

The Tameside Guide To Working With People Who Exhibit Hoarding Behaviours

This guide represents one segment of the work of a cross-sector Task & Finish Group led by TASPB. It was developed following a half-day workshop which saw a multi-agency group of professionals working alongside a group of people who exhibit hoarding behaviours – all of whom are members of the Tameside and Salford Peer Support Groups.

“Hoarding is a good friend that is a bad influence!”
(F - Peer Support Group Member)



What this guide is

- Practical
- Easy to follow
- Jargon-free

What this guide is NOT (and never can be!):

- Definitive/One-size-fits-all
- A ‘multi-agency’ PATHWAY to working with people who exhibit hoarding behaviours (That would entail a completely different type of development but might include a ‘guide’)
- A ‘how to hand-off ‘hoarders’ manual’/A signposter’s directory of services that specialise in supporting people who exhibit hoarding behaviours – they are few and far between (and not just across Tameside/Greater Manchester). We all need to ‘do our bit’ and by taking a CONSISTENT, COMPASSIONATE, COURTEOUS approach will move towards mutual understanding and, perhaps, a more adaptive/‘joined up’ set of multi-agency contributions.

If you’re currently working with or living with or alongside people who exhibit hoarding behaviours OR you are a person with lived experience, then this guide was written by people like YOU – for people like YOU.

- It has been designed to a brief developed by a large group of multi-agency workers and people with lived experience of ‘hoarding’.....

NB: Because of the complexity of the 'disorder' – there is NO QUICK FIX (and no SKIP big enough to provide one!).

**DECLUTTERING OUR THINKING ABOUT...
HOARDING**

Hoarding can be tempting to write off as:

An eccentric novelty

The result of laziness

OR

"A lifestyle choice"

BUT, it is NONE of these things.

Hoarding is an overwhelming psychological condition defined, in part, when someone cannot discard or part with their items without feeling extremely distressed. And it's always a vast array of items they feel they must 'save', for a variety of reasons.

In short, it is a recognised mental health disorder but, unlike other mental health issues it is continually defined by what people have in their HOMES, instead of what people have in their HEADS! Hoarding is poorly understood, people who exhibit hoarding behaviours are poorly understood and this guide aims to address BOTH of these issues.

People who exhibit hoarding behaviours often experience shame, embarrassment and/or self-loathing due to some of the unhelpful responses and the following common myths:

Myth: You can go in and clear out all of the clutter and that will help the person to keep it that way.

Truth: NO – this approach will usually further traumatise the person concerned and lead to the rapid accumulation of items which very quickly become problematic again, sometimes to a greater degree than was previously the case (the 'rebound' effect)

Myth: People who exhibit hoarding behaviours generally 'self-neglect' and live in dangerously unhygienic conditions

Truth: NO – the combination of self-neglect/ domestic squalor ('Diogenes Syndrome') and 'hoarding' is rare and relates to other forms of mental health issues. In addition, a severely 'cluttered' environment doesn't necessarily mean that the person is exhibiting hoarding behaviours.

Myth: : "Hoarding only affects older people"

Truth: NO – Most hoarding behaviours begin before the age of 20 and (unfortunately) the average age when people start to seek support is around 50. All of which, can mean that by the time people make themselves 'visible' to support services they carry with them all manner of additional issues and impacts which add to the complexity of their situation.

Myth: : "Hoarders are just generally dirty and lazy"

Truth: NO – Usually just the OPPOSITE is true. In fact, people with hoarding behaviours have often undergone traumatic experiences and/or had a huge period of instability in their lives. Incorrect interventions can often cause further trauma because a person's relationship with their 'stuff' can act as a coping mechanism or 'comfort blanket' – hence the HUGE negative impact when 'hoards' are haphazardly discarded; something which often results in a re-triggering of the trauma and/or escalation of the hoarding behaviours.

Myth: Hoarding is a 'lifestyle choice'

Truth: NO – this is analogous to saying that people CHOOSE to be 'depressed' or CHOOSE to live with Obsessive Compulsive Disorder (OCD)!

