Hoarding Disorders UK
Community Interest Company

CHOICE, CONTROL AND COLLABORATION

Effective Support for People Affected By Hoarding Behaviours

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UK Hoarding Partnership

PoHoC
POSSESSIONS AND HOARDING COLLECTIVE

ann craft trust
acting against abuse

EVERY VOICE EVERY CHOICE

Safeguarding Adults Conference 2026
Trent Conference Centre, Nottingham
18 November

Workshop Aims

1. Develop insight into what hoarding behaviours are and aren't, and why it’s a mental health issue.

2. Explore practical approaches for embedding choice and control into care and support

3. Awareness of what harm reduction could look like in practice whilst upholding the core principles of the Care Act 2014 (empowerment, prevention, proportionality, partnership) and making safeguarding personal.

Group Commitments

- Interactive- but I will never call on anyone or use role play!
- Look after yourself- permission to take a break, move around, whatever you need.
- Respectful language / no identifiable details

Who are we?

Hoarding Disorders UK CIC is a not-for-profit organisation that helps people whose homes have become overwhelming—whether because of **hoarding behaviours** or the build-up of clutter, linked to **chronic disorganisation**.

Founded in **2014** by Jo Cooke, we've become a trusted source of support both nationally and internationally, grounded in lived experience and delivered by a team with strong social care and mental health backgrounds.

What do we do?

- We offer **kind, practical, trauma-informed** help to individuals, families, and professionals.
- **Dedicated peer support and support groups-** hoarding behaviours, loved ones and programme facilitators (in person; online; telephone)
- **Advice and guidance and specialist consultations-** individuals, families, professionals- housing, social care, health, emergency services.
- **Education, awareness raising and training.**
- Contribute to vital **research**, **innovation**, **service modelling** and **partnership** development.

Who’s in the room?



Activity 1

What words and phrases have you heard used about people with hoarding difficulties?

Note: this is not what you think; it's what you hear.

www.mentimeter.com

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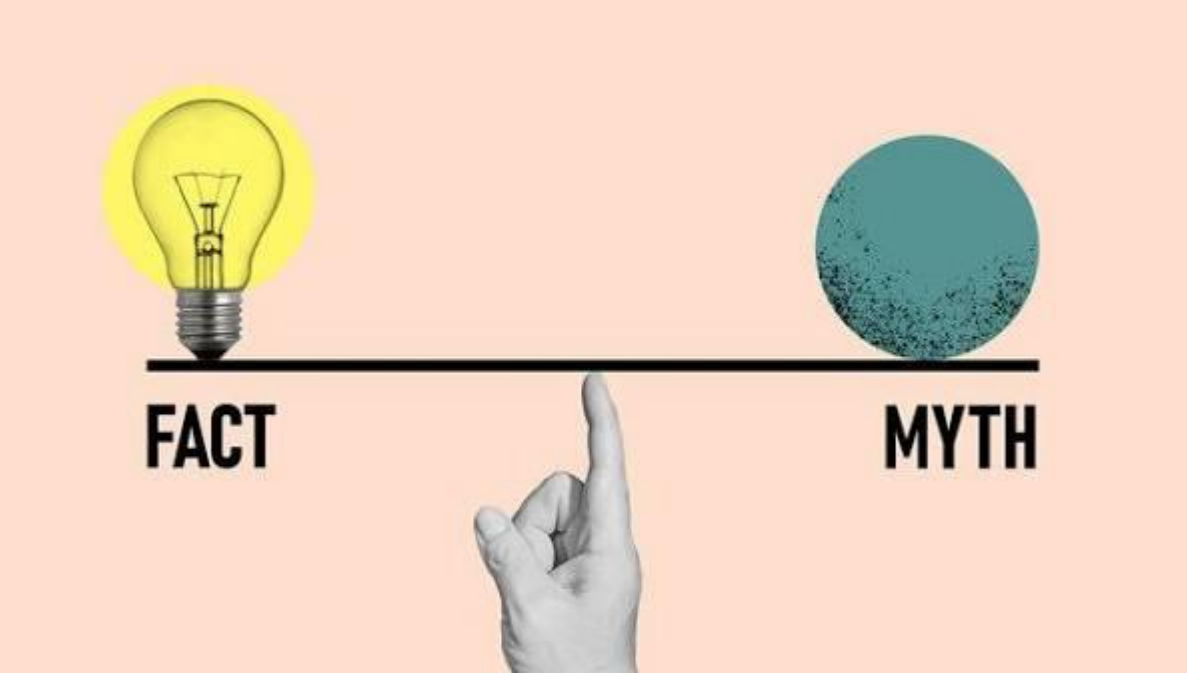
Activity 2



Agree or Disagree?

