

# This Full House

A Pilot Intervention Program to  
Assist Elderly Compulsive  
Hoarders

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# Presentation Outline

1. General Overview of Hoarding
2. What we did – pilot data and our experience
3. Client and Professional Testimonials

# Data Sources

- OCD Conference, Boston, MA, U.S.A. - August 2008
- This Full House Program, Age & Opportunity, Winnipeg, Manitoba
- Compulsive Hoarding and Acquiring – Therapist Guide & Buried in Treasures – Dr. Gail Steketee, Dr. Randy Frost, Dr. David Tolin
- Clinical – In the field - referrals

# Definition of Compulsive Hoarding

- The acquisition of, and failure to discard a large number of possessions that appear to be of useless or limited value
- Cluttered living spaces that cannot be used as intended
- Significant distress and/or impairment caused by the clutter

(Frost & Hartl, 1996)

- Only pathological if it meets #2 and #3 = clinical problem (e.g. – surfaces full, no organization, inappropriate things in places like kitchen, main door blocked)
- Not the saving that's the problem – it's the dysfunction (e.g. saving everything – valuable and non-valuable)

# Hoarding behaviors may also be present in the following disorders:

- Obsessive Compulsive Personality Disorder
- Attention Deficit Hyperactivity Disorder
- Impulse Control Disorders
- Depression
- Eating Disorders – Anorexia Nervosa
- Brain Injury
- Bipolar Affective Disorder
- Schizophrenia
- Various Dementias

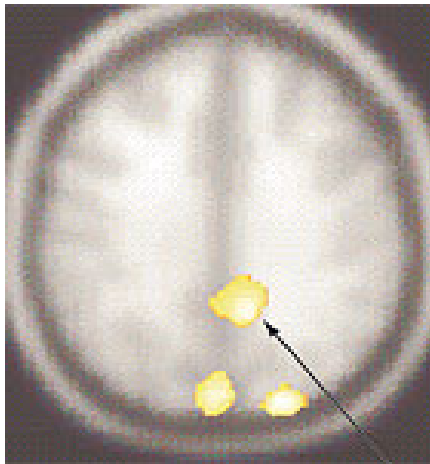
# Co-morbid Problems (in addition to hoarding)

- Depression – 57%
- Social Phobia – 29%
- Generalized Anxiety Disorder – 28%
- Obsessive Compulsive Disorder – 17%
- Attention Deficit Disorder – 15-20%
- Personality Features – Anxious/avoidant, dependent, paranoia, Dementia

## DSM-IV Criteria

- Anticipated that within the next few years, will have its' own classification in the DSM-IV
- Currently, listed as accompanying other disorders (e.g. OCD with hoarding)

# Neurobiologically Distinct Disorder



Lower levels of brain activity in the anterior and posterior cingulate gyrus – those parts of the brain associated with focused attention, motivation, decision-making and problem-solving, as well as spatial orientation and memory.

(<http://www.ucla.edu>)

# Other Significant Factors:

- Genetic Links – a large number had relatives who hoard – hoarding phenotype
- Personality traits – aloof, reclusive, eccentric, socially withdrawn, suspicious
- Usually a long-term behaviour pattern – (e.g. can't decide and fear of putting things out of sight)
- Usually single or divorced
- Usually more women than men

# Epidemiology

- Samuels et al., 2008 – *Prevalence and correlates of hoarding behavior in a community-based sample*, Behaviour Research and Therapy 46 (2008) 836-844

Adjusted prevalence rate of hoarding in adults = 5% - Over 10 million people in the US have clinically significant hoarding

With increasing age, the prevalence is higher – average age is 50

# Clutter and Hoarding

- Clutter is the product of a hoarding problem (behavioral manifestation – e.g. avoidance of distress, avoiding what is hard)
- Decision making may be the central feature of hoarding
- Physically reducing clutter does not address the hoarding problem
- Changing beliefs and the meaning of possessions eventually reduces clutter
- Improving organizing habits is a necessary component for change

# Manifestations of Hoarding

- **Acquiring** (compulsive buying, compulsive acquisition of free things, stealing) – **in excess**
- **Saving** (sentimental – e.g. card, instrumental – e.g. toilet paper roll, intrinsic – e.g. bottle caps) and difficulty discarding – mostly clothes and books – saving is normal but for people that hoard, the saving is **exaggerated, applied to large # of items, intensity of attachment**
- **Disorganization** (random piles, fear of putting things out of sight e.g. organized visually and spatially vs. categorically, indecisiveness, churning the piles – decision making process but can't do it – feeling overwhelmed)

