

Practitioner Toolkit

Definition of Self-Neglect

There is no accepted operational definition of self-neglect nationally or internationally due to the dynamic and complexity of self-neglect.

A review of literature suggests the following definition for self-neglect:

- Persistent inattention to personal hygiene and /or environment
- Repeated refusal of some/ all indicated services which can reasonably be expected to improve quality of life
- Self-endangerment through the manifestation of unsafe behaviours.

Indicators of Self-Neglect

There are numerous indicators of self-neglect; the following list is not exhaustive and should be considered in conjunction with *all* information within this document:

- Where the person may have a history of mental illness which may manifest itself in behaviours of self-neglect and hoarding
- Living in very unclean, sometimes verminous circumstances, such as living with a toilet completely blocked with faeces
- Neglecting household maintenance, and therefore creating hazards within and surrounding the property
- Obsessive hoarding therefore creating hazards within the property for both themselves and other parties
- Poor diet and nutrition, for example, evidenced by little or no fresh food in the fridge, or what is there, being mouldy
- Persistent declining or refusing prescribed medication and / or other community healthcare support
- Continued refusing to allow access to health and / or social care staff in relation to personal hygiene and care, including the non-attendance and or registration with a General Practitioner
- Refusing to allow access to other organisations with an interest in the property, for example, staff working for utility companies (water, gas, electricity), housing services
- Repeated episodes of anti-social behaviour – either as a victim or perpetrator
- Being unwilling to attend external appointments with professional staff in social care, health or other organisations (such as housing)
- A significant lack of personal hygiene resulting in poor healing / sores / pressure ulcers, long toe nails leading to a risk of falls, unkempt hair, uncared for facial hair, and or body odour.

It is important to acknowledge that poor environmental and personal hygiene may not necessarily always be as a result of self-neglect; they can arise as a result of cognitive impairment, substance misuse, and compromised vision or functional and financial constraints.

An individual may therefore be considered as self-neglecting and therefore maybe at risk of harm where they are:

- Either unable, or unwilling to provide adequate care for themselves
- Not engaging with a network of appropriate support
- Unable to or unwilling to obtain necessary care to meet their needs
- Following a mental capacity assessment is unable to make reasonable, informed or mentally capacitated decisions due to mental disorder (including hoarding behaviours), illness or an acquired brain injury
- Unable to protect themselves adequately against potential exploitation or abuse
- Refusing essential appropriate support without which their health and safety needs cannot be met and the individual lacks the insight to recognise this.

Definition of Hoarding

Hoarding disorder is now considered a standalone mental disorder. However, hoarding can also be a symptom of other mental disorders. Hoarding disorder is distinct from the act of collecting and is also different from people whose property is generally cluttered or messy.

It is **not** simply a lifestyle choice. The main difference between a hoarder and a collector is that hoarders have strong emotional attachments to their objects which are well in excess of the real value.

It can affect anyone regardless of their personal circumstances.

There are five diagnostic criteria for identifying a case of hoarding disorder:

1. Persistent difficulty discarding or parting with possessions, regardless of their monetary value.
2. A perceived need to save items and the individual experiencing distress with discarding items.
3. The accumulation of possessions that congest and clutter in active living areas.
4. The hoarding causes clinically significant distress or impairment in social, occupational, or other important areas of functioning.
5. The hoarding is not attributable to another medical condition or mental disorder.

Anything can be hoarded, in various areas including the resident's property, garden or communal areas. However, commonly hoarded items include but are not limited:

- Clothes
- Newspapers, magazines or books
- Bills, receipts or letters
- Food and food containers
- Animals
- Medical equipment
- Collectibles such as toys, video, DVD, or CDs

Types of Hoarding

There are three types of hoarding:

- **Inanimate objects**

This is the most common. This could consist of one type of object or a collection of a mixture of objects such as old clothes, newspapers, food, containers or papers.

- **Animal Hoarding**

Animal hoarding is on the increase. This is the obsessive collecting of animals, often with an inability to provide minimal standards of care. The hoarder is unable to recognise that the animals are or may be at risk because they feel they are saving them. In addition to an inability to care for the animals in the home, people who hoard animals are often unable to take care of themselves. As well, the homes of animal hoarders are often eventually destroyed by the accumulation of animal faeces and infestation by insects.

- **Data Hoarding**

This is a new phenomenon of hoarding. There is little research on this matter and it may not seem as significant as inanimate and animal hoarding. However, people that do hoard data could still present with same issues that are symptomatic of hoarding. Data hoarding could present with the storage of data collection equipment such as computers, electronic storage devices or paper. A need to store copies of emails, and other information in an electronic format.

Hoarding Characteristics

There are a number of hoarding characteristics;

- **Fear and anxiety:** compulsive hoarding may have started as a learnt behaviour or following a significant event such as bereavement. The person hoarding believes buying or saving things will relieve the anxiety and fear they feel. The hoarding effectively becomes their comfort blanket. Any attempt to discard hoarded items can induce feelings varying from mild anxiety to a full panic attack with sweats and palpitations.
- **Long term behavior pattern:** possibly developed over many years, or decades. Collecting and saving, with an inability to throw away items without experiencing fear and anxiety.
- **Unrelenting standards:** people who hoard will often find faults with others, require others to perform to excellence while struggling to organise themselves and complete daily living tasks. A person who hoards may appear unkempt and disheveled, due to lack of toileting or washing facilities in their home.
- **Socially isolated:** people who hoard will typically alienate family and friends and may be embarrassed to have visitors. They may refuse home visits from professionals, in favour of office based appointments.
- **Large number of pets:** people who hoard may have a large number of animals that can be a source of complaints by neighbours. They may be a self-confessed “rescuer of strays”.
- **Mentally competent:** people who hoard are typically able to make decisions that are not related to hoarding.