1. Hoarding is a lifestyle choice

2. Clearing the home is the best way to solve the problem

3. If someone has capacity, there is still a lot we can do.

4. If someone is “failing to engage”, it means they don’t want help

5. Loved ones are the best people to support people with hoarding difficulties

6. A “safe” good enough home can be a successful outcome

Thinking points...

- Words matter
- Clearing isn’t helping
- Capacity doesn’t end our role
- Loved ones need support too
- Good enough can be success

History of hoarding

Animal instincts

Winter reserves

Wartime rationing

Collyer brothers

Andy Warhol

TV programs

Cultural context



What is hoarding disorder?

Hoarding disorder has been formally recognised as a diagnosable mental health condition in the UK since 2018. It is defined as a pattern of accumulating possessions to the point that living spaces can no longer be used for their intended purpose, combined with a persistent inability to discard items regardless of their value.

What is hoarding disorder?

It is <u>NOT</u> a lifestyle choice nor Obsessive Compulsive Disorder (OCD).

Commonly observed behaviours:

- **Accumulating large amounts of items** in ways that impact daily living or the lives of others- ***<u>so not general clutter.</u>***
- **Difficulty organising or managing possessions**, even when the volume becomes unmanageable.
- **Strong emotional attachment** to items, making discarding extremely distressing.
- **Persistent urge to acquire more**, even when there is already an excess.
- **Positive or comforting feelings when obtaining new items**, reinforcing the cycle.

Hoarding disorder: DSM-5 & ICD-11 compared

Key difference	DSM-5 (APA)	ICD-11 (WHO, 6B24)
Core definition	Difficulty discarding, driven by a perceived need to save and distress at parting	Excessive acquisition or difficulty discarding, regardless of value
Acquisition	A specifier only: "with excessive acquisition"	Part of the core definition, so acquisition alone can qualify
Insight	Specifiers: good or fair, poor, absent or delusional	No insight specifier
Exclusions	Explicit criteria: not due to a medical condition or another mental disorder	No criteria list; covered by differential diagnosis guidance

Shared by both: Classed with obsessive-compulsive and related disorders. Clutter compromises the use or safety of living spaces, even if it only looks tidy because others intervene. Significant distress or impairment is required.

What do we know?

- Estimated 2.5-6% UK impacted by hoarding- 4 million+ individuals or 1.7 million households across the UK.
- More prevalent than Schizophrenia and OCD combined
- Affects men and women in relatively equal numbers- women more likely to seek support
- Age- this is not just an issue for “mature” individuals
- 92% of hoarders have co-occurring mental illnesses.
- Clearances have a 97% fail rate.
- Currently no NICE guidelines, no formal NHS support, Talking Therapies will not treat it.

Why clearances fail

Common outcomes include:

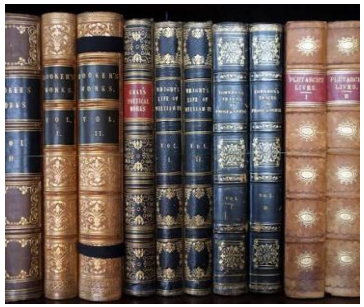
- **Re-traumatisation:** Loss of control, violation of space, emotional collapse
- **Loss of Trust:** Damaged relationships with services, reluctance to re-engage
- **Rebound Accumulation:** Rapid re-hoarding due to unresolved emotional drivers
- **Lack of Consent and Emotional Readiness:** Without psychological safety, change cannot be sustained

When is it not hoarding?

