Late Life Hoarding Disorder

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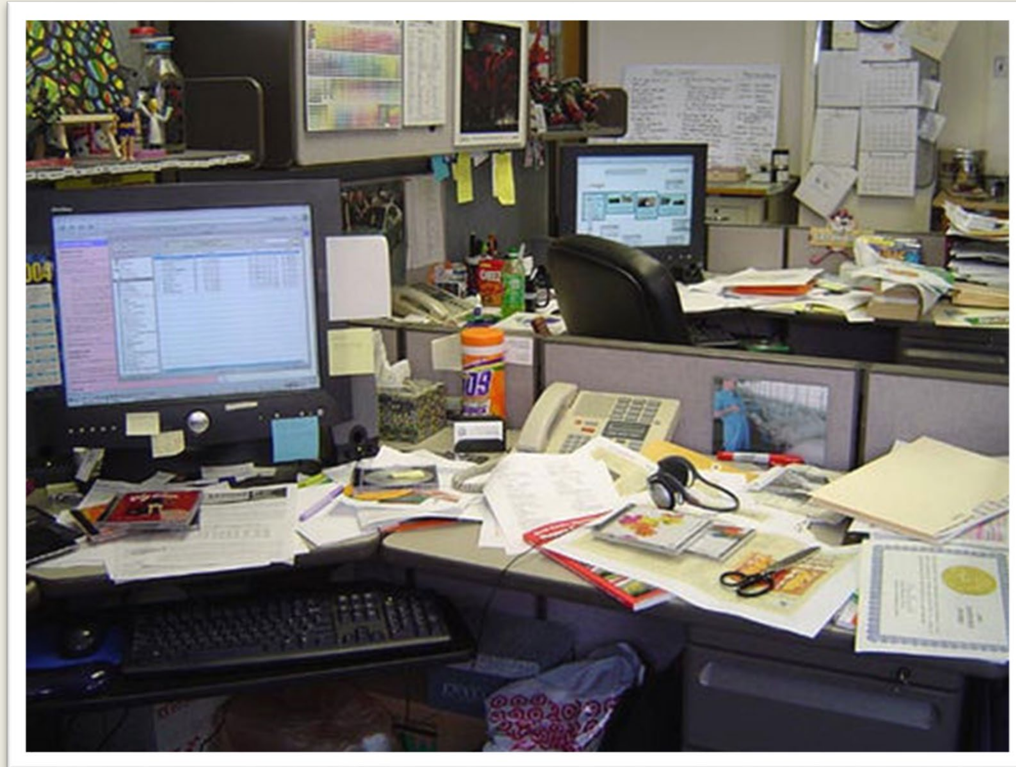
Hoarding Disorder is not…



"Everybody thinks it's just a pile of old news, but to me it's a treasure!"

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DSM-5 Criteria for Hoarding Disorder (HD)

- A. Persistent difficulty discarding or parting with possessions, regardless of their actual value.
- B. This difficulty is due to a perceived need to save the items and distress associated with discarding them.

Hoarding Disorder Criteria

- C. The symptoms result in the accumulation of possessions that clutter active living areas and substantially compromise their intended use. If living areas are uncluttered, it is only because of the interventions of third parties (e.g., family members, cleaners, authorities).

Why focus on older adults?

- Highest severity & prevalence
- Serves as a model where we can find the largest signals of change
- Largest implications for physical health

Symptoms over the Lifespan

Prevalence, Onset, and Course

- Hoarding occurs in 2-7% of adults
- Hoarding onset starts early adolescence - 68% of onsets before age 20
- Course tends to be chronic with very few reports of spontaneous remission
- Late onset hoarding is rare

(Ayers et al., 2010; Cath et al., 2017; Grisham et al., 2006; Samuels et al., 2008; Tolin, Meunier, Frost & Steketee, 2010)

Frequency in Older Adults

- Prevalence of provisional HD diagnoses increased linearly by 20% with every 5 years of age
- 15% of nursing home residents and 25% of community day care elder participants hoarded small items
- Frequency counts are available:
  - Elders at Risk Program, Boston 15%
  - Visiting Nurses Association., NYC 10-15%
  - Community Guardianship, NC 30-35%

