



During a recent in-home session, Ri Parrish and her therapist Phillip Salas work on discarding exposure therapy, going through boxes of items together to decide what Parrish should keep and what she should discard.

Stacks in the Corner: One-of-a-Kind Clinic Provides Hope for Treatment of Hoarding Disorder

Climbing the steep gravel path to Ri Parrish’s house, a serene, empty silence hovers above the stark vistas surrounding the property, dotted and perfumed by occasional pine trees.

More than 20 years ago, Parrish, a 66-year-old electronics engineer, built her house almost from the ground up, after purchasing the property when its previous owners ran out of money while remodeling. “I have worked on every inch,” said Parrish. “Every texture was done by my hands.”

When asked why she chose to live out here, among the boulders and brush beyond Pine Valley, a sparsely populated community located in the Cuyamaca Mountains of east San Diego County, Parrish replied, “I was driven to this house by a mission. I’m a very spiritual person, and I felt a connection pulling me out here. When I saw the place for the first time, I just knew I had to live here.”

Inside, the house is airy, with an enormous great room connecting to the kitchen, dining room and living room, all decorated in warm tans and reds. Framed photos of family and friends line bookshelves.

In one corner of the great room, there are tidy stacks of boxes, waist-high and filling an area the size of a small office. They are a hint of why a therapist from UC San Diego Health's Cognitive Rehabilitation Exposure and Sorting Therapy (CREST) program is visiting Parrish on this sunny December day.

Parrish has been diagnosed with hoarding disorder, and she is in the process of learning how to physically and emotionally let go of those stacks in the corner, which have grown unabated over the years.

Now, in the face of the COVID19 pandemic, people like Parrish are more at risk than ever; those with hoarding disorder are typically already isolated, many suffer from preexisting physical and mental health issues, and panic-buying trends can reinforce hoarding behaviors. Catherine Ayers, a professor in the Department of Psychiatry at UC San Diego School of Medicine and director of the CREST program, believes that this is why the program is so important at this moment in time.



Catherine Ayers is a professor in the Department of Psychiatry at UC San Diego School of Medicine and director of the CREST program, where she leads a team of clinicians providing in-home care to local seniors struggling with hoarding disorder.

A lifetime of collecting

For Parrish, her hoarding behavior began as a child, as it does for most people. Experts consider hoarding to be a lifelong, chronic condition that gets worse over time without treatment. It can run in families. “My parents came from an age following World War II, so they re-used everything,” Parrish said. “I learned to save and repair things as a kid—people would bring me their radios, remote controls, garage door openers, anything that I could have the satisfaction of fixing.”

But a lifetime of collecting stuff wasn't a problem for Parrish until 8 years ago when she came out as transgender, and subsequently, went through a divorce. “I was very alienated from all of my surroundings, my wife, my family. And so what else could I do, but hold onto things when nobody else wanted them?” she said. “I could bury myself in a world that was protected by the things I was familiar with. My wife didn't want to take anything with her, and so I was left with all of this stuff. And that's an awfully big load to take on by yourself.”

As Parrish rebuilt her life and made new relationships, she struggled with feeling overwhelmed and embarrassed by the clutter in her home. Many people with hoarding disorder frequently find themselves socially isolated, uncomfortable with the idea of having others in their home.

Then, a couple years ago, Parrish ran across a flier for the UC San Diego Health CREST Program and it struck a chord. She signed up and was among the first persons in Pine Valley to receive assistance when the program expanded to include the region.

The CREST Program at UC San Diego Health is the only one of its kind in the nation: an innovative care center dedicated to providing comprehensive treatment to individuals struggling with hoarding disorder, working with people in their homes to help them overcome the challenges associated with the condition. The in-home care and multifaceted approach to therapy, including exposure therapy and executive functioning training, is what makes the CREST program so unique.

