



Supporting people affected by Hoarding Disorder

Ayrshire Multi-Agency Guidance







Assisting staff to help people who are affected by Hoarding Disorder and other chronic conditions that result in clutter and disorganisation

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Who is this guidance for?

This document is intended to provide initial guidance for any member of staff of any Ayrshire organisation who might come into contact with people who are affected by Hoarding Disorder - and other chronic conditions that result in clutter or disorganisation - in the course of their work.

Usually, the staff this guidance has been designed for will have come into contact with the individual because they are providing support (eg Social Work staff or Voluntary Sector staff etc) or a service (eg Housing etc) and the hoarding issue may only come to light as a result of their involvement with the person in relation to other issues.

This guidance is intended to provide a concise overview of what hoarding is and some of the issues that practitioners should take into account when supporting or providing a service to people affected by Hoarding Disorder.

For those who are not directly working with those affected by Hoarding Disorder, this guidance will provide some information on how to identify hoarding issues and provide some helpful signposting information.

Definition

"Hoarding disorder is characterised by accumulation of possessions due to excessive acquisition of or difficulty discarding possessions, regardless of their actual value. Excessive acquisition is characterized by repetitive urges or behaviours related to amassing or buying items.

"Difficulty discarding possessions is characterized by a perceived need to save items and distress associated with discarding them. Accumulation of possessions results in living spaces becoming cluttered to the point that their use or safety is compromised.

"The symptoms result in significant distress or significant impairment in personal, family, social, educational, occupational or other important areas of functioning."

~ International Classification of Diseases (ICD-11), World Health Organisation

Case Study 1 – Sue’s Story

Sue was born into a family who were struggling. Her father had suffered with addiction issues for many years and her mother had a long history of mental health issues.

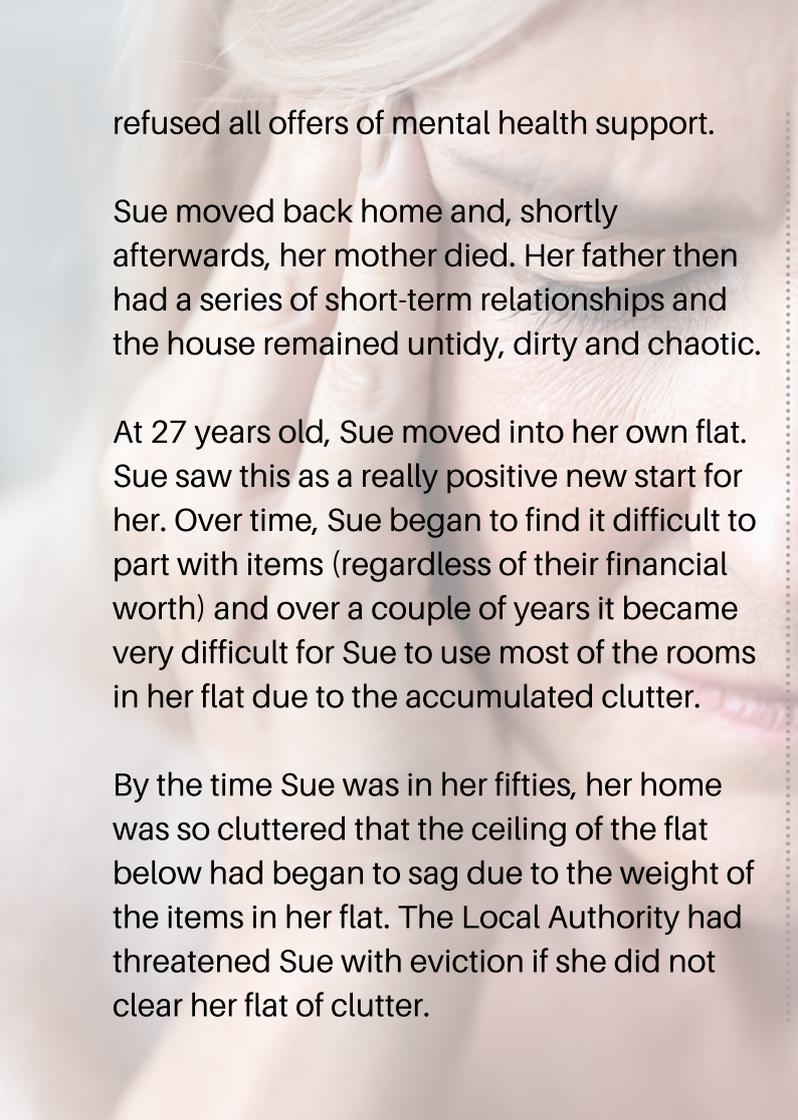
During Sue’s childhood there was often domestic violence. The house Sue grew up in was dirty and untidy. Nothing of value remained in the house for very long, either getting broken or going missing.