Myth: : Hoarding is a recent phenomenon

Truth: NO – Despite only being officially recognised as a 'disorder' in 2013, examples of hoarding behaviours have been 'exposed', written about, exploited, sensationalised but, ultimately, MISUNDERSTOOD for over 100 years (at least!). It's time we did something about that!

Dos & Don'ts at a glance.....



Good Omens (Dos)	Bad Vibes (Don'ts)
1. DO....Start with compassion, kindness and an attempt to understand the PERSON	1. DON'T.... Display any 'stigma-reinforcing' phrases e.g. 'self-neglect' or visible behaviours e.g. that 'shock-horror' look! i.e. DON'T become part of the person's problem!
2. DO....Remain consistent, constructive and non-judgemental	2. DON'T... Use threats, the language of enforcement or coercive behaviours – these create negativity, anxiety and lead to CLOSED DOORS!
3. DO....Build rapport, trust and remember that 'hoards' aren't built in a day – so they can't be addressed in one either!	3. DON'T....Ignore the impact on or perspectives of 'significant others' in the person's life i.e. family (including) children, friends or any support the person has already got
4. DO....Proceed at the person's pace and COLLOBORATE in order to agree realistic steps/goals/objectives	4. DON'T....Impose YOUR own personal values on the person and/or their situation. What you consider to be an 'organised', 'acceptable', 'liveable' etc is largely irrelevant!
5. DO....Accept that this will be a long haul (irrespective of whether you can stay for the duration!) and that there is NO QUICK FIX!	5. DON'T.... Assume authority or agency over the person – make decisions WITH them – not FOR them!

WORKING WITH PEOPLE WHO EXHIBIT HOARDING BEHAVIOURS.

There are 4 'phases' involved:

Staying Out

Getting In

Staying In

Getting Out

STAYING OUT

This phase involves:

- ◇ Initial contact/relationship-development;
- ◇ Starting to think and negotiateabout supporting people to do whatever it is that's required in the first instance.

- Start by establishing RAPPORT ('Trust' will take longer!), THEN try to gently explore the person's relationship with/attachment to/feelings about their belongings. For example:

Start by asking the person to choose an item of 1. great value to them (they define 'value' in any way they like) & 2. Something they would be extremely reluctant to discard or give away. Ask them to tell you the story around the item.

- Please avoid using 'catch-all' phrases like: "Why don't you just.....?"
- When you have developed that initial rapport demonstrate **Compassionate Curiosity** for example:

DON'T ask: "What's WRONG with you?"; ASK: "What HAPPENED to you?" or "I'd like to hear a part of what happened to you in your life if you wouldn't mind telling me please?" (or similar!)

- THINK: **Relationship, relationship, relationship**. Even if you're not likely to play a major role in the person's 'support journey', you can start to develop a good relationship with the person before 'handing-off' or brokering the next set of communications with another colleague
- Ask yourself: "How many productive relationships start with CONFLICT?". The answer is "Not many!" So, try to remain objective and non-judgmental - there's a whole lot of meaning and life in that "mess" (never use that phrase by the way!). For example:

Ask the person to think back to a time before their environment became problematic for them and ask what they miss most - it's another conversation-starter but will also give you/them some kind of a future 'goal' to aim for

- Don't set goals or make plans until you have a shared/agreed understanding of the issues involved.

GETTING IN

This phase involves:

- ◇ Negotiating a collaborative approach;
 - ◇ Testing things out via 'small steps';
 - ◇ Assessing 1. Functionality; 2. Fire Risk; 3. Safety; 4. Hygiene/Property condition; 5. Personal leisure space.
- Initially, this can involve re-visiting the conversation you had with the person in relation to that item of great personal value that they would be extremely reluctant to discard or let go of (see 'Staying Out' phase example – above). For example:

Remind the person of that chat and then ask them the following question:
"What % of all of the items you have in your home meet those two criteria (1. Immense personal value (and people define 'value' in their own way) and 2. Extremely reluctant to discard?"

The answer to this is rarely above 70% so a response could be: "Let's talk about the other 30% to begin our collaboration?"

