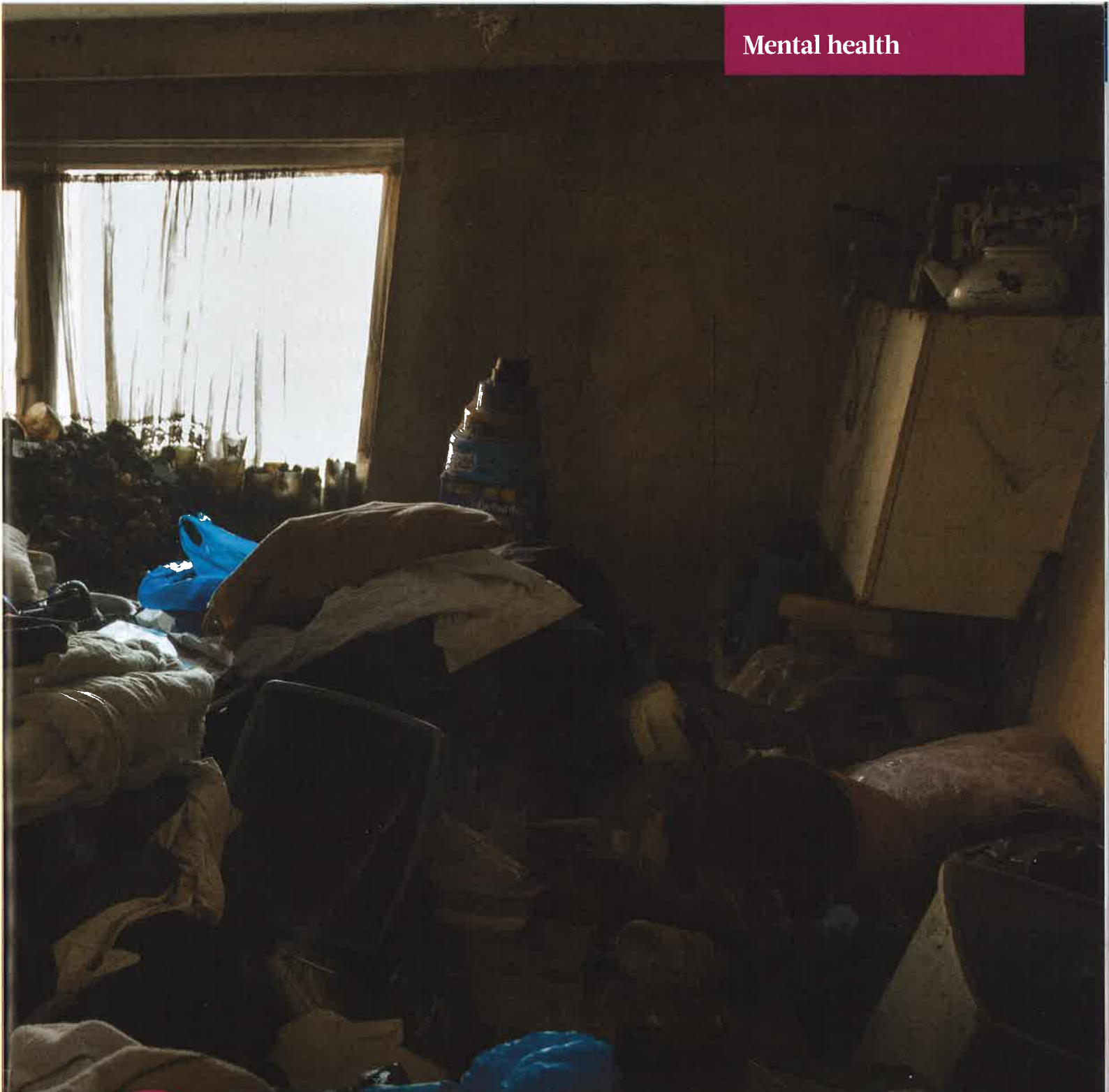


'I TRIED TO KEEP A LID ON IT'

Hoarding disorder is now recognised as a mental health condition, but local authorities still have much to learn about dealing with the problem

BY PENNIE TAYLOR / PHOTOGRAPHY BY MANU VALCARCE



STEPHANIE EVANS began hoarding after the traumatic birth of her daughter, Kathryn, in 1990. As baby clothes, toys and an array of infant accessories piled up, her marriage fell apart and Steph grew increasingly fearful of letting anything go, no matter how useless or broken.