Sue never invited friends from school to her home and worked very hard to try to ensure that no one found out about the issues at home.

Sue was an extremely sad and lonely child, but never took up the offers of going to other children’s homes or attending schoolfriend’s parties etc, as she was always worried that a return invitation would be expected.

Sue excelled at school, which was a haven for her – away from the chaos of home. She was delighted to gain a place at university and saw moving out of home as a real opportunity to make a fresh start and finally make some friends.

However, Sue experienced severe panic attacks and crippling anxiety, which led to her having to give up her place at university. She



refused all offers of mental health support.

Sue moved back home and, shortly afterwards, her mother died. Her father then had a series of short-term relationships and the house remained untidy, dirty and chaotic.

At 27 years old, Sue moved into her own flat. Sue saw this as a really positive new start for her. Over time, Sue began to find it difficult to part with items (regardless of their financial worth) and over a couple of years it became very difficult for Sue to use most of the rooms in her flat due to the accumulated clutter.

By the time Sue was in her fifties, her home was so cluttered that the ceiling of the flat below had begun to sag due to the weight of the items in her flat. The Local Authority had threatened Sue with eviction if she did not clear her flat of clutter.

Sue had a visit from a Housing Officer who she did not initially allow into her home. Over a few weeks she felt more confident that the Housing Officer was there to help her.

Over time Sue was able to allow the worker into her home and they began to slowly remove some items from the house and arrange for some items to be taken away. The Local Authority halted eviction proceedings when they were made aware that Sue was attempting to deal with the clutter.

Over time, Sue was able to use her home more easily and safely and the items in her home were kept to a reasonable level, with continued support.

Sue went on to accept a referral to be supported with her mental health issues.

Case Study 2 - James's Story

James is in his mid-seventies and is an owner-occupier of a flat within a block where the other residents are Local Authority Tenants. His hoarding was having an impact on the neighbouring properties.

James eventually agreed to have a referral made to a Voluntary Sector Organisation for support with his Hoarding Disorder.

James was very reluctant to engage at the initial visit. This visit was made by a member of staff of the voluntary agency.



Initially the worker met with James to get to know a bit about him and James agreed to allow the agency to make an appointment to discuss with him the plan to clear some of the contents of the house.

When the workers attended his home to begin some clearing work, James was very reluctant to allow them to remove anything from the property.

One staff member noticed that he had a shed in the garden and asked if they could

move some of the contents from the house into the shed.

The gentleman agreed, but when the staff looked at the shed it was also full of bags and assorted items.

At this point the staff suggested they empty the shed and transfer items from the house that he wished to keep into the shed.

James agreed with this proposal, so the staff checked the shed was watertight before they started to move items chosen by James out into the shed.

