed but I stayed in contact with regular motivational/sympathetic email correspondence. Sarah explained that she felt humiliated. She eventually agreed to meet Emily down the road from her house. This took place in December and Sarah invited Emily into her home. Emily fixed many of the leaks and built a trusting relationship with Sarah. Emily arranged for her friend to fix the boiler. Another friend helped with the roof. The last email I received from Sarah said:

*'I wanted to send an email to update you. Emily* (the plumber) *has been an absolute angel. It really feels like she has been my saviour. She has fixed the leaking toilet and sink, and brought over friends who have helped to fix my heating and do a temporary mend on the roof that was leaking into the bathroom. To have heat again after a month without has made me feel human again. Even typing about it brings tears to my eyes. Thank you for putting me in touch with her. She has been amazing. It is hard not to think of her as my new best friend, as she has been so kind and helpful. I am so grateful for all she has done for me.*

*I don't want her or her friends to be out of pocket, and she hasn't mentioned anything about cost. You had mentioned there might be something available from the council... Is there a fund I can apply for to cover that? My redundancy consultation is nearly done and is due to end tomorrow, with my notice period ending on 18/01/21. Additionally, I have reached out to Hoarding Support run by Jo, and attended two telephone group sessions. It is going to be a long road and I often get off track, but I am starting again.'*

## What is the learning from this case?

It takes time, patience, and the right person to build trust with someone. It was easy for Sarah to drop away from facing her fears; her behaviour required a tenacious and explicitly non-judgemental approach. Sarah was very self-aware regarding her hoarding behaviour and the impact it had on her life. Her home was neither safe nor functional - she described her experience as "paralysis".

My relationship with Sarah was based on trust. I got to know her a bit and understood how she wants to be treated and I 'held the baton' until someone else could take over from me and treat her with the same respect and compassion. It was Sarah who allowed me to bring Emily in and Emily then brought her friends in. I still don't know Sarah's address and I didn't need to know it, but all of us formed a 'circle of trust' around her and what we have in common is a strong set of values. We like to interact with people and we accept people as they are without judging and we nurture our volunteer networks; that way we can confidently reach out and offer support with the best person for a particular piece of work.

Using trusted volunteers in sensitive situations is effective, but services cannot rely on this as a free resource. Nurturing relationships takes investment, but people feel motivated by the altruism and share their appreciation with the volunteers.

## Lucy

Lucy is an older female who lives alone in her own semi-detached property in a village on the outskirts of Swindon. Lucy likes to online shop and buy craft materials. Lucy has poor physical mobility, but she is also limited in her movement by lack of access to the upstairs of the property. Lucy is a volunteer phone befriender for a local charity and had disclosed her hoarding behaviour to a worker from the charity who arranged a Safe and Well visit by Dorset and Wiltshire Fire and Rescue Service.

Lucy's kitchen had been stacked with possessions and there were no surfaces available or accessible floor space. She used a small deep fat fryer for her cooking. The Fire Service had offered Lucy some help to clear her kitchen to make it safer and functional but in doing so blocked her access to her wardrobe. We were asked to mobilise volunteers to help clear Lucy's craft materials to a workshop in the garden. Given the sensitivity of the situation, staff members volunteered to assist with this task. Lucy's family had made a start by clearing a large workshop in the garden. We completed this task and then began moving craft items to the workshop. Thousands of pounds of equipment was moved and stored in the workshop. Lucy had aspirations of making goods and selling them at craft fares. She was also keen to support youth groups etc. with craft activities and resources.

## What is the learning from this case?

Moving items out of sight does not resolve things for the person. Long-term resolution needs time, an understanding of any underlying problems, and the right support. Lucy's health and mobility are still a barrier to her fulfilling her aspirations and our intervention has not addressed this loss. Since the intervention, Lucy has resumed the mass purchasing of craft equipment and pathways in her home are severely obstructed again.

She has told us she needs our help, but as she is clinically extremely vulnerable (to contract Covid), she doesn't want us in her home yet.

If multidisciplinary teams worked together, we could save time and resources and deliver services that provide a better experience to the person with hoarding behaviour.

During successive lockdowns in 2020/2021, we were asked to go into people's homes and prepare the property for hospital discharges. On numerous occasions, we would find that the house was extremely cluttered. When paramedics brought the person home they would raise a Safeguarding concern and say that the home was not ready for the patient to return. We have also been asked to assist when people are being moved because their property is no longer suitable for habitation. If there was no long-term intervention which prevents further hoarding, we have been called back into the new homes for the exactly the same reasons.