= Clutter

# Course of Compulsive Hoarding

- Saving can begin in childhood, onset age 13
- Little evidence for history of material deprivation – e.g. war times
- Hoarding may be precipitated by **loss**
- Chronic or worsening course
- Insight fluctuates
- Severity range from mild to life-threatening

# Hoarding Complications in Elders

- Fire hazard
- Risk of falling
- Unsanitary conditions
- Medical problems

(Kim, Steketee, & Frost, 2001)

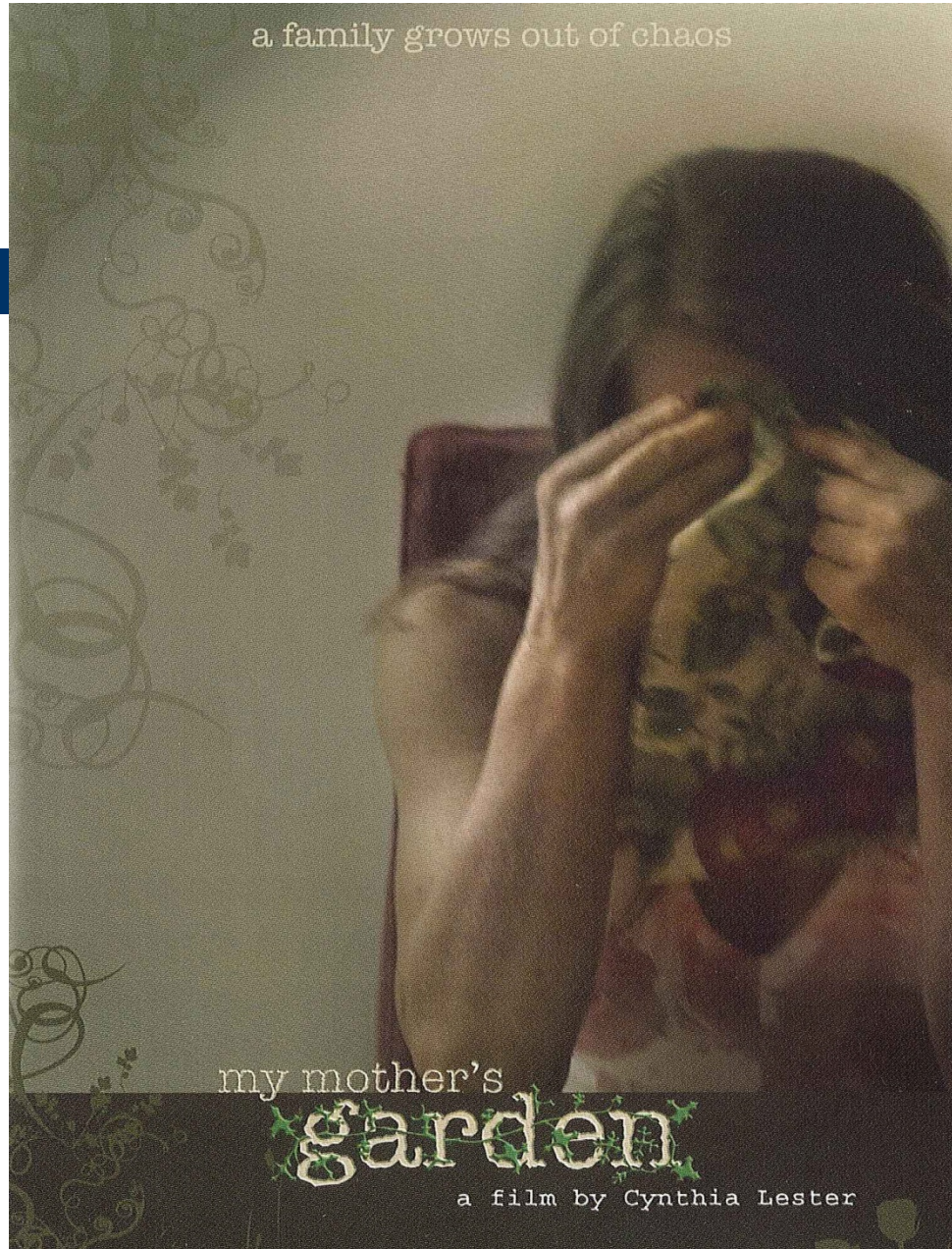
# Awareness of Problem (insight) among Elders

