Self Neglect and Hoarding: A Primary Care Perspective

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Webinar plan

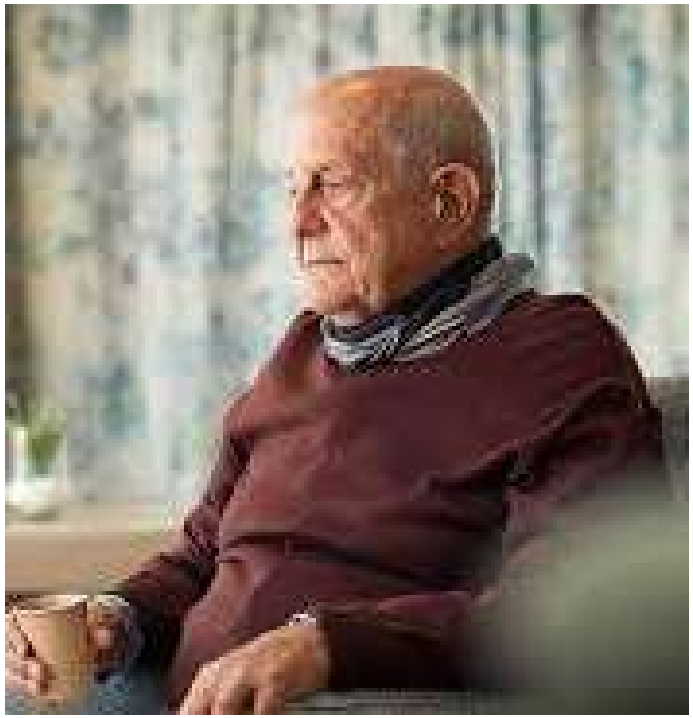
- Case Review: Jack's story
  - Barriers to care
  - Vulnerability factors
- Case Review: Jane & Karen's Story
  - Risk assessment
  - Assessment frameworks
  - Role of Primary Care
- Local resources
- Questions

Learning objectives

- Awareness of hoarding vulnerability factors and risk assessment
- Review relevant legal frameworks including Care Act 2014, MCA 2005 and MHA 1983 (2015) and their application to patients with hoarding disorder
- Consider our role as GPs and the wider MDT looking after patients who self neglect and hoard
- Improved awareness of local hoarding support services

Jack's Story

- 70 year old retired teacher
- **Well-educated, 'precise' and intelligent.** 4 degrees
- **Wife left** him after about 3 years of marriage, then **lived alone.** 1 daughter. **Younger brother and mother nearby.**
- Dec '03: 'hearing voices' – **schizoaffective disorder**. CPA reviews.
- Oct '04: OT assessment: no central heating and no running water. Cooker not connected. Stone flooring, small electric grill and hot plate. **Limited ability to prepare meals and mum apparently doing cooking and laundry**. Jack using open fire "when necessary"



Jack's Story (cont)

- Sept 2007 – discharged from MHT back under care of GP
- 2010: **Jack's mother diagnosed with dementia** and referred to Adult Social Care for assessment
- May 2012: GP Mental health review - 'stable on medications'. Bloods fine
- July 2012: Jack's **mother entered permanent residential care**
- April 2013: A+E with **bilateral periorbital haematomas** – fell after drinking a bottle of whisky. Jack said 'one off'. Smelled of alcohol, looked self-neglected. Denied any problems. Had capacity.
- Dec 2013: Arrested for stealing whisky from a store. Adult Safeguarding Referral by police. Brother concerned for Jack who was **not coping following their mother going into residential care year before**. 'No role for ASC' – referred back to MHT. Stopped medications a year ago. GP assessed.
- Aug 2014: Complaint from neighbour to housing association re **smoke from Jack's solid fuel burner** in their house. Repair officer visited, case resolved.