- **Poor insight:** a person who hoards will typically see nothing wrong with their behavior and the impact it has on them and others.

Where there is evidence of animal hoarding at any level and or potential neglect of animals this should be reported to the RSPCA.

What causes hoarding? *(This section is taken from the Mind publication "Hoarding")*

No one knows exactly what causes hoarding. There are lots of theories and different people will have different explanations for their own experiences. It's likely to be a combination of things.

Difficult feelings

Hoarding can be to do with difficult experiences and painful feelings, which people may be finding it hard to express, face or resolve. Some people report that hoarding helps them cope with other mental health problems, or distracts them from feeling very anxious, upset or afraid.

Perfectionism and worrying

Lots of people who hoard feel very worried about making mistakes (also known as perfectionism), or find it hard to make decisions, plan ahead or work out how to do tasks. These could be possible reasons why some people are more vulnerable to having problems with hoarding.

For example, people might struggle to sort or group possessions into types, or to decide what to keep or throw away. The idea of this might seem so difficult or upsetting that it feels easier not to try.

Childhood experiences

Some researchers believe hoarding can be linked to childhood experiences of losing or not having possessions, or not being cared for. This might include experiences like:

- money worries and living in poverty
- having their belongings taken or thrown away
- being deprived or neglected – for example if their basic needs weren't met, or they feel they weren't treated warmly or supportively.

Trauma and loss

People might be able to link the start of their hoarding to a stressful event or period in their lives, such as:

- being abused or attacked
- breaking up with a partner
- becoming very unwell
- someone close to them dying
- feeling extremely lonely.

For some people, experiences like these can also lead to an increase in existing hoarding.

Family history or habits

It's common for people who hoard to have family members who share this, such as a parent or sibling. Some studies suggest this could be due to shared genes, or that a person's genes could make them more vulnerable to hoarding.

But family links are likely to be much more complex and shared environments could also be a factor. For example, people might have learned habits and behaviours from their parents or carers, including ways of arranging and managing their home and belongings.

If an adult lives together with people who also hoard, this can result in them having more clutter in their home overall. It might be especially difficult to make changes because they disagree with each other on what to keep or throw away.

Other mental health problems

People might start hoarding due to another mental health problem, for example:

- depression
- anxiety
- obsessive-compulsive disorder (OCD)
- bipolar disorder
- psychosis, including schizophrenia
- obsessive compulsive personality disorder (OCPD).

In these situations, hoarding is usually seen as a symptom and not a main diagnosis.

People might also hoard alongside addiction to recreational drugs or alcohol.

Literacies for Self-Neglect

For effective work with self-neglect we MUST draw on a range of literacies (Braye and Preston-Shoot 2016).

Legal	Knowledge and skilled application of legal options or requirements
Ethical	Reflective and critical consideration and application of values
Relational	Engaging with people's biographies and lived experience Demonstrating concerned curiosity
Emotional	Managing stress and anxiety Recognising the impact of personal orientation to practice
Knowledge	Drawing on different sources of evidence
Organisational	Understanding accountability and management of practice within a multi-agency context Challenging procedures, cultures and decision making where these make error more likely
Decision-making	Sharing information Managing the multi-agency partnership Explicitly weighing the evidence for different options

Key Legislation

Mental Health Act 1983

S.135 Provides the Authority to seek a warrant authorising a police officer to enter premises if it is believed that someone suffering from mental disorder is being ill-treated or neglected or kept otherwise than under proper control anywhere within the jurisdiction of the Court or, being unable to care for themselves, is living alone in any such place.

An adult who is removed to a place of safety in the execution of a warrant issued under this section may be detained there for a period not exceeding 72 hours.

S.136 This section allows police officers to remove adults who are believed to be “suffering from mental disorder and in immediate need of care and control” to a place of safety for a period of 24 hours (starts at the time they arrive at the place of safety or when the Police Officer entered the property in cases where the person is kept at a place of safety). A further 12 hour period can be authorised by the doctor responsible for the assessment only in cases where an assessment is not practicable within 24 hours owing to the person’s condition.

S. 7-10 A guardianship application may be made in respect of a patient on the grounds that—

- (a) They are suffering from mental disorder of a nature or degree which warrants his reception into guardianship under this section; and
- (b) It is necessary in the interests of the welfare of the patient or for the protection at other persons that the patient should be so received.

A guardian has the authority to make sure that:

- The person lives at a specified place.
- The person goes to the place where they are required to live if they do not (or cannot) go there without assistance.
- The person attends specified places for medical treatment, occupation, education or training.
- Access be given to the person by a doctor, Approved Mental Health Practitioner (AMHP) or other specified person.

The guardian cannot authorise medical treatment, and has no control over a person's money or property.