- Recognise that not everything needs to be 'discarded' (which can mean donated, recycled, recycled, thrown away) – sometimes people need help to reorganise what they have in order to create 'safe spaces' or spaces to reorganise (sifting/sorting etc)! For example:

Organising 'sorting spaces' can sometimes feel like a step backwards but is often the first step in enabling people to choose a place/category of stuff they'd like to start with. Alongside this, the issue of 'storage' is often raised as a barrier – but people often have storage solutions WITHIN their environment/ items that they just haven't been able to see and/or take advantage of

- Building a directory of places which will take/NEED 'donations' and knowing your recycling centres etc will also be of some practical use.
- Begin discussions about the person's ACQUIRING behaviours – important that we understand the 'flip-side' to the 'hoarding' coin too!
- Unrealistic aims at this stage lead to FAILURE. So help the person to choose achievable goals sometimes referred to as 'quick wins'. SMALL STEPS (please avoid the term 'baby steps' because we want these steps to be a bit more stable than that!) help a person gain MOMENTUM, confidence and start to see what might be possible – as opposed to feeling overwhelmed at what looks impossible. Sincere praise and encouragement for ANY progress made or any learning that results from TRYING is also a must-do!

- Functionality can be collaboratively assessed when the person agrees to allow you access to their home. For example:
- Functionality refers to the number of rooms/spaces that can be used for the purpose for which they're intended; Fire risk can be subjectively/crudely assessed as can perceived general safety and the general hygiene/condition of the environment (i.e. "on a scale of 1 to 10 where 10 is....and 1 ishow would you assess your home?". This can be seen as a 'baseline' assessment which can be revisited alongside the person during a later phase of support. It's also appropriate to include an assessment of the amount of leisure space the person has for themselves/family members (including children) – again, this can be a conversation-starter i.e. "What and how would you LIKE to improve in the future?"

STAYING IN

This phase involves:

- ◇ Stretching those goals;
- ◇ Assisting people to cope with change/progress
- ◇ Moving towards a negotiated 'optimum'
- During this stage CONSISTENCY & SENSITIVE PERSISTENCE are vital because not all steps will be forward steps! For example:

Change doesn't happen in neat, sequential, linear fashion – ALL change is MESSY! So, a good tip is to make sure that the person takes 'before' & 'after' photos (if possible) of any 'de-cluttering' activities for themselves. The main reason for this is that when they take some backward steps (and, at times, they will!) then the photos can be used as a reminder of what 'good' looked and felt like – this is often a way to regain forward momentum.

- Another reason for taking photographs is that the very act of doing so can put a person on the 'outside looking in' which can help them to change or self-challenge their perspective.
- In order to support/facilitate change in others, be prepared to embrace change yourself. In this phase, the strength of your relationship should be able to support the notion of 'stretching the goals' i.e. helping people to take 'bigger steps'. However, once again, shared understanding and sensitive negotiation are key – try to move too quickly/unrealistically and you'll 'lose' the person or induce a 'paralysis'.
- Clarity in PLANNING prior to DOING is crucial at any phase but in particular this one.
- Begin sensitive/non-judgemental discussions with the person around how they might start to address their 'acquiring behaviours'

- Periods of 'stuckness' will also be common (for a number of reasons which will include 'self-sabotage' – this is often a response to a lingering lack of self-worth/esteem but can also be indicative of a fear of significant progress or change) – don't ignore this by focusing on 'practical stuff' because when this happens it's time to take stock, listen and try to both understand the main features of the person's 'stuckness' and then work WITH them to generate some ways in which they might become 'unstuck'.
- This is also the phase when a discussion about what the person might envisage as their OPTIMUM might be useful. We use the term 'optimum' to mean the stage when what the person has in their home is no longer problematic for them. Also, remember the 'Fridge Magnet 4/5' and maybe revisit some of your initial (baseline) discussions.
- Remember, the majority of our people will never live in minimalist/'ideal home exhibition' environments – and nor should they! Having a lot of (legal) 'stuff' isn't against the law but there are circumstances when a person's preferred 'optimum' needs to be negotiated. For example:

Once you have demonstrated 'compassionate curiosity' over a period of time; People will understand when you start to introduce the 'statutory obligations/requirements' e.g. gas and electricity checks to ensure their safety and the requirements for an 'optimum' to include ensuring access for these essentials to happen. Please don't use these 'givens' as a way of 'winning an argument'/putting people on the defensive – that's the nature of a collaboration i.e. doing things WITH people, as opposed to doing things FOR/ON people.