## Jeff

Jeff has a private property, which was one of the most cluttered properties we have ever entered. Jeff's life is severely impacted by the clutter in his home. He also has access to his parents' property (they have passed away) and he has a difficult relationship with his brother.

Jeff came to the attention of the council's Environmental Health team after he was discharged from hospital, having had something fall on his head in his home. Jeff's small home is covered in high stacks of various items. He is a big man. His bedroom is the front room and he cannot lie on his bed as it is covered by items. Jeff can only get the top half of his body onto his bed, his feet stay on the floor. This is also the case where he watches TV and eats. When we went to Jeff's home he had no access to running water, and no access to his fridge. He could not get upstairs as the stairway was blocked. He has a fork and buys tins of food that can be eaten cold.

Working with an Environmental Health Officer, we made a path to his fridge and cleared his bath so he had access to running water. We referred Jeff to Adult Social Care colleagues, but Jeff feels he cannot let go of anything in his home. We explained we were concerned that Jeff's property was unsafe and that there was a significant risk to him from items falling on him. A Safeguarding concern was raised, but Jeff has told professionals that he understands the risks and will 'go through things' at his own pace, and as he has the mental capacity to make this decision, so no action was taken, but we have referred Jeff to a social work professional to monitor the situation.

## What is the learning from this case?

There is no quick fix with hoarding. Any solutions are reliant on interventions from skilled 1:1 workers with a good understanding of poor mental health, the ability to be patient, non-judgemental and solution focussed. The ability to draw together multidisciplinary teams that collaborate and cooperate is vital.

## Housing Case Study

## CR

CR is a 66 year old male with a diagnosis of schizophrenia and currently supported by Chatsworth House. CR lived with his family up until the age of 20 years, then he had been placed in supported mental health accommodation for approximately 30 years until he became homeless. He was evicted due to aggressive behaviour and was then allocated a Swindon Borough Council secure tenancy in 2012 at Salzgitter Court.

It was soon discovered by the Sheltered Housing Officer (SHO), that CR was an excessive cigarette smoker and alcohol dependant individual, due to the fire alarm activations and within 9 months of residing at the property the SHO arranged for a heat detector to be installed in his flat.

CR received a weekly visit from a Community Psychiatric Nurse (CPN) and in 2014 concerns were raised: lack of food in the property, the property was unclean, excessive drinking of alcohol and a refusal of his Depo injection. The CPN asked the SHO to remind CR to carry out these basic day to day tasks when conducting the daily calls.

Sheltered Housing (SH) arranged for a deep clean of his property, only 12 months into his tenancy and arranged meetings with his CPN due to the on-going issues of not maintaining his tenancy and refusing the Depo injection. During this time, CR's health deteriorated and he was sectioned under the Mental Health Act. SH hold extensive notes on how the SHO continued to monitor CR after his discharge, ranging from collecting and clearing his rubbish, chasing the next Depo injections and other prescriptions of vital medication required. The SHO would help to arrange appointments with Doctors, however CR would fail to keep to them.

The SHO discovered CR had a benefit account that is now obsolete to many users. If the money is not withdrawn within a certain time frame, the money would return back to the DWP. CR could only withdraw his money from a post office and due to his vulnerabilities and illness, he would not always manage his own finances and would often be without funds, placing his rent account into arrears.

January 2019 - concerns were raised again about signs of self-neglect. No food in the cupboards, he refused to turn on his fridge and was incapable of storing food correctly. His appearance deteriorated, his hair was long and matted and he wore the same clothes covered in cigarette burns. The flat would also contain 8-10 bags of dustbin liners containing plastic containers most weeks. Stacks of unused medication and unopened post. SH submitted a safeguarding alert for self-neglect and a person centred fire risk assessment.

SH contacted Chatsworth Housing asking for an urgent assessment. Meetings were conducted with all partner services including CR to improve his wellbeing. It was established that he did not own any photograph ID or a bank account. It also transpired that CR had thousands of pounds owing to him of state benefits, due to not making regular withdrawals. SH supported Chatsworth House in providing food and clothing for CR, whilst awaiting referrals to the Money Management Team. The food had to be given daily by the SHO as CR would binge on all the food if given to him all at once. The support worker also noticed sores on his feet and back. A health check was finally arranged and CR was under weight, although refused a blood test. SH applied for a birth certificate to assist with obtaining photographic ID and funded another deep clean.

The pandemic hit and staff members stopped entering people's homes and the food banks closed. It was soon apparent that CR was without food again. SH contacted Chatsworth House and immediately set up a meals on wheels service.