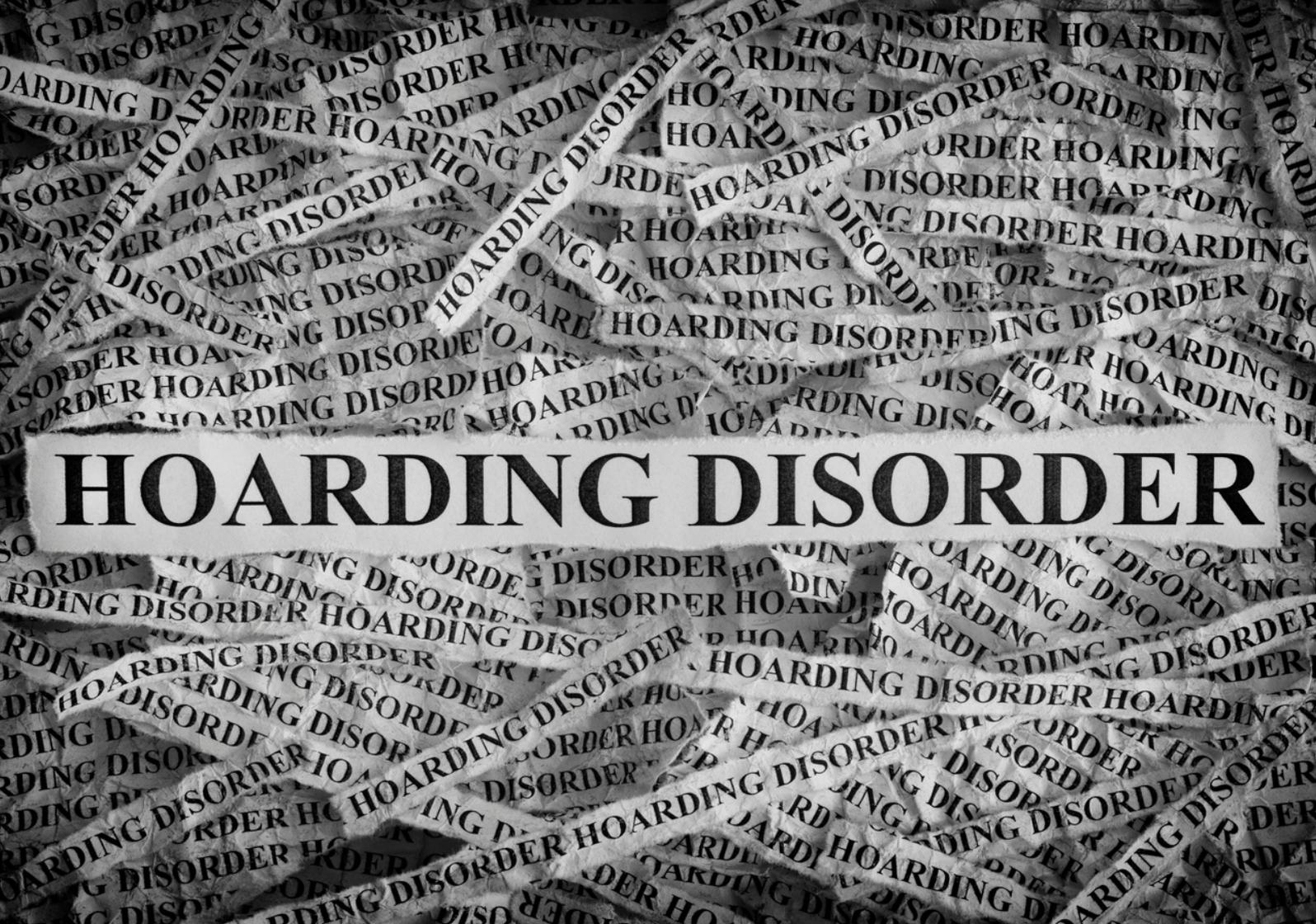
The staff secured the shed and agreed with James that they would come back the next day to help clear some more items from the house.

By this time the staff had started to build up trust with James, as he felt that they had his best interests at heart, were moving at his pace and only acting with his agreement.

It was also agreed at this point that the items he wanted to keep would be restricted to one room, which meant the rest of the house was habitable and safe.