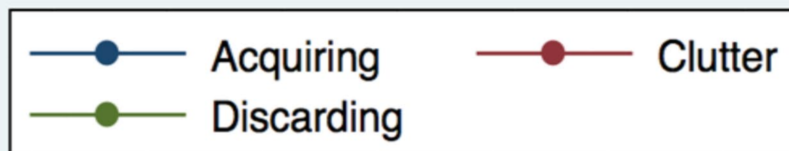
Predictive Margins of Hoarding Symptom Severity with 95% CIs

Hoarding Severity

0
1
2
3

0-10
10-20
20-30
30-40
40-50
50-60
60-70

Decade



(Dozier and Ayers, 2015)

Percent with Moderate to Severe Hoarding Worsens over Time

Age range	Percent (approx.)
0-5	
10-Jun	
15-Nov	
16-20	
21-25	
26-30	
31-35	
36-40	
41-45	
46-50	
51-55	
56-60	
61-65	
66-70	

Tolin DF, et al. Depress Anxiety. 2010.

Characteristics of HD in Older Adults

(c) UC Regents 2011

Heritability

- Older adults with HD report:
  - On average 2 biological relatives with HD symptoms
  - ~50% having a mother with HD symptoms

(Ayers & Dozier 2015)

Gender

- Older women with HD reported significantly higher hoarding severity than men on hoarding symptom self report measures; however, not on visual clutter.
- This may suggest that clutter levels are equivalent
- Women generally present more to treatment studies (~70%)

Ayers and Dozier (2015)

Marital Status

Demographic characteristics in (N = 71) older adults with HD		
Characteristic		%
Marital status		
	Married	21.54
	Divorced	33.85
	Separated	4.62
	Living with Partner	6.15
	Single	29.23
	Widow	4.62

* Married participants report lower clutter levels but equivalent levels of urges to save and difficulty discarding

Ayers and Dozier (2015)

Other Demographic Characteristics

Relatives with hoarding tendencies		
	Mother	47.69
	Father	26.15
	Brother	21.54
	Sister	24.62
	Son	15.62
	Daughter	14.29
Type of home		
	Single family	66.15
	Apartment	32.31
	Single room	1.54
Employment status		
	Retired	58.73
	Unemployed	4.76
	Disability	4.76
	Other	1.59

Ayers and Dozier (2015)

Older adults and HD leads to further isolation and loneliness

- Older adults with HD are isolated and report social dysfunction
- Increasing social support may improve treatment retention, reduce boredom and increasing self-control during treatment

(Ayers and Dozier 2015; Weiss et al., 2020)

Co-morbid Conditions in Older Adults with HD

- 63% reported at least one psychiatric comorbidity
  - MDD: 33 -50%
  - OCD: 26%
  - GAD: 24%
- Number of comorbid psychiatric disorders related to urges to save and difficulty discarding, but unrelated to clutter volume

Co-morbid medical conditions in older adults with HD

Condition	Percentage
Cardiovascular conditions	61%
Arthritic conditions	35%
Renal conditions	3%
Hematological conditions	10%
Lung conditions	6%
Sleep apnea	29%
Head injury	20%
Cancer	17%
Gastric conditions	8%
Seizures	6%
Diabetes	21%
Other conditions	46%

Personality Traits in Older Adults with HD

- The majority of participants (*n* = 64; 88.89%) had an elevated score (≥75) on at least one of the MCMI-III Personality Disorder scales
- Over half of participants (*n* = 41; 56.94%) were elevated on two or more scales.
- The most frequent elevated scores were for the Avoidant (34.72%), Dependent (37.50%), Depressive (30.56%) and Schizoid (26.39%) scales.

Executive Dysfunction

Older adults with hoarding symptoms have difficulty with:

- Categorization
- Problem Solving
- Shifting Set
- Organization
- Inhibition

(e.g., Ayers and Dozier 2017; 2019; Mackin et al., 2013)

Potential Manifestations of Neurocognitive Deficits in Daily Living

- Organization: difficulty learning and sticking to an organizational plan, routine schedules for eating & sleep, setting schedules
- Problem-solving: difficulty figuring out solutions to daily problems
- Poor planning: chronically late, little idea how long tasks will take

Manifestations of Neurocognitive Deficits in Daily Living (cont.)