- Clear insight = 15%
- Partial insight = 12%
- No insight = 73%

## Implications for service providers

- trust
- motivation
- average length of intervention = 1 – 1.5 years
- hoarders like to talk about past & their relationships/losses and less on problem-solving

a family grows out of chaos



my mother's  
garden

a film by Cynthia Lester

# This Full House – Pilot Intervention Program to assist Elderly Compulsive Hoarders

- Pilot began in December 2007 – December 2008 (extension to January 2009)
- Funding provided by the Government of Canada, New Horizons for Seniors Program
- This is only the second program in Canada to specifically address hoarding behavior among seniors. The first program is being delivered at Age & Opportunity, a senior serving organization in Winnipeg

# Pilot Specifics

1. Explore the need for a “This Full House” program in Edmonton
2. Learn from the Winnipeg experience and customize our program to meet the needs in Edmonton
3. Pilot the program with a limited number of people to validate the program design

# Pilot – #1 – The Need in Edmonton

**No other program or agency in Edmonton with formal approach or program geared specifically to hoarding in seniors**

**Very little known about hoarding and seniors**

## Program Advisory Committee:

- Environmental Health
- Capital Health Home Care
- University of Alberta, Faculty of Extension
- Alberta Seniors Citizens' Housing Association
- The United Way
- Alberta Geriatric Mental Health Services
- Alberta Seniors & Community Supports
- Senior citizen
- Greater Edmonton Foundation
- Edmonton Fire Rescue Services

# Pilot - #2 – Winnipeg Program – Customize Edmonton Program

Age & Opportunity Consultant – Spring 2008 (similarity of organizations and findings)

- Delivered in Winnipeg since 2004
- Increase in cases where intervention required (2000 = 38 cases, previous years = 1-2)
- Vulnerable persons committee interested – effective community development approach
- Costly in terms of professional time devoted to issue
- Costly in terms of hiring other professional services
- Some homes require a major “clean-up” prior to This Full House involvement
- Health & Safety Issues

## Pilot - #3 – Validate Program Design

- As of December 15, 2008 – 32 clients have been referred – referral sources effective
- Protocol effective
- Community based approach best – Advisory Committee

# Objectives, Outcomes, Indicators of Success

- Work in Progress
- Data – based on the # of clients who have accessed program
- Testimonials:
  - Client
  - Professional
- University of Alberta, Faculty of Extension – Research Grant: will explore and gather data on individual quality of life, family involvement, health service collaboration, organizational impact and community engagement and building

# Pilot Objectives

To reduce hoarding behaviors in order to:

1. Keep seniors in their homes for as long as possible
2. Improve their health and well being
3. Maintain positive social contacts
4. Contribute to healthy neighborhoods.

# Pilot Outcomes

1. Prevent homelessness by bringing homes up to a habitable standard.
2. Connect seniors to other needed community services.
3. Improve senior's quality of life or overall wellness.
4. Develop the capacity of the community to respond to the need.

# Indicators of Success

1. # of referrals received = 32 ( 5 = info. only, 2 = not hoarding, 1 = deceased, 2 = moved into care homes, 2 = no assessment wanted, 9 = clean-ups, 11 = not ready for intervention/file still open - \*\*low insight)
2. # of referrals that have agreed to home visit & assessment = 30
3. # of clean-ups in progress = 2
4. # of clean-ups completed and/or in maintenance stage = 7

# Indicators of Success (cont.)

5. # of evictions prevented (where eviction notice received) = 100% (6/6)
6. # of people still living in their homes = 100% (2 moved into care homes, 1 deceased – due to changed health status not hoarding)
7. # of seniors who have connected to other support services (e.g. housekeeping, health services, meal delivery, etc..) = 100% (9/9)
8. # of seniors who state a better quality of life/state of wellness by an increase or maintenance in the domains of physical, emotional, spiritual and/or mental wellness = client testimonials