Throughout this time, one member of staff worked closely alongside James, to help reduce his anxiety and to reassure him he was in control and that only items he had chosen would be disposed of.

In time, the situation in the house was much improved and James's relationship with his neighbours was also much better.



HOARDING DISORDER

Prevalence and reasons for hoarding

Not all clutter is linked to hoarding.

A person who lives in a cluttered and chaotic home could be 'chronically disorganised' as a result of a cognitive impairment.

Alternatively, someone could be 'situationally disorganised' - following a traumatic life event.

Hoarding is different from collecting. Both activities involve acquiring items to which a person gives a special value that may go beyond the item's actual worth.

Collectors tend to organize and display items

carefully. Collectors are usually proud of their items and like to talk about them or show them off.

Hoarders, on the other hand, are often embarrassed about their living situation and may avoid inviting people into their homes.

In most situations, hoarding is only problematic if it causes distress or is a health or safety issue.

People may also only have issues with hoarding behaviour at an especially stressful time in their lives or they may have chronic hoarding disorder.

Signs of a 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
- Buy new items and store these (sometimes unopened)
- Find it hard to categorise or organise items
- Have difficulties 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

Hoarding can start as early as the teenage years and gets more noticeable with age. For many, hoarding become more problematic in older age, but the problem is usually well established by this time.

It's thought that around 1 or 2 people in every 100 have a problem with hoarding that seriously affects their life.

Items people may hoard

Some people with a hoarding disorder will hoard a range of items, while others may just hoard certain types of objects.

Items that are often hoarded include:

- Books
- Clothes
- Newspapers and magazines
- Leaflets and letters, including junk mail
- Bills and receipts
- Containers, including plastic bags and cardboard boxes
- Household supplies
- Food