- Decision Making: great difficulty making day to day decisions – and often avoid making decisions completely
- Categorization: have difficulty keeping similar items in one category
- Impulsivity: make impulsive choices

Dementia and Hoarding

- Largely case study based
- One study showed out of 133 dementia patients, 30 (22.6%) showed hoarding behaviors
- Hoarding was found in various types of dementia
- History of hoarding is important to determine HD vs. Repetitive/disruptive behavior vs. need for security.

e.g., Hwang et al., 1998

Consequences of HD

Brian Stauffer

Personal Consequences of Hoarding Increase with Age

- Fire
- Food poisoning/contamination
- Loss of social support
- Falls
- Hygiene consequences
- Pests, rats, etc.
- Relocation/ Nursing home placement
- Fines
- Jail time
- Death

Health and Safety Problems in Late Life HD

- 19% reported no health or safety concerns

Falling: 63%	Nutrition: 22%	Insect infestation: 25%
Fire: 58%	Medical problems: 35%	Animal infestation: 9%
Hygiene: 54%		Mold: 30%

- Number of health and safety problems endorsed significantly related to HD severity

Ayers and Dozier (2015)

Percentage of Appliances not Useable

(N = 62 older adults, Case Worker Interview)

60%
50%
40%
30%
20%
10%
0%

Stove/Oven
Fridge/Freezer
Kitchen Sink
Bathtub
Bathroom Sink
Toilet
Heat

Steketee et al., Health Soc Wk 2001; 26:176-184

Increased Risk of Falling

Blocked Exits

Mobility Hazards

Diefenbach et al., 2012; Frost et al., 2000; Kim et al., 2001

Profiles of Hoarding Fires

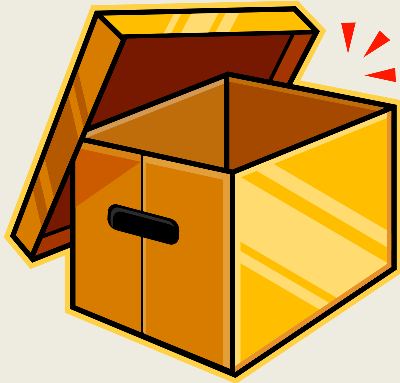
- Death in house fires - 6%
- 8 times the cost of ordinary fires
- 77% are men
- Nearly 40% are 65 or older

Frost et al. (2000)

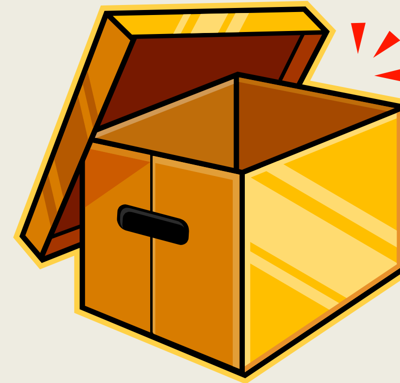
Late life HD Consequences

- Chronic and age-related medical illnesses (Ayers et al., 2010; Ayers et al., 2015).
- Medication and dietary mismanagement leading to a worsening of medical conditions (Ayers, Schiehser, Liu, & Wetherell, 2012a; Diefenbach, DiMauro, Frost, Steketee, & Tolin, 2012; Kim et al., 2001).
- Increased fall risk (Diefenbach et al., 2012; Kim et al., 2001).
- Significant impairment in their activities of daily living (Ayers et al., 2012a; Diefenbach, et al., 2012; Steketee, Schmalisch, Dierberger, DeNobel, & Frost, 2012).
- Social isolation (Ayers et al., 2010; Kim et al., 2001)
- Premature relocation to senior housing or eviction (Whitfield, Daniels, Flesaker, & Simmons, 2011)

Treatment of Hoarding



KEEP



DISCARD

Considerations for Geriatric HD

- Possible cognitive impairment (beyond those associated with HD)
- Disability levels
- Not familiar/comfortable with psychiatric treatment
- Role of family members and other social supports
- Limited/fixed income
- Multiple medications/multiple medical providers
- Possible negative life events (e.g., loss)
- Risk of losing independent living status
- Serious medical issues and health risks

