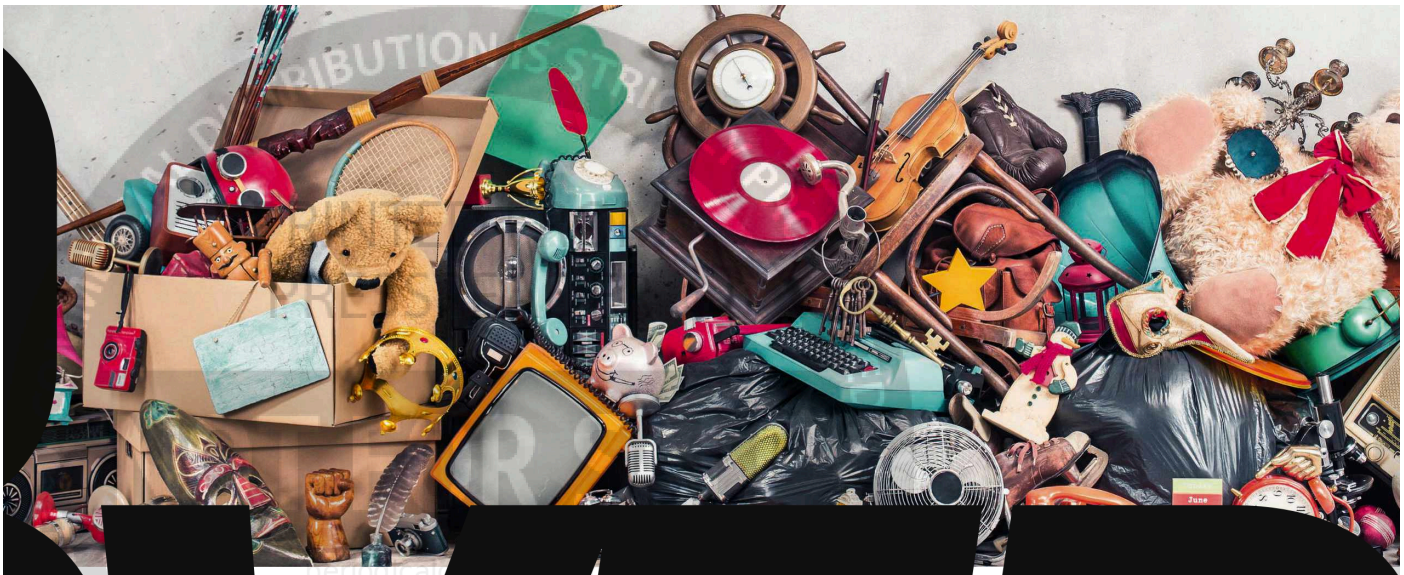
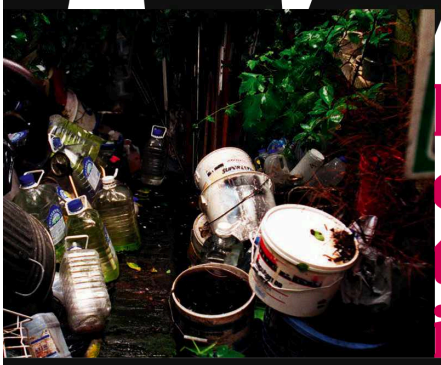
- Messiness

MIND OF CLUTTER





HOARDER



Hoarding disorder is more common than we think. But the neuroscience behind it is starting to become clear

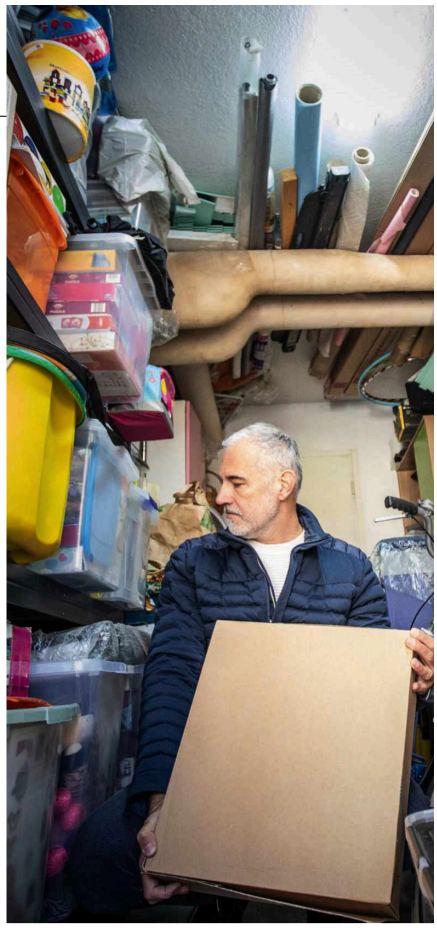
by DR LIAM DREW

Speaking to Lynn over Zoom, I can't help but inspect the shelves behind her. The upper two hold a handful of vases and some ceramics. On the lowest shelf sit two small, neat piles of papers and books. All is tidy, the scene uncluttered.