Environmental Health Legislation

Public Health Act 1936 as amended

Section 79: Power to require removal of noxious matter by occupier of premises

The Local Authority (LA) will always try and work with a householder to identify a solution to a property affected by self-neglect and/or hoarding. However, in cases where the resident is not willing to co-operate the LA can serve notice on the owner or occupier to, remove accumulations of noxious matter. Noxious is not defined, but usually is, ‘harmful or unwholesome’. No appeal to this action is available. If not complied with in twenty four hours, the LA may carry out works in default and recover expenses.

Section 83: Cleansing of filthy or verminous premises

Where a local authority is satisfied that any premises is either;

- a) Filthy or unwholesome so as to be prejudicial to health; or
- b) Verminous (relating to rats, mice other pests including insects, their eggs and larvae)

The Local authority shall serve a notice requiring the recipient to take such steps as may be specified in the notice to remedy the condition of the premises by cleansing and disinfecting them. The notice may require among other things the removal of wallpaper or other wall coverings, and in the case of verminous premises, the taking of such steps as may be necessary for destroying or removing vermin.

If the recipient of the notice fails to comply with the requirements of the notice then the local authority may carry out works in default in accordance with the requirements specified in the notice. The local authority may recharge the recipient of the notice for the cost of carrying out such works. There is no appeal against this notice but an appeal can be made against the reasonableness of the authority's requirements set out in the notice.

Section 84: Cleansing or destruction of filthy or verminous articles

The local authority shall cause any article that is considered to be in so filthy a condition as to render its cleaning, purification or destruction necessary in order to prevent injury, or danger of injury, to the health of any person in the premises will cleanse, purify, disinfect or destroy that article. If necessary, the local authority may remove any article that is verminous, or having been used by, or having been in contact with any verminous person to be cleansed, purified, disinfected, destroyed or removed from the premises at the recipient's expense.

Prevention of Damage by Pests Act 1949

Section 4: Power of LA to require action to prevent or treat Rats and Mice

Local authorities have a duty to take such steps as may be necessary to ensure their districts are kept free from rats and mice as far as it is reasonably practicable to do so. This may include; carrying out inspections of land, ensure the destruction of rats and mice on all land within its jurisdiction and ensuring the land is kept free of rats and mice so far as it is reasonably practicable to do so.

The local authority may serve notice on the occupier (or owner if the land is unoccupied) of land/ premises where rats and /or mice may be present due to the conditions at the time. The notice should provide a reasonable period of time to carry out reasonable works to treat for rats and/ or mice, remove materials that may feed or harbour them and carry out structural works if such works are necessary in keeping the land free from rats and/ or mice. The local authority may carry out works in default and recharge the occupier/ owner in full for the cost of carrying out such works.

Environmental Protection Act 1990 as amended

Section 80: Dealing with Statutory Nuisances (SNs)

Statutory Nuisances (SNs) are defined in section 79 of the Environmental Protection Act. A number of defined nuisances are relevant in cases of self-neglect and/ or hoarding in Section 79(1) including;

- (a) Any premises in such a state as to be prejudicial to health or a nuisance;
- (b) Fumes or gases emitted from [private dwellings] premises so as to be prejudicial to health or a nuisance
- (e) Any accumulation or deposit which is prejudicial to health or a nuisance
- (f) Any animal kept in such a place or manner as to be prejudicial to health or a nuisance

(fa) any insects emanating from relevant industrial, trade or business premises and being prejudicial to health or a nuisance;

Relatively few circumstances will be considered to be 'prejudicial to health' but 'nuisance' encompasses both public and private nuisances. A public nuisance is any act which, without specific legal authority for it, results in an unreasonable reduction in amenity or environmental quality that affects 'a class of her Majesty's subjects'

A private nuisance consists of damage arising from a substantial and reasonable interference with the use of land or some right over it.

Local authorities have a duty under the Act to inspect their areas from time to time to detect statutory nuisances and must take such steps as are reasonably practicable to investigate any complaints of statutory nuisance made by persons living within their area. However, if the local authority does find that a statutory nuisance exists or is likely to occur or recur, that must serve an abatement notice to abate the nuisance. Any person breaching the requirements of an abatement notice commits a criminal offence which could result in the matter being referred for prosecution. The local authority may also carry out works in the default and can recover its costs from the recipient(s) of the abatement notice.

Housing legislation

The housing health and safety rating system (HHSRS) is a risk based evaluation tool to help local authorities identify and protect against potential risks and hazards to health and safety from any deficiencies identified in dwellings. It was introduced under the Housing Act 2004 and applies to residential properties in England and Wales. The HHSRS assess 29 categories of housing hazard. Each hazards ha a weighting which determines whether the property is rated as having category 1 (serious) or category 2 (other) hazards. The local authority must take action to address category 1 hazards and has some discretion in whether any action is taken for category 2 hazards.

Housing providers (the landlord) deal with any concerns relating to self-neglect and or hoarding raised, which may be through contractors, in a sensitive manner. The housing officer (HO) would arrange a visit to inspect the condition of the property and action will be taken as appropriate. It is standard practice for the HO to ask a tenant if they would like support to deal with a range of issues and they will make the necessary referrals if consent is given.