Intervention Attempts in Older Adults with HD

- 76% reported no intervention attempt
- 15% reported their landlord attempted to intervene
- 17% reported an intervention attempt from at least one government agency
  - Adult protective services: 6%
  - Police department: 6%
  - Animal protection: 4%
  - Child protective services: 5%
  - Fire department: 4%
- **No relationship between intervention attempt and hoarding severity**

Full or Partial Cleaning of Home

- Causes distress for individuals with hoarding
- Cleaned areas are often cluttered again
- Not a useful approach in the long-term

Study 1

Cognitive Behavioral Therapy (CBT) for HD
in Older Adults

CBT for HD

- Standard CBT for hoarding shows less response for older adults
- Negative impact of neurocognitive deficits on treatment?
- Modest response in adults across multiple studies
  - Low motivation
  - High attrition
  - Did not achieve remission at end of treatment (26 sessions)
- Poor response in older adults

(Ayers et al, 2010; Turner et al., 2007)

Study 2

Cognitive Rehabilitation and Exposure/Sorting Therapy (CREST) Open Trial

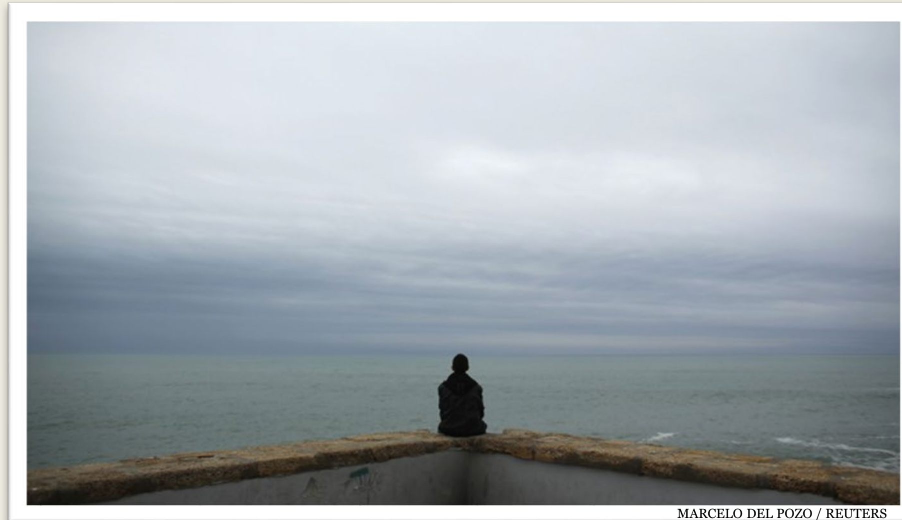
CREST for HD in Older Adults

- Cognitive Rehabilitation and Exposure/Sorting Therapy
- Behavioral manual geared to compensate for cognitive deficits using cognitive rehabilitation with exposure therapy

Funded by VA Career Development Award (Ayers PI)

CREST

1. Emphasis on behavioral approach (exposure)
2. Teach skills to support/improve:
   - Executive functioning
     - Planning, preparation, organization, abstract reasoning, cognitive flexibility, problem solving skills



MARCELO DEL POZO / REUTERS

CREST

Cognitive Rehabilitation and Exposure/Sorting Therapy Session Outline
1. Introduction and Psychoeducation
2. Calendar Use
3. Linking Tasks, Using a "to do" list
4. Problem Solving
5. Thinking Flexibility and Planning
6. Discarding Preparation
7. Organizational and Exposure Preparation
8. Introduction to Exposure Therapy
9. Exposure
10. Exposure
11. Exposure
12. Exposure
13. Exposure
14. Exposure
15. Exposure
16. Exposure
17. Exposure
18. Exposure
19. Exposure
20. Exposure
21. Advanced Exposure (longer home visit with team)
22. Advanced Exposure
23. Relapse prevention and maintenance
24. Relapse prevention and maintenance