Jack's Story (cont)

- Oct 2014: Mother's care home contacted brother. Concern **Jack was giving mum alcohol**, nightie noted to be wet around neckline and smelling alcohol
- Nov 2014: GP Med Review: lifestyle and mental health. BP taken and weight, smoking cessation advice. Written notes - 'abusive voices last week', 'no medication'
- Nov + Dec 2014**: Antisocial noise complaints** - Shouting, cursing and moving furniture at night. No action taken by police as not a 'statutory nuisance'
- Jan 2015: **Mother EoL** following heart attack. Jack **tried to feed his mother bread**. When staff intervened, became verbally aggressive, police called. Jack asked to only visit at specific times so that he could be supervised. Jack's **younger brother asked to address behaviour with Jack.**
- Feb 2015**: Jack's mother died. Further noise disturbance complaints.**
- Jan 2016: Attended ED following a **fall**. Sustained a laceration to head. **Drunk** and **verbally aggressive** to staff. Head wound cleaned and glued. Found to have **'a pair of knives in his sock'**. Self-discharged.

Jack's Story (cont)

- Jan 2017: DWP visit. **Concerns about living conditions**, no gas, no electricity, does have running water. Cooks on open fire in bedroom. Brother struggles to contact and speaking through wrought iron gate. Beer bottles, rotting fruit and veg in lounge, house freezing. Jack exceptionally dirty. Goes out to shop, **will accept support. Adult safeguarding referral.**
- Feb 2017: Social worker: **Does have electricity but chooses not to use it, does not have gas, property is cold** and lives as a recluse, **does not bathe**. Brother advised he visits weekly but does not always gain access. Brother supports with meals and neighbours contact him if concerned. Lives and cooks in bedroom. No support from GP or MH services. GP Visit arranged.
- Feb 2017: **Failed visit** - not in – **no TV or phone** confirmed by brother. Jack didn't return. Visit rescheduled but declined. Brother concerned about Jack's mental health

Jack's Story (cont)

- Sept 2017: Police attended – neighbour concern re keeping his neighbours cats inside his property, not letting them go or caring for them. House **cluttered and unclean, alcohol bottles on floor, rotten food**. Upstairs **faeces found in buckets**, **flies, cobwebs and the smell was unbearable**. Bedroom contained portable fire, used to cook food. No kitchen or toilet facilities. Property in a state of disrepair, ceilings were hanging down. Jars of thick black liquid and unidentifiable rotten items hanging from the ceiling (possibly pigs ears)**.**
- **Adult Safeguarding referral**. Referred to MH team. Intensive Home Treatment Team. Discussion with brother and referral to fire service.
- 1/1/18: **Fire** at Jack's address. Neighbour had called at the property earlier in the day as had smelt smoke. Jack reported to neighbour that he had lit a fire but this was now out. When crews arrived, the ground floor was well alight. Information from the Fire Investigation indicates that this had been a smouldering fire, which would not have been visible to Jack as it was behind an animal cage. Jack is likely to have been overcome by carbon monoxide – he suffered burns to his leg but not his upper body. Various dead animals throughout the house (pig in cellar, fish, rabbits) **-they were dead prior to the fire.** "Thousands" of empty alcohol bottles.
- Jack was sadly confirmed dead at the scene.

Jack's Story

What factors made Jack vulnerable to self neglect and hoarding?

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Vulnerability Factors

Genetic and Biological Factors

Family History

Neurodiversity: ASD and ADHD can impact executive function - planning, decision-making and organization

Brain Abnormalities

Abnormal brain activity in fronto-temporal cortex, para-hippocampal gyrus, and insula

Perfectionism

perfectionistic or indecisive personality, driven by anxiety about making mistakes

Psychological and Emotional Factors

Traumatic Life Events

Death of a loved one, abuse, or a major relationship breakup

Mental Health and Addiction

Depression, anxiety, OCD, schizophrenia, drugs, alcohol

Emotional Coping

Struggles with difficult feelings, including loneliness, isolation

Environmental and Learned Behaviours

Childhood Experiences

Growing up in a cluttered home or a deprived childhood where material objects were scarce

Learned Behaviours

Seen family members hoarding or never having gained skills to self care

Beliefs about Possessions

Fear of future unmet need, emotional attachment or belief in possessions bringing happiness

Barriers to engagement

Patient and Family Factors

- Poor Insight: lack of awareness that situation is problematic or a disorder, reluctance to disclose to healthcare professionals.
- **Secrecy and Shame:** embarrassment, shame, or a fear of judgment
- Refusal to accept help: pride or lack of insight
- Complex underlying health conditions: e.g. depression, trauma, anxiety, or cognitive impairment, which can be difficult to identify.
- **Emotional attachment and overwhelm**

Professional and Systemic Barriers

- **Limited Time and Resources**
- **Lack of Training**
- Difficulties with Capacity Assessment, especially when patient refusing help.
- Multi-Agency Collaboration – challenges with information sharing and unclear responsibilities.
- **Misconceptions** -Not simply a lifestyle choice or 'messiness'- strong emotional attachments to items hindering disposal.