Lynn, who's 66, says she was forced to confront her hoarding behaviour around 12 years ago when her widowed father wanted to move in with her but couldn't because her house was too full of stuff. "There were bags everywhere. I couldn't have sat at the dining room table like this," she says.

Her dad, like many people unfamiliar with hoarding, thought he could help by starting the clearing process. This wasn't helpful. She recalls coming home one evening to find he'd put a load of paperwork in the recycling. The next morning, Lynn tipped out the recycling bins and desperately rummaged for all the documents she didn't want thrown away.

Her sister, in contrast, understood. "She wouldn't say, 'Get rid of this. Get rid of that. Why have you got this?'" says Lynn. "She would just hold a bin bag while I debated about things." And if Lynn wasn't in the mood, that was fine too – her sister stayed for a cup of tea, and they tried again another day.



RECOGNISED, BUT OVERLOOKED

Lynn is one of an estimated 2.5 per cent of the population that meet the criteria for hoarding disorder – a medical condition that has been officially recognised for over a decade, but which experts say is neglected by the research and healthcare community. "There are very few people who are actually looking at this," says Prof Nick Neave, a psychologist at Northumbria University, in the UK.

What's more, Neave and others suspect that the condition is more common than the data suggest and that it's becoming more prevalent by the day.

"It's a crisis," says Jo Cooke, director of Hoarding Disorders UK. According to Cooke, leaders of the UK's handful of hoarding-support charities are receiving ever more requests for help. "We must get about six phone calls every day: 'Help! My mother's got rats in her house.' 'Help! I'm going to lose my tenancy!'," she says.

Cooke met Lynn 10 years ago when the housing association where Lynn worked asked Cooke for advice on how to deal with hoarding among its tenants – an issue that was compromising the safety of people's homes and impacting their quality of life.

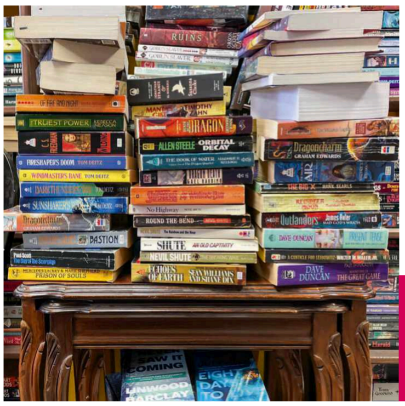
Cooke linked up different council departments and created a coordinated support network, while also working with Lynn to establish a support group for hoarders. Numerous people benefitted from this initiative, but there are still many hoarders around the UK who can't get the support they need.

"It's a postcode lottery," says Neave. "What people are doing is based on gut instinct and things that might or might not work," he says. "There are no trials. There's no standard in interventions."

Neave formed the UK Hoarding Partnership, a working group of about 200 academics, charity workers and local council figures with the aim of helping interested parties learn from each other and drive this issue up the public health agenda. In May, the group wrote an open letter to the UK government calling for national guidelines to address hoarding.

The letter states that such guidelines are needed to link the mental health services, social care teams, environmental health workers, professional organisers and housing authorities required to address the personal and practical consequences of hoarding. Such guidelines, it says, would better equip frontline workers to intervene when they encounter people living in hoarded homes. But, Neave says, to produce guidelines that are evidence-based means prioritising and funding new research. And this can only be done by educating people about the root causes and nature of this often-maligned disorder.

"There's always been this stereotype that hoarding is a lifestyle choice and that it's lazy people," Neave says. "There's still a real lack of understanding that it's a genuine complex mental health condition."



Books are one of the most common items stockpiled by hoarders, although newspapers, magazines and greetings cards can also find their way into the accumulations

DEFINING HOARDING

Hoarding's medical standing underwent a step change in 2013, when the American Psychiatric Association listed hoarding disorder as a distinct mental health condition in the fifth edition of its Diagnostic and Statistical Manual of Mental Disorders (DSM-5). In 2018, the World Health Organization followed suit, adding it to its 11th International Classification of Diseases (ICD-11).

