Self-Neglect and Hoarding – Learning from Safeguarding Adult Reviews

Jonathan Douglass

19 May 2021

Ground Rules

- Please stay “muted” to avoid problems with the sound
- Do ask questions via chat or by “raising your hand”
- Please show respect for other people’s views. We do not always agree with each other.
- Safeguarding is a difficult subject. Please take a break if needed.
- Copies of the PPT will be shared after the session, if you request a copy via chat or email – jonathandouglass@barnsley.gov.uk

Learning Outcomes

- Be able to summarise the key learning from recent Safeguarding Adult Reviews regarding Self-Neglect and Hoarding
- Be able to understand key learning from these Safeguarding Adult Reviews
- Be aware of summaries, tools and guidance that have been produced as a result of any findings from SARs
- Have had the opportunity to reflect on your own practice and knowledge
- Have had the opportunity to identify additional training needs

Some things to reflect on during the workshop

- Do you feel confident in recognising the signs of self-neglect and/or hoarding?

- Is it possible to identify patients who are registered, but have not arranged appointments in many years?

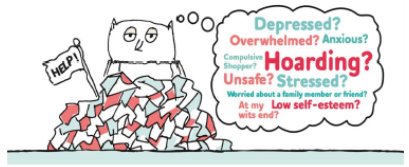
- Have you raised a safeguarding concern before?

- There was a 60% increase in the number of safeguarding concerns raised by GPs in 20/21 from 19/20 (19 increasing to 32).

Today.....

- We will consider the learning from the SARs conducted for Valerie and Ian from March 2021.
- We will look at overlaps with learning from Jack and Clive
- We will look at a SAR conducted by Salford City Council for Eric from October 2020. This highlights similar learning.
- We will also look at a SAR in Rotherham for David from January 2021.
- Introduction to the Hoarding Ice-Breaker and BSAB's Self-Neglect and Hoarding Policy.

Hoarding Ice-Breaker and Clutter Rating



www.hoardingicebreakerform.org

HOARDING, CLUTTER & DISORGANISATION Ice-Breaker Form

Empowering people whose health has been adversely affected by **clutter, disorganisation, compulsive acquiring/shopping** or **hoarding** to start a conversation with their GP or other medical professional, and get professional help and support

Dear Medical Professional

PLEASE HELP ME - I have a problem which is affecting my health

I think I have / I live with / I know someone who has a problem with hoarding / clutter / decluttering / compulsive shopping/acquiring

(delete as applicable)

I/my family member/my friend have *(tick all the boxes that apply):*

- ☐ A difficulty stopping acquiring things and accumulating them at my home
- ☐ Persistent difficulty discarding or parting with personal possessions
- ☐ Strong urges to save items
- ☐ A large number of possessions that fill up the active living areas of the home, workspace or other personal surroundings, and prevent normal use of the space (eg. can't use the toilet or kitchen; can't access the boiler or radiators; no heating/lighting, etc).
- ☐ Safety dangers in the home caused by too many belongings or faulty equipment (eg. slip/trip/fall hazards and/or fire risks)
- ☐ Become overwhelmed and find making progress to reduce the problem very difficult
- ☐ Severe difficulty with things like prioritising, planning, time-keeping, organising paperwork or paying bills regularly

*The most cluttered area of my/their home is rated _____ on the **Clutter Image Rating Scale** (it can be any room or outside space, not just a bedroom, as shown here).*