Theoretical basis for compensatory training

Cognitive compensation

- “Working around” deficits (e.g., using a cane to support a weak leg)
- Taking advantage of cognitive strengths
  - By using different strategies
  - By using different brain areas

Habit learning

- Habits –good or bad –are hard to break and are particularly resistant to forgetting
- Relies on intact neostriatalpathways rather than declarative memory systems

COGSMART; Twamley et al., 2008

Integration of cognitive compensatory training and exposure:

60
40
20
0
Session 1
Session 5
Session 10
Session 15
Session 20
Session 26
Exposure
Cog Rehab

Problem Solving

- Emphasis on making decisions, creating steps, finding solutions
- Follow the 6 step method:

  1. **Define** the problem

  2. **Brainstorm** solutions to the problem

  3. **Evaluate** each solution in terms of ease of implementation, costs and benefits,

  and likely consequences

  4. **Select** a solution to try

  5. **Try** the solution

  6. **Evaluate** the solution: Did it work? Do you need to try another one? If so, go back to step 4.
- Practice in session & then give as homework

Prospective memory

- Strategies
  - Calendar systems and programming calendar use
  - Daily checking
  - Weekly planning
  - Entering both events and reminders prior to events
- Linking tasks (new task linked to automatic task)

Prospective memory

- Automatic places (keep items in same place)
- Using to do lists and sticky notes with calendars
  - Short-term prospective memory strategies
  - Write on hand
  - Leave self a message
  - Use visual imagery
  - “Can’t miss” reminders

Cognitive Flexibility

- ✓ Looking at all options
- ✓ Strategy verbalization (self-talk while solving problems)
- ✓ Hypothesis testing by looking for disconfirming evidence
- ✓ Set shifting/ maintenance

Exposure

- Rationale for exposure treatment
- Discuss role of avoidance in maintaining hoarding
- Teaches new information about discarding: the behavior and emotions are safe
- Explain the process of distress tolerance
- Exposure directly combats avoidance
- Develop a hierarchy
- Establish rules to use during exposure (e.g. therapist may not touch any possessions)
- Repetition of exposure treatment rationale

Hoarding Severity Changes

Measure	Baseline n=11	Mid-Treatment n=10	Post-Treatment n=11	Baseline to Post-Treatment	% Change from Baseline to Post-Treatment n=11
Savings Inventory-Revised	59.90 (10.17)	54.66 (12.27)	37.50 (14.78)	$F_{1,8}$= 167.64, p=.000	38.36%
UCLA Hoarding Severity Scale	27.30 (5.67)	22.77 (7.17)	16.60 (8.19)	$F_{1,8}$= 97.60, p =.000	40.86%
Clutter Image Rating Total	3.43 (2.09)	Not administered	2.60 (1.89)	$F_{1.6}$= 24.40, p=.012	25.96%

Study 3

Randomized Controlled Trial for CREST

Changes in Saving Inventory-Revised

CREST	Case Management
• Significant improvement at post assessment • Average post score *below clinical severity* • **39% Reduction**	• Significant improvement at post assessment • Average post score *still clinically significant* • **25% Reduction**

Changes in Clutter Image Rating

CREST	Case Management
• Significant improvement at post assessment • Average post score *below clinical severity* • **41% Reduction**	• Significant improvement at post assessment • Average post score *still clinically significant* • **15% Reduction**

Long term outcomes: Hoarding severity

Mean SI-R Score
70
60
50
40
30
Baseline
3-mo
Post-treatment
9-mo
12-mo
StudyPhase
CREST
CM

Study 4 County Innovations CREST

San Diego, California

State Innovations CREST

CREST Demographic Characteristics from 175 Clients 2016 to 2020

Demographic Characteristics	Total
Average Age (Range)	69 (57-95)
Gender Identity	
Male	52
Female	119
Other	4
Ethnicity	
Non-Hispanic/Latino	161
Hispanic/Latino	15
Race	
White/Caucasian/European	129
Asian	7
African/African-American/Black	7
Two or more races	18