The HO will usually set small actions for the tenant to complete and then revisit to monitor on a regular basis. Whilst the tenant continues to engage with the housing provider and improve the condition of the property then the HO will continue to visit, but if they cease to engage or do not take steps to improve the condition then a referral may be made without consent to adult social care or other agencies. The decision to take this course of action will often be made having referred the case to housing management following a thorough review of the case with colleagues in the Anti-Social Behaviour and Tenancy Enforcement Team (ABATE) and Environmental Health. Only when the housing provider has exhausted all avenues to get the tenant to engage and take responsibility for clearing the property themselves would they consider enforcement action and is considered a last resort.

Housing providers have a range of enforcement that they can take and this is summarised below:

- **Schedule 2 of the Housing Act 1985** sets out the grounds for possession of properties let under secure tenancies. These grounds include:

Ground 1 – rent lawfully due from a tenant has not been paid or an obligation of the tenancy has been broken or not performed. This would include breach of clauses within a tenancy agreement which relates to tenants keeping the parts of the home that we are not responsible for to a reasonable standard and which may also state they must maintain their home to a standard of hygiene and good order so as not to damage the fabric of the building, cause a nuisance or annoyance to neighbours or create a hazard for our staff or contractors.

Ground 4 – allows the landlord to seek possession if the tenant has allowed the condition of the property to deteriorate owing to acts of waste, or neglect, or default.

Housing providers could use either of these grounds to seek possession of a property due to hoarding. Under these grounds the Court must decide if it is reasonable to grant an order for possession which can be challenging if the tenant has mental health issues or other vulnerabilities.

Provisions of the Housing Act 1996 allow housing providers to take possession action of properties let under introductory tenancies. These should be more straight forward as the housing provider needs to prove a breach of any clause of the tenancy agreement. The court does not have to consider whether it is reasonable to grant possession but should merely consider whether the landlord has followed the correct process i.e.; served the correct notices and given the tenant the opportunity to appeal the service of any notice. However, in practice many District Judges do consider any vulnerability the tenant may have when considering an application of this type. Housing providers also have the option to apply for an injunction which would force the tenant to bring the condition of the property up to a reasonable standard. They would work closely with environmental health teams who have the power to serve notices under the Environmental Protection Act 1990 which will allow the landlord to enter a property to clear it and re-charge the tenant the cost of doing so.

Practitioners should consult and seek advice from Strategic Housing and Environmental health to determine the most appropriate approach.

When is self-neglect a safeguarding issue?

Whenever and wherever there is a belief an individual is, or may be, self-neglecting there needs to be a response. It should never be ignored. It makes no difference whether the person is a home owner, in a rental property, in supported housing or in a care home. There will be circumstances when there is a statutory duty to respond under the safeguarding adults duties. The statutory duty applies when the adult is unable to protect themselves because of the care and support needs that they have.

In other circumstances, staff and volunteers should follow their own agency's procedures.

The statutory duty is set out in the Care Act 2014. A The supporting statutory guidance recognised self-neglect as a category of abuse and neglect, and within that category further identified the behaviour of hoarding.

If the individual is a carer for an 'adult at risk', i.e. provides unpaid care to someone who meets the definition of an 'adult at risk, then the circumstances should always be discussed with Adult Social Care to come to a decision as to whether a safeguarding response should be put in place.

In accordance with the Care Act 2014, DH Care and Support Statutory Guidance 2017, 'self-neglect may not prompt a section 42 enquiry' and 'an assessment should be made on a case-by-case basis' with a decision on whether a response is required under safeguarding dependent on the adult's ability to protect themselves by controlling their own behaviour.

Role of the individual

Regardless of role, responsibility or organisation, protecting adults and safeguarding people from harm is everyone's responsibility. See www.rbsab.org/

Raising a concern is not optional. If the adult at risk does not want any action taken, it may be possible to do nothing further about the concern, but, initially, the concern must be raised and recorded.

Timescale

A concern must be raised and reported immediately or no later than the end of the same working day.

If a person with (or appears to have) care and support needs and there are safeguarding concerns this must be raised with Rochdale Adult Care.

To contact Adult Care – to make a referral or for advice

Call (*during office hours*): 0300 303 8886

Call (*out of office hours*): 0300 303 8875

Email: adult.care@rochdale.gov.uk.


If children are present contact Children's Social Care: 0300 303 0440

If you feel an adult is in immediate danger please contact the police on 999

Strengths Based and Impact on Wellbeing Approach

The strengths-based approach focuses on how practitioners build partnerships with persons in suspected or substantiated abuse or neglect safeguarding situations. The approach is also a very adaptable and can be used as an effective tool for practitioners to use within managerial and/ or clinical supervision.

What does it mean when recognising and responding to self-neglecting situations?

