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SUPPORTING PROFESSIONAL WORKFORCE DEVELOPMENT ACROSS ADULTS' AND CHILDREN'S SOCIAL CARE SINCE 2002

Safeguarding Adults: Self-Neglect and Hoarding Toolkit

Some key tools and top tips for decision making and defensible recording in cases of self-neglect

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Pavilion

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*Following her earlier report for CareKnowledge on the more general subject of **Section 42 Enquiries**, Deborah Barnett now asks us to consider the S42 enquiry information and apply this to cases of self-neglect. This new Special Report looks at the more specific question of working with people who self-neglect, and/or who exhibit hoarding behaviours. The report includes a wide range of the risk-assessment and other tools she has developed to support the professionals who may be involved in such work, including some of those (for ease of reference) that appear in the Section 42 report.*

Deborah begins her report with a personal account of her own family's experience of self-neglect and hoarding.

Foreword

Sheila just wanted friends and a community, but no one wanted her. No one understood, or even tried to understand the turbulence of her life. She was an odd character, my grandmother. I am not sure whether it was a cultural difference, a mental illness, a generational perspective, or maybe all these things that made her seem so different to me. I never knew her birthday, nor her age. I didn't know where she was brought up, or what her family was like. I piece together bits of information and try to create a picture of my family background, like a jigsaw puzzle – one that is deeply frustrating with many pieces missing.

Sheila's history is of both Jewish and Gypsy traveller background, and having lived through the war I suspect that she either didn't know her birthday, or was too afraid to give too many details to anyone who might ask. Sheila identified as 'a traveller' and lived in caravans and canal boats most of her life. My grandfather seems to have been very distantly related to Sheila's family, although there is even less detail about his family history. My grandfather spent the last of the war years working on the Burma Railway. Not long after the war my mother and her brother were born and Sheila left the travelling community to settle into a house with her family. Sheila had been ostracised from many different communities in her life, always finding safety in the travelling community. However, when she moved into a house, that community rejected her.

When my mother was six years old and her brother four, my grandfather died of tuberculosis, contracted during the war. Sheila couldn't cope with the isolation of a home life with two small children without the wider community and returned to travelling, making amends with old friends.

Sheila was afraid to take her children out into what she perceived to be a dangerous world full of prejudice, so my mother and her brother were left in the care of an elderly neighbour, who struggled to look after them. Eventually Dr Barnardo's came to their rescue and my mother and brother travelled to Northumberland to be raised in care. Their identity, place of belonging, religious and cultural background all changed overnight. Church of England became the religion that my mother was raised with and a community of children, ever-changing, came and went in her life. My mother rarely saw Sheila throughout her childhood.

I was nine years old the first time that I met my grandmother. Sheila said that she was unwell and no longer welcome in her community. She needed her family. My mother found a house for her and supported her to move near to us. Sheila and my mother were never really close, but I was curious and would stop by her house most nights after school. It was a fascinating and sometimes scary house, full of small china cups, crystal balls, tarot cards, lacy table cloths and pictures of Shirley Temple that Sheila had drawn herself. Sheila talked about old traditions and tales of travellers. The stories were not your average fairy tales, they were tragedies and stories with some moral attached which often went over my head. It was a cluttered, but organised house, crammed full of things to explore.

Sheila would play the accordion and even after she finished playing she would sit rocking in her chair. The

teaspoons were made of real silver and she would polish them endlessly. I arrived at her house one day to find a pony tied to the drain pipe. I couldn't tell you where it came from, or where it went, but it certainly looked strange in the middle of a terraced street. I think this was the point that Sheila's mental health began deteriorating, but it was difficult to tell eccentricity from mental ill health.

Sheila was telling me a tale of the waterways and seas one day when water started flooding down the stairs. I ran out of the house and home, convinced that it was invoked by the tales that she told. Sheila's house was flooded and much of her furniture destroyed, the bath had been left running. This was the final straw for Sheila and again she upped sticks and left, saying that she was going back to travelling.

When I was 13 years old my mother received a phone call from the police to say that her mother had been found dead in a squat. My mother and I travelled to what she called her home. The police said that I was not allowed in as it would be too distressing, so I stood at the door looking in and waiting. Four or five cats ran out of the open door past me and the smell of cat urine was so strong I lifted the sleeve of my parka to my nose. It seemed like I could taste the urine from the air. I peered inside and saw dark unpainted walls, bare wires, newspapers and articles piled high. Post-It notes covered every surface, reminding Sheila of daily tasks. I could see one armchair piled high with china and silver objects all tarnished a nicotine brown. I couldn't see a bed, or anywhere to cook. My mother came out of the house crying, holding a mass of newspaper clippings. Sheila had repeatedly advertised for friends, but it seemed that no one had answered. The police said that she had died of bronchial pneumonia, she had neglected herself and had not eaten, or cleaned up and had been very isolated.

Would a neighbour not have recognised her distress and sought help? Did they see her as the nuisance squatter who made a mess? Did no one want to find out about her, her history, her culture, and her tales? Could no one engage with her enough to just make a little difference?

Sheila would have rejected traditional Western medicine in favour of herbal remedies picked from a garden, or river bank. Sheila wouldn't go to the doctors or social services herself, she didn't have a home address, or date of birth to register and if she wouldn't, or couldn't tell her family her details, then most certainly she wouldn't tell the authorities.

Someone trying to understand her could have assisted her to get a little help, as long as once that help was sought it respected her values, her traditions, her way of life and recognised the personal sacrifices and traumas that she had suffered to maintain her culture. It would take a lot not to judge her, if you didn't know her background. It would be easy to say that it was her choice to live that way.

It was clear that Sheila's mental health had suffered. However, no one considered whether she was able to make decisions or not. Sheila would have become agitated if things were imposed upon her, however, she was desperately lonely and just wanted someone to work with her, to help her in a way that was meaningful to her. The police confirmed that Sheila had been smoking in the property and along with the vast quantities of newspaper and urine, this had posed a significant fire risk to others in the block. Neighbours had complained, but this merely meant that Sheila refused to leave the property, even for food, for fear that she would not be allowed back in.

All of this illustrates the difficulties of helping people in these circumstances, but it also makes me all the more convinced of the need for those of us with the opportunity to intervene, to take action.

We shouldn't be afraid to make a safeguarding referral and make enquiries about a person. We should ensure that once that referral is received that the person is treated with dignity and respect. We should ensure that culture and background are part of the assessment and that we work with the person rather than against them. Even if a person has lost capacity to make decisions, we need to support them in the best way possible and ensure that responses are proportionate to the risks (least restrictive), whilst

considering their identity. It would have been an easy answer to place Sheila in residential care before she died, but it wouldn't have been the right answer for her. Who would have thought to find her a caravan? It might have saved her life.

Have a look at the self-assessment tool featured later in this report, and consider these issues:

- No one recognised Sheila's situation as self-neglect
- No one identified the need to safeguard her
- No one assessed her capacity to make decisions
- No one tried to engage with her
- No one talked to her about her cultural and religious beliefs
- No one understood her life story
- No one fully assessed her needs, or addressed her housing situation
- Sheila was regarded as strange, obstructive, eccentric and labelled as 'bad'
- No one identified her failing mental health, but neighbours called her 'mad'
- Eviction and clearance was on the cards, but she would resist that. Authorities had tried to do that to her all her life
- No one tried to engage her with a community, or made an effort to find out about her passion for drawing, painting, open spaces and music
- Sheila should have had human rights, but who would have considered the rights of someone who is labelled as mad and bad?

It is the person's life story that allows us insight into why things occur, the narrative that they hold on their life. This is the key to opening a door to a different, less isolated world where just listening and engaging will have a profound effect.

Don't be afraid of safeguarding a person, don't be afraid of assessing needs. When you do share a very personal space, a life of potential loss and disappointment, make sure that you are sensitive, proportionate, compassionate and think outside of the box. It is important that the person feels in control of the situation and is given the right information, in an appropriate manner for them, at the right time. Do not forget to apply safeguarding principles to every interaction. Remember, information may be shared without the consent of the person if there is a risk to others, potential crime, coercive and controlling behaviours, or the person lacks capacity to make certain decisions. In the vast majority of cases, these complex matters cannot be determined without enquiries being made. It is a duty under the Care Act statutory guidance for agencies to share information for safeguarding purposes:

'When an employer is aware of abuse or neglect in their organisation, then they are under a duty to correct this and protect the adult from harm as soon as possible and inform the local authority, CQC and CCG where the latter is the commissioner. Where a local authority has reasonable cause to suspect that an adult may be experiencing or at risk of abuse or neglect, then it is still under a duty to make (or cause to be made) whatever enquiries it thinks necessary to decide what if any action needs to be taken and by whom. The local authority may well be reassured by the employer's response so that no further action is required. However, a local authority would have to satisfy itself that an employer's response has been sufficient to deal with the safeguarding issue and, if not, to undertake any enquiry of its own and any appropriate follow up action (for example, referral to CQC, professional regulators)'.

(Care and Support Statutory Guidance 2018 S14.69)

Nothing can be done in relation to the care and support of the person without lawful reason or consent and therefore all responses must be person-centred and capacity must be considered for each aspect of care and support.

The rest of this report now sets out a toolkit for use in cases where there is evidence of self-neglect and/or hoarding behaviour.

1. Introduction

This toolkit is intended to be person-centred and solution-focused, utilising outcome-based models of practice to work with people who hoard and self-neglect. The toolkit is for multi-agency use and should be particularly useful for housing providers, adult and children's social care, health workers and other agencies working with those who may be at risk of hoarding or self-neglecting.

Self-neglect and compulsive hoarding are highly complex and require a collaborative and integrated approach. This toolkit aims to ensure that practitioners are equipped with methods of working with people in a manner that is meaningful, co-ordinated and grounded in a multi-agency partnership. The toolkit aims to facilitate positive and sustainable outcomes for people, by involving them in the process at all stages. The toolkit provides guidance, advice, process maps, assessments and methods of working that can be utilised and adapted by organisations to meet the needs of the individuals that they work with. All examples that are used for hoarding can also be adapted for self-neglect.

The toolkit includes reference to pieces of legislation that may be relevant to working with people who hoard and or self-neglect.
This is a toolkit and therefore the appropriate tools should be selected using professional judgement about the suitability of the tool for the person and the benefits to them in practice.

2. Who might use the toolkit?

There is an expectation that everyone engages fully in partnership working to achieve the best outcome for the people who hoard or self-neglect, while meeting the requirements and duties of individual agencies. Housing workers, domiciliary care providers, health workers, GPs, children and adult social care workers, and mental health workers may therefore find this toolkit useful.

3. The Care Act 2014, hoarding and self-neglect

The statutory guidance to the Care Act 2014 identifies self-neglect as a safeguarding responsibility and defines the term as covering a wide range of behaviours, such as neglecting to care for one's personal hygiene, health or surroundings and includes behaviour such as hoarding. Falling under the safeguarding policies and procedures means that all safeguarding adults duties and responsibilities apply. Some cases of self-neglect may solely be due to disability or inability and therefore may not require further enquiries to be made, if an assessment and care and support plan, would meet those needs.

4. Eligibility Criteria for Safeguarding

The safeguarding duties apply to an adult who:

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

The safeguarding duties have a legal effect in relation to organisations other than the local authority, on, for example, the NHS and the police. Safeguarding a person who hoards or

self neglects requires an enquiry into the reasons behind a person's hoarding and self-neglect. Agencies have a duty to share information with the local authority for safeguarding purposes. The local authority has duty to make enquiries, provide advice, guidance and signpost. In some cases safeguarding procedures will be invoked by the local authority. Information within this toolkit is designed to be used in conjunction with safeguarding adults' policies and procedures and therefore be consistent with Care Act 2014 guidance.

5. Aims

This toolkit aims to guide the practitioner through decisions and considerations for safeguarding purposes when supporting someone who self-neglects.