Ethical Dilemmas

- Balancing patient autonomy with duty of care – the challenge of unwise decisions in a capacitous patient
- Insidious Nature: can develop slowly and gradually over many years, making hoarding harder to detect

Primary Care SCR Learning Themes

1. Self-neglect as a complex **human rights issue** needing **multiagency approach**
   - Capacitated individual's autonomy vs practitioner's duty of care to protect adult
   - Belief that 'lifestyle as a choice' may be given priority over vulnerability and risk
   - Importance of multi-agency communication but personalised MDT approach
2. Importance of **formal capacity assessment**
   - Jack's capacity was assumed on the basis of information given by his brother
   - Likely fluctuating capacity – impact of mental health and alcohol
3. Repeatedly **relying on the brother as an intermediary** due to difficulties contacting Jack
   - Family members may have limited knowledge of available options
   - Develop tolerance by getting used to problems over time
   - Family may not see themselves as carers. Eg. Jack's mother and brother
   - No carers assessment. If Jack's mother's role had been acknowledged ,the effect of her illness and move into a Care Home might have been anticipated

4. Potential Missed Opportunities

- **Routine review opportunities**
  - Bereavement support following loss of mother
  - GP Mental Health Reviews – Arden's template e.g. "Are you managing to keep on top of things at home, or are you finding it difficult at the moment?"
- **GP Response to external concerns**
    - post OT assessment in 2004
    - A+E discharge summaries – drunk and periorbital haematomas, fall whilst drunk,
    - Following MASH communications
    - DWP visit – importance of multiagency communication
    - Police communications with GP
  - Coding and documentation
  - In-house safeguarding MDT
- **Professional Curiosity**
  - Observation by practice team of poor self care
  - Smell of alcohol / unusual behaviour

5. **Continuity of care and Consent** – Making Safeguarding Personal
   - Working relationship requiring considerable tenacity, patience and resource
   - Accepting that sometimes may not be able to gain entry to patient's home
6. Response to patients on **SMI register who DNA appointments**
7. Ensuring **mental health background summary** easily visible on medical notes – use of safeguarding node
8. **Fire and rescue service** involvement at an earlier stage
9. Risk that people who are reclusive and reluctant to engage will be **over-looked by services** due to service pressures
10. Role for **environmental health**
11. **Practitioner Support and training** for those involved with complex neglect cases
    - Joint agency visits
    - Information-sharing
    - Multi-agency self-neglect and hoarding policy

Destiny's Story

- 46 year old Ethiopian lady. Newly registered from local practice – struggled to walk there, so re-registered
- Walks into practice requesting appointment with nurse for a wound on her leg
- Receptionist notices she looks unkempt and thin and informs duty doctor
- Seen by duty doctor and practice nurse - has a leg ulcer and infected thigh abscess
- Prescription from previous surgery – Type 1 DM. Admits to IV drug use. No previous social care input.
- Moved to UK 7 years ago with adult daughter. Works as a cleaner.
- Lives alone. Family abroad. Daughter moved out a year ago to live with partner in Manchester.

Destiny's Story (cont)

- Regular dressing changes with Practice Nurse. Agreed to engage with local drug and alcohol service. Social prescriber input and foodbank voucher
- Referred to MH team to support with PTSD linked to sexual abuse in own country
- 6 months later, ulcer not healing, diabetic control poor. Refusing hospital admission.
- DNA hospital diabetic clinic. DNA CBT appointment.
- Pharmacy phone call to GP – concerned re not consistently picking up insulin and looking unkempt.
- DNA GP appointment and no response to phone calls or texts from GP or social prescriber
- Despite close, trusted relationship with practice nurse, stopped attending for dressings.
- Leg redressed in A+E – refused admission. 'Has capacity'
- Practice Adult Safeguarding MDT – Concern Destiny at risk of serious harm
- Plan: Adult MASH referral + GP Home Visit.