1. What are you worried about?	<p>Worries and concerns identified.</p> <p>Who is worried and why?</p>																
2. What's working well?	<p>Understand the person's wishes & feelings in relation to risk.</p> <p>What strengths or positive factors exist that might mitigate some of the impact of the risks?</p> <p>Who can help support with the consequences and associated fear or guilt?</p>																
3. Where do you rate this situation today and the impact on well-being?	<p>Scale of: 0 to 10 where 10 means the concern is safely managed as much as it can be and zero means things are so bad for the person you need to get professional or other outside help.</p> <p>Put different judgment numbers on the scale for different people.</p> <p>0  10</p> <table border="1" data-bbox="753 1496 1302 1839"> <tr> <td>Person</td> <td></td> </tr> <tr> <td>Family/Other</td> <td></td> </tr> <tr> <td>Practitioner</td> <td></td> </tr> <tr> <td>Consultant</td> <td></td> </tr> <tr> <td>G.P.</td> <td></td> </tr> <tr> <td>District Nurse</td> <td></td> </tr> <tr> <td>Other Professional</td> <td></td> </tr> <tr> <td></td> <td></td> </tr> </table>	Person		Family/Other		Practitioner		Consultant		G.P.		District Nurse		Other Professional			
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	<p>Can we promote the person's safety without interfering with the benefits they gain or infringing their rights?</p>																

4. What needs to happen?	<p>Can we help change the situation to reduce the risk to acceptable levels whilst still respecting their choices & promoting their quality of life?</p> <p>What could go wrong and how could we respond in that case?</p> <p>Shared responsibility for promoting safety:</p> <ul style="list-style-type: none"> • What will the person do? • What will staff do? • What will others who are important to the person do?
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It is important services do not work in isolation or work with a lack of comprehensive knowledge of the wider support on offer across the borough, as this would lead potentially to a less efficient and effective response to safeguarding and support.

Partners must be able to evidence the concept of defensible decision making:

- Has there been an exploration and understanding what was happening rather than assumptions made and/ or accept things at face value (professional curiosity / respectful uncertainty / safe uncertainty)?
- Has the person been involved in the safeguarding response exploring desired outcomes and at a pace that suits them?
- Has the persons support network been involved in the response?
- Have all reasonable steps been taken?
- Have reliable assessment methods including assessment of risk/s been used to inform decisions?
- Has a multi-agency approach been explored to achieve positive outcome?
- Has the use of all legal frameworks bespoke to each case been thoroughly explored?
- Has information been collated and thoroughly evaluated?
- Have decisions been recorded, shared and communicated with relevant parties?
- Have organisational policies and procedures been followed?
- Has the Care Act statutory guidance been cross referenced?
- Has a proactive, analytical approach and non-judgement approach been explored?
- Has critical evaluation been employed to information and maintain an open mind?
- Has there been a focus on risk enablement which balances safety and risk management that takes into account changing information, different perspectives and acknowledges that certainty may not be achievable?
- Have safeguarding been lawful and are decisions made defensible?

Six key principles of safeguarding

Empowerment	People being supported and encouraged to make their own decisions and informed consent.
Prevention	It is better to take action before harm occurs.
Proportionality	The least intrusive response appropriate to the risk presented.
Protection	Support and representation for those in greatest need.
Partnership	Local solutions through services working with their communities. Communities have a part to play in preventing, detecting and reporting neglect and abuse.
Accountability	Accountability and transparency in delivering safeguarding

Prevention

In the majority of self-neglect cases, early intervention and preventative actions will negate the need for adult safeguarding procedures to be used. The Care Act is clear in its direction that partners should work cohesively to address the issues at the earliest opportunity.

The needs of children whose parents self-neglect, and the subsequent effect on their development, is also a critical consideration.

It is imperative that the views and wishes of the adult are sought and what their desired outcome is. Consideration should also be given to gathering the views of other people who know the individual well.

If a person lacks mental capacity the views and wishes of the adult at risk and their representative should be part of the best interest decision.

Identifying level of risk or harm

A “Professional Decision-Making Tool in Response to a Safeguarding Alert” has been created and is available to all staff. Rochdale Borough Adult Care Service have a risk assessment process which will also help identify the level of risk or harm a person is experiencing. The Tool is available at www.rbsab.org/

Making Safeguarding Personal

In addition to the six principles, Making Safeguarding Personal (MSP) aims to ensure that the safeguarding process:

- Is person-led and outcome-focused
- Enhances the individual's involvement, choice and control, and
- Seeks to improve the quality of life, wellbeing and safety of the individual.

Engage the Adult

- Ensure they have necessary information in a format they can understand
- Check out that they do understand options and consequences of their choices
- Listen to their reasons for mistrust, disengagement, refusal and their choice

The above three points may need to be a conversation over time i.e. "not a one off" Repeat all the above if risk to their health/safety increases.

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

Consideration needs to be given at an early stage, to determining if the individual has the mental capacity to understand and make informed decisions about their responses to agencies concerns about their apparent self-neglecting behaviour. In cases of self-neglect it will often take considerable time to build the relationship that enables the person to want to make changes and this needs to be understood by all agencies engaging with the individual. It is always important to involve the family and carers. The Rochdale Borough Safeguarding Adults Board (RBSAB) Multi Agency Information Sharing Protocol provides the framework for sharing information.

Remember the individual may have experienced significant trauma in their life such as bereavement, homelessness, sexual / physical / emotional abuse or health issues. They may have had poor experiences of engagement with services in the past and these factors may be the reason why they appear to be unwilling to engage.