- Chronic Disorganisation / Executive Dysfunction
- Depression and grief- “nests of depression”
- Self neglect?
- Poverty and resource scarcity
- Large collections vs hoarding

Relationship with Possessions Continuum









Typical Saving
Useful retention

Collecting
Intentional acquisition

Cluttering
Increasing accumulation

Hoarding
Significant impact

Experiences exist on a spectrum rather than fitting into fixed labels

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Why Hoarding Occurs, and Stays Hidden

What drives it

- Anxiety, perfectionism and fear of mistakes
- Difficulty deciding, categorising and trusting memory
- Trauma: “people hurt me, but my things don’t”
- Learned behaviour; some genetic predisposition
- Co-occurring depression, anxiety, psychosis

Why it stays hidden

- Shame, stigma and fear of intervention
- Often found only in a crisis: eviction, health emergency, bereavement
- Around 2–6% of households, rising with age- and more likely to come to attention of agencies with a more mature adult

The Impact of Hoarding

- Isolation, loneliness: stigma and shame
- Family conflict and estrangement
- Attachment issues / blueprint for children / trauma
- Basic needs not met / functionality of home– loss of heating, structural damage, loss of water, bed to sleep in
- Impact on health – dust and damp, mildew and mould
- Fire risk- to the individual and community
- Repairs in the house cannot be carried out

Care Act and Mental Capacity Act

Care Act 2014

- Hoarding can be self-neglect, triggering safeguarding duties
- Section 42: enquiries where an adult with care and support needs is at risk and unable to protect themselves
- Least restrictive, person-centred, multi-agency

Mental Capacity Act 2005- Autonomy & Decision Making

- Presume capacity; support decision-making first
- People may make unwise decisions
- Capacity is decision-specific: understand, retain, weigh, communicate
- If capacity is lacking: best interests, least restrictive option

In hoarding cases, consider trauma, neurodivergence and executive dysfunction, not just surface risk.

Multiagency Collaboration

It is not the role of just one agency or person….



Tools- Local Hoarding Protocol



- Vulnerable Adults Panel / Hoarding Case Panel
- Practitioner Question Guide & Clutter Rating Image Scale
- CRL 4 upwards requires attention
- CRL 7 upwards constitutes a safeguarding alert

Clutter Image Rating - Kitchen

1


1


2


3

2


4


5


6

3


7


8


9

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Tools- Homes Risk Assessment

HOMES® Multi-disciplinary Hoarding Risk Assessment

❑ **Health**

❑Cannot use bathtub/shower ❑Cannot access toilet ❑Garbage/Trash Overflow
❑Cannot prepare food ❑Cannot sleep in bed ❑Cannot use stove/fridge/sink
❑Presence of spoiled food ❑Presence of feces/Urine (human or animal) ❑Cannot locate medications or equipment
❑Presence of insects/rodents ❑Presence of mold or chronic dampness

Notes:_____

❑ **Obstacles**

❑Cannot move freely/safely in home ❑Inability for EMT to enter/gain access
❑Unstable piles/avalanche risk ❑Egresses, exits or vents blocked or unusable

Notes:_____

❑ **Mental health** (Note that this is not a clinical diagnosis; use only to identify risk factors)

❑Does not seem to understand seriousness of problem ❑Does not seem to accept likely consequence of problem
❑Defensive or angry ❑Anxious or apprehensive
❑Unaware, not alert, or cont

Notes:_____

❑ **Endangerment** (evaluate threat based on other sections with attention to specific populations lis

❑Threat to health or safety of child/minor ❑Threat to health or safety of older adult
❑Threat to health or safety of person with disability ❑Threat to health or safety of animal

Notes:_____

❑ **Structure & Safety**

❑Unstable floorboards/stairs/porch ❑Flammable items beside heat source ❑Storage of hazardous materials/weapons
❑Leaking roof ❑Caving walls
❑Electrical wires/cords exposed ❑No heat/electricity
❑No running water ❑Blocked/unsafe e

Notes:_____

HOMES® Multi-disciplinary Hoarding Risk Assessment (page 2)

Household Composition

# of Adults _____ # of Children _____ # and kinds of Pets _____
Ages of adults: _____ Ages of children: _____ Person who smokes in home ❑ Yes ❑ No
Person(s) with physical disability_____ Language(s) spoken in home_____

Assessment Notes:_____

Risk Measurements

❑ Imminent Harm to self, family, animals, public:_____
❑ Threat of Eviction: _____ ❑ Threat of Condemnation:_____

Capacity Measurements

Instructions: Place a check mark by the items that represent the strengths and capacity to address the hoarding problem