Previously, hoarding had been considered a variant of obsessive-compulsive disorder (OCD), explains Dr Hannah Levy, a psychologist at the Institute of Living in Hartford, Connecticut, in the US. But gradually research showed that OCD's defining psychological characteristics differed from those in hoarders, as did patterns of symptom-related brain activity revealed by neuroimaging studies. Finally, it became

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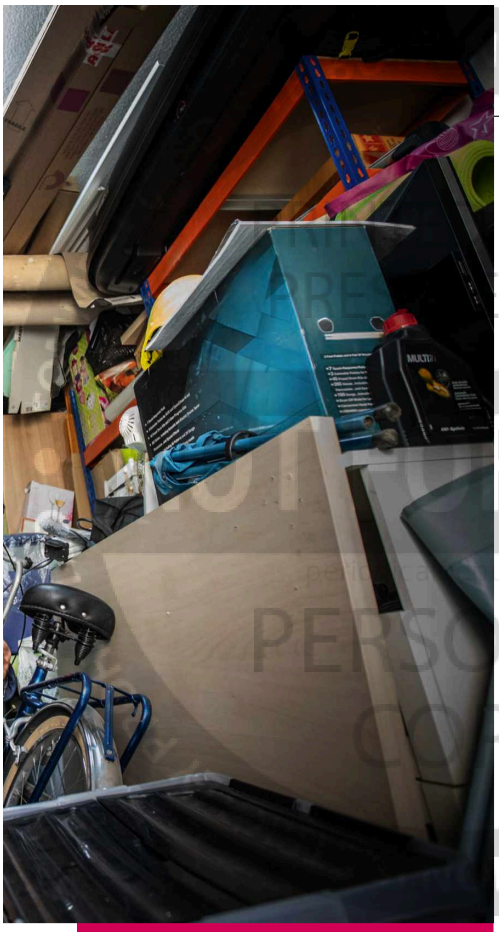

People with hoarding disorder have very strong attachments to their objects. The emotional significance placed on each item can make it very difficult for people to part with them

clear that treatment programmes used for OCD provided little benefit to hoarders.

"The hallmark of folks who have hoarding disorder is a very difficult time parting with possessions," Levy says. "They'll say that it's really emotionally uncomfortable to have to get rid of something."

Hoarders vary in terms of what they accumulate. Some amass a wide range of items, others have mountains of books; then there are those who are surrounded by broken appliances they think are too good to throw away. Lynn says she has far too many clothes.

Neave describes a woman who never threw away bus tickets. No matter how mundane or routine the journey had been, they served as mementos. "Hoarders have very strong attachments to their objects," he says. "Every single one of those tickets had some emotional significance."

When encountering someone living in a cluttered home, it's essential to establish whether these types of attachments or other emotional issues are the cause. Levy says that depression can rob a person of the energy or motivation to clear their living space, while someone with dementia or another cognitive impairment may not have the capacity to maintain their home. These cases require very different types of support.

"What also tends to happen with a hoarder," Neave says, "is that they go out and actively seek stuff, and it's often really quite cheap stuff." While excessive acquisition isn't part of the DSM-5 and ICD-11 diagnoses, Levy says research shows at least 85 per cent of people with hoarding disorder are prone to it.

If having too many possessions or shopping too much are common complaints in today's capitalist societies, Cooke says hoarding becomes a disorder "when it negatively impacts your life". For Levy, the tipping point "is a level of clutter that compromises the normal use of your living space".

Serious hoarders often can't cook in their kitchens, shower in their bathrooms or sleep in their beds. One of the worst cases Lynn encountered was a man who slept on the floor in his hallway. The man ate and washed at the café of a local supermarket. Lynn says you wouldn't have known he had a problem if you met him on the street, but when they cleared his house, it filled 18 skips.

Broken gadgets often appeal to people with hoarding disorder, perhaps because of an assumption that the device itself, or some of its components, might be salvageable



This way of defining hoarding disorder can, however, distort who's recognised as having a problem, says Neave. A person with a large house and outbuildings, for example, has the luxury of space and might acquire many needless possessions without impacting their quality of life. Whereas for someone living in a one-bedroom apartment, the story will be very different.

SEARCHING FOR CAUSES

Even though hoarding disorder has been officially recognised for over a decade – and even though it's estimated to be more common than deeply researched conditions such as schizophrenia and bipolar disorder – Levy and Neave say few academics research it. Thus, the neuroscience and psychology of hoarding remain poorly understood.

Levy and her colleagues have, however, used functional magnetic resonance imaging scans to examine hoarders' brain activity. "The one thing that seems to be a reliable ingredient is problems in an area called the anterior cingulate cortex (ACC)," she says.