"Fretting about that added to my anxiety and depression," she says. "Over the years, as the flat got more full of stuff, I tried to keep a lid on it. I wouldn't invite people round or answer the door. I lived in fear of someone reporting it and taking Kathryn away."

When her daughter left home to go to college, Steph's isolation intensified, as did her hoarding. "I was very unhappy, struggling with lots of change," she says. "I kept everything: books, magazines, newspapers, clothes, and I had enough linen to stock a few hotels. I hated being at home in amongst it all, but the efforts of my family to get me to sort it out only ramped up my embarrassment and negative feelings. When they tried to do it for me I felt so ashamed, which only made the hoarding worse."

Withdrawing into the mounting chaos inside her Birmingham home, teaching assistant Steph stubbed her toes, sprained her ankle, and once even had the contents of a kitchen cupboard crash down on her head. "It was becoming dangerous, but I couldn't see what to do about it," she says. "Getting the right kind of support is vital. It is no use someone else doing it for you. But they can help rather than hinder, if they know how."

Hoarding disorder is characterised by excessive acquisition and chaotic storage of things that may include inanimate objects, or even animals. The root cause of the condition is not fully



These photographs were taken during decluttering sessions with hoarders in 2015. The photographer, Manu Valcarce, was a volunteer with the charity Making Room, which works with hoarders to help them identify the reasons behind their hoarding and develop strategies to prevent it

understood, but it is notoriously difficult to treat because people who hoard often do not want help.

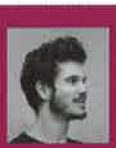
Once thought to be an adjunct to other mental health problems such as obsessive-compulsive disorder (OCD), hoarding disorder was finally recognised as a condition in its own right in 2013, when it was listed in the fifth edition of the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders* (DSM). Then, last year, hoarding disorder was included in the World Health Organization's *International Classification of Diseases* (ICD) for the first time. Both guides are used worldwide, and listing means greater clinical recognition and more research.

Classification has been welcomed by many EHPs, often the first point of contact for people concerned about the risks of hoarding. "We need to change national practice when it comes to dealing with hoarding behaviours," says Ellis Turner, senior lecturer in EH at the University of the West of England, Bristol. "In the past we have sometimes been a bit too robust, leading to brutal, traumatic interventions that involved forcibly removing the person, clearing their home, sanitising it and then reinstating them.
In my experience, that doesn't work – and the shock can actually kill people. That is my motivation for making change happen."

"We need to change national practice when it comes to dealing with hoarding"

It is generally estimated that between 2% and 5% of people live with hoarding disorder, which is usually kept well hidden. Evidence indicates that it can affect people of any age, ethnicity, gender and income bracket; typically, it is only when neighbours complain about overspill or vermin that professionals get involved.

Ayeisha Kirkham is environmental protection manager at North Kesteven District Council in Lincolnshire. "It's not something we come across often, perhaps three cases per officer per year, but it can be extremely time-consuming," she says. "We have to engage with the person, persuade them to allow us to inspect the property, then get them to appreciate why things may have to change. It can be a very long haul."



ABOUT THE PHOTOGRAPHER
Manu Valcarce's work focuses on human rights. The images on these pages are from his 'The Meaning of Things' project, which promotes an understanding of hoarding and tries to reduce the stigma attached to it.

As a practitioner, Ayeisha has experience of intervening, using the definition 'filthy and verminous premises' from the 1936 Public Health Act to justify enforcement. "But if there is nothing in place to prevent recurrence, it just builds up again," she says.