6. Objectives of the toolkit

The objectives of this toolkit are to promote:

Investigation, enquiry and information sharing

- To explore the problems associated with hoarding and self-neglect from different professional and community perspectives

Co-ordinated responses and identify support mechanisms

- To support a person who hoards or self-neglects in a structured and systematic way
- To ensure consistent approaches that utilise the resources of all agencies to promote a person's wellbeing
- To clarify agency responsibility in relation to hoarding and self-neglect

Reduced need for compulsory solutions

- To support a person as soon as possible to promote wellbeing and prevent the need for compulsory clearance, legal responses or imposed sanctions

Person-centred solutions

- To ensure that there is a process for planning solutions, tailored to meet the needs of the individual concerned
- To co-ordinate responses of professional support, monitoring, repairs, temporary or permanent re-housing

Best practice around the wellbeing of the person

- To understand the underlying factors that contribute to hoarding and self-neglect
- To recognise sensitive and supportive approaches
- To improve knowledge of legal frameworks
- To ensure that the person has control of their own decision-making and risks taken (Mental Capacity Act)

7. Why do people self-neglect/hoard, and what are the risks?

People may self-neglect, or turn to hoarding, for a variety of reasons, including those associated with much earlier experiences:

- Inability to maintain own self-care and household chores
- Parents who hoarded and/or experience of childhood neglect
- The impact of more recent abuse or neglect
- The impact of domestic abuse
- The impact of loss or bereavement
- The loss of a job, house or status
- The loss of a strongly held value system
- The loss of independence as a result of an accident, trauma, major ill health or frailty.

These latter losses can cause a person to lose self-esteem, feel less valued, or experience a lack of power and control over their own life. They may feel upset, or ascribe negative characteristics to themselves such as guilt, lack of capability or shame.

Individuals can also lose trust in other people as a result of these losses and withdraw from human engagement. Sometimes attachments that were once formed with people are developed with objects, because objects cannot hurt your feelings and do not leave you. There is more personal control over objects. Sometimes these same attachments are developed with animals. Objects (or animals) can provide a sense of security and give structure to a person's day.

When feeling such loss, the person seeks to control the anxiety and distress in a number of ways:

- Collecting things
- Maintaining control over things
- Seeking brief comfort and escape through use of alcohol or drugs
- Considering on-going use in objects and/or recycling things to demonstrate their positive contribution
- Self-harming or neglecting oneself
- Considering beauty in things when others do not
- Retaining items with sentimental attachment and which preserve memories
- Gaining new purpose through the joy that acquisition creates
- Rejecting traditional western medicine in favour of other cultural, herbal or environmentally/animal-friendly options.

These coping mechanisms can become the cause of the problem, as excessive accumulation presents difficulty in managing daily tasks, exacerbating the personal lack of self-esteem through the feeling of being unable to achieve that which others achieve regularly. Guilt, shame and self-deprecation increase and debilitate the person.

The impact of trauma, or loss also has an effect on the person. Responses to trauma are often interpreted in the area of the brain used in high stress situations, and which utilise primitive responses: fight, flight, freeze, flop. The person can resist intervention, fighting to preserve personal autonomy. They can hide from others and feel as if they are constantly running away from the intrusion of others. They can freeze and become unable to confront tasks that are required to maintain wellbeing. Or they can flop and become passive, feeling exhausted by the daily tasks they are supposed to achieve.

The same area of the brain used in response to trauma and loss does not have order, chronology or the

ability to structure and plan things. The chronological memory is affected and the person's ability to plan and maintain order and cleanliness is damaged. The person is in a perpetual state of readiness, in a crisis situation, and the brain has not informed them that the event is over because there is no time context within this area of our brain function.

Instead, this area of the brain focuses on the senses, preparing to respond to the crisis. What visual stimulus is there, what sounds can be heard, what is available for use as a tool, what can I prepare myself with in order that this does not happen again? Interestingly, these aspects of sensory response equate to the qualities that people who hoard describe in the value of their goods.

People who self-neglect and refuse care, services, and treatment are essentially self-harming. Refusing essential services will eventually result in discomfort and pain. Self-harm is described as a coping mechanism for those hoping to deal with the anxiety and overwhelming distress of loss, abuse, or neglect.

Social isolation and self-neglect are a toxic mix and will only result in increasing deterioration in physical and mental wellbeing. Added to the risk to personal wellbeing are:

- Fire risk
- Falls risk
- The risk from poor housing structures and lack of repairs
- The risk from falling objects
- Nutritional risks
- Risk from insanitary conditions
- Risk to others.

Without sensitive and lawful intervention, over a prolonged period of time, there is a definite possibility that these behaviours will result in the death of the person concerned. The behaviours can represent a continuum of deterioration towards a fatal final outcome and all public sector services have a duty to do everything that is within their lawful capability to support the person in a manner that is appropriate and proportionate to their needs, to prevent this potential outcome.

In complex physical and emotional situations the prevention of deterioration can require greater resources and the partnership support of a number of agencies, willing and able to offer their services, without judgement or discrimination. The barriers presented by the person's mechanisms for coping with the emotional turmoil experienced, should not be removed without thinking through, and planning for the provision of, the support that might replace current coping mechanisms.

That requires comprehensive multi-agency assessment, early development of rapport and support to engage in gainful activities with others who have similar interests within the community. The person will need to develop self-worth through active and rewarding participation with others. Positive feedback is essential to provide direction, identity and belonging, qualities often described as missing by people who have suffered loss, bereavement, trauma, abuse or neglect. Psychology support is important to look at the comorbid mental health issues created through trauma, loss and bereavement

Clearing clutter without the necessary support in place will only make things worse and the person is highly likely to begin collecting again, only this time feeling more powerless and less in control. The person may also be more suspicious of services and more likely to resist support.

8. Hoarding and Clutter Rating

Determining the level of hoarding and the person's responses to the collection of clutter can be a valuable tool to begin discussion regarding the risks. The clutter-rating tool has been adapted for this purpose and to determine when consideration for safeguarding is required.

Adapted from Frost, RO, Steketee G, Tolin DF, Renaud S. Development and validation of the Clutter Image Rating. Journal of Psychopathology and Behavioral Assessment. 2008;32:401–417

Level 1



1	2	3

Low level clutter – Develop a rapport with the person concerned. Consider the person's ability to understand the tenancy agreement. Support person to engage with topics of interest and meet with others who have similar interest in local community – develop relationships.



1	2	3



Images created by Steketee and Frost / modified by Deborah Barnett.

Level 1 ***Clutter image rating 1 - 3***	Household environment is considered standard. No specialised assistance is needed.

1. Property structure, services & garden area	• All entrances and exits, stairways, roof space and windows accessible • Smoke alarms fitted and functional or referrals made to fire brigade to visit and install. • All services functional and maintained in good working order • Garden is accessible, tidy and maintained.
2. Household Functions	• No excessive clutter, all rooms can be safely used for their intended purpose. • All rooms are rated 0-3 on the Clutter Rating Scale • No additional unused household appliances appear in unusual locations around the property • Property is maintained within terms of any lease or tenancy agreements where appropriate. • Property is not at risk of action by Environmental Health.
3. Health and Safety	• Property is clean with no odours, (pet or other) • No rotting food • No concerning use of candles • No concern over flies • Residents managing personal care • No writing on the walls • Quantities of medication are within appropriate limits, in date and stored appropriately.
4. Safeguard of Children & Family members	• No concerns for household members.
5. Animals and Pests	• Any pets at the property are well cared for • No pests or infestations at the property.
6. Personal Protective Equipment (PPE)	• No PPE required • No visit in pairs required.

Level 2

4	5	6

Moderate clutter – may require a safeguarding referral. Identify the most suitable person to engage with the situation. Enquiries to consider why and when this began, capacity of person to make each relevant

decision including capacity to understand tenancy agreement. Multi-agency response may be headed by the most suitable agency. Risk assessment required and work with the person concerned at their pace. Do not discuss removing any goods until rapport developed and full assessment of the person's needs, values and wishes conducted. Safeguarding duties and responsibilities apply.



4	5	6



Images created by Steketee and Frost / modified by Deborah Barnett.

Level 2 ***Clutter image rating 4 – 6***	**Household environment requires professional assistance to resolve the clutter and the maintenance issues in the property.**
1. Property structure, services & garden area	• Only major exit is blocked • Only one of the services is not fully functional • Concern that services are not well maintained • Smoke alarms are not installed or not functioning • Garden is not accessible due to clutter, or is not maintained • Evidence of indoor items stored outside • Evidence of light structural damage including damp • Interior doors missing or blocked open.
2. Household Functions	• Clutter is causing congestion in the living spaces and is impacting on the use of the rooms for their intended purpose. • Clutter is causing congestion between the rooms and entrances. • Room(s) score between 4-5 on the clutter scale. • Inconsistent levels of housekeeping throughout the property • Some household appliances are not functioning properly and there may be additional units in unusual places • Property is not maintained within terms of lease or tenancy agreement where applicable. • Evidence of outdoor items being stored inside.

3. Health and Safety	• Kitchen and bathroom are not kept clean • Offensive odour in the property • Resident is not maintaining safe cooking environment • Some concern with the quantity of medication, or its storage or expiry dates • No rotting food • No concerning use of candles • Resident trying to manage personal care but struggling • No writing on the walls.
4. Safeguard of Children & Family members	• Hoarding on clutter scale 4 -7 doesn't automatically constitute a Safeguarding Alert • Please note all additional concerns for householders • Properties with children or vulnerable residents with additional support needs may trigger a Safeguarding Alert under a different risk.
5. Animals and Pests	• Pets at the property are not well cared for • Resident is not unable to control the animals • Animal's living area is not maintained and smells • Animals appear to be under nourished or over fed • Sound of mice heard at the property. • Spider webs in house • Light insect infestation (bed bugs, lice, fleas, cockroaches, ants, etc.).
6. Personal Protective Equipment (PPE)	• Latex Gloves, boots or needle stick safe shoes, face mask, hand sanitizer, insect repellent. • PPE required.

Level 3



7	8	9

High level clutter – A safeguarding referral will be required. Where there is a risk to the persons physical and mental wellbeing safeguarding processes should be followed and a full multi-agency meeting held to plan the enquiry and assessment process.



7	8	9

Images created by Steketee and Frost / modified by Deborah Barnett.

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 referral due to the significant risk to health of the householders, surrounding properties and residents.**
1. Property structure, services & garden area	• Limited access to the property due to extreme clutter • Evidence may be seen of extreme clutter seen at windows • Evidence may be seen of extreme clutter outside the property • Garden not accessible and extensively overgrown • Services not connected or not functioning properly • Smoke alarms not fitted or not functioning • Property lacks ventilation due to clutter • Evidence of structural damage or outstanding repairs including damp • Interior doors missing or blocked open • Evidence of indoor items stored outside.
2. Household Functions	• Clutter is obstructing the living spaces and is preventing the use of the rooms for their intended purpose. • Room(s) scores 7- 9 on the clutter image scale • Rooms not used for intended purposes or very limited • Beds inaccessible or unusable due to clutter or infestation • Entrances, hallways and stairs blocked or difficult to pass • Toilets, sinks not functioning or not in use • Resident at risk due to living environment • Household appliances are not functioning or inaccessible • Resident has no safe cooking environment • Resident is using candles • Evidence of outdoor clutter being stored indoors. • No evidence of housekeeping being undertaken • Broken household items not discarded e.g. broken glass or plates • Concern for declining mental health • Property is not maintained within terms of lease or tenancy agreement where applicable • Property is at risk of notice being served by Environmental Health.