The ACC is a region of the frontal cortex involved in executive functions, such as planning and organisation, as well as some forms of emotional regulation. Levy's group observed that when hoarders were placed in a brain scanner and asked to imagine giving away a possession or discard a piece of mail they'd brought with them, their ACCs became hyperactivated.

By contrast, when hoarders imagined discarding someone else's possessions, their ACCs were no more active than those of non-hoarders. "So, we're interested in the ACC as a potential mechanism," says Levy. "But it's still early days."

When it comes to what causes hoarding disorder, Neave says the common understanding is that it's rooted in

"EVEN THOUGH HOARDING DISORDER HAS BEEN OFFICIALLY RECOGNISED FOR OVER A DECADE, LEVY AND NEAVE SAY FEW ACADEMICS RESEARCH IT"

childhood trauma. He cites having unresponsive or unreliable parents or carers, or a chaotic or impoverished childhood as risk factors. "Hoarding in adulthood seems to be a coping strategy for problems that arose in childhood."

For Lynn, therapy led her to realise that her hoarding tendencies likely began when she was sent to boarding school aged 11, while the rest of her family moved overseas.

Levy agrees that childhood trauma is heavily implicated in hoarding, but notes that incidences of trauma are more common across many psychiatric disorders. "It can't be the whole story, because there are many people who have a history of trauma who don't end up having hoarding disorder," she says. She suspects that further genetic and neuropsychological factors remain to be found.

Regardless of its exact cause, research indicates that most hoarders begin having maladaptive attachments to possessions early, usually in adolescence. But, Levy says, the average age of treatment-seeking is 55. This is partly because it can take decades for a person's possessions to overwhelm their living space, but also because the condition can intensify over time.

The challenge this creates is that most people seeking help for hoarding disorder in their 50s are confronting a condition deeply ingrained in their way of life.

LEARNING TO DISCARD

Currently, the only evidence-based treatment available for hoarding disorder is tailored cognitive behavioural therapy (CBT). Levy says CBT outcomes remain relatively poor, though – a recent meta-analysis indicates that only around one in three people benefit from it – and that developing novel therapies is an active research area. Levy also notes that there are no recommended medications and that there have been very few drug trials.

The backbone of CBT at Levy's practice is helping hoarders overcome their avoidance behaviours. That is, tackling their resistance to discarding items because they find it so emotionally taxing. "We practise sorting and discarding," says Levy, describing how people bring a collection of their possessions to a treatment session, then are asked whether they'll save, discard or donate each one.

Her team also teaches emotional regulation skills to help people feel more comfortable about discarding, as well as techniques to improve decision-making and motivational skills. "The clutter didn't accumulate overnight," Levy says. "So, it's not going to go away overnight. It's going to be a long haul of work."

While acknowledging that it helps some people, Neave is concerned that CBT doesn't address the original traumas underlying people's hoarding behaviours. Various groups, he says, are exploring alternative therapies such as psychotherapeutic and grief counselling-led approaches.

Lynn has noticed how relieved people are to be surrounded by other hoarders who understand them. This connection and community, she feels, helps people face another common aspect of hoarding: the stigma and shame that often accompany it.

Cooke says that around three-quarters of the requests for help that Hoarding Disorders UK receives aren't from hoarders, but from concerned family members and neighbours. And she has noticed a spike in psychologists, local councils and fire departments asking how they can deal with the issue. This diversity speaks to the nature of the problems that hoarding causes. Yes, addressing a hoarder's mental health and helping them modify their behaviour is paramount. But invariably, they also need practical help.

"It doesn't just sit with adult social care," Cooke says. "It's a mental health disorder. It's an environmental health concern and you've got to let the fire services know, so if there's a fire, they'll bring out three crews rather than one."

The national guidelines that Neave

"PEOPLE FAMILIAR WITH HOARDING DISORDER DESPAIR AT THE TV SHOWS THAT MAKE A SPECTACLE OF HOARDERS AND DO LITTLE TO EXPLORE THE COMPLEX NATURE OF THE CONDITION"



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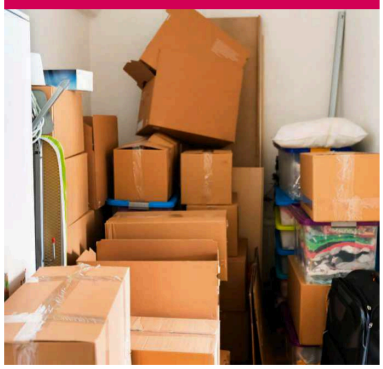


The amount of available space in a person's home can be a complicating factor when it comes to identifying someone with hoarding disorder

and his colleagues are calling for would aim to make integrated, psychologically supported interventions the norm. "As a social worker or a housing officer, you turn up and you're faced with these conditions that can be quite horrific. And you go, 'Oh, the obvious thing to do is to get rid of it all.' Well, that traumatises people," he says.

