

Lessons from people experiencing hoarding

4th National Hoarding and Squalor Conference

June 2016



Supported by:

Western Sydney
Partners In Recovery

Project **Uncover** is a partnership project between Parramatta City Council, Family and Community Services, Hume Housing, Evolve Housing and Western Sydney Local Health District.

National hoarding statistics

- Hoarding is estimated to presently affect 600,000 people
- This number has increased from about 400,000 in 2012
- At a cost of \$1.8 billion to the nation

Action on hoarding in Parramatta

In response to increased concern the Collaboration and Recovery in Parramatta Working group was formed:

- WS FACS
- Parramatta City Council
- Evolve
- Hume Housing
- WSLHD – Mental Health Services
- Catholic Community Services

Learning together with Project Uncover

Funding received from WSPIR for twelve months to:

- Improve understanding of incidence and impacts of hoarding and squalor locally
- Learn from people with personal experience of problem hoarding
- Improve worker knowledge, practice, skills, expertise and confidence
- Improve service collaboration and outcomes
- Better support people affected by hoarding and/or squalor and their family, friends and neighbours

The Collectives is born

Following consultation a lived experience leadership group established to:

- Help others
- Reduce stigma about hoarding
- Raise community awareness
- Provide advice to service providers about how best to assist and support

The group chose for themselves the name, **the Collectives**.





How the Collectives works

Bringing together lived experience and professional expertise

- The Group is chaired by Judy, Nicholas who has personal experience of problem hoarding
- Project staff comprising a coordinator, Leanne Craze and an experienced peer worker, Douglas Holmes, provide secretariat services and assist with facilitation
- The Collectives meet monthly for two hours and more frequently when required Collective wisdom
- The Collectives formulated their own group rules priorities and work plan

How the Collectives work cont.

Bringing together lived experience and professional expertise

- A community artist attends meetings and works alongside the group
- Members receive a gift voucher for their assistance and for the contribution they make through the Collectives
- The Chair attends and provide input to each session of the Training and Information Exchange Program for professionals
- The Working Group seeks the advice of the Collectives

The work of the Collectives

Initial work of the Collectives

- A booklet - Collective wisdom, a collection of personal accounts and lessons
- Information flyers – What is problem hoarding through the eyes of personal experience and Practical ways to help someone with problematic hoarding – Both launched today
- Self help resource – coping with hoarding and recovering
- An information resource about sources of assistance
- Conference papers – including today's presentation



HAPPY
HIGH

Cool

frustrated

LOVE

WEIGHT ISSUES

PUBLISHED

I OWN MY OWN HOME

ACCEPT MY OSO

BE LESS DISCIPLINED

MAKE OWN LIFE

FINANCE

CONTR

Advice about language

Some principles

- Respectful language with sensitivity
- Accompanied by honesty – “call a spade, a spade”
- Use words that don’t imply judgement e.g. rubbish, junk or trash
- Describe risk e.g. fire hazard, risk to health and safety
- Describe impacts e.g. prevents access to bathroom, blocked hallways and doors, obstruct, disruptive, distressing and loneliness



Preferred language

Some preferred language

- Distinguish between hoarding and squalor
- Problem hoarding or problematic collecting
- Belongings, possession and collections – a lot or too many
- Clutter
- Alternatives to squalor – health and safety risks / hotspots, fire hazard, pest hazard, household dangers or danger to pets
- Remember squalor might not be present

What about the term ‘hoarding disorder’?

- Mixed views – mainly around ‘disorder’ or ‘mental’
- Knowing it is a mental health issue, implies help and hope for recovery – “set me on a pathway to help”
- Reflects experience – “what I knew deep down”, “light bulb moment”
- ‘Problem hoarding’ or ‘unhelpful hoarding practices’
- Pragmatic – “at least a diagnosis might lead to resources”

Toughest things

People with hoarding

- Out of control and trapped – “Took over my life to the exclusion of relationships”, “controls me”, “enslaved”, “lost control”
- Despair – “that I could not escape it, knowing there may not be a cure ”
- Isolation – “I can’t have anyone over”
- It’s impacts on others – “I lost my husband”
- Fear – e.g. about health and safety
- Grief and loss
- Physical and emotional exhaustion and ageing

Toughest things

Family, friends and neighbours

- Sense of powerlessness and helplessness – “lost her”, “lost myself”, “lost my friends, they have all gone”
- Overwhelmed, deeply bewildering and confronting
- Physical barriers, relationship conflict and much loss and grief
- Understanding why lack of acceptance of problem
- Safety fears – “worried sick”, “home is distressing”