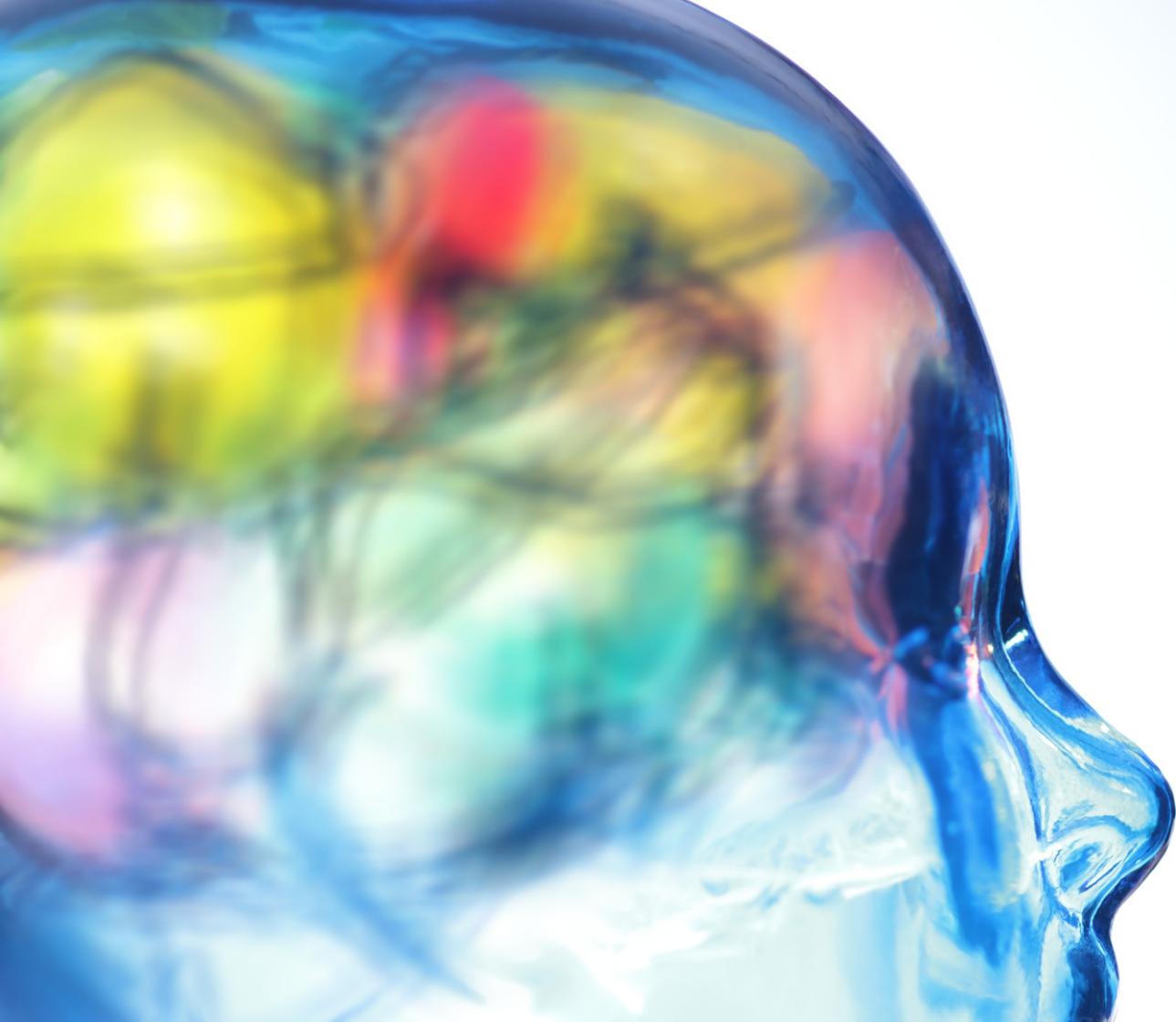


Some people also hoard animals, which they may not be able to look after properly.

Occasionally people can hoard bodily fluids (urine etc) within their home.

More recently, hoarding of data has become more common.

This is where someone stores huge amounts of electronic data and emails that they're extremely reluctant to delete.



Why people hoard

This can be complex - it is normal for us to experience the desire to collect and keep items of importance to us. Evidence would suggest that people who hoard can often experience significant emotional attachment to objects and this makes these hard to part with.

There is evidence of a 'cognitive bias' in some people who attribute beauty to objects that others do not (eg an old bottle cap, the cardboard inside of a toilet roll) and some people can become very anxious that they will need a certain item at a later date.

Often the reasons for this strong attachment can be complicated and are informed by someone's past, their psychological make up, their beliefs and attitudes.

Hoarding often runs in families and can frequently accompany other mental health disorders, like depression, social anxiety, bipolar disorder and impulse control problems. A majority of people with compulsive hoarding can identify another family member who has the problem.

There may be several overlapping issues impacting on someone who has developed Hoarding Disorder.

When hoarding becomes problematic

A hoarding disorder can become problematic for several reasons.

First and foremost, it is important to recognise that while a number of difficulties can arise as a result of hoarding behaviours, the individual themselves may not consider this to be a problem.

Often people will come to the attention of services due to concern raised by others (neighbours, family members) rather than approaching services for help directly.

This is extremely important to recognise, as it underlies a number of barriers or issues which can arise when working with people who

experience Hoarding Disorder, including low motivation to change, resistance to help and support and feelings of shame.

Practical difficulties from having so many items and materials in their house can make it difficult for a person to actually move from room to room.

This can detrimentally affect someone's personal hygiene, health and ability to engage with day to day activities. Often, as a result, their performance at work may suffer and interpersonal relationships can become strained.

The person hoarding is usually reluctant or

unable to have visitors or even allow tradespeople in to carry out essential repairs, which can cause isolation and loneliness.

People who hoard often suffer emotionally as a result of these factors, but also because of the perceived stigma and shame they feel because of the condition of their living environment.