# Pilot Data

Average Age = 72

Single or divorced = 29/32

Male = 5

Female = 27

Type of Dwelling:

- House = 16

- Apartment = 16

# Pilot Data – Cont.

## Referral Sources

- Self = 5
- **SAGE** (other programs – e.g. Home Services, Social Work) = 5
- Family = 4
- Capital Health, Geriatric Psychiatry = 7
- Capital Health, Public Health Division, Environmental Public Health Services = 3
- Apartment Managers = 2
- Hospital = 2
- Capital Health, Home Care = 1
- Other Health Care Professionals (neuropsychologist) = 1
- Other community Agencies = 1-

# Data – January – June 2009

24 referrals:

- 9 assessments completed
- 1 hospitalized before assessment
- 7 assessments on waitlist
- 7 inquiries about program from community

## 2009 Date Cont.

10 clients from 2008 on long-term caseload of Social Worker for ongoing support in 2009.

This Full House being delivered by 1 Social Worker, who also has a long term caseload for clients referred from **SAGE's** Social Work Intake Service.

## 2009 Data Cont.

Started a Lunch Group/Support Group in April with an average attendance of 6 people per group. Co-facilitated by Mental Health Nurse.

Attended Hoarding Conference in San Fransisco, January 2009 – for professionals offering services to clients. Learned of and adopted Harm Reduction Approach that is now at the forefront of all action plans with clients.

# 2009 Data Cont.

## Request for Presentations:

- Alberta Health Services, Community Geriatric Psychiatry Grand Rounds
- Other Seniors Centres
- Local Churches
- City of Edmonton
- City of Calgary
- Articles published in community newsletters and association newsletters

\*\*Program Chosen by Government of Canada as a success program from Alberta and article written to highlight success.

# Hoarding Protocol

1. Referral received
2. Appointment for office or home visit
3. Assessment Process (home visit) – Assessment Tool used to assess level of risk
4. Develop Action Plan – goals and objectives, timelines, costs
5. Offer resources
6. Hands-on
7. Other senior related Social Work resources
8. Individualized and client centered
9. Relationship building and trust – foundation of any successful intervention

# Our Experience – What we've Learned

1. **Value of home visit** – pictures only tell part of the story (e.g. smells, size living space, amount of stuff/kind of stuff) - \*\*Don't assume everything is worthless
2. **Affect on family members** – stress on relationships, confusion and frustration on how to help and where to get help, financial burden
3. **Intense emotions and high stakes** – e.g. anxiety, anger, sadness - can be amplified in crisis like eviction
4. **Ineffective communication and helping strategies** - e.g. forced intervention; (?) arguing, pressuring, “telling” the person how and when to feel, giving verbal and non-verbal cues that are judgemental, making decisions for the person

# Our Experience – cont.

## 5. **Effective communication and helping strategies**

- Understand before moving to action
- Use respectful, non-judgemental language
- Work with the person instead of doing it for them (assign homework)
- Be clear about expectations and limitations
- Help with changing beliefs – simply taking out clutter does nothing for behavior
- Don't rush into intervention too soon – build trust

## 6. **Motivation & Insight – helping with motivation**

- Substantial amount of ambivalence – “I want to change but I don't” – Level of importance placed on motivation
- Confidence level in dealing with problem – encouragement, reminders of support, ask open-ended questions (non-judgmental), see & feel affects of small changes (e.g. don't miss items as much as they thought)

# Our Experience – cont.

## 7. Progress – Helping to Make Progress

- Encourage client commitment (e.g. manageable, time limited, scheduled, concrete) – Contract (?)
- Take baby steps (??)
- Follow-up and ask how the work went; celebrate successes – even small ones

## 8. Don't assume anything

- Varying financial status and educational backgrounds
- Stage of intervention could be trial and error – stop & go...stop & go....stop & go
- Level of understanding from community varies