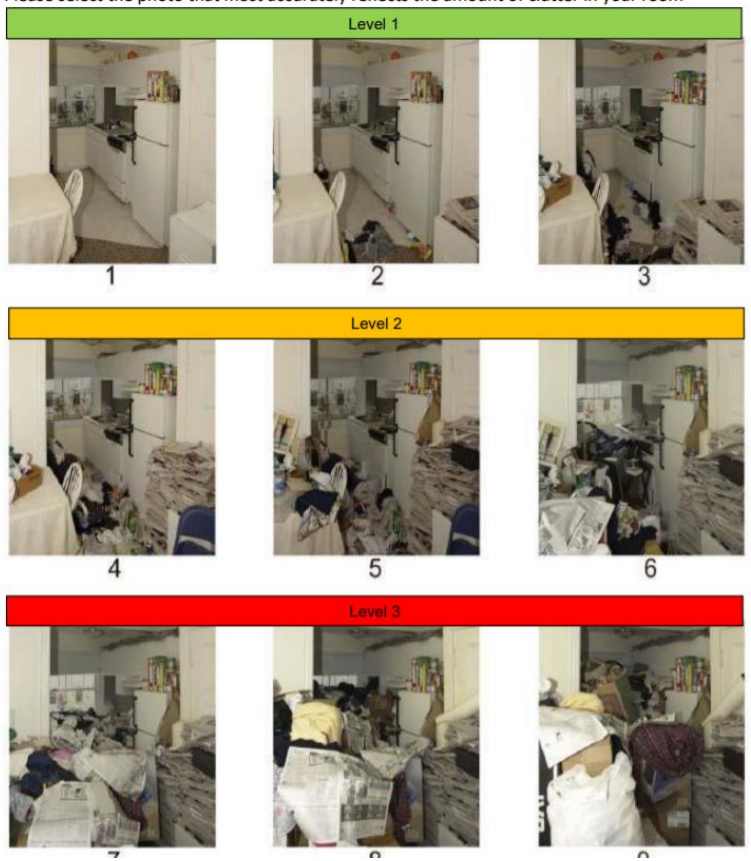
CLUTTER IMAGE RATING SCALE (bedroom)

I'm now at the stage at which I need to appeal to you, as a professional, to help me/them.

- ☐ I/we feel unwell because of this

Clutter Image Rating – Kitchen

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



When are SARs conducted?

- An adult at risk dies (including death by suicide) and abuse or neglect is known or suspected to be a factor in their death; or
- An adult has sustained a potentially life threatening injury through abuse, neglect, serious sexual abuse or sustained serious and permanent impairment of health or development through abuse or neglect;
- **and one of the following:**
- Where procedures may have failed and the case gives rise to serious concerns about the way in which local professionals and/or services worked together to safeguard adults at risk;
- Serious or apparently systematic abuse that takes place in an institution or when multiple abusers are involved. Such reviews are likely to be more complex, on a larger scale and may require more time;
- Where circumstances give rise to serious public concern or adverse media interest in relation to an adult/adults at risk
- ***Their purpose is to learning from what went wrong/could be improved and to share that learning to improve practice and outcomes.***

What is Self-Neglect and Hoarding Disorder?

- Gibbons et al (2006) defined it as “the inability (intentionally or non-intentionally) to maintain a socially and culturally acceptable standard of self-care with the potential for serious consequences to the health and wellbeing of those who self-neglect and perhaps to their community”.
- The Care Act Guidance states that self-neglect covers a wide range of behaviour; neglecting to care for one’s personal hygiene, health or surroundings and includes behaviour such as hoarding.
- Might be –
  - Lack of care for yourself
  - Lack of care for your environment
  - Refusal of assistance that might resolve these issues.
- Hoarding Disorder is defined in BSAB’s Self-Neglect and Hoarding Policy as “pattern of behaviour characterised by the excessive acquisition of and inability or unwillingness to discard large quantities of objects and / or animals that cover the living areas of the home and cause significant distress.”

About Valerie and Ian

- Ian was 86 years old when he died in April 2019.
- Valerie was 75 years old when she died in December 2019.
- Ian worked in the mines, and enjoyed gardening when he was younger.
- Valerie enjoyed doing puzzles, and always made sure that Ian got to his GP appointments. However, she would not go herself.
- They had 4 children together, who would do some shopping for them, and cook some meals. However, they were not allowed in the house.
- They would tell people that they had a “big dog that could be vicious”. However, this was not the case.