Destiny's Story (cont)

- GP Visit: No answer at the front door. Music on inside. Property in poor state of repair. Neighbour said 'probably asleep as she works at night'. Unable to gain access.
- Police 'safe and well' check:
  - Highly cluttered house (clutter score 7), filled with rubbish bags and clothing ?stolen. Minimal food. Drug paraphernalia
  - Daily injecting heroin and cocaine, life revolving around this and her concerns about a debt that she needed to repay. The
  - Lights not working and the smoke alarm bleeped continuously
  - People seen leaving via the back of the property. Unclear whether or not Destiny was involved in prostitution to earn money or whether these people were fellow drug users.
  - Destiny found to have cellulitis and refusing hospital admission.
  - Mental capacity to understand the risks to her health by not accepting a hospital admission

Destiny's Story (cont)

- **Multi-agency Risk Management Meeting (MARM)**
  - Attended by Social Care, Police, GP, Practice Nurse, Social Prescriber, Drug and Alcohol Services, Housing.
  - Destiny invited but did not attend.
  - Housing - not received complaints from her neighbours but 'an area of high tolerance'
  - Daughter contacted with Destiny's permission
  - Decisional vs executive capacity
  - Destiny consented to hospital admission after encouragement from practice nurse, daughter and GP.
  - GP liaised with the hospital to ensure smooth admission.
  - Daughter agreed to clear Destiny's property
  - Housing agreed to prioritise securing the property to help Destiny feel able to go to hospital
  - Review meeting 3 weeks later

Destiny's Story (cont)

Outcomes

- During her stay in hospital, concerns were raised ? Psychosis. Mental Health Assessment.
- Agreed to voluntary treatment though Community Psychiatric Nurse and social worker
- Drug and Alcohol service - agreed to be prescribed methadone (greater monitoring and less need to secure finances to buy other drugs), although the need remained.
- Diabetic clinic simplified insulin regime and re-engaged her
- Destiny's daughter cleared the property and housing made home more secure and fixed the wiring.
- Attendance at the GP surgery increased to twice per week for leg dressing
- Accepted sporadic welfare checks by the police (could place her at risk within her community)
- Mobility scooter - increased her freedom and independence (facilitating executive capacity)
- Risk of future relapse, mitigated in part by multi-agency involvement

Destiny's Story

What key learning points from this case will you take back to your practice?

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Key points of Good Practice

- Vulnerability factors identified and addressed through Multi-agency MDT approach
  - Destiny's self neglect / hoarding resulted primarily from her addictive use of drugs
  - Other factors:

  Mental health, Daughter moving away, past history of trauma, poor mobility affecting ability to get rid of waste, debt
- Excellent teamwork from clinical and non-clinical members of Primary Care Team
- Hospital admission as an opportunity for holistic interventions
  - Old routines are temporarily broken and the impetus for change can be at its greatest.
  - New things were learned about Destiny (e.g. psychotic symptoms)
  - Opportunity to re-engage and offer new services through face-to-face communication
- Recognition that Destiny had decisional capacity but not necessarily executive capacity to carry-through with her decisions. 'talk the talk but no walk the walk'

Hoarding Definition and Statistics

- Estimated 2-5% of the population

- DSM-V ‘Hoarding Disorder’ 2013
- WHO 2018 ICD-11

Parent Category: Obsessive-compulsive and related disorders (20-30% of people with OCD)

Diagnostic Criteria:

Excessive Acquisition/Difficulty Discarding: excessive urge to acquire items or a marked difficulty in discarding possessions, regardless of their actual value.

Accumulation of Possessions: clutter in living areas, such that usual use is compromised.

Significant Distress or Impairment: significant distress or impairment in personal, social, occupational, or other important areas of functioning

Types of Hoarding

- **Compulsive hoarding** – this could consist of one type of object or collection of a mixture of objects, such as old clothes, newspapers, food, containers, human waste or papers. This will often manifest from an emotional attachment to inanimate items creating conflict in disposal
- **Biblomania / Data Hoarding** – books and written information, such as newspapers, magazines and articles, as well as DVDs and videos. It can also include 'data hoarding', which is the excessive storage and reluctance to delete electronic material which is no longer of use – such as computers, electronic storage devices, copies of emails, and other information in an electronic format.
- **Animal hoarding** – this is often accompanied with the inability to provide minimal standards of care. The person may be unable to recognise that the animals are at risk. The homes of animal hoarders are often eventually destroyed by the accumulation of animal faeces and infestation by pests.