3. Health and Safety	• Human urine and or excrement may be present • Excessive odour in the property, may also be evident from the outside • Rotting food may be present • Evidence may be seen of unclean, unused and or buried plates & dishes. • Broken household items not discarded e.g. broken glass or plates • Inappropriate quantities or storage of medication. • Pungent odour can be smelt inside the property and possibly from outside. • Concern with the integrity of the electrics • Inappropriate use of electrical extension cords or evidence of unqualified work to the electrics. • Concern for declining mental health.
4. Safeguard of Children & Family members	• Hoarding on clutter scale 7-9 constitutes a Safeguarding Alert • Please note all additional concerns for householders.
5. Animals and Pests	• Animals at the property at risk due the level of clutter in the property • Resident may not able to control the animals at the property. • Animal's living area is not maintained and smells • Animals appear to be under nourished or over fed • Hoarding of animals at the property • Heavy insect infestation (bed bugs, lice, fleas, cockroaches, ants, silverfish, etc.) • Visible rodent infestation.
6. Personal Protective Equipment (PPE)	• May be required.

9. Guidance regarding diagnosis of Hoarding Disorder and co-morbid mental health issues

The Diagnostic Statistics Manual V (DSM-V) (American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: Author.) identifies hoarding as a distinct disorder in its own right. In addition to consideration of this diagnosis, mental health practitioners should also consider the impact of childhood experiences and attachment issues, the impact of trauma and neglect on matters such as self-care, impulse control and the development of anxiety and depression may also need to be explored. There are separate diagnostic frameworks for post-trauma, childhood trauma, anxiety and depression. If the person is presenting paranoid thoughts then the Paranoia may need to be assessed and the person therapeutically / medically supported with these issues. The first focus must be on establishing the person's experiences, life history and how this impacts on the decisions and choices exhibited today, alongside any other comorbid mental health presentation. A psychologist and psychiatrist are key to addressing each aspect of mental health presentation. For practitioners referring to GP services in support of a person accessing mental health services it is helpful to identify any observed presentations and traumas. This will assist the appropriate mental health response.

Hoarding Disorder diagnosis is identified by:

- Persistent difficulty discarding or parting with possessions, regardless of their actual value

- This difficulty discarding possessions results in the accumulation of possessions that congest and clutter active living areas and substantially compromise their intended use
- If living areas are uncluttered it is only because of third party intervention
- The hoarding causes clinically significant distress or impairment in social, occupational, or other important areas of functioning (including maintaining a safe environment for self and others).
- The hoarding is not attributable to another medical condition (e.g., brain injury, cerebrovascular disease, Prader-Willi syndrome).
- The hoarding is not better explained by the symptoms of another mental disorder (e.g., obsessions in obsessive-compulsive disorder, decreased energy in major depressive disorder, delusions in schizophrenia or another psychotic disorder, cognitive deficits in major neurocognitive disorder, restricted interests in autism spectrum disorder).

Mental Health Practitioners may recognise these symptoms, but maintain that there is no treatment pathway for 'Hoarding Disorder' and therefore no point in obtaining a diagnosis. There is a treatment pathway for anxiety, depression, childhood trauma, post trauma, paranoia, compulsive behaviours and many of the other presenting mental health issues displayed by people who hoard and self-neglect. It is the duty of all health practitioners to preserve life and prevent mental and physical wellbeing deteriorating and therefore equitable service provision must be accessed by people who hoard and self-neglect. The key to treatment is to consider the self-neglect and hoarding as a symptom of other, deeper mental health issues.

For the person hoarding/self-neglecting to gain 'access' to mental health services, the practitioner will need to make an effort to fully engage with the person. Appointments should not be sent out by letter, if the person does not open their mail, and appointments should not be made in environments where the person would panic, or anxiety would increase. By demonstrating commitment to help the person, an interest in their life/experiences and a non-judgmental attitude about their collecting, or self-neglecting behaviours, you will gain engagement. It is helpful if the trusted person becomes available to support the introduction of other agencies or relevant people to provide care and support.

The issue of clearance or removal of clutter should not be addressed until the person is ready to do this for themselves. This usually occurs after around 3-6 months of psychological treatment on a weekly basis. At this point it is helpful for a community psychiatric nurse to work alongside the person to support the decluttering process or address the feelings associated with acceptance of treatment.

10. Guidance on recording against the Risk Assessment (This applies to the tool which follows)

The Self-Neglect Assessment Tool is to be used as a guide or checklist to determine the level of risk. Safeguarding procedures should be followed when other forms of abuse or neglect are identified.

Even if the risk is determined as low on the assessment, you can still raise an alert and record a rationale if you have concerns. State what action you have taken to prevent deterioration of wellbeing for the person and prevent abuse from occurring.

If you are going to make a referral for adult protection procedures to be invoked record the situation against the Risk Assessment Tool to provide a rationale. Any disagreement can be settled by a conversation about where professionals feel risk fits within the tool's factors.

Depending on the assessed level of risk, the needs of the person and the complexity of the situation, safeguarding responses may be:

- Low level advice-guidance or signposting
- An assessment of need by an allocated social worker
- The provision of aids and adaptations required following an assessment by OT allocated to assess and meet need
- The local authority may determine another agency is better equipped to lead the enquiry, for example if mental health, housing or nursing services have been involved with the person over a long period of time and understand the person and situation better, they may in a better position to convene and chair multi-agency safeguarding arrangements, with support, oversight and guidance from the local authority
- The local authority may make multi-agency safeguarding arrangements and coordinate these with psychology-led interventions.

In using this guidance, the eligibility criteria for safeguarding must be considered. The person should be aware of all parties involved and be offered the opportunity to fully participate in the assessment process, unless it would be unsafe to do so.

The rest of this report provides a full range of tools that can be used to support work in relation to self-neglect and hoarding. The tools cover a number of practice areas and are intended to provide a wide choice of material that you can use as you judge appropriate.

The tools are, to some extent, designed as stand-alone resources, and there is some overlap in their contents. If you imagine a toolbox, your toolbox compartments represent the legislation that contains the frameworks that you are working within. Your key tools such as hammers, screwdrivers are selected in relation to the task required. The risk assessments, mental capacity act assessments and safeguarding processes are selected in relation to the task required. The other tools are selected for specialist jobs. Select the wrong tool for the work required and it becomes difficult to achieve positive outcomes. This toolkit requires you to consider the needs of the individual and the circumstances presented and select the tools to create positive outcomes. There are brief introductions to explain what each of the tools can be used for.

The following risk assessment tool can be used to analyse risk in relation to assessments and to monitor whether risks are increasing. It can be used to triage responses to safeguarding referrals, or to explore in further detail information with a referrer, the person self-neglecting or concerned family members. Whenever there is a requirement for consistent risk assessment processes this may be used.

Self-Neglect and Hoarding Risk Assessment Tool

Factors	Guidance			
1. The vulnerability of the person	**Less vulnerable**	**More vulnerable**		• Does the person have capacity to make decisions with regard to care provision / housing, aids and adaptations, care and support offered etc? • Does the person have a diagnosed mental illness / require mental health support? • Has the person suffered abuse, neglect, bereavement or loss? • Does the person have support from family or friends or are they dependent upon family members for care provision? • Does the person accept care and treatment? • Does the person have insight into the problems they face?
2. Types of seriousness of hoarding	**Low risk**	**Moderate**	**High / Critical**	• Refer to the table on the following page - Types and Seriousness of Hoarding and self-neglect. Look at the relevant categories of hoarding and self-neglect and use your knowledge of the case and your professional judgement to gauge the seriousness of concern • Incidents that might fall outside invoked Adult Protection procedures (Low Risk) could potentially be addressed via preventative safeguarding measures such as engaging with the person, developing a rapport, supporting the person to address concerns, getting the person to engage with community activities and develop / repair relationships, access to health care and counselling or a single agency response. The aim is to effectively safeguard the person • If a Social Worker or nurse is involved in the care, report concerns to them as part of preventative measures. **This tool does not replace professional judgement and does not aim to set a rigid threshold for intervention. Note: professional decision making reflects the fact that the type & seriousness of hoarding and self-neglect may fall within the low risk threshold, other factors may make the issue more serious and therefore warrant progression via safeguarding procedures.**
Hoarding property				
Hoarding household functions				
Hoarding health and safety				
Hoarding safeguarding				
Self-Neglect				
3. Level of self-neglect / hoarding	Low risk	Moderate risk	High risk	Determine if the hoarding / self-neglect is: • A fire risk?

(See clutter rating scale for hoarding)				• Impacting on the person's wellbeing (Care Act 2014 definition)? • Preventing access to emergency services? • Affecting the person's ability to cook, clean and general hygiene? • Creating limited access to main areas of the house? • Creating an increased risk of falls? • Affecting the person's ability to sleep, keep warm and dry or access care and support?
4. Background to hoarding / self-neglect	Low impact		Seriously affected	• Does the person have a disability that means that they cannot care for themselves? • Does the person have mental health issues and to what extent? • Has this been a longstanding problem (Begin with childhood relationships and attachment when people are hoarding)? • Does the person engage with services, support and guidance offered? • Are there social isolation issues? • When did hoarding / self-neglect begin, wheat made it worse when was it better?
5. Impact on others	No one else affected	Others indirectly affected	Others directly affected	Others may be affected by the self-neglect or hoarding. Determine if: • Are there other vulnerable people (children or adults) within the house and / or affected by the persons hoarding / self-neglect? • Does the hoarding / self-neglect prevent the person from seeing family and friends? • Are there animals within the property that are not being appropriately cared for?
6. Reasonable suspicion of abuse	No suspicion	Indicators present	Reasonable suspicion	Determine if there is reason to suspect: • That the hoarding / self-neglect is an indicator that the person may be being abused • The person may be targeted for abuse from local people • That a crime may be taking place • That the person is being neglected, coerced or controlled by someone else • That safeguarding is required for matters in addition to the self-neglect / hoarding.
7. Legal frameworks	No current legal issues	Some minor legal issues not currently impacting	Serious legal issues	Try to determine whether: • The person is at risk of eviction, fines, non-payment issues, legal issues • There is an environmental risk that requires action – Public Health issues • There are safeguarding and animal welfare issues • There are fire risks that are a danger to others.

Types and Seriousness	These cases may be referred where a person meets the three part safeguarding eligibility criteria.	The examples below are likely to indicate the need for a referral for formal procedures. If there is any immediate danger of a crime or abuse to an individual evident, call 999 straight away and make a safeguarding referral.	
Level of Risk	**Minimal Risk**	**Moderate**	**High / Critical**
Hoarding property	• All entrances and exits, stairways, roof space and windows accessible • Smoke alarms fitted and functional or referrals made to fire brigade to visit and install • All services functional and maintained in good working order. • Garden is accessible, tidy and maintained.	• Only major exit is blocked • Only one of the services is not fully functional • Concern that services are not well maintained • Smoke alarms are not installed or not functioning • Garden is not accessible due to clutter, or is not maintained • Evidence of indoor items stored outside • Evidence of light structural damage including damp • Interior doors missing or blocked open.	• Limited access to the property due to extreme clutter • Evidence may be seen of extreme clutter seen at windows • Evidence may be seen of extreme clutter outside the property • Garden not accessible and extensively overgrown • Services not connected or not functioning properly • Smoke alarms not fitted or not functioning • Property lacks ventilation due to clutter • Evidence of structural damage or outstanding repairs including damp • Interior doors missing or blocked open • Evidence of indoor items stored outside.
Hoarding – Household functions	• No excessive clutter, all rooms can be safely used for their intended purpose • All rooms are rated 0-3 on the Clutter Rating Scale • No additional unused household appliances appear in unusual locations around the property • Property is maintained within terms of any lease or tenancy agreements where appropriate.	• Clutter is causing congestion in the living spaces and is impacting on the use of the rooms for their intended purpose. • Clutter is causing congestion between the rooms and entrances. • Room(s) score between 4-5 on the clutter scale • Inconsistent levels of housekeeping throughout the property	• Clutter is obstructing the living spaces and is preventing the use of the rooms for their intended purpose. • Room(s) scores 7 - 9 on the clutter image scale and not used for intended purpose • Beds inaccessible or unusable due to clutter or infestation • Entrances, hallways and stairs blocked or difficult to pass • Toilets, sinks not functioning or not in use • Resident at risk due to living environment