Brief Timeline

- Early Summer 2018 – Housing Offer (HO) from Safer Neighbourhood Services made referral – “severe self-neglect”, no bathroom and “a big dog that could be vicious”.
- Social Worker (SW) and HO tried joint visit, but were not allowed access. Couple were “very unkempt”, and refused to give contact details for family.
- HO tried further visits, but did not get inside.
- SW tried to find out who Valerie’s GP was, but couldn’t.
- Summer 2018 – SYFR visit, based on information from HO. They were not allowed inside.
- Autumn 2018 – HO and SYFR tried to visit again. They were not allowed in. Advice was given and the case closed.
- April 2019 – Ian was admitted to hospital. He died the following day.
- Valerie went to the Emergency Department as she was “unable to cope”. She used a coal fire, but was unable to light it. She had no hygenic surfaces for food preparation, a bucket was used as a toilet, she slept on the sofa and had no fresh food. She died within 24 hours.

Findings Included

Lessons Learnt

- We may need to consider a new approach – there has been training, but it may not have lead to a change in culture and working practices.
- Cases involving self-neglect continue to be closed without a risk assessment and without an understanding of why someone might refuse help.
- Struggle to balance people's private life and life style choices with our duty of care.
- Asking questions where there is a discrepancy between what someone is saying and their lifestyle – we need to show professional curiosity
- Impact of bereavement.
- Executive Capacity is not understood, or considered.
- The importance of building long term relationships and continuity.
- People being invisible to services, even if registered.

Good practice

- Housing Officer identifying the potential need and trying to engage with Valarie and Ian, and liaise with other agencies.
- BSAB is engaging with research (led by King's College London and LSE) looking at responses to self-neglect and hoarding in older people and what works in practice.
- Safer Neighbourhood Services have a pilot project to follow up on self-neglect and hoarding cases that have been closed – initially, this is cases closed in the previous 12 months. This is to try to build relationships with individuals and support long term checks.

Important characteristics of Valerie and Ian, Jack and Clive SARs include:

- Men and women were involved
- Ages of those involved ranged from 59 to 86
- Living arrangements varied and included owner occupier; private rented; Berneslai Homes
- Self-neglect was a feature in all three SARs
- Hoarding was a feature in all three SARs
- Open fires were present in two of the three SARs
- Family members were involved in all cases but their input was restricted by the individuals involved
- All were deemed to have capacity
- Alcohol featured in one case
- All received some form of external support: in two cases this came from family members and in one from ASC
- Bereavement played a role in all cases
- Professionals supported family and/ or friends to have a major influence on their contact with the adult and/ or allowed them to make decisions about whether services became involved or not Table 3 gives more details of parallels between the three SARs.

Eric

About Eric

- Eric had lived in Salford all his life, he was married, had a daughter and passed away in hospital age 81, with the cause of death being starvation.
- He is described by his family as someone who ‘lived life to the full’. He was passionate about classic cars, motorbikes and he enjoyed watching and playing various sports.
- He also enjoyed spending time outdoors and socialising.
- Eric was a private family man who perhaps struggled with getting older, the loss of friends and experienced episodes of depression.

Key Learning

- Be mindful of our own perspectives and how they impact our judgement and decision making – we should be open to other possibilities.
- Documented that *“no reason to doubt”* Eric’s mental capacity. However, whether he could act on decisions was not considered.
- Are there legal options that should be pursued.
- Escalate concerns through managers and get legal advice if required.

David

About David

- David was a man in his 60s when he died.
- He had worked as a butcher and in steel works.
- He was successfully treated for throat cancer in 2010, but it effected his eating and his quality of life.
- David had a long term relationship and a child. The relationship ended in 2015 as a result of his drinking. He had been dependent on alcohol since 2004.
- Alcohol remained an issue in David's life and care.
- He was supported by his mother, brothers and their wives. They raised multiple concerns about David.
- They said that David was *"not always easy to help"*. He would forget appointment and not follow through on care and treatment.
- He was found collapsed by a neighbour 10 months after moving into a new property. He had had no contact from services for the prior 7 weeks. He died 6 days later in hospital.