Legal Frameworks: Care Act 2014

- ‘Self neglect’ is recognised as a category of abuse under Section 42 of the Care Act 2014
- Hoarding is **not** a category of abuse – MH disorder, aspect of self-neglect
- What is the legal definition of an ‘Adult at risk’ from the Care Act 2014?
    1. Aged 18 or over AND
    2. Has care and support needs AND
    3. Is experiencing or is at risk of abuse or neglect AND
    4. Is unable to protect themselves from that abuse or neglect as a result of those needs

Note ‘Adult at Risk’ term does not reflect an individual’s CAPACITY

Legal Frameworks: Mental Capacity Act 2005

Mental Capacity Assessment:

- two-stage **functional** test, can patient make **a specific, informed decision** at a **specific time?**
- Stage 1 (Diagnosis): Is there an impairment of the mind or brain, such as from dementia, illness, or temporary confusion?
- Stage 2: If YES - Does this impairment make the person unable to make a particular decision, even with support?

Can the patient:

- **Understand, Retain, Weigh up, Communicate** decision

Principles of the Mental Capacity Act 2005 (>16 years):

- Presumption of capacity
- Support to make a decision
- **Ability to make unwise decisions**
- Best interest
- Least restrictive option

- **Decisional vs executive capacity** – person may be able to make **decisions** around personal welfare or environment, but be unable ACT to keep themselves safe (**executive** capacity)