	• Property is not at risk of action by Environmental Health.	• Some household appliances are not functioning properly and there may be additional units in unusual places. • Property is not maintained within terms of lease or tenancy agreement where applicable. • Evidence of outdoor items being stored inside.	• Household appliances are not functioning or inaccessible and no safe cooking environment • Resident is using candles • Evidence of outdoor clutter being stored indoors. • No evidence of housekeeping being undertaken • Broken household items not discarded e.g. broken glass or plates • Concern for declining mental health • Property is not maintained within terms of lease or tenancy agreement where applicable and is at risk of notice being served by Environmental Health.
Hoarding – health and safety	• Property is clean with no odours, (pet or other) • No rotting food • No concerning use of candles • No concern over flies • Residents managing personal care • No writing on the walls • Quantities of medication are within appropriate limits, in date and stored appropriately • Personal protective equipment is not required.	• Kitchen and bathroom are not kept clean • Offensive odour in the property • Resident is not maintaining safe cooking environment • Some concern with the quantity of medication, or its storage or expiry dates • No rotting food • No concerning use of candles • Resident trying to manage personal care but struggling • No writing on the walls • Light insect infestation (bed bugs, lice, fleas, cockroaches, ants, etc.) • Personal Protective Equipment required: Latex gloves, boots or needle stick safe shoes, face mask, hand sanitizer, insect repellent.	• Human urine and or excrement may be present • Excessive odour in the property, may also be evident from the outside • Rotting food may be present • Evidence may be seen of unclean, unused and or buried plates & dishes. • Broken household items not discarded e.g. broken glass or plates • Inappropriate quantities or storage of medication. • Concern with the integrity of the electrics • Inappropriate use of electrical extension cords or evidence of unqualified work to the electrics • Concern for declining mental health • Heavy insect infestation (bed bugs, lice, fleas, cockroaches, ants, silverfish, etc.) • Visible rodent infestation.
Hoarding – Safeguarding of children, family	• No Concerns for household members.	• Hoarding on clutter scale 4 -7 doesn't automatically constitute a safeguarding alert.	• Hoarding on clutter scale 7-9 constitutes a safeguarding alert. • Please note all additional concerns for householders.

members and / or animals		• Please note all additional concerns for householders • Properties with children or vulnerable residents with additional support needs may trigger a safeguarding alert.	
Self-Neglect	• Person is accepting support and services • Health care is being addressed • Person is not losing weight • Person accessing services to improve wellbeing • There are no carer issues • Person has access to social and community activities • Person is able to contribute to daily living activities • Personal hygiene is good/	• Access to support services is limited • Health care and attendance at appointments is sporadic • Person is of low weight • Person's wellbeing is partially affected • Person has limited social interaction • Carers are not present • Person has limited access to social or community activities • Person's ability to contribute toward daily living activities is affected • Personal hygiene is becoming an issue.	• The person refuses to engage with necessary services • Health care is poor and there is deterioration in health • Weight is reducing • Wellbeing is affected on a daily basis • Person is isolated from family and friends • Care is prevented or refused • The person does not engage with social or community activities • The person does not manage daily living activities • Hygiene is poor and causing skin problems • Aids and adaptations refused or not accessed.
RESPONSIBILITY	**All workers to engage with the person, develop a rapport, supporting the person to address concerns, getting the person to engage with community activities and develop/repair relationships, access to health care and counselling, improve wellbeing – preventative measures.**	**Workers to follow the process below and use resources in the toolkit.** **Consult with local authority for advice and guidance. Inform social worker or nurse if involved with person.**	**Referral to Social Services to follow process below and use resources in the toolkit.**

For further information on the risk assessment processes please see Barnett, D (2018) *Self-Neglect and Hoarding: A Guide to Safeguarding and Support.* London: Jessica Kingsley

11. Support Processes

Assessment	• Trauma, abuse, neglect or loss • Early parental relationships • Things that affected the person • Capacity Assessments • Mental Health assessment • Carers assessments (Including any capacity assessments) • Needs assessment
Risk Assessment (See previous tool)	• Environmental health • Risk to children, other adults, neighbours, others • Risk assessment relating to the person in their situation • Level of engagement • Level of clutter • Obstructive family members / friends • Housing structure, eviction threats, legal matters. mains services, finance
Multi Agency Involvement	• Commitment and compliance of agencies in line with safeguarding and treatment procedures • Safeguarding coordination (Chair) with Psychology led intervention (Combined approach to safeguarding and treatment) • Fire service support - Identify any high risk issues and work with the person to move objects away from these areas. Identify need for emergency service access. Place on high risk property list. Fire safety devices. • Social Work - assessment, response to mains services, manage eviction procedures, prepare services for when the person wants to begin decluttering, identify and obtain white goods required by the person and key furniture required. Help with community engagement, consider family / carer relationships (Carers assessments including capacity of carers to provide care) • CPN - support with mental health issues and psychology led decluttering process • Nurse / GP - Physical health matters • OT- Rehabilitation process
Therapeutic Intervention	The level of self-neglect / hoarding often equates to the level and strength of emotional turmoil the person experiences. Psychological assessment is required to untangle the complex comorbid mental health issues that manifest in self-neglect / hoarding behaviours. Childhood experiences, attachment issues, loss, bereavement trauma, abuse, neglect, grief can all be significant and result in anxiety, depression, paranoia, substance misuse, post trauma and many other mental health presentations, all of which require assessment and appropriate intervention

When using the tool above please remember that safeguarding is everyone's business. For cases of self-neglect/hoarding a multi-agency response may be required even if your local authority safeguarding team decide that they are not going to invoke safeguarding procedures. The Mental Capacity Act requires agencies to determine whether the person has the capacity to consent to actions, tenancies, repairs, services, assessments etc. It is likely that a number of agencies will be required to conduct capacity assessments, or support someone to undertake capacity assessments with the person self-neglecting. Other forms of abuse or neglect must be ruled out.

We have an obligation to ensure the safety of others. This may mean that planning is not just about the individual with whom we are working and therefore may have limitations, or restrictions on their choice. No one's choice should cause a crime to be committed against, or a harm to occur to, someone else. Some examples of this may be where there is a fire risk, safeguarding concerns for children or other vulnerable adults, where there is reasonable suspicion of a crime, risks to animals, public health issues.

We must record referrals that we have made to ensure the safety of others. In addition to this the person may not have choice when their mental wellbeing is significantly affected and they require detention under the Mental Health Act for their own safety and wellbeing and that of others. After all other considerations have been made, we must differentiate between the person's own autonomous decision making where they have the capacity and ability to make a decision, even if we consider this to be an unwise decision and those situations where we must assess capacity and make Best Interest decisions under the Mental Capacity Act. If a person has capacity and is considered to be making an unwise decision, this does not mean that we should disengage with the person. We should record the information and advice given, attempts at assessment and dates for review. In all cases we should:

- Record the dates and contact details for all referrals made
- Ensure that the safeguarding plan identifies required capacity assessments and responsible agency for conducting those assessments, including assessment completion date.
- Capacity assessment outcomes are recorded in the safeguarding records against the requests for the assessments to be conducted
- Referrals to GP, psychology, psychiatry are recorded and the Safeguarding Adults Board holds agencies accountable for safeguarding the person concerned
- Mental Health Services consider the presenting mental health matters and create a programme of therapeutic and/or mental health interventions to support the person with issues such as anxiety, depression, post-trauma, attachment issues, sensory stimulus issues, impulse control, compulsions etc. The treatment plan should be prepared and recorded. Intervention with the person by all agencies should be therapeutically led by psychology
- Legal requirements are identified and discussed keeping the person central to the discussion and considering the person's human rights – record what they did said, expectations and requested outcomes. Provide a rationale for proportionate responses and lawful justification, if required to act against the wishes of the person. Establish what being safe means to the person
- Medical and social needs assessments are conducted and recorded with a clear care and support plan that incorporates any harm minimisation approaches and safeguarding matters
- Carers' assessments are conducted and recorded. Capacity assessments are conducted on any carers where there are obstructive behaviours creating restricted access of services to the person self-neglecting/hoarding and/or where there are concerns. Legal obligations and risks in obstruction are explained to the carers and coercive and controlling behaviour is considered in relation to domestic abuse and appropriate referrals. Carers struggling to cope are offered support. The impact on carers' health and wellbeing is considered throughout safeguarding interventions.

12. Mental Capacity

As noted earlier, there will be a range of situations where capacity issues have to be considered. This section provides brief information on these matters. 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:

- A person must be assumed to have capacity unless it is established that they lack capacity
- A person is not to be treated as unable to make a decision unless all practical steps have been taken without success
- A person is not to be treated as unable to make a decision merely because he makes an unwise decision
- 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
- 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.

When a person's hoarding behaviour poses a serious risk to their health and safety, intervention will be required. With the exception of statutory requirements, any intervention, or action proposed must be with the person's consent. In extreme cases of hoarding behaviour, the very nature of the environment *should* lead professionals to question whether the person has capacity to consent to the proposed action or intervention and trigger a capacity assessment. This is confirmed by the MCA code of practice, which states that one of the reasons why people may question a person's capacity to make a specific decision is "the person's behaviour or circumstances cause doubt as to whether they have capacity to make a decision" (4.35 MCA Code of Practice, P. 52). Arguably, extreme hoarding behaviour meets this criterion and an assessment should take place. Consideration must be given where there is dialogue, or situations that suggest a person's capacity to make decision with regard to their place of residence or care provision may be in doubt.

Any capacity assessment carried out in relation to self-neglect/hoarding behaviour must be time-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 multi- disciplinary team, they are responsible for making the final decision about a person's capacity.

If the person lacks capacity to consent to the specific action or intervention, then the decision maker must demonstrate that they have met the requirements of the best-interests 'checklist'. Due to the complexity of such cases, multi-agency meetings to coordinate capacity assessments may be required. Where the person denies access to professionals the person who has developed a rapport with the person self-neglecting will need to be supported by the relevant agencies to conduct capacity assessments.

In particularly challenging and complex cases, it may be necessary for the local authority to refer to the Court of Protection to make the best interests decision. Any referral to the Court of Protection should be discussed with legal services and the relevant service manager.

What is the difference between competency and capacity, and why is this important when working with people who self-neglect and / or hoard?

Competency

To be competent means that the overall function of the brain is working effectively to enable a person to make choices, decisions and carry out functions. Often the mini mental state test is used to assess

competency as part of the diagnostic process. For many people who have, suffered trauma, have a hoarding disorder or have early symptoms of mental ill health the basic test is not sufficient on its own to explore the complexities associated with executive function. Further tests would be required. .

Executive Function
The executive function of the brain is a set of cognitive or understanding/processing skills that are needed to plan, order, construct and monitor information to set goals or tasks. Executive function deficits can lead to problems in safety, routine behaviours, voluntary movements and emotional wellbeing – all associated with self-neglect and hoarding behaviours. The executive functions are the first to be affected when someone has, for example, dementia.

Capacity
Capacity is decision-making ability and a person may have quite a lack of competency, but be able to make a specific decision. The decision-making ability means that a person must be able to link the functional demands - the ability to undertake the tasks, the ability to weigh up the risks and the ability to process the information and maintain the information to make the decision. In some way shape or form the person has to be able to let the person assessing them know that they are doing this. Many competent people make what others would consider to be bad decisions, but are not prevented from taking risks and making bad decision. This is not a sign that a person lacks capacity to make the decision, just that they have weighed everything up, considered the factors and determined that for them this would be what they wanted. The main issue in the evaluation of decision-making capacity is the process of making the decision, and not the decision itself.