Given this, people familiar with hoarding disorder despair at the TV shows that make a spectacle of hoarders and do little to explore the complex nature of the condition. Frequently, they present a quick fix of cleaning and restyling a person's home.

"But we don't care about the home before and after, we care about the person before and after," says Cooke.

FINDING ORDER IN THE DISORDER

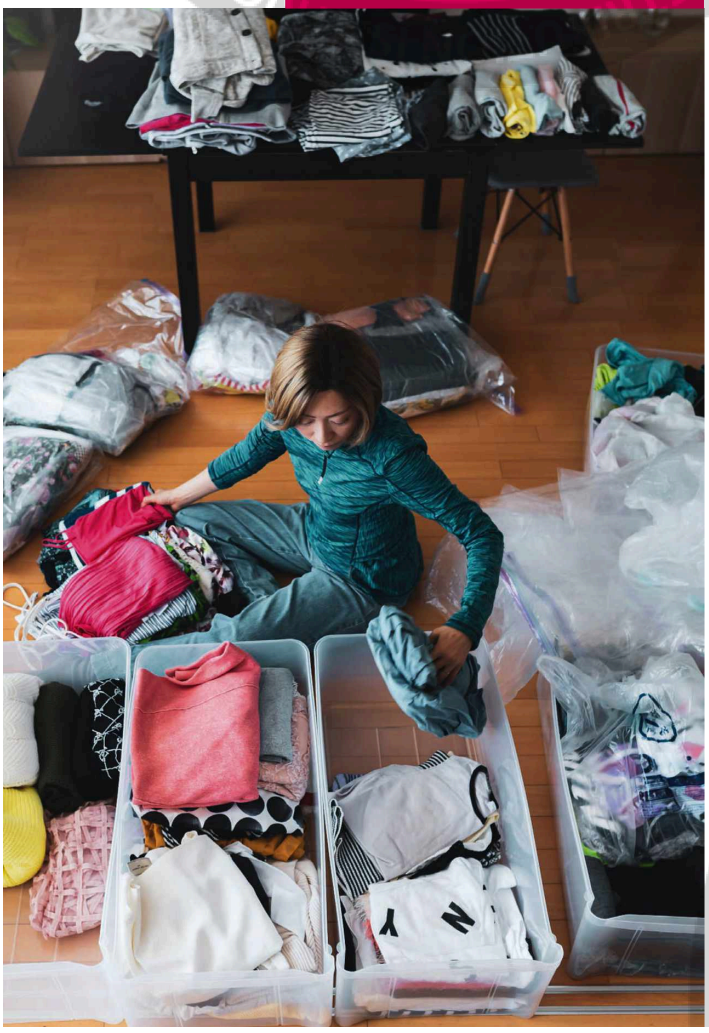
When I ask Lynn how her hoarding is now, she turns her camera away from her shelves to reveal a collection of bags blocking the entrance to her garden. Walking with her laptop, she reveals a clear staircase, an almost empty sofa and her husband making a cup of tea in a kitchen no messier than a million others. But then, there's her utility room – accessible, but choc-a-bloc with bags and clothes. And next a shed, which is bursting with large, overfilled bags.

Hoarding comes to her now in waves, she says. There's order in the disorder. The house is in a liveable state and she's grateful to have had so many people in her life who accept her. "I haven't felt that need to hide the situation or feel ashamed," she says. "It's just something now that's... You know, it's me."



Lynn and other advocates like Neave, Cooke and Levy, will keep pushing for more research, understanding and compassion. They are encouraged by the US Senate Special Committee on Aging issuing a report last year calling for more research into hoarders. Whereas in the UK, Neave says that two months after sending his letter to 20 government ministers and high-ranking officials, he's received just one brief reply, saying 'thanks, I'll take a look...' **SF**

Discarding items can be difficult for people with hoarding disorder and may require several rounds of sorting before a definitive decision can be reached



With the right support, people with hoarding disorder can begin to sort through and clear out the items that make living their lives difficult



by **DR LIAM DREW**
Before becoming an award-winning journalist, Liam was a neuroscientist at UCL and Columbia University.

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