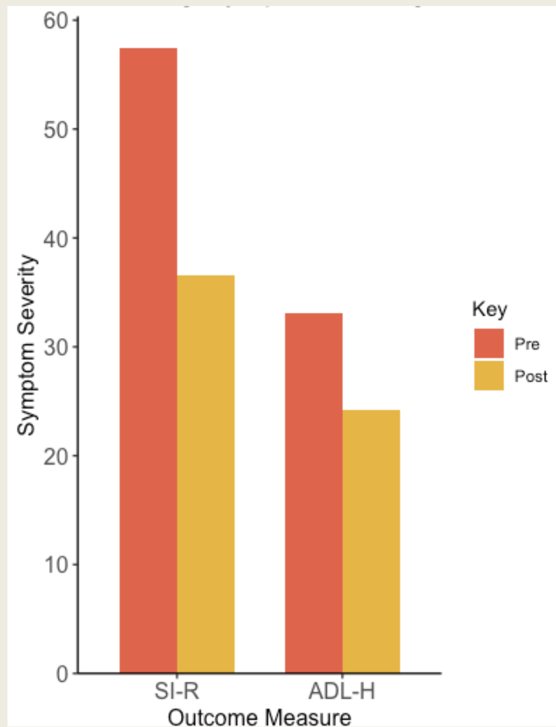
Clinical and Statistically Significant Reduction in Symptom Severity after CREST Discharge!

Measures	Pre-treatment		Discharge				
	Mean	SD	Mean	SD	n	t	% change
Saving Inventory-Revised	57.48	12.8	36.55	14.23	69	11.0***	36.41%
Clutter Image Rating	4.41	1.75	2.93	1.63	73	6.4***	33.56%
Activities of Daily Living	33.12	12.62	24.23	10.35	66	4.6**	26.84%
Homelessness Risk Factors	1.45	1.13	0.84	1.04	58	3.6*	42.07%

Note. * $p < .001$; ** $p < .0001$; *** $p < .00001$

After treatment, CREST client scores no longer meet clinical cut off for hoarding disorder.

Statistically significant symptom reduction



CREST clients achieved improvement in:

1. Hoarding Symptom Severity: difficulty discarding, acquiring, and clutter

2. Activities of Daily Living: ability to use home as intended, complete routine every day activities

SI-R = Saving Inventory-Revised; ADL-D = Activities of Daily Living-Hoarding

CREST -Actual Cases Before & After

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After

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Bathroom Before

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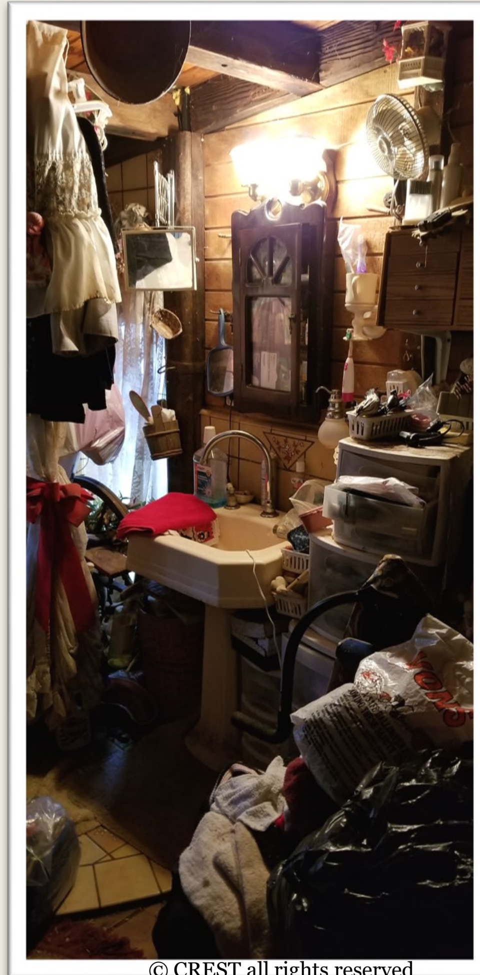
Bathroom Before