Through perseverance from the SHO and SH asking for assistance, CR now has a care company attending to his basic needs, he has a bank account and a personal allowance overseen by the money management team. A landline has also been installed to assist with contact and other services offering support.

## Adult Social Care Case Study

## Alina

Alina's husband died 3 years previously in covid-19. Since this time she begun to drink heavily and is grieving the loss of her husband. It was found that she had been doing her food shopping and leaving this on the floor to rot, self-medicating her grief by drinking alcohol. Alina had a fall outside her home and a neighbour contacted the Ambulance Service for support. When paramedics visited, Alina declined admission to hospital. Paramedics referred for the Fire Service to visit and raised a Safeguarding. Alina refused entry to the fire service when they visited. It took 3 months for an allocation of a social worker to complete care needs assessment, however, Alina was open to the safeguarding team during this time.

Alina had many contacts from agencies, police, fire, paramedics and social workers and declined support from all. She was assessed as having capacity and asked professionals to leave, saying she did not want them. When the Social worker was allocated they started with a person centred phone call to Alina, explaining who they were and that they were aware there were a lot of people concerned about her welfare. They asked what was important to Alina and how she viewed how things were at the moment, Alina ended the call.

Due to the concerns, the social worker visited the property the next day as the risks were high and duty of care overrode Alina declining support. Alina was upset and verbally abusive through the window, saying she did not want the social worker to return. However, the social worker continued to visit daily to start building up trust, gaining information that would support a Care Act assessment was not the focus at this time. The social worker referred to Environmental Health without consent from Alina due to the level of concerns.

Alina cut visits short but by the end of the week with consistent visits daily, Alina allowed the social worker to enter the property and hallway, enabling them to see what the property and some of the rooms were like. Alina consented to the social worker visiting again within a couple of days, Alina allowed the social worker to enter her property and asked the social worker to sit on the sofa, which was identified as a health hazard. The property had a strong smell, flies, maggots and rotten food over the floors, the level of self-neglect was evident and high, and the stairs and living room floor were hoarded with empty alcohol bottles built up over years. It was important not to show any judgement or disgust in how Alina was living, as this would have set back the trust already starting the build. The social worker saw they needed to adapt how they appeared and dressed to reduce the power dynamic between them and ensure Alina felt comfortable. Alina said others judge her and how she is living, the social worker understood the importance of showing that she was not judging Alina. This was a challenging situation for both Alina and the social worker, Alina pushed boundaries and 'tested' the social worker who experienced physical and emotional abuse from Alina and made personal comments. The social worker understood that it was important to treat each day new to support Alina to move towards safer living conditions and life.

The social worker was able to have an honest conversation with Alina and asked if she would like advocacy support, explaining what this meant, over time Alina accepted that this would be helpful. When the advocate started to work with Alina she felt that someone was on her side and started to build trust with the advocate. As trust started to grow with the social worker and advocate, honest conversations were able to be had. One example of how this relationship was built was through the social worker observing that Alina was very hungry, she had not eaten for four days, the social worker made her a sandwich and this supported further transparent conversations about the risks. However, the relationship was up and down and Alina continued to decline support and respond to the social worker with intense verbal and emotional abuse. The social worker also engaged with Alina's family.

After six weeks of support, Alina begun to accept support from Environmental Health to clean her property as they served her with a notice, due to the environmental health risks. However, it was nine weeks before support was accepted. The social worker maintained a high number of visits and contact with Alina, doing home visits three times a week. At times the social worker would visit in the morning, and be declined entry or conversation and asked to come back in the afternoon on the same day.

Alina agreed for a cleaning company to visit her home, although three quotations from different companies was needed, it was not achievable as Alina would only allow one company to visit. Instead photos taken were shared with other cleaning companies, and a more affordable quote was gained. Alina was kept informed about all the process and she was happy with the plan.

The cleaning company and environmental health requested that Alina move out while her property was getting cleaned. Options such as hotel or temporary accommodation was offered to Alina while her property was made safe. Alina was assessed as having capacity with the decision on her accommodation, care and support needs and this capacity and management of risk needed to be weighed to ensure that she was safe. There was no reason to doubt Alina's mental capacity in regards to this specific decision. Alina was clear in her wish to not leave, saying this is her home and she wished to be part of the cleaning and make decisions what to keep and what to throw away. Through the deep clean Alina lost a lot of her furniture that needed to be removed and was supported to get a new sofa and bed among other items.