❑ Awareness of clutter
❑ Willingness to acknowledge clutter and risks to health, safety and ability to remain in home/impact on daily life
❑ Physical ability to clear clutter
❑ Psychological ability to tolerate intervention
❑ Willingness to accept intervention assistance

Capacity Notes:_____

Post-Assessment Plan/Referral_____

Date: _____ Client Name: _____ Assessor: _____

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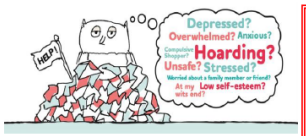
Tools– Ice breaker form



www.hoardingicebreakerform.org

CLUTTER, DISORGANISATION & HOARDING BEHAVIOURS

Ice-Breaker Form

Empowering people to start a conversation with their GP/doctor, clinician, professional or other trusted person, and get **practical advice**, **treatment**, and **support** to feel better

For instructions on how to complete the form, and information about preparing for the conversation with your trusted person, please refer to our website www.hoardingicebreakerform.org

Dear Trusted Professional

I have a problem which is affecting my health & wellbeing

The problem applies to: Me ☐ Someone I live with ☐ A family member ☐ Other ☐

(Tick all the boxes that apply)

I / they have:

A difficulty stopping acquiring things and accumulating them.	
Persistent difficulty or distress discarding or parting with personal possessions.	
Strong urges to save items.	
Areas full of possessions – eg. living areas, gardens, sheds, vehicles, etc.	
Areas where normal use of the space is difficult or impossible (eg. access to or use of toilet, kitchen, boiler, radiators, heating, hot water, lights, etc).	
Safety risks* inside or outside the home (eg. slip/trip/fall hazards; fire risks; blocked doors/windows/stairs; mould; faulty/broken electrical or gas equipment; rats/mice; overgrown garden, etc). Please explain your answer on the next page.	
Children, adults and/or animals that are not being looked after properly.	
Become overwhelmed and find making progress to reduce the problem difficult.	
Been reluctant to talk to people who say they want to help, and/or not permitted them to enter the property or the areas affected.	
Severe difficulty with things like timekeeping, prioritising, planning, organising (eg. paperwork or paying bills on time), making phone calls; making decisions.	
Been told to make changes (eg. by a family member, landlord, Environmental Health Officer, etc), and that action will be taken if nothing is done by a certain date.	

SAFETY INFORMATION



The **Clutter Image Rating** (CIR)** shown here (in a bedroom) is a scale used to give an approximate measurement of levels of "clutter" in a room (1 to 9).

What number (level) on the **Clutter Image Rating** Scale is the most cluttered area that is affected, or you are concerned about?

Please show your trusted person photos or videos of the areas affected, so they can advise you better.

Click HERE to view, download or print a FREE version of the full set of Clutter Image Rating images (Kitchen, Bedroom, Living Room), devised by Jordana Muroff, Patty Underwood and Gail Steketee for Group Treatment for Hoarding Disorder: Therapist Guide, Appendices © Oxford University Press 2014 (the CIR is on the Treatments That Work section of the Oxford Clinical Psychology website).

In what year did you first realise it had become a problem, and why?
***What safety risks are there?**
Who or what else is affected or involved (eg. young children, adult relatives, pets, friends, neighbours, Police, local authority, etc) and how?

Please add additional relevant information on other sheets of paper.

I'm now at the stage at which I need to appeal to you to help me because:

(Tick all that apply)

I feel unwell because of this situation.	
I feel distressed, and/or indecisive about what to do to make things better.	
It's hard for me / them to talk about this.	
I feel alone and need support.	
Other people don't seem to understand.	

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Activity 3
Sams Case Study

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Activity instructions- 20 mins

- Speak from your own role and agency- make a note of which agencies are missing.
- 4-5 minutes per stage and question- nominate one person to feedback.
- One person to record key points on the flipchart- both where you agree and where there's tension
- Keep Sam's voice in the room. What does Sam want, and how do we find out?

Choice, control and harm reduction

1. Start with what matters. Ask what matters to the person- listen carefully

2. Build trust over time- consistent faces, small steps

3. Work at a person's pace and centre their choices

4. Use tools collaboratively e.g
   Clutter Image Rating Scale / HOMES risk assessment

Choice, control and harm reduction

5. Harm reduction = safety- not “cleared”

6. Good enough- agree what this looks like

7. Hold risk and choice together: record decision making, the persons wishes, risks, capacity considerations, who agreed this and when it will be looked at again.