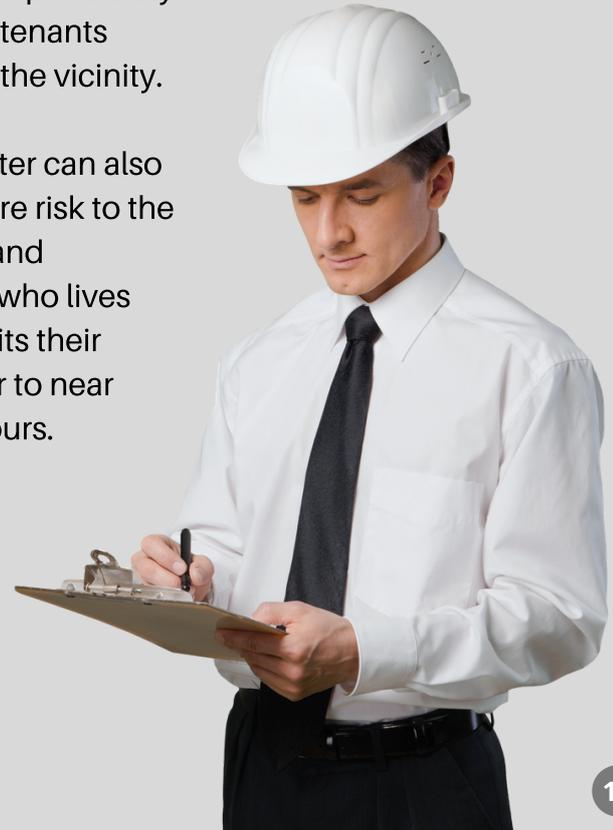
The clutter can pose a health risk to the person and anyone who lives in or visits their house.

In addition, there can be environmental impacts which go beyond the home and on occasion the Environmental Health Service has to consider its legislative responsibilities to address the impact

on neighbours and the wider community.

A Local Authority or Social Landlord may also have a responsibility to other tenants living in the vicinity.

The clutter can also pose a fire risk to the person and anyone who lives in or visits their house or to near neighbours.



Supporting people

Not only can people who experience Hoarding Disorder become very distressed at the thought of parting with items which they have been hoarding, they can understandably become distressed and upset about others seeing their clutter and being within their home environment.

Consequently, it is not uncommon for someone to be reluctant about seeking support, or to be defensive about the fact that their hoarding behaviours are problematic.

Before we consider if or how clutter can be managed or reduced, it is important to approach home visits and discussions

regarding clutter in a respectful and considered way.

Given the underlying reasons why people hoard, it is recommended to not only seek permission to enter the home environment but also regarding whether you can touch or move any items before you enter.

This can help the person feel less anxious or distressed.

It's generally not a good idea to get extra storage space or call in an agency to provide a quick clean up. This won't solve the problem and the clutter often quickly builds up again.

Life Pod are an Edinburgh based Social Enterprise who are chronic disorganisation and hoarding specialist and they state the rate of the issue reoccurring for those who hoard, following an enforced 'deep clean' is 97%.

Someone may think they are helping by removing clutter or throwing items out on behalf of someone who hoards, but this is more likely to be perceived as a breach of trust and could be potentially very damaging to the relationship.

The main psychological therapy approach for difficulties with Hoarding Disorder is Cognitive Behavioural Therapy (CBT).

The therapist will help the person to understand the reasons why the clutter has built up and may explore, for example, why throwing things away is difficult, or why they

have compulsively bought in the past. If desired, a systematic approach to reducing clutter is then taken.

It is important to note that ambivalence to change and engage in therapy are highly prevalent and without this motivation and readiness, formal therapy is not possible.

Often, the most helpful way for any person working to support someone with hoarding behaviours is to develop a trusting relationship, and to accept that it may require time to help support a change in behaviour and environment.

Frequently, this support will be provided by someone who is not a 'mental health professional'. People who hoard report a great benefit from feeling understood and validated.