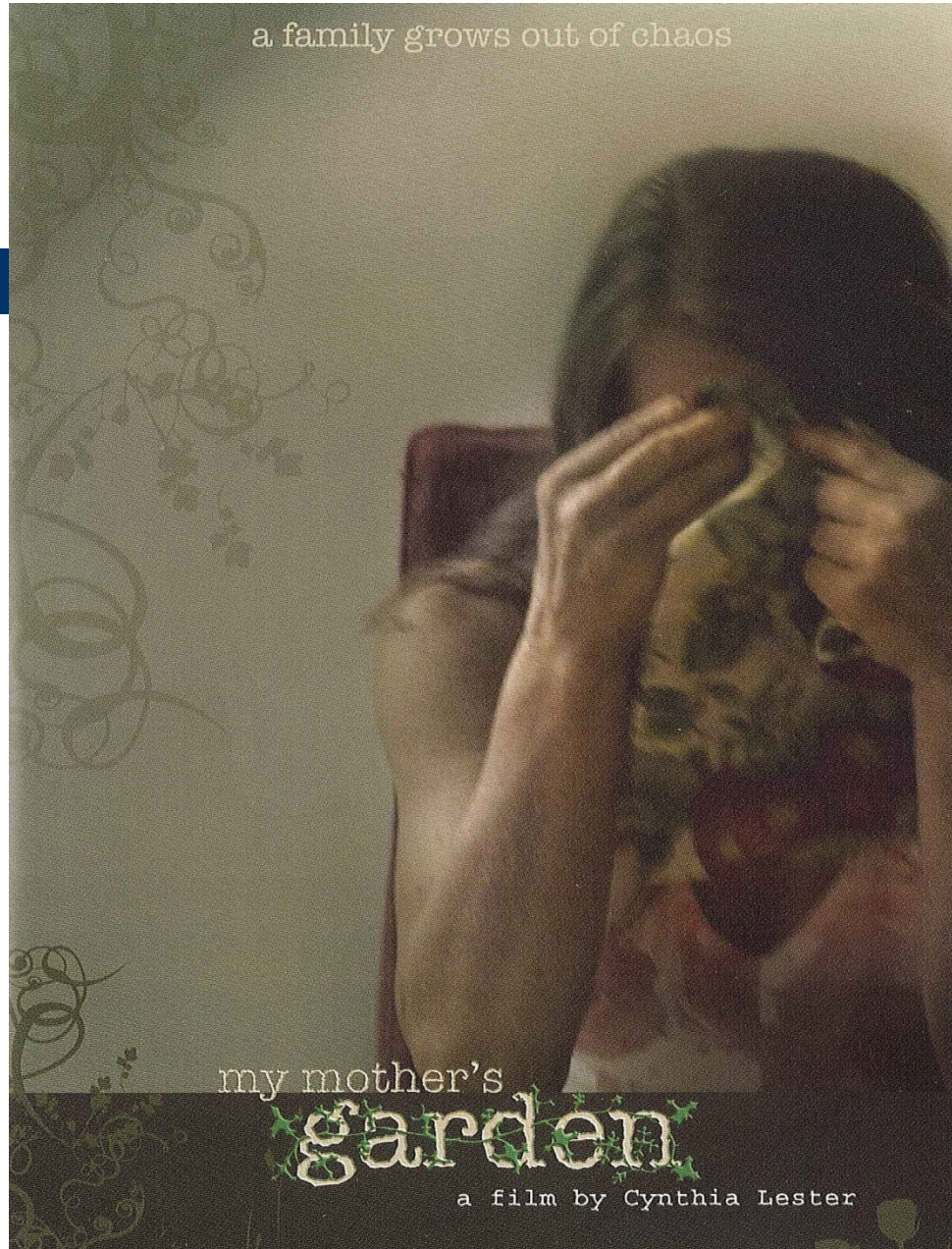
# Future Considerations

- Support Group for family members
- Increased funding for clean-ups
- Increased community capacity (e.g. volunteers, peer supporters)
- “Clutter” Classes (non-crisis) for seniors & families
- Increased community awareness
- Adopting new and proven Intervention and Maintenance Strategies
- CBT- Cognitive Behavioral Therapy program for Compulsive Hoarding and Acquiring (Dr. Frost & Dr. Steketee)
- Continued partnerships with academic community for ongoing data collection, analysis and research.

# Closing Comments

- In 2008 – 32 Referrals, In 2009 in 2 months – 12 referrals (could double by year end)
- Tidal Wave – 2011 – Baby Boomers turning 65
- Powerful work – giving people back their most intimate space
- Take time to listen and understand why

a family grows out of chaos



my mother's  
garden

a film by Cynthia Lester

# Questions & Answers

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Thank you