Hoarding is a risk for house fires, while illness and injury can result from infestation by insects or rodents and build-up of stored material. Bringing together local agencies – including fire and rescue services, health providers, housing associations and charities – has been a priority for Ayeisha, and in 2017 North Kesteven became the first district council in Lincolnshire to have a hoarding policy. "It sets out who can do what, and how they can be contacted," she says. "It's already making a difference, as we are all talking more and cooperating better."

SENSITIVE MANAGEMENT

Although many people who hoard do not recognise it as a problem, there is growing appreciation of hoarding as a mental health condition that requires sensitive management. "There is just not enough support out there for people who hoard," says Ayeisha. "There ought to be greater choice for those who need help."

In Lincolnshire, referrals may be made to the Wellbeing Service, which works to support people who hoard,

in ways that are appropriate to them. But as yet there is no agreed national guidance.

That is something that newly qualified EH officer Abbi Hilton wants to change. "EH professionals really don't know how to help," she says. "My research has shown that while there is interest in making improvements, there is not yet the evidence to prove the best approach."

It was while she was studying for her MSc in EH at the University of the West of England that Abbi surveyed all 400 or so local authorities in England and Wales to scope out their hoarding policies. "Around 25% responded, which is relatively high, and shows the interest in hoarding that there is on the ground," says Abbi.

Thirty per cent of Abbi's respondees reported that they have no hoarding policy of any description. "Given that hoarding is now classed as a mental health condition, that clearly needs to change," she says.

WINNING TRUST

Abbi, who now works for Gloucester EH department, is in the process of building a hoarding team there and developing a local policy. "I would urge all local authorities to put staff on special hoarding awareness courses," she says. "How you speak to a person who hoards makes all the difference, and you can learn the dos and don'ts. It's all about winning trust."

Megan Karnes, founder and director of the charity HoardingUK (www.hoardinguk.org), heartily agrees. "Public agencies have a duty to manage hoarding behaviour, rather than punish it," she says. "It is important to recognise it, and anyone who attends a house to undertake tenancy checks or gas and electrical checks, for instance, has a safeguarding duty to raise severe cases. Unfortunately, with no clear pathways of support, this is often a dead end. We need a more systemic approach right across the country."



"I believe hoarders have to decide they want to change and to throw away their clutter, piece by piece. For this to happen they need support, patience and space," says photographer Manu Valcarce

"I urge all local authorities to put staff on hoarding awareness courses"

As well as developing and delivering multidisciplinary training, HoardingUK has advised local authorities on hoarding policy. It also offers advocacy services and operates a telephone helpline. "We aim to support people to make their homes safe and habitable again in a sustainable way," says Megan. "It's a really person-centred approach, and it works."

For Steph Evans, making contact with her local hoarding support group was the key to recovery. "I had watched a TV programme that gave me hope. Instead of being sensationalist and stigmatising, it was kind and understanding, and showed me that I did need help," says Steph. "So, in 2016 my daughter told me about a group that had just started up here. Thanks to them, I have managed to reclaim my space - and maintain it for more than two years."

Now part of a community choir, making new friends and enjoying time in her home, Steph describes herself as a 'former hoarder' and says her life has been transformed. "I really want other people who hoard to know that they don't have to struggle on alone," she says. "There is help available that recognises your need to be in control. It's great to get support, but ultimately making the changes is down to you. I'm proud of what I have achieved – and so is Kathryn."

SIGNS OF HOARDING DISORDER

Someone who has a hoarding disorder may typically:

- Keep or collect items that may have little or no monetary value, such as junk mail and carrier bags, or items they intend to reuse or repair.
- Find it hard to categorise or organise items.
- Have difficulty making decisions.
- Struggle to manage everyday tasks, such as cooking, cleaning and paying bills.
- Become extremely attached to items, refusing to let anyone touch or borrow them.
- Have poor relationships with family or friends.

Source: NHS.uk