If you are going to be helping the person yourself, there are many useful resources available. If you are not going to be the person helping the individual who is hoarding, you may want to signpost the person to an appropriate service.

There is a Resource in East Ayrshire who works with adults who have Hoarding Disorders – they consider referrals from across Ayrshire (there is a cost attached to this work) – see Contacts at the end of this booklet for information on this Project and other local and National resources.

You should also consider if the adult is an adult at risk of harm and if so, you will be required to invoke your organisation's process for making an Adult Support and Protection referral.

Clutter Scale

We have included the clutter scale on the following page – not to 'sensationalise' Hoarding environments, but because we recognise that people have different thresholds and whereas one person may feel that a bit of untidiness constitutes hoarding – another may not view even quite extreme hoarding environments as an issue.

The clutter scale (borrowed from our Scottish Fire and Rescue colleagues) allows us to identify a quantitative number, which can help others to be aware of the level of Hoarding and assist with risk assessment, what the impact of the hoarding may be on the individual and knowing what the best type of support to offer may be.

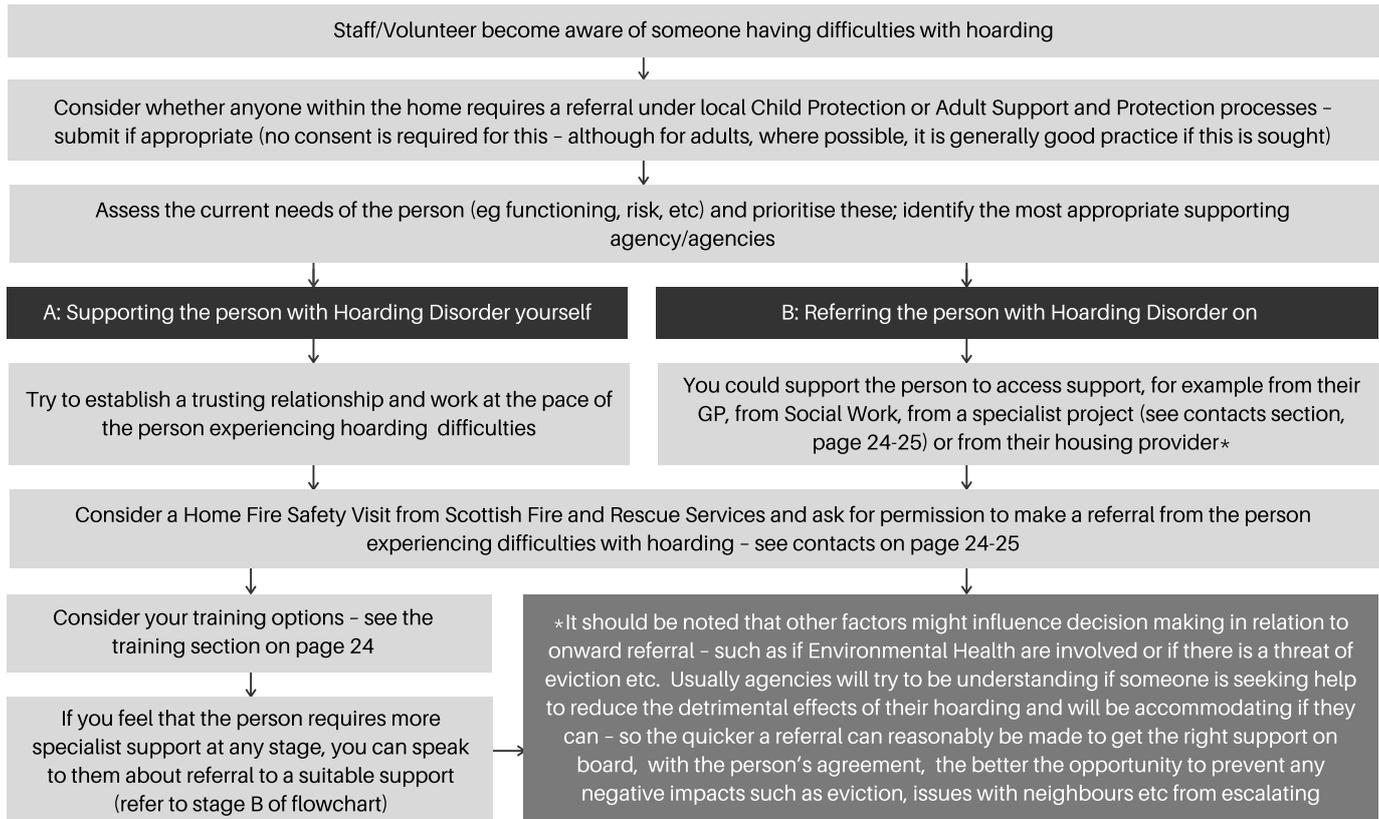
Clutter Image Rating Scale (CIRS)