Why do I need to know this?
This is important because the first test of the capacity assessment asks: is there an impairment of the brain function or mind? Someone who hoards or self-neglects can take huge risks with their own health, and often professionals presume the person to have capacity. They are deemed competent due to their clear communication and sometimes a lack of diagnosis. The person is therefore considered to not meet criteria for a capacity assessment and is said to be making poor decisions, that are autonomous and therefore they are able to make this choice without professional intervention. If you are concerned then an assessment of the executive functions of the mind would support the capacity assessment in the functional aspect (Part 1). Diagnosis of Hoarding Disorder may be required.

The second part of the test should be directly related to the first part. This means that a person can only be said to lack capacity if the reason for the inability to understand the decision to be made – and weigh up the risks and positives of a situation, and retain and communicate the decision – directly links to the functional aspect of the test or the impairment of the brain function or mind. If the first element of the test is not accurately assessed then this creates difficulty in understanding whether the person can undertake these decision-making tasks.

Even when someone is diagnosed as lacking capacity this does not mean that services make the decision on their behalf for their 'own safety,' this means that appropriate risks should be managed and considered to facilitate not merely a safer life for the person but also a happier and more fulfilled life.

Capacity decisions should not be broad decisions about care, services or treatment, they should be specific to a course of action. If a practitioner requires the consent, agreement, signature or understanding of the individual, then they should determine the capacity of the person to consent to that action using the assessment process defined in the Mental Capacity Act (2005). This may be for tenancy, individual treatment options, aspects of care offered, equipment required, access to services, information sharing or

any intervention. If you understand the course of action being proposed and offered to the person, then you will be the person required to assess the individual's capacity to consent to the proposed care, service or treatment. If there is only one agency able to gain access to the person, all agencies are responsible for developing questions, for that agency to ask, to determine their capacity as well as is practicably possible. Some examples may be:

Housing – The housing officer understands the tenancy agreement, therefore they will be the appropriate person to determine whether the person understands the tenancy agreement. The Housing Officer will need to conduct (and record) a capacity assessment where there is doubt about the person's ability to provide consent. If the person is deemed to lack capacity to make that decision a 'Best Interest' decision must be made. A third party cannot sign a tenancy agreement on behalf of another person unless they have Court Appointed Deputyship or a Lasting Power of Attorney that specifies such actions under 'Finance'.

Health – If a health professional is proposing a course of treatment, medication or intervention, they understand the intervention proposed, therefore they are the person to determine whether the person self-neglecting understands the intervention. If the Health professional doubts the person's ability to understand they must conduct (and record) a capacity assessment. If the person is deemed to lack capacity to make that decision a 'Best Interest' decision must be made. A third party cannot give consent on behalf of another person unless they have Court Appointed Deputyship or a Lasting Power of Attorney that specifies such actions under 'Welfare'.

Occupational Therapy – The Occupational therapist (OT) understands the rehabilitative process/equipment required by the person to meet their needs. If the person does not appear to understand then the OT must assess the person's capacity to make a decision about the proposed equipment or offered services.

If services are refusing to conduct capacity assessments for safeguarding purposes (wrongly deferring to Social Workers to conduct assessments that they know little about), and where a person's wellbeing or even life may be at stake, then the Safeguarding Adults Board needs to consider whether those agencies are truly considering consent and how many people may be affected by capacity and consent not being considered appropriately. This practice may constitute a violation of a person's right to autonomy and access to person centred provision of care and support. Agencies should be supported to change, but at some point (Where there is a serious risk to mental / physical wellbeing and life) they must be held accountable where organisational practices constitute a violation of rights and therefore abuse. We have a duty both lawfully and ethically to save a person's life, or prevent deterioration of their wellbeing if we can.

13. Mental Capacity Assessment

1. Diagnostic Test

Is there an impairment or disturbance of the functioning of the brain or mind (permanent or temporary)?

Yes

No

If impairment is not present, record advice, support and guidance offered, record refusal, make any arrangements possible with the person regarding safety. If there are significant risks and the person's decision making may be affected by something not diagnosed or considered to date then the inherent jurisdiction of the court may be used to make a decision. Speak with legal services and consider making a referral to the Court of Protection.

2. Functional Test

A. Understand
With all possible help / support given and recorded, the person is able to understand the information relevant to the decision.

Yes

B. Retain
Is the person able to retain the information long enough to make the decision?

Yes

C. Weigh-up
Is the person able to weigh up the information as part of the decision-making process?

Yes

D. Communicate
Is the person able to communicate the decision?

Yes

Answer =
If the answer is **yes** to all four questions in the functional test then the person has capacity to make that decision at that time. The assessment is justification for enabling the persons autonomous decision making.

One 'NO' answer to questions A – D= the person lacks capacity to make that particular decision at that time

A 'Best Interest' decision will need to be made. The person will require an appropriate advocate.

A decision made in someone's best interests does not mean a risk averse decision. The decision must be proportionate to the risks, the situation and the strength of the person's wishes, values and feelings in relation to the decision being made. No one wants to live a 'Safe but miserable life'.

14. The Need for a Multi-Agency Response

In all complex cases of self-neglect, where there are concerns that the person's wellbeing will deteriorate, or that the person may eventually die if agencies do not provide the appropriate support, then a multi-agency response will be required. Where the diagnostic criteria for Hoarding Disorder is met, or where self-neglect/hoarding are related to a former trauma, or loss, then it is essential to coordinate agencies and have involvement of mental health services.

It does not have to be the local authority who chair any necessary meetings, the most appropriate service with knowledge of the issues and legal frameworks can coordinate the multi-agency response and feed back to the local authority. Psychology led interventions in relation to the person's therapy, treatment and interactions with others will gain the most successful results, with an OT conducting rehabilitation support for continued and maintained mental wellbeing. This is coordinated a little like a joint Care Plan Approach (CPA) with a safeguarding meeting to consider both the treatment and the safeguarding as part of the same journey of support. Communications and interventions with the person are most effective when under psychology direction.

So far we have identified the need to coordinate the risk assessments, the needs assessments, the capacity assessments, the carers assessments and the legal frameworks within the multi-agency approach. The responses will need to be timely in relation to the treatment plan and therefore clearance will be required when the person is ready, mains services will need to be addressed, bills and finances considered, and health care matters and engagement with local community thought through. This requires planning in conjunction with ongoing rehabilitation. The other aspect of planning required is information sharing and governance. What information can be shared with whom and when?

15. Information Sharing

Who will share information with the person self-neglecting, how will information be shared. Consider accessibility and the person's ability to access services and how appointments should be offered to the person. Methods of communication will also need to be coordinated, it is important that the person feels supported and not overwhelmed by the safeguarding process. The person's autonomous decision making (where capacitated) will be central to this process. All decisions directly relating to the individual wishes, values and expectations will be made by the person concerned when they are capacitated. Your duty of care means that you must respect the autonomy of the person including the ability to make unwise decisions. The person has a right to private life that means autonomous decision making without the intrusion, or disproportionate intervention of professionals. When a person is deemed as lacking capacity to make a decision, then the least intrusive, least restrictive and most proportionate intervention should be considered with an emphasis on the wishes and values of the person.

The Care Act 2014 states that information sharing should be consistent with the principles set out in the Caldicott Review published 2013 entitled, "Information to share or not to share: the information governance review" and we now have the General Data Protection Regulation (GDPR) which states that we must not seek consent in circumstances where there is lawful reason to share the information.

Information will only be shared on a 'need to know' basis when it is in the interests of the adult:

- Confidentiality must not be confused with secrecy
- Informed consent should be obtained but, if this is not possible and other adults are at risk of abuse or neglect, it may be necessary to override the requirement

- It is inappropriate for agencies to give assurances of absolute confidentiality in cases where there are concerns about abuse, particularly in those situations when other adults may be at risk
- Where an adult has refused to consent to information being disclosed for these purposes, then practitioners must consider whether there is an overriding public interest that would justify information sharing and wherever possible the Caldicott Guardian should be involved
- Decisions about who needs to know and what needs to be known should be taken on a case by case basis, within agency policies and the constraints of the legal framework
- Principles of confidentiality designed to safeguard and promote the interests of an adult should not be confused with those designed to protect the management interests of an organisation. These have a legitimate role but must never be allowed to conflict with the welfare of an adult. If it appears to an employee or person in a similar role that such confidentiality rules may be operating against the interests of the adult then a duty arises to make full disclosure in the public interest.

Whether information is shared or not (and whether this is 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 recorded proportionately demonstrating why a course of action was chosen – I did this because… I ruled this out because… I chose this because…
- Be shared securely.

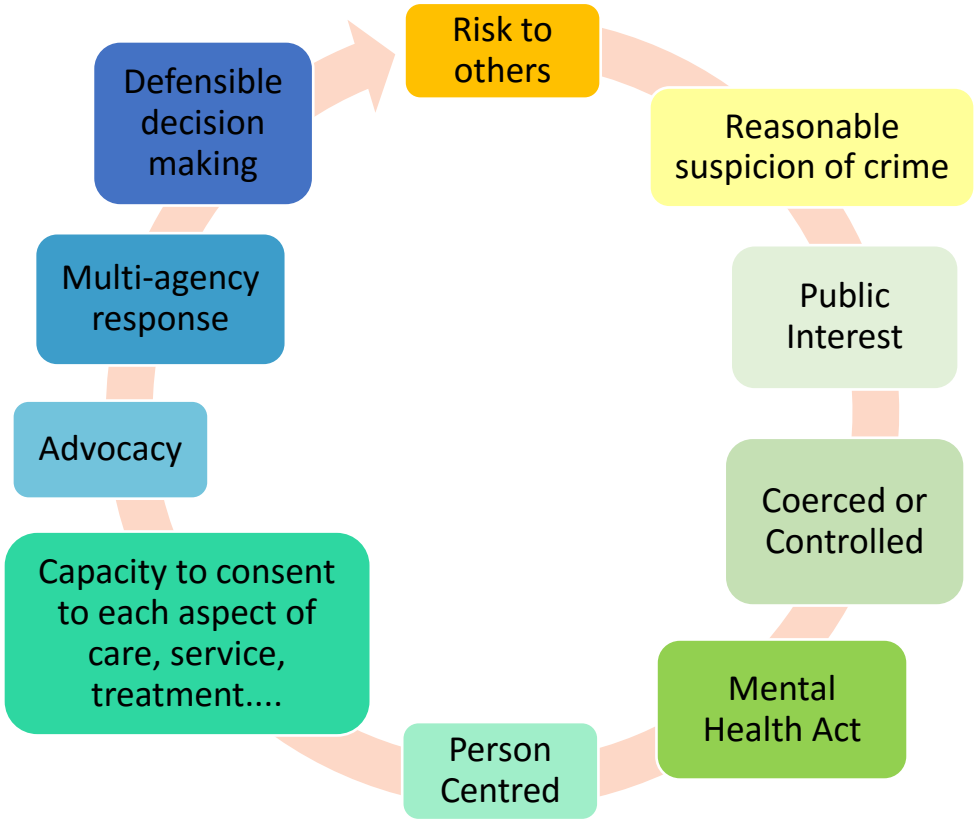
16. The Circle of Information Sharing Decisions

The circle of information sharing can be used to inform the process of decision-making and information sharing, and is particularly helpful where a person has capacity and does not want a safeguarding referral made. As already noted, safeguarding is not just about the person themselves, but also the safety issues of others.

The safeguarding enquiry (S42 of the Care Act, 2014) will need to consider Steps 1, 2 and 3 as set out in the diagram below and address the presenting risks. Beginning with step 1, the referral for safeguarding means that the enquiry can consider whether there is a potential risk to others, for example, rats, vermin, fire risk, toxic substances. Next, step 2, the enquiry will need to consider whether the person is subject to any criminal activity such as anti-social behaviour, domestic abuse, financial abuse, or historical abuse. Step 3 will rule out any public interest issues such as explosive substances, high risk perpetrators, and structural issues that pose a risk, or any public health matters. In situations where a person may appear capacitated to make a particular decision but other influences such as coercion or severe mental ill health may impact upon the decision-making ability the enquiry will have to consider whether there is true consent. The enquiry will identify whether the person has been subject to coercive or controlling behaviours and therefore cannot consent in step 4. The person's mental health may be significantly affected and it may be considered that they require a Mental Health Act assessment requiring potential detention under the Mental Health Act (1983 / 2007).

