“How Do You Expect Someone to Live Like that?” HIV & Hoarding – a case study.

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Speaker Name	Statement
Shaun Watson	I have undertaken non-promotional paid work for Gilead and Gilead's Outcome Services and Support Team. I undertake unpaid work for NHIVNA which is supported by Gilead, ViiV, MSD and Pfizer. I am a member of the Clinical Reference Group.
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What is Hoarding?

Compulsive hoarding is characterized by:

- the acquisition of, and failure to discard, a large number of possessions
- clutter that precludes activities for which living spaces were designed
- significant distress or impairment in functioning caused by the hoarding (Frost and Hartl, 1996).

Hoarding may be as prevalent in patients with other anxiety disorders as it is in patients with OCD (Meunier et al, 2006)

Many patients with compulsive hoarding report little distress or recognition of the problem (Fitch et al., 2007; Steketee and Frost, 2003)

Case Study

- **Steven, 51**
- HIV positive for 20 years.
- **Referred to community support for 'adherence support' and 'housing issues', his home is 'infested'. Lives 4th floor of a 20-storey tower in central London.**
- Due to start ART, discharged from hospital with 'venflon' insitu!
- **Phone calls x 9, walk by x 13 before eventually gaining access.**
- Rarely goes out – paranoid and delusional but, at times, rational in his thought processes, talking superfast, rambling and incoherent.

Steven's Home

- **Floors in every room covered with newspaper and magazines, clothes, old vinyl records (approx. 40 cm deep). Wet in places!**
- The flat smelt of rotten food, ammonia (toilet blocked, urine soaked floor), No working shower, windows blocked by mattresses (could hear people talking about him), bedroom not accessible at all.
- **Fruit flies, maggots, cockroaches (alive and dead), possible bed bugs.**
- Holes in ceiling and light bulb hanging on a wire in the middle of the room.
- **Steven sleeping on the back of an upturned sofa, all surfaces covered with cigarette butts, needles and syringes, condoms, lube, money.**
- Had a cat but said it was cruel to keep her "living like this".

Clutter Image Rating: Bedroom

Please select the photo that most accurately reflects the amount of clutter in your room.

1

2

3

4

5

6

7

8

9

Clutter Image Rating: Living Room

Please select the photo below that most accurately reflects the amount of clutter in your room.

1

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Clutter Image Rating Scale: Kitchen

Please select the photo below that most accurately reflects the amount of clutter in your room.

1

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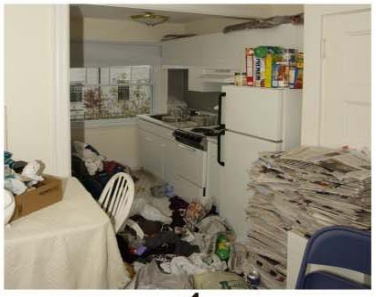

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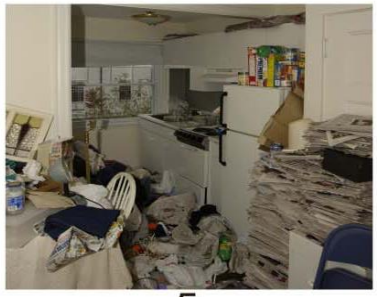

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The Issues

- Steven wants housing association to fix the broken sinks, shower and toilet.
- **He wants to clear his flat BUT systematically going through everything before it is thrown away ('it's not all rubbish')**
- Does not think he has any ill-effects from his crystal meth use ("you think I'm like this because of drugs").
- **Does not want mental health or drug agency involvement (Mental health refused referral as he has a drug problem)**
- Steven doesn't acknowledge a problem…changed clinics as the doctor attempted a section!
- **Wants to start ART (in a bag on top of a mountain of furniture).**

The Plan

- **Social work** – need to clear flat but have to get Steven out for a day.
- **Housing** – 'powerless to gain entry' despite complaints from other residents. Can clear flat but he has to give written agreement.
- **Environmental health** – visited and reported, fire risk, recommended clearance!
- **MDT** – social work, housing, community HIV CNS, Clinic nurse and consultant.
- **No meaningful contact for 6 weeks. Would only allow me brief access.**
- **SECTIONED!**

The Value of a Home Visit

- You can see the whole person and the place they call home. Do they present differently in clinic?
- **Vigilence around issues at home, how warm, cold, cluttered, infested, ordered or chaotic is the home?**
- You can assess adherence easily (how and where is ART stored? Is it ordered? How do they remember to take it?)
- **Who is there with/for them, assess for isolation (photos)**

Outcome

- **Flat cleared (4 days/5 skips). Everything removed due to infestation**
- Brother redecorated flat and now stays one day a week
- **Supported by mental health team (bi-monthly visits)**
- Maintained on ART by Community HIV CNS (every 2 weeks), vigilance of environment/mood/manner/drug use.
- Now undetectable!

Lessons learned

- **It's not an easy/timely process…it can take months/years.**
- Use the 'clutter index' so patients can identify the problem.
- **It takes a coordinated approach, who do they trust to help? If you don't have a community HIV CNS request social worker visit with GP/DN support.**
- It takes a lot longer to clear than you would think…plan for days not hours.

Where to get Help

- **Hoarding support in most boroughs & cities.**
- Refer to Community CNS Team/community complex care….if there isn't one report concerns to GP, social services and housing if applicable, more problematic if own property.
- **Discuss with friends and family if possible.**
- Use Fire Department and Environmental health to aid raising the issue and offering advice.
- **Case manage with the person who has the better relationship**