GETTING OUT

“I think that ‘aftercare and support’ is something equally as important as all support given during clearing/reorganisation” (P, Peer Group Member)

This phase involves:

- Support to sustain and maintain progress over time.
- Relapse prevention
- In this phase we're reinforcing the progress that has been made and attempting to set in place a number of support features which will enable people to MAINTAIN what they've achieved and SUSTAIN momentum towards their 'Optimum' level (if they haven't already attained that)
- If you do need to start withdrawing from your support role then try to do so GRADUALLY and let the person know (it's called 'strategic withdrawal' and is an essential feature of any support intervention).
- A 'watching brief' is a far better alternative to 'closing cases'.

- Decluttering and 'De-hoarding' are not the same thing. Decluttering happens (predominantly) within our environments; 'De-hoarding' happens (predominantly) within our heads as we change the way we think about things e.g. attachment, value, the need to acquire etc. In order to support maintenance and try to avoid 'relapse', then a group-based peer support/intervention can be suggested and explored if one is available within the local area.
- Irrespective of the lack of a formal multi-agency pathway in relation to people who exhibit hoarding behaviours, 'joined up'/truly collaborative working is required – as opposed to merely 'passing the buck' (or what I call death by referral).
- Hoarding is NOT a disease – therefore, it's unlikely that there can be a 'cure'. However, this may well be the phase when the person might be in need of some support to explore some of the contributing factors/experiences which drive/maintain their hoarding behaviours. This is likely to involve referral to other services but, again, needs to be carefully considered and discussed with the person you're supporting.
- Make sure that the person is actively involved in and consulted about any future support suggestions.

Multi-Agency 'Memo':
Remember – if you don't play your part well then, you'll make it more difficult for the next person to take up the supporting role!

The thing about hoarding...
The most important thing about hoarding...
Is that it's about more than just hoarding.

In short, PLEASE see the person NOT the HOARD!

Points to think about when working with Autistic Adults

Two people who live with Autistic Spectrum Disorder (ASD) and attend Peer Support groups were asked:

Can you give me specific pointers that people need to be aware of in order to support you effectively? I would like 'specifics' as opposed to the 'general but essential things we try to promote eg see the person not the hoard etc?

I then needed to clarify by saying: anything specific to supporting people living with ASD and also exhibiting hoarding behaviours: What do they (support people) need to understand, take into account, respond to etc...?

The support person should get to know the person who has Autism. In order to get to know how their condition affects them because it affects different people in different ways, so the Support Person knows what to say and do, to not upset the supported person.

The Support Person should be very aware of the care plan and how the supported person wants to be supported.

The Support Person need to be able to suggest things ie. "shall we go and tackle whatever in this room in the house"

The Support Person should work in partnership with the person to help to make a plan for what to do eg. if stuff is moved, where is it going to be going.

It is important that the Support Person is honest about the situation and talks about it sensitively.

It is important that the Support Person talks about the positive outcomes such as the pleasure of being able to find stuff, watch the TV, get a bath/shower, get a good night's sleep in their own bed.

Acknowledgements

Thank you to the Peers from the HHH groups in Tameside & Salford in the development of the guide.



Useful contacts

Adult Social Care

Tameside's Early Support & Advice Hub (ESAH) are the first point of contact for anyone looking for information or advice on adult social care.

Contact the team on **0161 342 5656**

8.30am to 5.00pm Monday to Wednesday,
8.30am to 4.30pm Thursday,
8.30am to 4.00pm Friday

hoardershelpinghoarders.com

Tameside and Glossop Mental health Open Door, single point of contact Tel: **0161 716 4247**

24/7 Helpline 0800 014 9995

Military Veterans Service **0300 323 0707**

Greater Manchester Fire and Rescue Service

Provides home fire safety advice to keep you safe.

Visit manchesterfire.gov.uk or telephone our Contact Centre on **0800 555 815** for further details.