8. Involve loved ones carefully

Reflection Question

Is there one thing on that list that your service doesn't do yet, or perhaps doesn't do consistently?

Write down one thing you are going to take away with you from this session as a clear action / commitment?

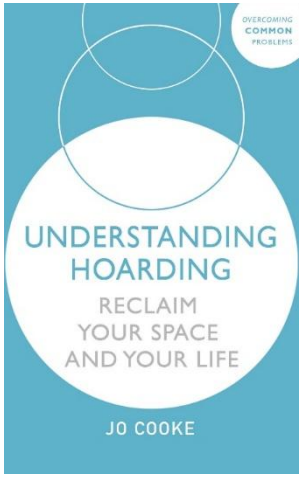
Final Key Takeaways

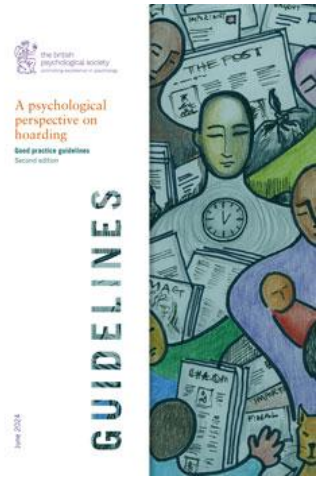
1. Hoarding is a mental health issue, not a lifestyle choice or a housing problem. The words we use shape how we respond

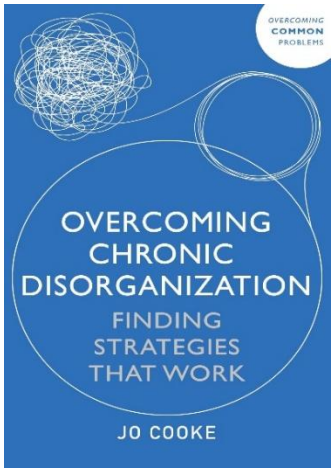
2. The person's voice and choices come first, and harm reduction lets us hold risk and choice together

3. No one agency can do this alone- work with the person and each other

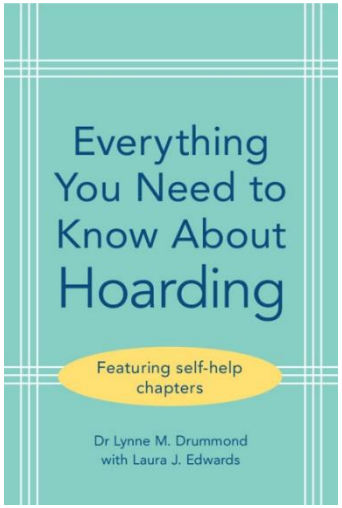
Recommended Resources



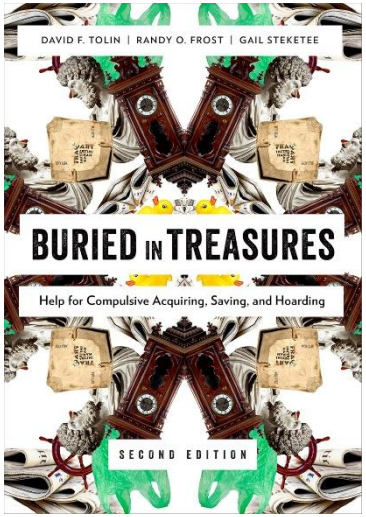


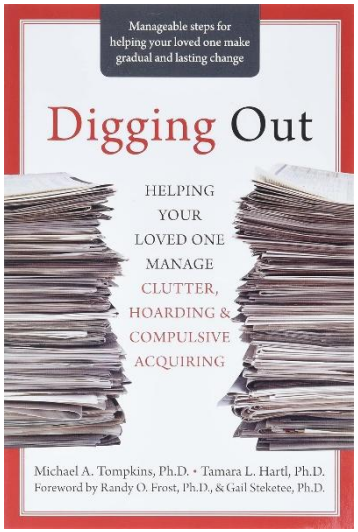












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