Risks associated with Hoarding

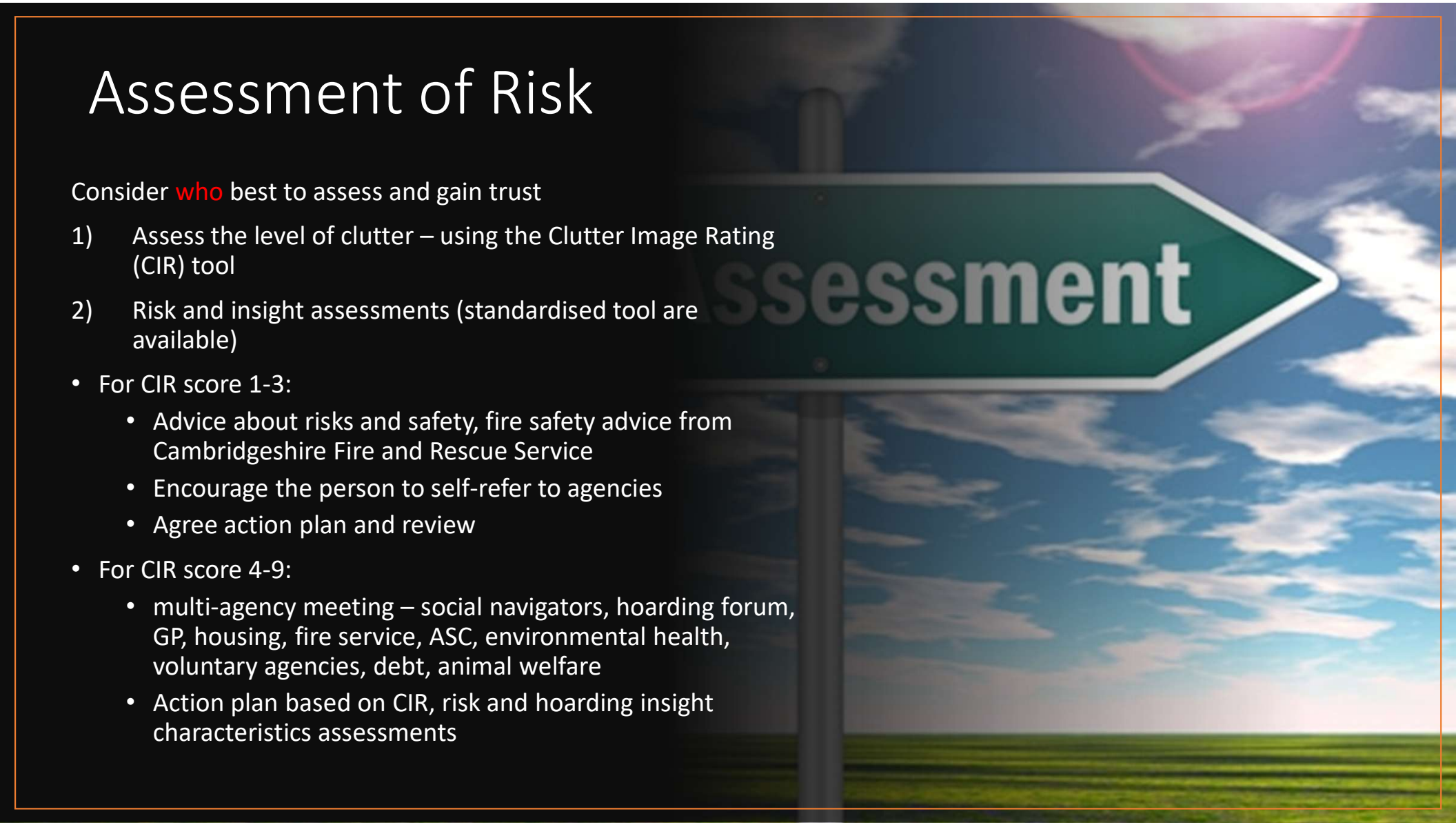
Harm to patient

- Physical health – breathing difficulties, gastroenteritis, nutritional
- Mental health – worsening anxiety, depression, OCD, alcohol, PTSD
- Accidents from clutter and poor state of repair of house
- Fires – 1/3 of people who die in house fires are hoarders
- Isolation and loneliness