“When a referral is made, we’ll go and do outreach with the client—sometimes right in their own home,” said Ayers. “We’ll do an assessment to determine if they have hoarding disorder and if so, we enroll them in the program. We find that people with hoarding disorder have lower scores on executive functioning measures, so they have problems with problem-solving, planning and prospective memory—recalling planned actions in the future. So we go in and teach them skills that will improve their executive functioning, to make it easier for them to make decisions that will support their recovery.

“Then we start the process that actually treats the hoarding, which is exposure to discarding. We use basic exposure therapy principles where clients work on a hierarchy, starting with rooms that are easier and working toward rooms that are harder. Clients go through their possessions one by one, and they learn over time that they can tolerate the distress from discarding possessions. They learn that it becomes easier for them.”

Discarding items with exposure therapy, step by step

Parrish has been in the program for about six months. Her therapist, Philip Salas, a licensed marriage and family therapist with the UC San Diego Health CREST Program, estimates that she’s about halfway through the program.

“At this stage of treatment, we’re on exposure,” Salas said. “During a typical session, we’ll get the boxes of items that Ri wants to go through and create stations—a discard station, a donation station and a keep station. She’ll start going through items and make decisions. I like to encourage her to think out loud as she works. It helps Ri, and it helps me to see where she is in the treatment, and how she’s handling the stress. Our goal here is not to shy away from that distress, but rather to embrace it—the more she embraces it, the better she gets at handling those challenges.”

During a recent home session, Parrish visibly struggles with discarding items, while trying to remain lighthearted about the challenge, bargaining with Salas (and herself) over why it's important to keep a toothbrush or a disassembled remote control. In many cases, she's convinced that she needs to have multiples of various items.

She places a small battery tester in the "keep" box, and jokes "I don't need more than six of'em...I mean, two of them!" She laughs. "We don't want to talk about quantity right now, because sometimes what I say is necessary has to be...reviewed."

"Yes," replies Salas. "Even though you make a convincing case. Remember those water pumps? Where you needed a backup, and a backup for the backup?"

"Well, two of them could go out in the same day!" Parrish counters.

"When I'm going through boxes to filter through what I can get rid of or what I need to keep, everything's a trigger," Parrish said. "A lot of these items bring up memories of a good time or a bad time, or something that got broken. And so you just take a box, and put the item in the box, and put something else on top of it, and it goes away for a while.

"Now, I'm being asked to revisit those emotions, and each time, the stress level spikes. Because it'll be like, 'Ooh, I forgot all about that. That was a really bad time. Or, I can't get rid of this because it meant so much.' And that's where I need the exposure, the help to confront those things."

Despite the need for physical distancing, the CREST program has been able to maintain treatment for patients thanks to digital tools, such as Zoom. "Most of our clients are able to use video conferencing tools," said Ayers. "This is good for keeping them safe, and keeping our therapists safe. We're even able to continue discarding exposure exercises in this format."

More than a myth about a messy house

Spending time with Parrish and observing a therapy session makes it clear that hoarding is so much more than a messy house.

"There are a lot of myths about hoarding," said Ayers. "People think that a person with hoarding disorder is just lazy or messy, or not cleaning up after themselves. Hoarding itself is a genetic condition. It's not something that someone chooses to have. People with hoarding disorder have a lot of difficulty parting with possessions, and it causes them great distress to have to throw things out. Right now, in the face of COVID-19 and stay-at-home orders, that behavior can be exacerbated by stress, anxiety, depression, and isolation. This is a mental health disorder that requires treatment and it's not going to get better on its own."

Over the last several months, Parrish has made notable progress, both in discarding items and in developing new habits and skills to prevent future clutter. She is tracking her progress in the handbook provided by CREST clinicians, a critical component of the treatment program. It's a place where Parrish can record her feelings and learn new skills, completing "homework" assignments that help her stay on track between therapy sessions. The handbook can also be used after treatment is over, serving as a resource patients can tap to brush up on their acquired skills.

"Ri's dedication to the program is exceptional," said Salas. "She never misses a session." But Parrish still faces a long road. While she has been successful at cleaning out her home, she still has several outbuildings on her property overflowing with belongings.