Once all this information has been established through the enquiry process, then the needs, wishes, expectations and outcomes that the person wants are central to any decisions made about them and for them. To achieve this, capacity assessments will need to be coordinated and conducted by all relevant professionals. The person may require an advocate to speak up on their behalf. Consideration will need to be given about what agencies are involved and who needs to be involved in supporting the

person and practitioners need to ensure that all actions and recording are legal and state how the law has been applied.



Since the beginning of policing and care services there have been a set of ethics that state that people are entitled to make autonomous decisions, as long as they are:

1. Autonomous without mental ill health, coercion, or intimidation
2. Not presenting a risk to others
3. Not committing or facilitating a crime against others.

Our legislation has evolved around this set of ethics and it is for this purpose that the Care Act statutory guidance identified the duty to share information for safeguarding purposes. Sections 14.69 – 14.80 of the Care Act Guidance identify that agencies are under a duty to report abuse to the Local Authority and the Local Authority must be satisfied that the agency has satisfactorily safeguarded the person concerned or conduct and enquiry.

17. Diagnostic assessment

In assessing and working with a person who hoards we may need to consider whether a referral for diagnosis is required. Following the DMS-5 diagnostic criteria for Hoarding Disorder a structured interview process was developed (Nordsletten et al., 2013). The principles of diagnosis were further explored using scaling as a method of assessment in assisting the person who hoards to self-reflect. (Steketee and Frost, n.d.)

To consider whether someone has a hoarding disorder we may need to consider their **ability to discard things and the impact this has on them emotionally**. This might include their ability to throw things away, give things away, sell things or recycle things. It is useful to know how a person feels about getting rid of things and the level of distress that this causes the person. This would help determine whether further psychological assessments may be required or whether the clutter has another attributable reason. It may be useful to use a scaling system of 0-10 to establish the level of distress a person feels when discarding or being asked to discard objects. 0 = little or no distress, 10 = severe distress and anxiety.

The impact of the clutter on the person. How does the person feel obtaining the items? (The positive aspects). How would they feel if asked to stop **acquiring** the objects? (Again, you can use scaling to determine how they feel about this). How does the person feel about the clutter, how do they feel about others seeing the clutter and how does this affect them on a daily basis? Please refer to the clutter rating scale and ask the person to identify the image that most reflects the relevant rooms of the house, or complete this yourself if the person is not able to. Some people may not have insight into the level of distress caused by the clutter, or removal of objects. This may have to be sensitively tested, in a hypothetical situation.

When hoarding behaviours began. If the hoarding has been problematic for a relatively short period of time, is there a reason why the person has so much clutter. Consider things such as a recent house move, inheritance, or other circumstances which might explain the clutter.

What kinds of things they hoard and what do they find most difficult to discard? There are usually themes and patterns to the person's collecting that are not instantly recognisable. It is helpful to explore this in some detail with the person to establish their themes e.g., animal hoarding, newspapers and books, food and food products, bric-a-brac, humorous items etc. It is useful to look at the differences between hoarding behaviours and collecting behaviours to determine this.

Does the person intentionally save the items? Does the person intentionally and actively seek to collect items or do they passively allow the items to accumulate? This helps in determining whether the person has a hoarding disorder.

Can rooms be used for their intended purpose? It is useful to decide how well each of the main living spaces can be accessed and utilised. It may be helpful to ask the person how they feel about each room of the house including, hallways, garages and loft areas. You might find it helpful to use a rating scale of 0-10, with 0 being I can easily use and access all the facilities in this room and 10 being I cannot access this room and safely use the facilities. Has anyone recently helped the person to remove any items and if so what, how and what volume? This helps to judge whether the situation would usually be worse.

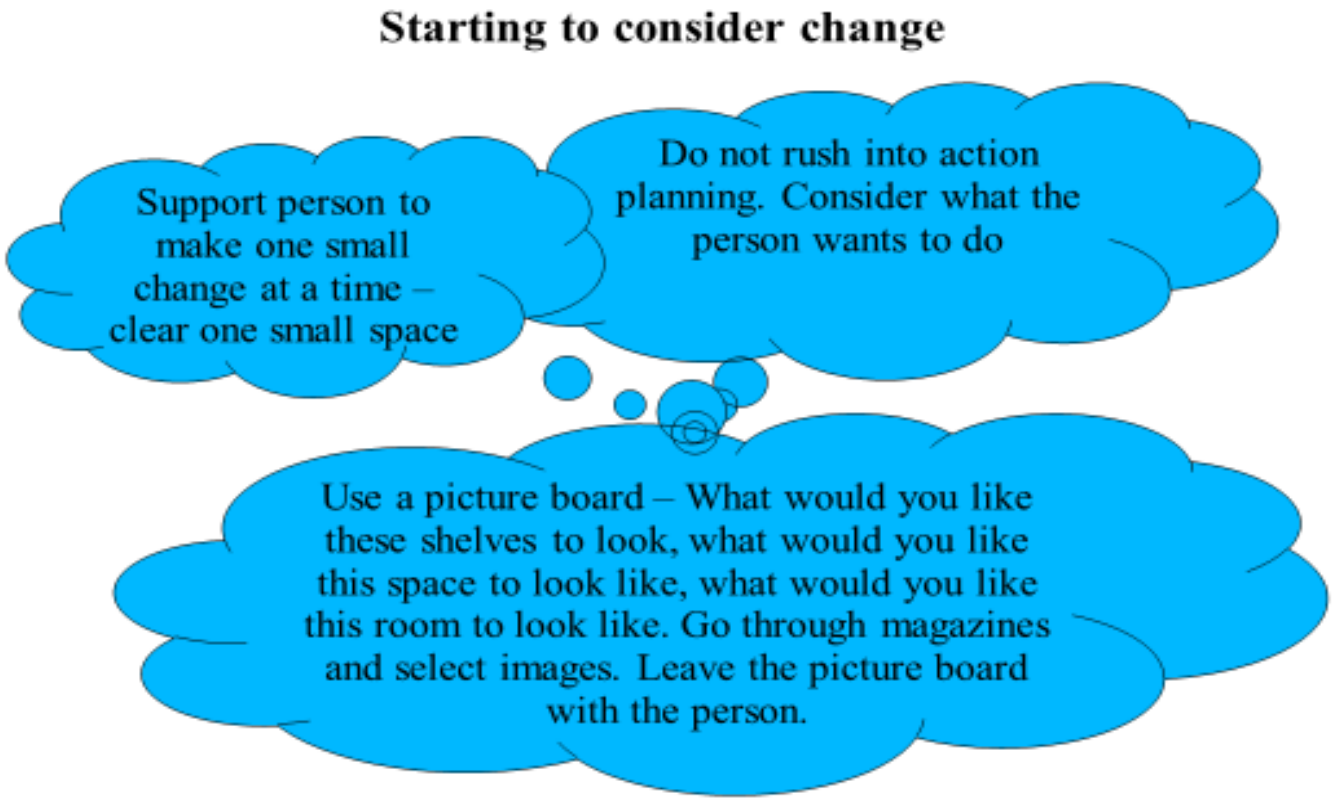
Does the person have difficulty sorting objects, or identifying appropriate places? How would the person feel about organising a small area? Is the person able to identify a specific purpose for the object or are there multiple reasons for keeping the object?

Is the person's ability to function socially and occupationally affected? Some people who hoard can interact well with others outside the home environment and their friends and colleagues may be unaware of the difficulties they face at home. Family member perspectives can be useful. It is also very useful to determine the roles that family members play i.e. do they live with the person, do they regard themselves as a carer for the person?

That hoarding is not associated with an inability to complete the tasks such as a learning disability, physical disability, Autistic Spectrum Disorder or other psychiatric problem. If a person is hoarding because they cannot physically achieve the task, or because their mental health condition prevents them from achieving the task and they have little or no emotional connection to the items, and could therefore discard the items without distress, a referral to the local authority will be required. This could be a safeguarding referral that would most likely result in a social work assessment to determine how these needs can be met.

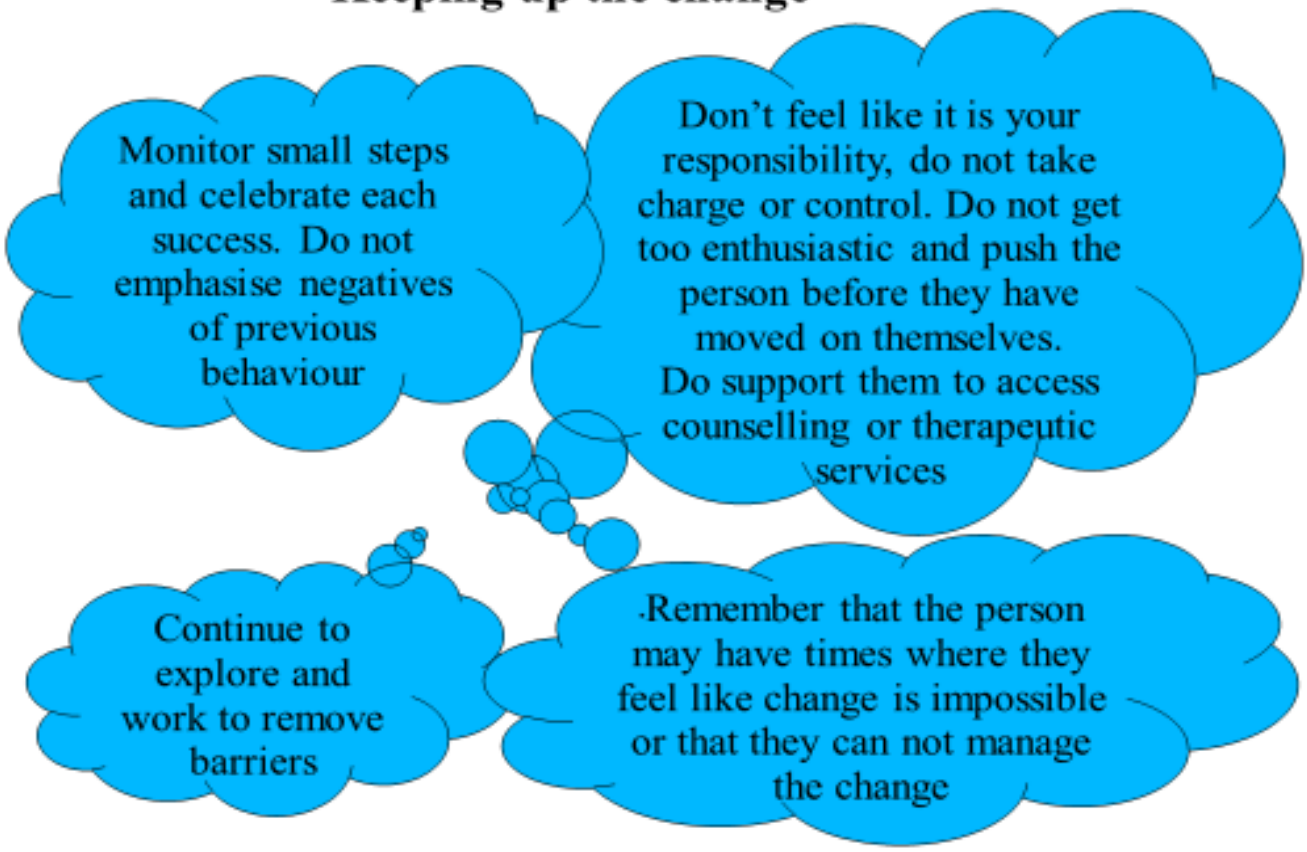
18. Beginning the Process of Change

Once the person has been supported by psychological and perhaps medical intervention to address any co-morbid mental health issues, in my experience it is they who are ready to begin the change, to stop neglecting, to declutter or to engage with others. Prior to this, the issues relating to the clutter or harm should only be addressed so far as harm minimisation with consent and cooperation of the person. Once they begin the process of change then a community psychiatric nurse or suitable OT with need to support the psychological issues associated with the goods that are hoarded.