- Consider if a family member, advocate or other professional may help the adult and you in these conversations and assist with assessment and/or support
- Always involve attorneys, receivers, person representatives if the adult has one
- Where an adult has fluctuating capacity it may be possible to establish a plan when they are capacitated which determines what they want to happen when they lack capacity
- Check whether the individual has made an Advance Directive when involved with significant decisions, re. health
- Involve the individual in meetings where possible

Engage & Support the Person's Family/Carers

Ensure the individual is aware and consenting to the proposed role of their family/carer/advocate in their care/treatment plan and:

- Involve them in the development of the care/treatment plan. They must be invited to planning/discharge meetings
- Ensure that the carers role and responsibilities are clearly recorded on formal care or treatment plans
- Check that they are willing and able to provide care/treatment
- Provide them with necessary training and information to do what is expected
- Mentor/supervise, review to ensure they understand and have the skills
- Carers Assessments must always be offered

This most obviously applies to family and friends but may equally apply to professional carers- e.g. health professionals should not assume that a care worker has the skills or capacity to undertake certain health related tasks.

Engage Other Professionals/Agencies

- Make referrals clear and timely, if others are regarded as essential to a care/treatment plan
- Consult and seek advice on areas which others may have more expertise- this does not always mean they should become actively involved in cases
- Where the risk is high and complex, ensure communication with other involved professionals about essential information is timely and accurate. Consider the need for a multi-agency professionals meeting with/without the individual and their representatives. This will aid co-ordination and a shared understanding of risk

Advocacy

It is essential to ensure all efforts are made to ensure the person suspected of self-neglecting and or hoarding is consulted with and included in discussions, with concerns raised directly with them at the earliest opportunity.

The individual concerned should be invited to participate in the multi-agency strategy meeting and offer the necessary support to do so by the case holding agency. If the person's choice is not to attend the meeting the case holding agency must feedback back any decision that is made to the person within a reasonable time period.

If there is concern that the person is in need of additional support to ensure they understand the concerns raised, the involvement of an appropriate advocate must be considered where it is deemed necessary to do so. This may be a friend or family member, or a representative from a voluntary agency such as Together – Your Voice Advocacy. Where the individual refuses to participate or engage with agencies or provide access, information obtained from a range of other sources may 'hold the key' to achieving access into the property or to determining areas / levels of risk.

Rochdale Borough Safeguarding Adults Board (RBSAB)

The Rochdale Borough Safeguarding Adults Board's web site contains a lot of useful information - <https://www.rbsab.org/>

Mental Capacity

When a person's hoarding behaviour poses a serious risk to their health and safety, professional intervention will be required. Any proposed intervention or action must be with the person's consent, except in circumstances where a local authority or agency exercises their statutory duties or powers. In extreme cases of self-neglect and/or hoarding behaviour, the very nature of the environment *should* lead professionals to question whether the client has capacity to consent to the proposed action or intervention and trigger an assessment of that person's mental capacity.

Any capacity assessment carried out in relation to self-neglect and or hoarding behaviour must be time and decision specific, and relate to a specific intervention or action. The professional responsible for undertaking the capacity assessment will be the person who is proposing the specific intervention or action, and is referred to as the '*decision maker*'. Although the decision maker may need to seek support from other professionals in the multidisciplinary team, they are responsible for making the final decision about a person's capacity.

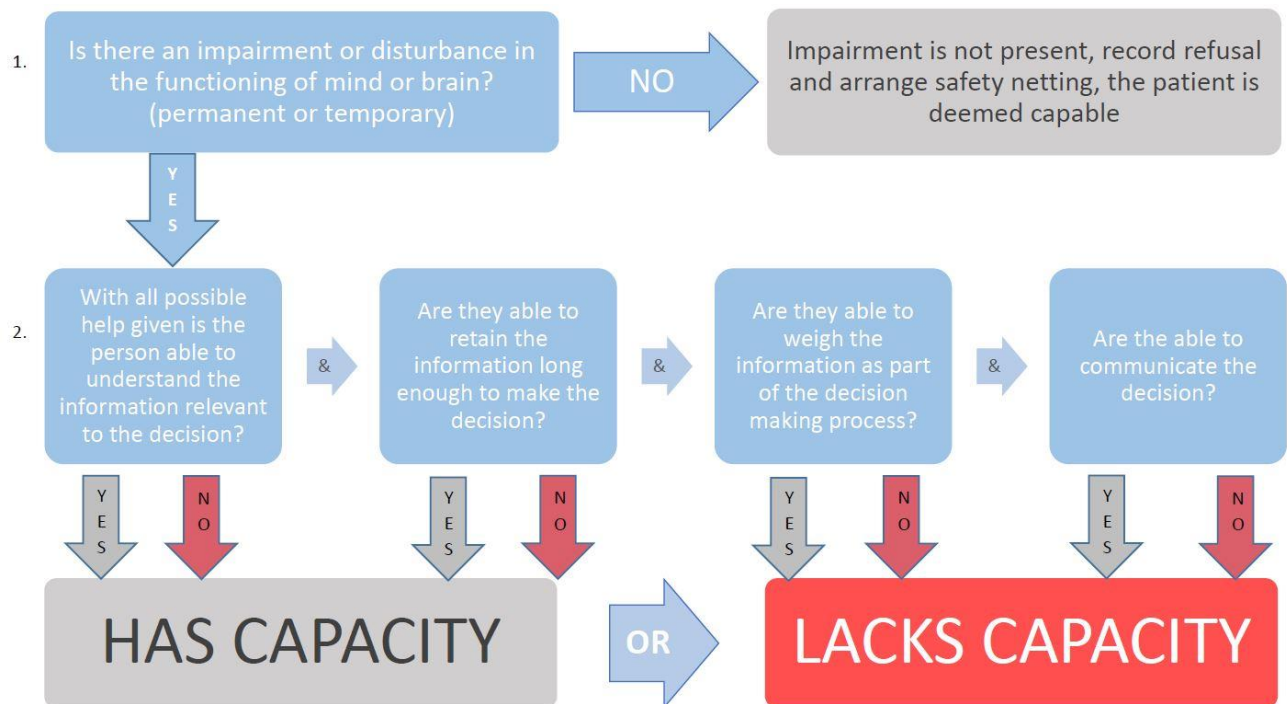
If the client lacks capacity to consent to the specific action or intervention, then the decision maker must demonstrate that they have met the requirement of the best interests 'checklist'. Due to the complexity of such cases, there *must* be a best interests meeting, chaired by a team manager.