Key Learning

- David had little continuity of care, other than from his GP, who was noted as *"going above and beyond*". However, there were even gaps in this relationship, particularly following a temporary admission to a nursing home.
- Learning from discharge planning of step-down beds and for management of temporary GP registrations.
- There was a lack of flexibility in long term support.
- David had periods of time when he appeared to cope, and then periods where he would relapse. This pattern was not identified.
- David had mental capacity, but couldn't follow through on decisions. This impacts risk management.
- A lack of formalised risk assessment. Plans were lost and drifted.
- Lack of communication about David's engagement. He may have been unwilling to engage sometimes, but had memory problems, didn't always have a phone and used the wrong door. No records of some visits taking place, which were due.
- The family were involved, but this could have been more structured through a Family Group Conference. They were carers, but there was no record of any carers assessment.

Common Lessons for all the SARs

- Failure to attend appointments must be questioned – this may identify simple issues that can be resolved.
- Organisations were aware of self-neglect, but are not always persistent in following up or trying to build relationships with people.
- Family members' attempts to seek help for people are not always taken seriously as the person does not initially consent to them.
- We need to make sure support of family members is coordinated with professional support e.g. who is doing what and are they able to do it.
- There is a need to facilitate relational working over a long term where necessary together with an appreciation that progress is likely to be slow.
- GPs frequently being a trusted professional and offering the most continuity.
- Workers not aware of available services e.g. DWP visiting services
- Identifying bereaved individuals at risk and mapping/ making available to them possible interventions
- Bereavement services were not easily accessible
- Information sharing and collaborative working between agencies e.g. people going to the wrong door, or trying to phone someone without consistent access to a phone.
- Assessment of mental capacity in relation to decisions about service involvement etc and understanding the role of executive capacity
- BSAB's Self-Neglect and Hoarding Policy has not been embedded in practice, including the use of risk tools.
- Effective risk assessments were not conducted or maintained under the self-neglect and hoarding policy
- Workers require escalation routes for staff dealing with complex high-risk cases – use of supervision and team meetings.

Multi-Agency Working

Benefits……

- Shared knowledge and expertise – particularly for assessing risk.
- Increased resources, skills and sources of support for the person.
- Reduce risk of their being less continuity – sometimes workers take extended leave or change roles/organisations. There may be greater opportunity for continuity with multiple partners.
- Shared responsibility.
- It can be stressful for the practitioners and workers, not just the person.
- Joint learning.
- Constructive challenge.

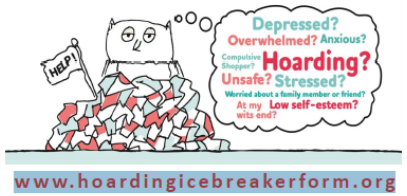
Be Mindful of…..

- Good multi-agency working does not mean all responsibility falls on one set of shoulders.
- Agencies must all be committed.
- Need clarity of roles – not just for the person, but for the practitioners too.
- Rigid ways of working can still mean that people slip through the net.
- Being mindful of different priorities within roles and agencies.
- Avoid delays in decision making.

Which agencies might be involved?

- Adult Social Care
- Children's Services
- Acute Hospital Trust
- Clinical Commissioning Group
- Housing Providers
- Mental Health Services
- Health/ GP/ District Nursing
- Safer Neighbourhoods
- Bereavement Services
- Ambulance Service
- Police
- Fire
- Providers of utilities
- Transport Providers
- Family/ neighbours
- DWP
- Advocacy
- Community Networks
- Faith Sector
- Community Safety
- RSPCA
- Prison Service/ Probation Service
- Environmental Health
- Care Agencies
- Community Health Services
- Social Prescribing
- Community/ Voluntary Sector

