

Self-Neglect & Hoarding Workshop

West of Berkshire Joint Conference

Outline for the session

- What is self-neglect and what commonly goes wrong?
- Hoarding Disorder
- Mental Capacity
- Thresholds for Safeguarding

Exercise 1 - perceptions

- On your tables spend **5 minutes** writing down what you think we mean when we talk about 'self-neglect'.
- **Don't overthink it!**
- You might use a word or a short sentence. You might write down one thing or a number of things.

Group reflection

Exercise 1:

- How similar or broad were your ideas?
- What kind of language did you use?
- How objective versus subjective were your views?

Qu. So....what commonly goes wrong when we are working with self-neglect?

Findings from research & SARs:

What are the problems in agencies working with self-neglect?

1. Lack of agreed position statements by agencies on working with self-neglect
2. No agreed definitions as to what constitutes self-neglect
3. Lack of toolkits for practitioners when assessing and working with self-neglect
4. No specific training
5. No clear pathways from referral to intervention
6. Poor application of the Mental Capacity Act 2005
7. Gaps in knowledge and understanding of the legal framework

What is self-neglect?

Care Act Definition: “*a wide range of behaviour, including neglecting to care for one’s personal hygiene, health or surroundings and behaviour such as hoarding*”.

Qu. What other behaviours do you think this may manifest in then?

In broader terms....

It is recommended agencies consider the following aspects in relation to self-neglect:

- Lack of self-care to an extent it threatens personal health & safety
- Neglecting to care for personal hygiene, health or surroundings
- Inability to avoid harm to self
- Failure to seek help or access services to meet health or social care needs

Agencies should think of these issues in a broad context – not just in terms of obvious manifestations such as hoarding. Other areas to consider, include:

- Substance misuse issues
- Individuals with diagnosis of high functioning ASD who may have difficulties that bring them into frequent contact with services
- Prostitution where there may be issues of situational incapacity or exploitation
- People subject to frequent 'Missing Persons' Alerts, wherein they be putting themselves at risk of significant harm
- People with significant mobility issues who are not taking action to protect themselves from fire risk
- Those who are non-concordant with medication
- Bariatric patients
- Others, who as a result of vulnerabilities linked to their care and support needs are putting themselves at repeated high risk of significant harm

Models of understanding

Self-neglect is NOT a “life style choice”!!!

Qu. So what ‘causes’ self-neglect?

Models

Disease Model

A psycho-medical condition mostly likely accompanied by other mental disorders.

Socio-cultural Model

A social construct, influenced by social, cultural and professional values rather than an objective phenomenon.

Social-psychological Model

The interplay of a variety of physical, mental, social, personal and environmental factors, both internal and external. This means there are a variety of important factors for consideration... [What?](#)

Did you know...

- Hoarding disorder is now recognised as a mental health disorder?
- 2 to 5% of the population in the UK hoard?
- Around 1.2 million people in the UK have hoarding disorder?
- According to a 1981 study, approximately 70% of those who hoard animals are single women?
- Hoarding is also associated with other mental health issues – 57% of hoarders in a 2006 study were found to have a major depressive disorder

Source: 2017 'Understanding Hoarding', Jo Cooke

Hoarding Disorder

- Until May 2013, hoarding was only considered a symptom of OCD (anxiety issues and compulsions are often exhibited)
- In May 2013 DSM-5 (US) recognised Hoarding Disorder as a mental health disorder
- Not yet entered into ICD-10 (WHO, international) but anticipated to be included in the next version, due publication in 2018

Diagnostic Criteria

1. Persistent difficulty discarding or parting with possessions, regardless of monetary value...
2. ...due to perceived need to save the items and distress associated with discarding them
3. The difficulty discarding possessions results in the accumulation of possessions that congest and clutter active living areas
4. Hoarding causes clinically significant distress or impairment in social, occupational, or to other important areas of functioning
5. Symptoms are not restricted to the symptoms of another disorder (e.g. hoarding due to obsessions in OCD or delusions in a psychotic disorder)

DSM-5, May 2013

Triggers

Qu. In your groups spend 5 minutes thinking about *why* people might hoard?

Contributory Factors

- Genetics and family history
- Excessive guilt about waste
- Trauma
- Bereavement (*most common*), divorce/separation, loss (evictions, loss of possessions), redundancy
- Learned behaviour
- Moving frequently as a child
- Perfectionism ('just in case')
- Deprivation in childhood or earlier life
- Absence of meaningful relationships
- Aesthetic or artistic motivations
- Sentimental reasons – attempting to preserve a time when life was 'good'
- Abuse
- Cognitive issues affecting decisions making and problem solving
- ADHD, anxiety, depression, OCD, ASD
- Chronic dis-organisation or being overwhelmed (prevents person dealing with the issue)

Clutter Blindness

- Many hoarders are initially unaware of the extent of their clutter
- They may be accustomed to it
- A person may not recognise it until it starts to impact on them, e.g. they can no longer find things, or have simply run out of room
- When this happens, they may simply attempt to create additional storage space, e.g. in the garden or in a car

Clutter Image Ratings

- Developed in the US in 2007 as a rating scale for assessment
- Pictorial tool measuring clutter on a scale from 1 (no clutter) to 9 (severe clutter) for three main rooms (kitchen, living room, bedroom) in a typical home
- Fire Service refer to the ratings as 'fire loadings'
- Removes subjectivity from scaling the level of clutter
- Can also be used as an outcomes measure, demonstrating progress made

Intervention

Research:

- Has proven that using short-term, coercive interventions is not effective when working with people whom self-neglect.
- Has evidenced successful intervention is dependent on professionals taking time to build a relationship and gain trust
- Has shown intervention has to go at the person's own pace
- Demonstrates comprehensive, multidisciplinary responses are needed from as early as possible

Literature:

- Indicates social care, health, cleaning services, environmental health, fire service, police and the voluntary sector all have a key role to play

Evidence:

- Indicates task-centred and psychological interventions have to be combined and what tends to work in practice is a balance between 'negotiation' and 'persuasion'

Mental Capacity

Qu. What do we need to think about when assessing capacity in the context of someone who is self-neglecting?

Mental Capacity

1. Isolate the **decision**
2. Capacity is **dynamic**
and
 1. Consider **executive functioning**

When someone won't engage

- If an adult who is capacitated (in accordance with the MCA) does not want any intervention or safeguarding action to be taken, it may be appropriate not to intervene any further at that point. In making this decision, it is essential to consider whether:
 1. anyone else is at risk
 2. their 'vital interests' are compromised or not – that is, establish that there is no immediate risk of death or significant harm
 3. all decisions have been fully explained and recorded
 4. other agencies have been informed and involved as necessary
 5. there is a route back to re-referral or accessing support should the person change their mind

Thresholds for Intervention

Toolkit

Resources

- Association of Professional Declutterers and Organisers (APDO) www.apdo.co.uk
- Clouds End CIC www.cloudsend.org.uk
- Rainbow Red Professional Decluttering, Organising and Project Management www.rainbowred.co.uk
- Your living room CIC www.yourlivingroomcic.co.uk
- Help for Hoarders www.helpforhoarders.co.uk
- Test yourself for compulsive hoarding www.compulsive-hoarding.org
- www.flylady.net
- www.hoardingdisorders.uk.org
- SCIE Report 46; 'Self Neglect and Adult Safeguarding: findings from research'
- RIPFA Strategic Briefing: Self-neglect

Jo Cooke – ‘Understanding Hoarding’