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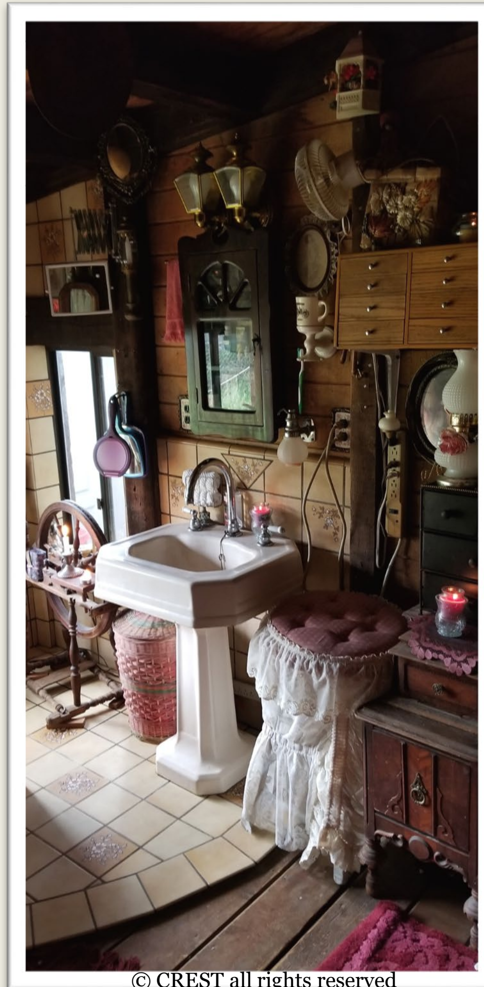
Bathroom After



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Tub Before

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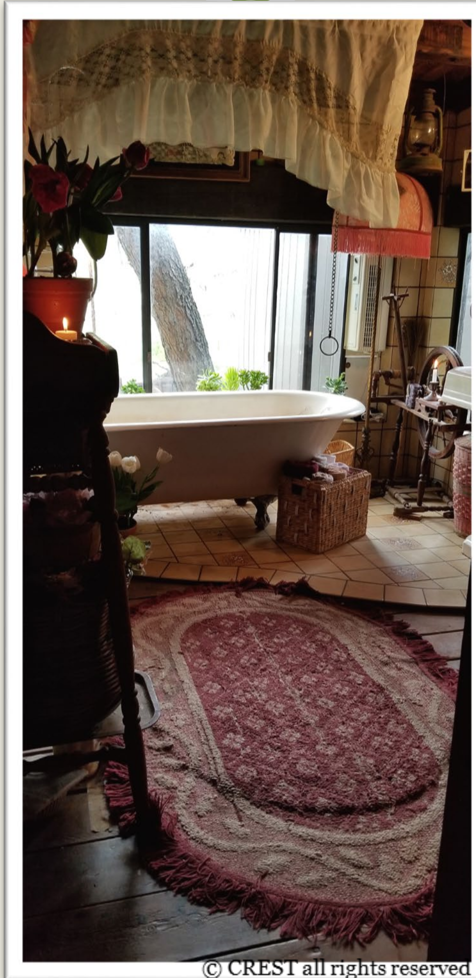
Tub After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Yard Before

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Yard After

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Agency Specific Tips: Medical Professionals

- Conduct initial screening in home if possible
- Use medical complications to discuss hoarding and need for hoarding interventions
- With consent, share information with other providers
- Serve as a cheerleader for addressing hoarding problem

How to help someone with hoarding:

- Know your area resources
- Visit the ocfoundation.org Hoarding Center for treatment referrals and education
- Use effective communication strategies
- Be patient – this takes time!
- Understand this is a psychiatric disorder that needs TREATMENT

Where to start…

- Ultimate goal: get the person into treatment
  - Educate about hoarding
  - Find local treatment resources
    - IOCDF Therapist Finder or other mental health agency
    - https://iocdf.org/find-help/
  - Warm hand off referral
- But if you can't…make sure that they are safe
  - Work with code enforcement or fire
  - Utilize harm reduction approach

Free treatment for hoarding in San Diego

- NIMH R01
  - 50 and older

- VA Merit Award
  - Open to all ages
  - Must be a Veteran

Call 858-552-8585 x 1251 or 619-543-6904

Thank you!

For questions, comments, or requests for staff trainings and/or in-service presentations please contact:

cayers@ucsd.edu

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