Harm to others

- Fire – adjoining homes
- Pests and vermin
- Alienation of family
- Accidents

Assessment of Risk

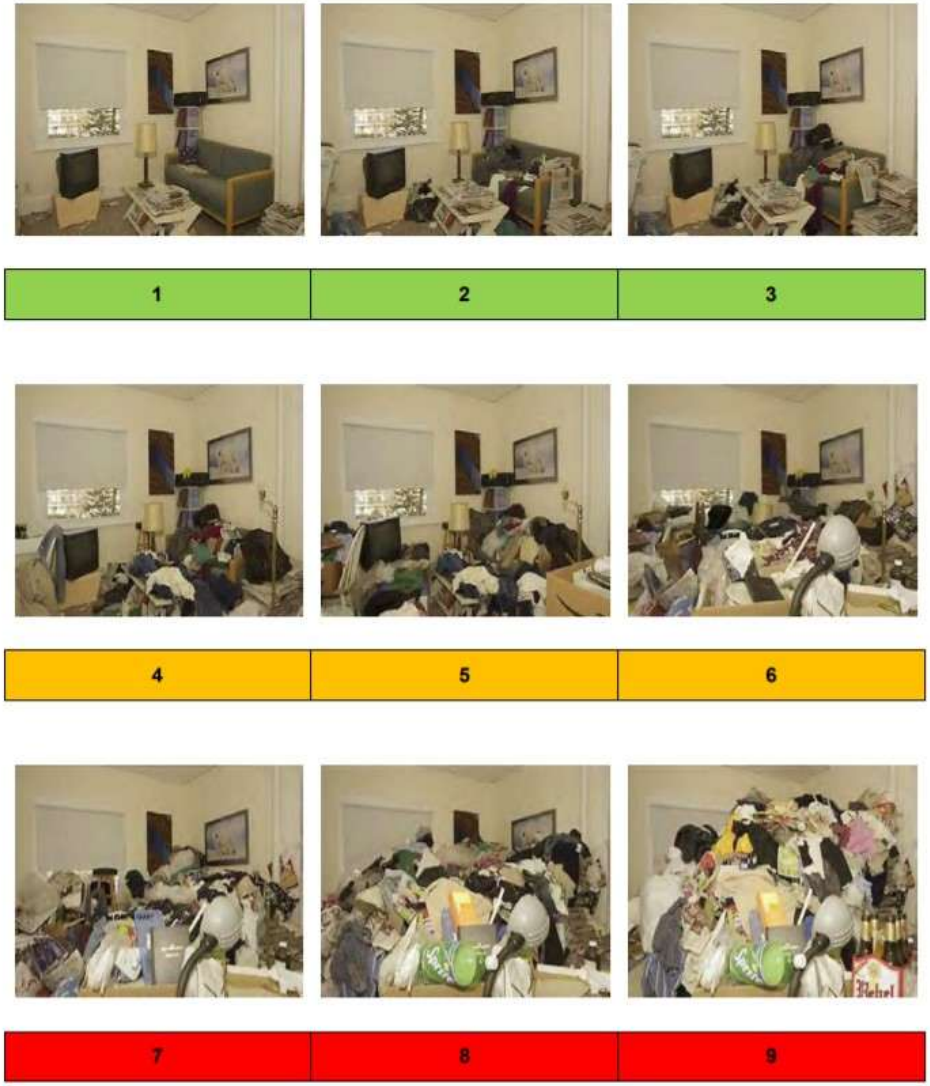


Consider who best to assess and gain trust

1) Assess the level of clutter – using the Clutter Image Rating (CIR) tool
2) Risk and insight assessments (standardised tool are available)

- For CIR score 1-3:
  - Advice about risks and safety, fire safety advice from Cambridgeshire Fire and Rescue Service
  - Encourage the person to self-refer to agencies
  - Agree action plan and review
- For CIR score 4-9:
  - multi-agency meeting – social navigators, hoarding forum, GP, housing, fire service, ASC, environmental health, voluntary agencies, debt, animal welfare
  - Action plan based on CIR, risk and hoarding insight characteristics assessments

CIR Score



Situation 1: Removal to Safety
'At Risk' and Lacks Capacity

Patient is **'Adult at Risk'** and **LACKS capacity**:

In an emergency (ie. life-threatening), police can remove patient (even from their home) when it is considered:

- **least restrictive option**
- **in their best interests**

(BUT **not** for the purposes of Mental Health Act assessment or treatment)

(Section 4B, 5 and 6 MCA)

Non-emergency: If there is a chance that the **subject may regain capacity** to make a particular decision, **delay decision**. Reassessment and support. **'Fluctuating capacity'**

Situation 2: Removal to safety
'At Risk' and Has Capacity

- Do they have a significant mental disorder in need of urgent assessment? MCA 1983 (2015)

YES?

- Section 136 MHA 1983 does NOT give police powers to remove patients from their home
- BUT if patient 'sectionable' with a mental disorder
- police warrant Section 135 MHA 1983 - place of safety for assessment / treatment of **mental disorder.**

NO?

- Most hoarding: **patient has capacity, no immediate risk of harm, no significant mental disorder.**

MCA 2005 Principle – Ability to make unwise decision.

- Adult Social Care referral (consent needed) + wider MDT support

Capacitated individual's autonomy vs practitioner's duty of care to protect adult

- MARM guidance used when:
  - **has the mental capacity** to understand the risks posed to them
  - continues to place themselves at **risk of serious harm or death**
  - refuses or is unable to engage with necessary care and support services.

Multi-agency Approaches

Medical

- **Address health needs**: focussing initially on patient's agenda and building trust
- **CBT / Psychotherapy**: addressing deeper rooted issues contribution to self-neglect

Social

- **Intervening through family members and carers** and social connections: engaging trusted people
- **Daily structure**: activities that can replace what is given up through giving up hoarded materials or making lifestyle changes
- **Peer support networks**: enabling links to be made between people addressing similar challenges
- **Life management**: skills in setting priorities, attending to finance, cleaning, food
- **Care packages**: small beginnings can lead to greater trust and acceptance
- **Carer support**

Multi-agency Approaches (cont)

Safety and Environmental

- **Enforced action if needed:** setting boundaries on the risk to self and others
- **Emergency respite:** a chance to test an alternative environment, and/or to improve home conditions
- **Deep cleaning** and making domestic environment safe, 'help break the spell of shame'
- **De-cluttering:** some items only with agreement and sensitivity. small achievable tasks – avoid words that devalue or judge, their pace. BUT can worsen hoarding behaviour.
- **Fire risk minimisation:** provision of equipment and advice
- **Adaptations and repairs:** reduction of risk through changes to enhance safety
- **Provision of equipment and/or furniture:** may improve food hygiene, fire risk, cleanliness as well as build relationship
- **Change of living environment:** a new start, minimised risks, care and support