In particularly challenging and complex cases, it may be necessary for the organisation to seek legal advice in order to refer to the Court of Protection (COP) to make the best interests decision.

The Mental Capacity Act (2005) provides a statutory framework for people who lack capacity to make decisions for themselves. The Act has 5 statutory principles and these are the values which underpin the legal requirements of the act. They are:

1. A person must be assumed to have capacity unless it is established that they lack capacity.
2. A person is not to be treated as unable to make a decision unless all practical steps have been taken without success.
3. A person is not to be treated as unable to make a decision merely because he makes an unwise decision.
4. An act done or decision made, under this act for or on behalf of a person who lacks capacity must be done, or made in his or her best interests.
5. Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

The two stage test of capacity



If the answer to 1. Is YES and the answer to any of 2. Is NO then the person lacks capacity under the Mental Health Act 2005

Information Sharing

Under the Data Protection Act 1998, we all have the responsibility to ensure that personal information is processed lawfully and fairly. All individuals have a right to view any information held about them. Practitioners should consider this when they are recording information about that person.

Reference should be made to the RBSAB Information Sharing Agreement.

The decision about what information is shared, and with who, will be taken on a case by-case basis. Whether information is shared and with or without the adult at risk's consent, the information shared should be:

- necessary for the purpose for which it is being shared
- shared only with those who have a need for it
- be accurate and up to date
- be shared in a timely fashion
- be shared accurately
- be shared securely

Risks

Determining risk may be subjective and complex in nature due to many competing factors. These may include the individual's behaviour and perception of the risks they face in living in self-neglecting and/or hoarding circumstances which will often differ from the professionals view on what is and what is not an acceptable standard within which to live. In such cases there are often clinical, social, environmental and

ethical decisions to be made in its managing a subject's expectations of what is considered to be acceptable.

Self-neglect and hoarding may carry the following risks:

- Impairment of, or an avoidable deterioration in, physical or mental health, and the impairment of physical, intellectual, emotional, social or behavioural development
- Financial hardship, tenancy / home security risk; risk of eviction
- Likely fire risks
- Social network presents high risk factors
- Environment presents high risks

The Multi-Agency Risk Management protocol

This protocol provides professionals with a framework to facilitate effective multi-agency working with adults who are deemed to have mental capacity and who are at risk of serious harm or death through self-neglect, risk taking behaviour or refusal of services, but are refusing to engage with services.

It aims to provide professionals from all Rochdale Borough Safeguarding Adults Board (RBSAB) partner agencies with a framework for the management of complex cases where, despite ongoing work, serious risks are still present. The MRM is available [here](#).

Safeguarding Children

Safeguarding Children refers to protecting children from maltreatment, preventing the impairment of their health or development and ensuring that they are growing up in circumstances consistent with the provision of safe and effective care. Growing up in a hoarded property can put a child at risk by affecting their development and in some cases, leading to the neglect of a child, which is a safeguarding issue.

The needs of the child at risk must come first and any actions we take must reflect this. Therefore, where children live in the property where there is an issue with safe-guarding and/ or hoarding a Safeguarding Children alert should always be raised.

Fire Safety

Hoarding can pose a significant risk to both the people living in the hoarded property and those living nearby as well as the emergency services personnel. Where an affected property is identified regardless of the risk rating, clients need to be advised of the increased risk and identify a safe exit route. Appropriate professional fire safety advice must be sought and a multi-agency approach is important to reduce risk. This will assist Greater Manchester Fire and Rescue Service (GMFRS) in responding appropriately and may undertake a safe and well visit as part of the multi-agency approach.

This will allow GMFRS to respond appropriately. Once the risks have been addressed information must be updated.

Record Keeping

- Ensure personal details of the individual and significant others are correct e.g. name, address, telephone etc. (Failed appointments could be due to letters going to the wrong place)
- Include all factual observations from visits and contacts which describe risk factors, e.g. person's appearance, comments, others present, health symptoms, environment etc.

Self-neglect situations are challenging and often involve judgements which are not clear cut and may need to stand scrutiny at a future date, e.g. coroner's court or other enquiry. It is therefore essential to record:

- Mental capacity – was an assessment considered necessary? In high risk situations it is advisable to record the decision to formally assess or not.
- Mental Capacity – formal assessment should be recorded on the recommended pro forma.
- The decisions made
- Who was involved in the discussion/meeting? How was the adult included?
- The rationale for decision making e.g. options considered, risks and benefits of options, least restrictive principles, individual's wishes and views of others etc.
- When the decisions were made and how they will be reviewed, i.e. the dates of meetings/discussions

In some cases these records may be in the form of formal meetings minutes which are necessary when there is a need to bring a number of people together to address complex or significant risk issues. Examples of such meetings include Discharge Planning meetings, Case Review meetings, Mental Capacity Best Interest Meetings. In less complex scenarios it suffices for the above to be included in case notes.