Hoarding Ice-Breaker and BSAB's Self-Neglect and Hoarding Policy



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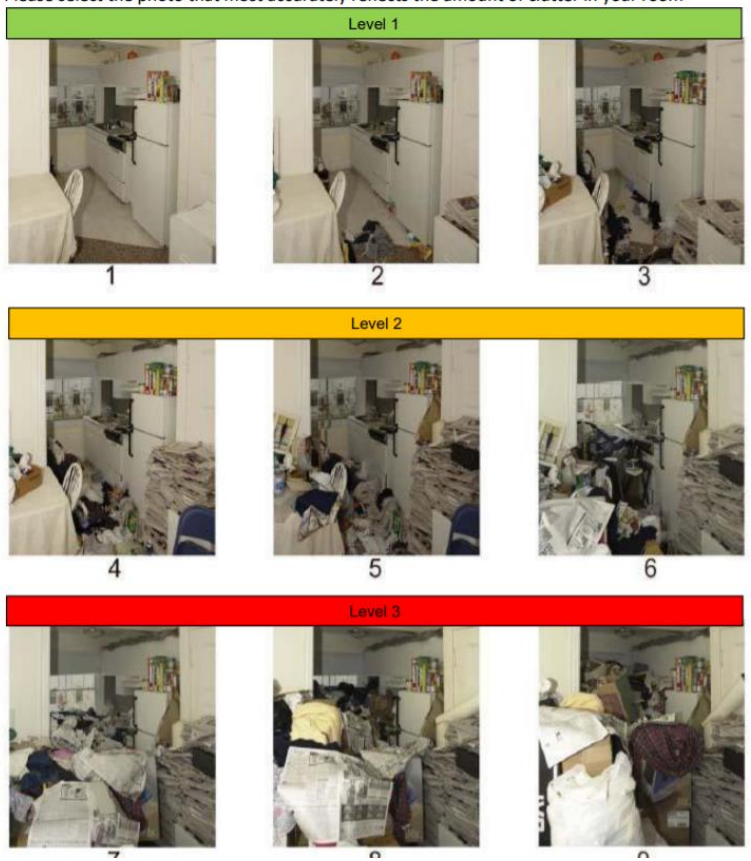

Questions for Self Reflection

- If contact is via the telephone, can you identify potential self-neglect and/or hoarding?
- How much do you understand about the work done by other agencies, and when people may be eligible for their services?
- How confident would you be in asking for additional support from colleagues and other agencies?
- Do you feel confident in constructively challenging the decisions of other agencies if you are concerned that someone is at risk of harm and their working is too rigid?
- How confident do you feel around assessing capacity and considering whether an individual has executive capacity to act on their decision?
- How confident are you at following the BSAB Self-Neglect and Hoarding Policy and risk assessment tools?
- Do your records reflect that you have done and your concerns?
- What additional support/training do you need?

Resources and Links

- BMBC Self-Neglect and Hoarding Summary Guidance - https://www.barnsley.gov.uk/media/14951/sn-and-hoarding-policy-summary-approved-july-2020.pdf
- BMBC Self-Neglect and Hoarding Full Policy - https://www.barnsley.gov.uk/media/15373/self-neglect-and-hoarding-policy-approved-bsab-may-2020.pdf
- Link to SAR reports for BMBC – including Valerie and Ian, Clive and Jack - https://www.barnsley.gov.uk/services/children-families-and-education/safeguarding-families-in-barnsley/safeguarding-adults-in-barnsley/barnsley-safeguarding-adults-board/safeguarding-adult-reviews-sars/
- Link to online Self-Neglect and Hoarding Course on POD - https://barnsley.learningpool.com/course/view.php?id=1781
- Link to the SAR for Eric in Salford - https://safeguardingadults.salford.gov.uk/safeguarding-adult-board/safeguarding-adult-reviews-sar/published-sars-and-other-reviews/
- Link to the SAR for David in Rotherham - http://www.rsab.org.uk/downloads/file/43/safeguarding-adults-review-david
- SCIE Guidance on Self-Neglect and Hoarding - https://www.barnsley.gov.uk/media/14951/sn-and-hoarding-policy-summary-approved-july-2020.pdf
- Hoarding Ice-Breaker - https://hoardingdisordersuk.org/research-and-resources/ice-breaker-form/