There were additional challenges with an ineffective MDT, where all professionals involved with Alina were not always in meetings and planning sessions. The social worker leading on the intervention was not aware of decision making processes happening outside of MDT. This resulted in the relationship with the social worker, other professionals and Alina going up and down as inconsistent messages were being shared with Alina by a range of professionals. Additional inconsistencies added to the confusion where Alina did not always share all the information and circumstances with the social worker and additional information came to light as time went on that increased the complexity of the case.

Alina's low mood was impacting on her meeting some of her day to day care needs; short term support was put in place to re-able and regain Alina's confidence. Alina agreed for short term morning and tea time support with meal preparation, maintaining a habitable home, managing a safe home, shopping and domestic tasks. The care provider was unable to start when planned due to the home not yet being deep cleaned. This was a concern, as Alina was not motivated to prepare meals. As there was not time to arrange meals on wheels, Therefore, Live Well supported to bridge the gap while awaiting care to start.

A person centred risk assessment took place over several visits, this was done openly with Alina who had advocacy support to respond to the risk concerns raised and how she wanted to be supported. Fire services reported that Alina had historically declined entry to her property. However, following social worker persistence a Safe and Well visit was conducted and fire services offered protective equipment to minimise risks of fire as ALINA was a smoker.

Due to Alina's living conditions, the Mental Capacity Assessment was challenged and executive functioning was questioned. However, in Alina's case she was making unwise decisions, since the death of her husband she expressed that she wanted to die. Alina pushed people and professionals away, she seemed to struggle to speak English, when a translator was offered, Alina declined. Alina had the opportunity of having the translator during her mental health assessment; however, declined to speak in her native language, and was assessed in English which she spoke fluently. Alina struggled with the social worker's race and that the social worker was younger than her; Alina made numerous comments about this. Alina expressed that in her culture a younger person should not be advising her what to do, Alina expressed that being in poverty is embarrassing and said, "I used to have lots of money and never needed any help from anyone". Due to Alina's low income, the food bank was utilised, however, there is a limit on the number of referrals. This was challenging as Alina was in process of applying for benefits.

Alina was supported by the social worker and Live Well to attend the job centre to apply for benefits, it took over two weeks to accept this support. Alina had opted to receive money from family, as she was embarrassed that she was being considered for benefits. It was unclear what Alina's income was, and did not wish to share her financial information. Approximately after 8 weeks Alina requested to be taken to her bank, after she had lost her bank card. Alina agreed for the social worker and Live Well to look through her bank statements to check if there were any suspicious transactions, it came to light that Alina's direct debits were higher than her income.

Intensive support took place over a period of 5 months; the social worker maintained consistency and visits to Alina multiple times a week. At the time of writing this case study there were risks that remained in place and support was ongoing. However, Alina is now living in a home that is not a health hazard. Being shown respect and worked with in a person centred way has resulted in a managed risk, Alina continues to self medicate her grief but expressed she is feeling more hopeful, she is in contact with friends and family, her confidence and self-worth have grown, she is resourceful and is looking to explore employment in the future.

Many professionals were involved, including:

1. **Local Authority:** Social worker; Manager; Assistant Team Manager; Safeguarding Enquiry; Live Well Team; Finance and Benefits team; Environmental Health Officer; Local Welfare Officer
2. **Health:** GP Surgery; Primary Care Liaison: Mental Health Nurse; South Western Ambulance Service (SWAS); Hospital
3. **Commissioned Services:** Care Agency; Advocate; Citizen Advice; Warm and Safe Team; Change Grow Live (CGL); Kennet Furniture Refurbiz (KFR)
4. **Charity Organisations:** Food Bank; Boxes of Hope
5. **Fire Services**
6. **Police**

## Lessons learned:

- At times with self-neglect we need to step outside of our 'normal role' to build a relationship, being human and at times going above and beyond to prove to individuals they can put their trust in us. For example, making a sandwich and drink for someone who is hungry and unable to do that for themselves in that moment.
- Do not judge
- Be persistent; it may take months to build trust enough for someone to let you into their life.
- It is important to feel you have support from supervisors and managers. For those working with self-neglect to feel that the risk is shared, it provides reassurance and can be the difference between workers going off sick due to stress and mental health being impacted on.
- Services being unwilling to provide support where properties are deemed 'unsafe', can leave the people living in that situation at additional risk and may require additional safeguarding and 'out of the box thinking' in their responses.
- MDT working needs to be structured, with agreed lead, roles and effective communication
- Be flexible in your approach to meet the person's needs and build a relationship.
- Utilising family and support networks can be beneficial.