Employees

For employees dealing with cases of self-neglect and or hoarding this can be a stressful time and all agencies should have robust support mechanisms and policies in place, to ensure the health and safety of its employees. This should include practice supervision, peer support, lone working systems and where appropriate access to health and welfare advisory support services.

To enable employees to be effective in dealing with cases of self-neglect and hoarding, employees should also have access to a range of learning and development opportunities either offered by their own organisation, or by a multi-agency approach.

Data information & performance management

It is expected that all agencies will have in place data information and performance management systems in order to capture information in regard to the identification and management of self-neglect and hoarding cases, and that these will be made available to the RBSAB and be populated within the RBSAB performance dashboard. This generally should not involve the sharing of identifiable personal data.

National Guidance

In March 2015 SCIE (Social Care Institute for Excellence) published research on learning from policies and practices that have produced positive outcomes in self-neglect work, from the perspective of key groups of practitioners, managers and people who use services.

Successful Practitioner Practice

Self-neglect practice was found to be more successful where practitioners:

- Took time to build rapport and a relationship of trust, through persistence, patience and continuity of involvement.
- Use of professional curiosity and working in a non-judgmental approach.
- Tried to 'find' the whole person and to understand the meaning of their self-neglect in the context of their life history, rather than just the particular need that might fit into an organisation's specific role.
- Worked at the individual's pace, but were able to spot moments of motivation that could facilitate change, even if the steps towards it were small.
- Ensured that they understood the nature of the individual's mental capacity in respect of self-care decisions
- Were honest, open and transparent about risks and explored real options with the person
- Had in-depth understanding of legal mandates providing options for intervention
- Made use of creative and flexible interventions, including family members and community resources where appropriate.
- Engaged in effective multi-agency working to ensure inter-disciplinary and specialist perspectives, and coordination of work towards shared goals.

Successful Organisational Arrangements

Arrangements that best supported such work included:

- A clear location for strategic responsibility for self-neglect, often the Local Safeguarding Adults Board (LSAB)
- Shared understandings between agencies of how self-neglect might be defined and understood.
- Data collection on self-neglect referrals, interventions and outcomes
- Clear referral routes
- Systems in place to ensure coordination and shared risk management between agencies
- Time allocations that allow for longer-term supportive, relationship-based involvement

- Training and practice development around the ethical challenges, legal options and skills involved in working with persons who self-neglect
- Supervision systems that both challenge and support practitioners.

Complex Interactions

At the heart of self-neglect practice is a complex interaction between knowing, being and doing:

- Knowing, in the sense of understanding the person, their history and the significance of their self-neglect, along with all the knowledge resources that underpin professional practice
- Being, in the sense of showing personal and professional qualities of respect, empathy, honesty, reliability, care, being present, staying alongside and keeping company
- Doing, in the sense of balancing hands-off and hands-on approaches, seeking the tiny element of latitude for agreement, doing things that will make a small difference while negotiating for the bigger things, and deciding with others when intervention becomes a requirement.

Pathways: Adults Refusing Services & Self Neglecting

Is this resulting in significant harm to an individual's health, safety or wellbeing?

Does the individual have capacity to make necessary decision(s) re, safety or wellbeing?		
Yes	Maybe/Fluctuating	No
<p>Provide individual with information relevant to decision.</p> <p>Signpost to relevant services, support as needed.</p> <p>Seek consent to share information with other appropriate agencies/family</p> <p>Discuss options and consequences of decisions</p> <p>Record the fact that the individual has capacity</p> <p>Offer Carers Assessment if appropriate</p>	<p>Mental Capacity Assessment record outcome</p> <p>Re-package information, to maximise individual's capacity to understand</p> <p>Consider possibility of a plan which takes account of fluctuating capacity</p> <p>Re-negotiate options for delivery of services/treatment</p> <p>Share appropriate risk information with other appropriate agencies</p> <p>Need for Advocate considered</p> <p>Consider need for Professional Meeting/ Case Conference/Protection Planning Meeting</p> <p>Monitor/Review</p>	<p>Lead agency/professional considers need for Best Interest meeting, especially if there is a disagreement</p> <p>Involve an Advocate if the person has no suitable representation</p> <p>DOLS Safeguards considered if appropriate</p> <p>Court of Protection considered</p> <p>Consider powers and duties to get person to a place of safety</p>
<p>Always consult your manager/supervisor before closing a case if significant risk remains. Record decision and rationale in case records.</p>		

If the Individual has capacity and service refusal continues and/or risk becomes critical, the Lead professional should inform the designated safeguarding officer in their agency to follow the Multi Agency at Risk Management (MRM) Escalation process (www.rbsab.org)

If the individual does not have capacity and service refusal continues and/or risk becomes critical the Lead professional should inform the designated safeguarding officer in their agency who will convene a Multi-Agency Professionals meeting to

consider whether all available powers and duties are exhausted and to consider the need for Court of Protection involvement.

Key Contacts:

Adult Care – 0300 303 8886

GMFRS - 0800 555 815

Children's Services – 0300 303 0440