Picture and story boards are a good way to engage a person. Ask the person where they would like to start organising. It may be a shelf area or a table top. Begin small and in a place that the person feels would benefit them. Ask the person to find pictures or images of what they would like that space to look like. Get the person to establish small targets. Support sorting and organization of goods with positive reinforcement.

Keeping up the change



19. The Do's and Don'ts

When talking to someone who hoards DO NOT:	
	**Use judgmental language.** Like anyone else, individuals who hoard will not be receptive to negative comments about the state of their home or their character (e.g. "What a mess!" "What kind of person lives like this?") Imagine your own response if someone came into your home and spoke in this manner, especially if you already felt ashamed.
	**Use words that devalue or negatively judge possessions.** People who hoard are often aware that others do not view their possessions and homes as they do. They often react strongly to words that reference their possessions negatively, like "trash", "garbage" and "junk".
	**Let your non-verbal expression say what you're thinking.** People who hoard are likely to notice non- verbal messages that convey judgment, like frowns or grimaces and may notice negative body language.
	**Make suggestions about the person's belongings.** Even well-intentioned suggestions about discarding items are usually not well received by those hoarding. You must work at the pace of the person concerned.
	**Try to persuade or argue with the person.** Efforts to persuade individuals to make a change in their home or behaviour often have the opposite effect – the person actually talks themselves into keeping the items.
	**Touch the person's belongings without explicit permission.** Those who hoard often have strong feelings and beliefs about their possessions and often find it upsetting when another person touches their things. Anyone visiting the home of someone with hoarding should only touch the person's belongings if they have the person's explicit permission.

When talking to someone who hoards DO:

	**Imagine yourself in that person's shoes.** How would you want others to talk to you to help you manage your anger, frustration, resentment, and embarrassment?
	**Match the person's language**. Listen for the individual's manner of referring to his/her possessions (e.g. "my things", "my collections") and use the same language (i.e. "your things", "your collections").
	**Use encouraging language.** In communicating with people who hoard about the consequences of hoarding, use language that reduces defensiveness and increases motivation to solve the problem (e.g. "I see that you have a pathway from your front door to your living room. That's great that you've kept things out of the way so that you don't slip or fall. I can see that you can walk through here pretty well by turning sideways. The thing is that somebody else that might need to come into your home, like a firefighter or an emergency responder, would have a pretty difficult time getting through here. They have equipment they're usually carrying and firefighters have protective clothes that are bulky. It's important to have a pathway that is wide enough so that they could get through to help you or anyone else who needed it. In fact, the safety law states that [insert wording about exits/ways out must be clear], so this is one important change that has to be made in your home.")
	**Highlight strengths.** All people have strengths, positive aspects of themselves, their behaviour, or even their homes. A visitor's ability to notice these strengths helps forge a good relationship and paves the way for resolving the hoarding problem (e.g. "I see that you can easily access your bathroom sink and shower," "What a beautiful painting!", "I can see how much you care about your cat.")
	**Focus the intervention initially on safety and organisation of possessions and later work on discarding.** Discussion of the fate of the person's possessions will be necessary at some point, but it is preferable for this discussion to follow work on safety and organisation.

20. Why do Agencies Struggle in Cases of Self-Neglect?

Key Factor	Impacting Issues	Potential Responses / Outcomes	Potential Solutions
Recognising and reporting self - neglect	• No clear safeguarding procedures on self-neglect • No clear definition of when to refer to safeguarding and when to manage as a single agency • Inconsistent definitions of self-neglect • No clear models of intervention • No clear risk assessment tools • No specific training in self –neglect across all agencies.	• Differing responses • Single agency left with complex case • No safeguarding procedures and multi-agency co-ordination • Inconsistencies in referrals to safeguarding • Defensive rather than solution focused practice.	• Clear procedures on for safeguarding in cases of self-neglect • A Care Act based definition of self-neglect across all procedures • A specified model for intervention • Tools to assess the level of risk • Specific multi-agency training • Practice that works on the strengths of the individual and solutions rather than defensive practice.
Recognising safeguarding as a response that addresses victim, perpetrator, family and community issues	• No recognition of the risks to others • No identification of the impact of behaviours on others e.g., neighbours, family and carers • No carers assessments • Not recognising other forms of abuse such as mate crime, financial abuse and anti-social behaviour.	• Complaints criminalise or impose penalties on the person self-neglecting exacerbating their difficulties • Family and support withdraw • Stress of carers is not supported • Perpetrator risks are not investigated and addressed (Financial abuse, anti-social behaviour of others, mate crime, physical and sexual abuse, neglect from carers).	• Earlier multi agency response • Co-ordinated responses with a key identified agency • Early rapport development with individual and family/carers • Address issues impacting on others via relevant legal frameworks • Safeguarding enquiries explore this issue.

Recognising the need for S42 enquiries in cases of self-neglect	• Reluctance to make appropriate enquiries • Lack of understanding about S42 enquiries • Lack of understanding with regard to a person's consent for safeguarding • Lack of understanding about the various potential responses to a S42 enquiry.	• Local authorities wait until self-neglect escalates to a severe situation before intervening – often this is too late • Some local authorities think that there must be consent for safeguarding – in cases of self-neglect the enquiry should be to determine capacity and consent. This results in the local authority withdrawing support at a critical time of intervention • Some local authorities feel that if safeguarding procedures are invoked that they need to be the key enquirer, or person to chair the safeguarding meeting and therefore do not invoke procedures early enough. There may be better placed agencies to manage the safeguarding issues with advice and guidance from the local authority, maintaining compliance with safeguarding duties and responsibilities.	• Lower level reporting of self-neglect (3-6 on clutter rating scale) • Clear training on when consent is not required for safeguarding purposes • Multi agency training in chairing safeguarding meetings in cases of self-neglect • Single point of contact trained and qualified to effectively triage safeguarding cases including cases of self-neglect.

Lack of understanding of the need to report 'Reasonable Suspicion of Abuse / Neglect'	• Agencies feel the need to investigate and therefore potentially destroy police evidence • Late police reporting • Inconsistent communication with police • Accumulating risk is not identified.	• Evidence is not preserved • Procedures are invoked at too late a stage to make a difference • Additional abuse and neglect is not explored • Carers who may be obstructive or disengage from care are not made aware of the potential consequences of their actions.	• Multi-agency enquiry/investigation training relating to 'Police Powers of Arrest' and why this links with the safeguarding process • Training explores accumulating risk and preservation of evidence • Policies and procedures clearly state that we do not need to know that abuse/neglect has occurred but only need reasonable suspicion.
Misunderstanding capacity and consent	• Individual agencies do not accept responsibility for capacity assessments and are not made accountable for capacity assessments • Capacity assessments are not coordinated.	• Capacity and consent is not assessed, recognised or recorded and potential responses to support the individual are missed • S42 enquiries do not explore the need to coordinate capacity assessments alongside risks • Advocacy and support is not considered • May violate the rights of the individual, or the rights of others to remain safe from harm • The person is assumed to have capacity when there	• The Safeguarding Adults Board to audit multi-agency capacity assessment standards • Multi-agency training in who does capacity assessments, when they are required, how to record capacity assessments and the consequences of not doing a capacity assessment • Enquiries consider social isolation, appropriate advocacy and a coordination of capacity assessments at an earlier stage of intervention

		are things that may indicate otherwise.	• Inherent Jurisdiction of the Court should be identified in Policies and Procedures as a consideration.
Holistic assessment	• Assessments are not conducted appropriately • Misunderstanding the requirement to assess when someone may lack capacity to make certain decisions and if there are safeguarding concerns • Lack of follow up in Mental Health Act procedures / Assessments under S117 • Lack of cultural and religious beliefs identified.	• The reasons for self-neglect are not identified and if appropriate supported • A clear holistic assessment across all agencies is not conducted • Risk assessments are not consistent • Risk management plans are not identified within appropriate legal frameworks • Support plans are from a single agency rather than a coordinated approach • There is no clear escalation process to manage spiralling risk • Services present barrier to access without having a clear picture of the risks • People disengage and services lose touch with them and their escalating risks • Models and methods of assessment with someone who is self-	• Safeguarding training that includes the duty to assess if there is reason to suspect that the person may lack capacity to consent to assessment • Training that includes the duty to assess where there is reasonable suspicion of abuse or neglect irrespective of whether the person engages • Policies and Procedures that reflect the above duties and maintaining contact with someone who self-neglects • A clear process of identifying and responding to people subject to S117 aftercare • Training in models of assessment - Assessment needs to explore potential mental disorder, trauma and trauma response, historical issues impacting on the person, social

		neglecting are not clearly identified. • Outcomes focus on clearing the clutter or healing the person before engaging with the person and their perspectives.	networks, physical health and nutritional requirements, personal philosophies and the identity of the person beyond what is observed and utilise cognitive and solution focused assessment alongside risk management approaches. • Executive Strategy Meetings or Executive Risk Assessment Meetings should cover multiple abuse or serious risk of harm to an individual with an overarching strategic response that supports individual operational responses. • Procedures should specify that clearing the clutter or focusing on the self-neglect does not work and only exacerbates the difficulties. A rapport must be developed before any removal of goods unless there is an imminent risk to others.

Information sharing	• Information is not shared with relevant agencies • Perceived barriers to information sharing • Lack of understanding of Caldicott Principles of information sharing.	• Agencies do not share relevant information as they fear it may be wrong to do so • Lack of recognition of duties under the Care Act to share information • Lack of understanding regarding the need to share information with the police and when to share information with the police • Barriers to gaining a clear picture of abuse and neglect.	• Clear information sharing procedures that explicitly detail responsibilities in relation to safeguarding • Safeguarding training includes information sharing procedures • GP and other health professionals have access to information even if not in attendance at meetings. Housing are made aware of key issues even if not in attendance at meetings and police where appropriate.
Pathways between services	• No clear pathways when multiple low level disabilities/mental health issues/substance misuse/previously 'Looked After' child. • No access and engagement of mental health services • No access and engagement of Substance Misuse services • No access to services for people who have Autistic Spectrum Disorders • Potential domestic abuse not identified.	• Someone who has multiple low level disabilities can be very vulnerable, but prevented from accessing Social Work Services • Key agencies do not know how, or are not able to support referrals to Mental Health services • Agencies send letters to people to offer appointments when the person is not able or not capable of responding to a letter and the case is closed in some of the most high risk cases	• Multiple risks are assessed holistically and an agency made accountable for this assessment • Clear procedures for access to mental health and substance misuse services including psychology and psychiatry– accountability and follow up • Face to face or telephone contact to ensure that the person has equitable access to services, where there has been no response to an appointment and risks of

		• Disputes between services about whether the person meets their particular criteria for intervention, disregarding the safeguarding eligibility criteria • Unclear accountability.	abuse/neglect identified. • Multi-agency safeguarding training identifies clear pathways for support • Safeguarding training addresses the need for domestic abuse to be identified and considered in relation presenting situation.
Multi agency response	• An early multi-agency response is not instigated.	• Issues of capacity and consent are unclear leading to little or no positive intervention or person centred work, other than leaving the person to their own devices. • Capacity assessments are not coordinated • A key person to have oversight of the process is not identified • There is no one allocated who can develop a rapport with the individual and involve them in the process • Historical abuse, trauma and neglect, or patterns of behaviour are not explored • Potential crime is not investigated	• The local authority do not need to manage all elements of the safeguarding process – they can have oversight and provide advice and guidance to others, when they are more appropriate to make enquiries or chair a multi-agency meeting. Policies and procedures should reflect this • Training in chairing safeguarding meetings and multi-agency responses should be offered to managers within all relevant agencies • All agencies need to be made accountable for safeguarding in cases of self-neglect and this should be address via policies