Monitoring

- Periodic visits to maintain contact and relationship
- Consideration of lead professional ?Social Care ?Social Prescribers

Professional practice questions 1

- Ambulance safeguarding / Police reports / MASH communications
  - Does you practice have a standardised ‘closed loop’ way of risk assessing these?
  - Is there a protocol for seeding these into safeguarding MDT?
- Challenges in providing continuity of care - trust and rapport take time to build
  - Does your practice vary the Support Lead for different individual patients, dependent upon the individual’s needs?
  - Roles of Named GP vs other MDT clinicians vs social navigator in practice MDT?
- Review of patients on Severe Mental Illness Register
  - "Are you managing to keep on top of things at home, or are you finding it difficult at the moment?“
  - Are staff using the Arden’s template to prompt holistic monitoring?
  - Does your practice have a protocol for SMI patients who DNA MH review appointments?

Professional Practice Questions 2

- Use of Safeguarding Node.
  - Are staff using the 'Safeguarding Node' to summarise ADULT safeguarding concerns and improve external multiagency communication?
- MARM assessments
  - Are staff aware of when to consider referring a patient?
- Importance of objective assessment of capacity vs carer reported 'capacity'
- Role of fire service at earlier stage as a supportive measure for patients who hoard.

- Professional Curiosity is key from all members of practice team

Hoarding Resources: Professional

- Cambridgeshire and Peterborough Hoarding Protocol:

https://www.safeguardingcambspeterborough.org.uk/adults-board/information-for-professionals/cpsabprocedures/hoarding/

- Additional C&P CCG hoarding resources

https://www.safeguardingcambspeterborough.org.uk/wp-content/uploads/2019/09/Appendix-4-Additional-contacts-who-may-be-able-to-assist-people-with-hoarding-behaviours.pdf

- 6 weekly Hoarding Forum. Lead by Stuart Brown, Adult Early Help Manager: 01480 373251, 07785 578237. Stuart.Brown@cambridgeshire.gov.uk
- Fire service Safety Support: Jill Gibbs firefire@cambsfire.gov.uk 0800 9179994

'Safe and Well' visit: dementia outreach, hospital beds, portable oxygen, proactive >65 + disability, smoke alarms, light bulbs

- Care Network's Community Navigator service.

Community Information and Advice – Care Network (care-network.org.uk). Links with SocNs.

Hoarding Resources: For Patients 1

- ‘Declutter Together’ is a peer support group for people in C&P living with excess clutter.
  - Free Online support group, first Tuesday of each month from 6.30 - 8pm
  - a safe, friendly space to share experiences and receive non-judgemental support and advice
  - To join email Stuart.Brown@cambridgeshire.gov.uk
- https://helpforhoarders.co.uk/ Help and support for hoarders and their families. Online forum
- Really helpful NHS summary: https://www.nhs.uk/mental-health/conditions/hoarding-disorder/
- Help with animal hoarding / welfare issues: Wood Green Community Outreach https://woodgreen.org.uk/contact-us/pet-support

Hoarding Resources: For Patients 2

- Cleaning services eg. Scenic Cleaning.
  http://www.sceniccleaning.com/trauma_and_hoarder_clean-up_service.php: declutter, sanitise and thoroughly clean the environment. Mob: 0742 874 2731
  E-mail: info@sceniccleaning.com
  Website: www.sceniccleaning.com
- Hoarding UK Charity: Advocacy, Healthy Homes Programme, Peer Mentoring: https://hoardinguk.org/
- MIND guide to Hoarding. Good to read through as a professional but is also one that can be given to the individual's we support or to their friends and family. This has good links in it including self-help ideas.

https://www.mind.org.uk/information-support/types-of-mental-health-problems/hoarding/about-hoarding/?gclid=EAIaIQobChMI-_Kf0d2W7gIVwsLtCh1CkAlsEAAYASAAEgIoovD_BwE

Questions?