Most helpful

- Respectful assistance and timelines
- Understanding professionals “who work with us”, “develop strategies and plans with us”
- Understanding what it is about and why it might be happening
- Help being available at the point of problem recognition and acknowledgment
- Being supported to take first small steps and further steps
- Knowing they may not be a cure but it can be managed
- Being able to work with a trusted person for longer term

Most helpful

- Having roles and responsibilities
- Learning strategies and skills e.g. for organising, discarding and reducing collecting
- Practical support that is flexible and can go the distance
- Peer support
- LifeLine group treatment program and similar programs e.g. Buried in Treasure
- Psychological therapy and counselling

Most helpful

- Peer support websites
- Buried in Treasure book & others
- Web and social media-based information and support e.g. Flylady.com, Freecycle, Helpinghands, free to a good home
- Youtube e.g.
Lee Shuer <https://www.youtube.com/watch?v=cJ7NvMKa6UU>
Bec Belofsky Shuer <https://www.youtube.com/watch?v=mnkmylcTTdE>
- Youtube e.g.
Dr Randy Frost <https://www.youtube.com/watch?v=Ke950ThjLLE>

Most helpful

- Agreed strategies in the face of legal sanctions e.g. agreed steps, warning and reminders of key dates by which actions are required, warning of inspections and offers of help
- Mediation – buy-in that reduces coercion and bullying
- Some family members reported – “nothing helped”

Not helpful

- People not understanding the level of attachment and level of psychological distress – feeling judged
- Compulsion and force
- Forced clean-ups – “counter productive both in short and long term”
- Anger, threatening, fighting, pushing, forcing, taking over
- Stigma and media portrayal e.g. the “Bondi house”

Not helpful

- Depression and anxiety being overlooked
- Poor physical health and physical limitations
- Lack of self confidence and self belief
- Lack of storage
- Not knowing where to turn or no help

Starting points for service providers

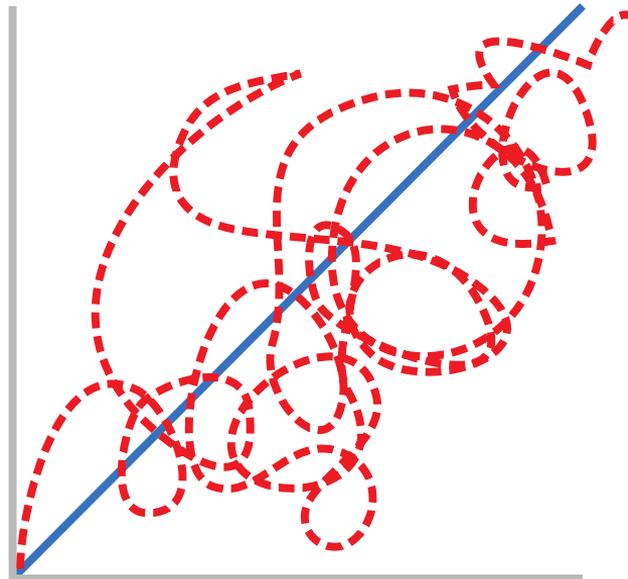
- Understand that “I feel deep shame”
- Understand trauma, loss and grief
- Understand the power of empathy, understanding and respect
- Understand the importance of giving power and choice back
- Understand “I can’t do this alone” – professional help is needed
- Understand “families can become so tired and feel so very alone”

Starting points for service providers

- Not all people with problematic hoarding live in squalor
- Sometimes it is more about impaired organisational skills e.g. as a result of physical injuries, illness or trauma
- Recovery takes time – “I’ve had this problem for 36 years” – it is hard work – “the toughest thing I have had to cope with”
- There will be setbacks
- Communities have a role to play
- Urban design is also critical
- Families, friends and neighbours need help and support

“Hoarding is a most difficult behaviour to change”

ROAD TO RECOVERY



- What people think it looks like
- What it actually looks like

“

Some families feel so guilty, helpless, distressed and overwhelmed.

We have been fighting this for so long – it is so deeply entrenched.

Our grief and sense of loss is constant and has gnawed away at us until we lose sight of ourselves and all we can think about is the needs and wishes of our loved one.

We put their needs above our own.

Please don't give up ”

Key recommendations

- Listen to and learn from personal experience
- Collaboration and coordination is essential
- Address chronic lack of resources e.g. psychological therapies both individual and group-based, peer support and in-home practical support, mediation etc
- Emphasis on promotion, prevention, early intervention and community awareness
- Use every possible avenue e.g. NDIS, My Aged Care, Better Access
- “Stick with us and please don’t give up on us”



For information and to register

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Family &
Community
Services



Health
Western Sydney
Local Health District

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