		• Coercive and controlling behaviours of others and the impact of this on the person is not explored • Carers needs/assessments are not identified • The persons Mental Wellbeing is not considered and referred appropriately • Preventative fire prevention is not considered • Risks to others are not considered • Support and advocacy for the individual is not considered • Therapeutic intervention is not considered • A single agency is left struggling to understand how to support the person and address risk.	and procedures and monitored via the Safeguarding Adults Board processes. • Examples of good multi-agency working should be shared and positive lessons learned from the experience.
Communication	• Systems prevent barriers to communication • Assessments and support plans do not include the interventions from other professionals • A key person to coordinate the assessment and support planning is not identified	• CPA and Safeguarding have competing outcomes • Too many meetings for an individual who may be unwilling to engage • There is no one person to contact to share information • Agencies disagree at critical points of care when they could be	• IT systems are not a barrier to communication. Staff should be encouraged to pick up the phone or go out to speak to each other. • Policies and Procedures should reflect Care Act requirements for

	• Communication breaks down between agencies • Agencies use differing and sometimes conflicting approaches.	discussed and conflict resolved earlier • IT dependent services identify systems as a barrier to communication without considering other methods • A clear picture of risk is not identified.	assessment and communication • Training in Care Act responsibilities: Maintaining wellbeing, preventing or delaying the need for services, community engagement, coordinated responses etc.
Non compliance	• Agencies withdraw from people who are obstructive or do not comply • The reasons for a person's resistance are not explored and clarified • People who may have a need for services are not aware of their rights to personalised services. They are not made aware that safeguarding is not imposing something (unless there is a crime or risk to others) but supporting the wishes, values, expectations and outcomes the person requires. • Labels are ascribed to a person due to noncompliance or behavioural responses.	• The underlying issues affecting the person are not fully assessed • The person has unrealistic perspectives and perceives that things can be imposed • The person is not made aware of their rights and their responsibilities in a clear manner • Services focus on the needs of the individual and do not offer an opportunity to consider themselves, others whom their actions impact upon • Attention of the professional is diverted to those cases where they feel they can do something and risks escalate, the persons emotions are not considered	• Training in motivational interviewing techniques to help a person begin contemplating their current situation and the incongruence with the desired outcomes • Support to assist the person engage in their local community resources – Care Act responses identified in training • Circles of Support identified around the person – procedures to identify this • Key person identified to engage with the person self-neglecting • Earlier intervention via a coordinated approach • Beware of labelling people as anti-social,

		and rapport is broken.	criminal or a nuisance without exploring the reasons behind these behaviours. – safeguarding training to address this.
Management and oversight	• Poor workload management • Inadequate resource allocation • Inconsistent perspectives • Supervision inconsistent • Poor caseload consideration.	• Time to engage and assess is not created • Appropriate resources and services are not mapped within the local area • Managers have a different perspective to practitioners • Competing caseload responsibilities are not discussed.	• Clear direction is given in policies and procedures • Supervision identifies cases of self-neglect and explores case load pressure • Managers to attend self-neglect training – more consistent responses • Services are identified to support work with people who self-neglect.
Knowledge and the legal framework	• Agencies do not have a clear knowledge and understanding of the relevant legal frameworks • Agencies are not aware of the Powers and Duties of the other agencies.	• Assumptions are made about the role or ability of other agencies to intervene. • Potential interventions are not explored or are missed • Recording does not reflect practice and is not justifiable or defensible.	• Policies and procedures reflect the legal frameworks available in cases of self-neglect • Multi-agency meetings/responses are developed to extract information from all professionals • Information is made available to all partner agencies.

21. Top Tips

1. Develop a rapport (Ideally this would be in conjunction with psychology-led interventions)

- Get to know the person, develop a rapport and find out when the self-neglect began
- Discover if there has been a time when things were different – what happened and how did this occur?
- Do not discuss change until rapport developed
- The earlier the intervention the easier it is for the person to consider change
- When a rapport has been established identify the life narrative of the person and find out about early experiences, any traumatic incident, abuse, neglect, loss or bereavement and how this affected the person.

2. Work, Activities and Education

- Find activities, work or education that the person enjoyed doing and try to help them to engage in community activities
- Getting out and meeting other people may help the person to reflect on their own situation. It may identify a structure for their day/week
- Meeting people and being valued by others may help in reducing the impact of trauma, loss, bereavement, abuse or neglect.

3. Self-Esteem

- Understand what feelings the person has about themselves, their house and why things are the way that they are
- Why the person is so attached to the current situation and if they were no longer in the situation, what would replace those feelings?

4. Strengths Based Approach

- Use a strengths based approach to determine the positive things that a person has in their life or can achieve for themselves and how they would like to manage risk
- Record capacity and consent issues effectively
- Use scaling questions – On a scale of 0-10, how do you feel about…?

5. Consider Methods of Motivation and Communication

- Part of the *change process* is to have *doubt, upset, anger, resentment and finally acceptance*. Plan how you can manage these changes and encourage the person to engage with appropriate counselling or *therapeutic support*.
- A person may well relapse, you can help the person to start the process over again with plenty of encouragement. Consider times when you have tried to change a behaviour or give something up, it often takes a few attempts.
- Use the miracle question: 'If you were to go to bed tonight and wake up in the morning a miracle has occurred. The house, surroundings and your life were suddenly transformed into your best

possible, realistic scenario. What would you see, hear, smell, be doing, feeling?'

6. **Create Cognitive Dissonance**

   - Often a person can see themselves in such a negative light that it disempowers them and prevents positive change, for example, 'I have always been untidy; I could never look as good as other people'.
   - By encouraging a person to **recognise their strengths** and then separating the identity as a hoarder from their hoarding behaviours, it may free that person to address the behaviours, for example, 'I know that the house is messy and cluttered, but I am an ordered and organised person; I recognise that I do not dress well, but I have always been good at making quality clothes'. Focus on the positive attributes of the person.

7. **Don't Rush – One small step at a time**

   - Take one small step at a time with lots of encouragement
   - Work together to identify the key issues in relation to safety and wellbeing
   - Work on making the person / property safe
   - Support the person in identifying what is important to them and what they would like to sort out first
   - Provide lots of positive reinforcement.

8. **Multi-Agency Response**

   - Consider the need for a multi-agency response; nursing, social work, public health, environmental services, housing, fire service, police, GP, mental health services in relation to assessing risk, preventing risk, addressing risk, support for the person and their family, capacity assessments and community engagement
   - Ensure that there is a co-ordinated response, chaired by someone who has enough seniority to delegate tasks and respond to situations. An action plan should be developed
   - Consider the assessment of any carers and the capacity of carers to provide care and support.

9. **Consider Wider Safeguarding Issues**

   Consider wider safeguarding issues such as:

   - Hate crime
   - Domestic abuse
   - Anti-social behaviour
   - Safeguarding other adults
   - Safeguarding children
   - Historical abuse
   - Risk from potential perpetrator to person and others.

10. **Do not Force Change if at all Possible**

- Moving the person only moves the difficulties to another place, unless the underlying factors are addressed
- If eviction is being considered, think about how to support the person to meet their needs before self-neglect escalates
- Often the sense of loss associated with large scale clean ups and eviction can have a negative impact, try to minimise this
- Safeguarding principles apply to all actions – don't forget the least restrictive, least intrusive intervention possible

11. Do Not Forget Defensible Decision Making

- Referrals made (Including safeguarding adults/children, mental health, police, Fire Service, medical)
- Appointments offered
- Capacity assessments
- Access to advocacy
- Person's choices and decisions
- Support given to help the person recognise/understand (information, advice and guidance given)
- Duty to assess and how that has been achieved
- Agencies involved – roles and responsibilities
- What was considered, what ruled out and why
- Based on law, policy, methods, models, theories, research
- Based on 'I statements' what the person wanted to achieve, or why this was not achieved and why choices made.

22. Issues for consideration

Homelessness increases – Up to 12% of people who hoard are threatened with eviction or have been evicted at huge cost to the person's mental and physical wellbeing and local authority budgets, with few or no positive outcomes (Tolin et al., 2007).

Increased use of mental health services - There is a five-fold higher rate of mental health service utilisation amongst people who self-neglect or hoard (Tolin et al., 2007).

Health impact of weight issues – People who self-neglect or hoard are three times more likely to be overweight (Tolin et al., 2007, Rust Ryan et al., 2016).

Cost to Housing/Local Authority – Average cost to Housing/Local Authority (er person hoarding) in North East £7,000 - £35,000 (Neave, 2017).

Cost and Resources, SARs – With SARs costing between £4,000 and £10,000 and utilising senior resource

intensive time, we could act ethically, spending less money and resources on saving lives rather than reviewing death.

Fire - "A quarter of all fire deaths are in homes where people hoard" - Steketee and Frost, 2014.

"The human cost of hoarding is a matter that causes anxiety across all Safeguarding Adults Board partnerships. We want to support people to live happy, fulfilled lives, maintaining mental and physical wellbeing for as long as possible. We want to prevent deterioration that leads to ill health and death" (Caiazza & Barnett, 2018)

Birmingham and the West Midlands fire and environmental health services estimate that supporting someone who hoards cost approximately £12,983 per case compared to costs of between £35,000 and £45,000 when not supported.

Targeted intervention – can lead to savings of around £2.70 and £3.50 for every £1 invested

General Points

- The prevalence of hoarding disorder is estimated between 1.5% and 6% (Lervolino et al., 2009, Timpano et al., 2011)
- Hoarding prevalence and severity of its symptoms intensifies with age (Ayers et al., 2010)
- Hoarding should be considered a serious and costly public health problem (Neave et al., 2017)
- Hoarding behaviours are progressive and chronic and linked to social isolation and high levels of distress (Tolin et al., 2007).

Early intervention and prevention of the deterioration of mental and physical wellbeing is necessary. We need a multi-agency psychology-led intervention to run parallel with and which informs safeguarding measures. We must re-focus upon what has caused the hoarding and self-neglect symptoms and gain appropriate support to address these issues. I hear many services state that they cannot afford to do this. For future resilience, legislative compliance and agency credibility, in addition to the obvious ethical and human factors, can we really afford not to?

23. Multi-Agency Support Services for Self-Neglect and Hoarding Disorder (HD-MASS)

Dr Roberta Caiazza (Senior Psychologist) & Deborah Barnett (Safeguarding Lead)

Creating a partnership between safeguarding and person-centred psychology-led interventions has proven to be highly successful, with 100% success over a 5-year period of working with people who hoard / self-neglect. We can work with your practitioners to demonstrate our approaches that have achieved positive results and service user feedback. We can show you how to safeguard people who self-neglect and / or hoard. Get in touch and discuss your needs. Allow us not only to tell you how to achieve this, but also to show you that our interventions are excellent in safeguarding people, completely person centred, save money and resources and create positive outcomes all round.

Tools and resources within this toolkit have been collected and adapted from a number of sources including Murton SAB, Durham SAB, Fire Service, Livin (Housing Durham) and resources from Steketee G & Frost R. These tools are intended to support practice consistent with the Care Act, but should not replace professional judgement.

- If you would like further training on self-neglect please get in touch
- Training can be single or multi-agency
- It is helpful to complete training in the Mental Capacity Act prior to attending the self-neglect training. T-ASC can provide Mental Capacity Act Training too
- If you require a consultant to discuss issues of safeguarding and self-neglect within your Local Authority I would love to hear from you
- If you require a Safeguarding Adults Review relating to self-neglect I am interested in being commissioned for any part of the process. Please forward Terms of Reference (No confidential information).

24. Contact details

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For further reading on the self-neglect and hoarding issues raised within this toolkit please read:

Barnett, D (2018) *Self-Neglect and Hoarding: A Guide to Safeguarding and Support.* London: Jessica Kingsley

careKNOWLEDGE

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