The purpose of this tool is to gauge the impact of hoarding on the person with the hoarding behaviour.

Please select the photo, left, that most accurately reflects the amount of hoarding.

Process flowchart



Trust [trA

confiden

Remember - you do not have to be a mental health professional or a hoarding specialist to help a person who is having difficulties with hoarding.

The most important thing is to establish trust and work at the pace of the person whom you are trying to help. You may have to accept that it could be a lengthy and time-consuming piece of work.

However, with good, on-going support, people can reduce their hoarding and limit the negative impacts on themselves, their neighbours and the community.

Training and Key Contacts

There are agencies in Scotland who provide specialist training in relation to becoming a certified Chronic Disorganisation and Hoarding Specialist - **Life Pod** in Edinburgh provide training courses at a cost.

If you would like to access local Basic Hoarding Awareness training that will complement the information in this booklet, please contact your local **ASP Training** facility via phone or e-mail.

Scottish Fire and Rescue also offer courses in relation to being able to identify fire risks and knowing how to make a direct referral for a Home Fire Safety Visit.

Local Contacts

Cleaning with a Conscience: Project based in East Ayrshire that works with those with Hoarding Disorders (referrals considered from across Ayrshire – there will be a cost attached)

11 – 15 Old Irvine Road, Kilmarnock, KA1 2BD
Telephone: **01563 550951**

Scottish Fire and Rescue Service: Access advice or get information on Home Fire Safety Referral Training by contacting East, North and South Ayrshire Community Action Team (CAT). Email **W. ENSA. CommunityAction Team@firescotland.gov.uk**

Further information on training relating to Adult Support and Protection and/or working with people experiencing Hoarding Disorder:

East Ayrshire:

Protection and Learning Team

Email: ***P<raining@east-ayrshire.gov.uk***

Telephone: ***01563 576728***

North Ayrshire:

ASP Learning & Development

Email: ***asptraining@north-ayrshire.gov.uk***

Telephone: ***01294 310628***

South Ayrshire:

Email: ***Training.ASP@south-ayrshire.gov.uk***

Making an Adult Support and Protection Referral:

East Ayrshire:

Email: ***HSCPCustomerFirst@east-ayrshire.gov.uk***

Website: ***www.eastayrshire.gov.uk/SocialCareAndHealth/Protecting-people/Adult-protection/AdultProtection.aspx***

North Ayrshire

Email: ***adultprotection@north-ayrshire.gov.uk***

Website: ***www.north-ayrshire.gov.uk/asp***

South Ayrshire

Email: ***ASP@south-ayrshire.gov.uk***

Website: ***www.south-ayrshire.gov.uk/adultprotection/***

Ayrshire Out of Hours Social Work

Telephone: 0800 328 7758

National Contacts

For further information and advice on Chronic Disorganisation and Hoarding, visit ***http://life-pod.co.uk*** (Scotland) or ***https://hoardingdisordersuk.org*** (UK)

Notes





East Ayrshire Adult Protection Committee

**Acting
against
harm**

www.east-ayrshire.gov.uk/asap