In what she calls the "barn", Parrish stores rows of plastic storage bins filled with mechanical, electronic and automotive items. She has an organizational system, but the accumulating objects are beginning to block the aisles and make access to the light switch difficult. This particular session is the first time that Parrish and Salas have ventured inside the barn together, to assess the situation and start discussing a strategy for clearing it out.

On the way to the outbuilding, Parrish's nervousness is evident; she is eager to make the space more usable, but anxious about the magnitude of the project. As she describes the layout of her belongings, she and Salas discuss goals. Parrish bargains with herself over why she needs to keep certain supplies and items, simultaneously insisting she's ready to clean the space out, that it *needs* to be cleaned out.

"I think we can get down to 20 percent of what's currently here," Parrish said. "But then I start the process, and I end up saying 'Well, we can probably go to 50 percent.'"

Parrish wants the CREST team to help her get a large dumpster on the property, plus recruit volunteers who can help her more rapidly discard at least half of the items in the barn. In the long term, she hopes the re-opened space and workbench will allow her to continue tinkering on various projects.

Unfortunately for Ri, her big spring cleaning event will have to wait until the COVID-19 situation has calmed down, but the CREST team is optimistic that these sessions will be available in the future, if they're able to maintain the program.

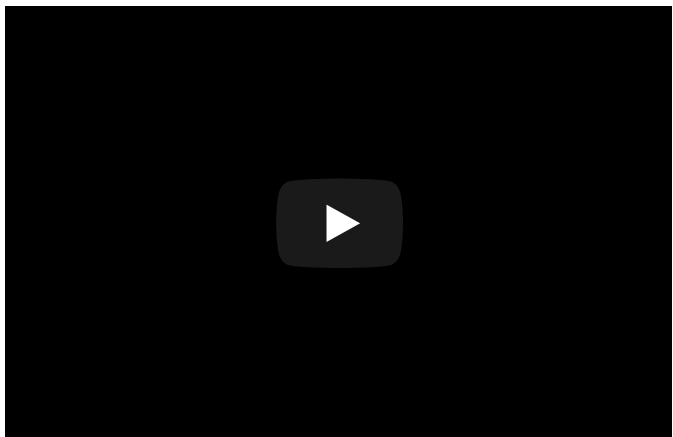
Working hard at this challenge

"Our goals for Ri are that she continues to work on the things we've been modeling with her, that she can continue this process by herself and make these decisions on her own while monitoring her own stress levels," said Salas.

After treatment completion, CREST clients like Parrish can participate in aftercare programs to maintain the skills they've learned, or receive "booster sessions" if they find hoarding symptoms returning.

Parrish said the program has changed her personality and life. "My energy level is up. I'm much more organized. This program has given me the tools and structure I needed to work hard at this challenge. It's very rewarding to be successful and have it acknowledged by someone outside of yourself. It's very satisfying, and I want to continue."

Right now, Parrish's ability to continue with the program is jeopardized by budget challenges. The CREST clinic may be forced to close its doors this summer. "Our funding is drying up," said Ayers. "We had been working to secure the resources to keep the program running, but unfortunately that money is being reallocated to support COVID-19 efforts. We're now in more of an emergency mode, trying to make the program sustainable by forming more community partnerships."



"San Diego saw that hoarding disorder was a real problem for some members of the community and they took action," Ayers continued. "This treatment is evidence-based and it works. This is something that can be treated, and we have the resources to do it. Now more than ever, we need to take care of this very socially isolated and vulnerable population. It's going to be important to get creative, think outside the box, and sustain programs like this for hoarding. If we're not able to provide treatment, these people will be left with nothing."

Parrish has a message for those who may be feeling overwhelmed by hoarding symptoms. "I want other people to know that you can be brave. And that bravery comes from taking that first step. Recovering from hoarding can feel like a journey where you can't see the end, but at the CREST program, there is someone to help you take those first steps.

"I didn't have much hope before. The stacks of boxes in the corner were like a physical manifestation of the way I was handling my feelings. I didn't want to acknowledge or deal with all of my items because I didn't want to deal with the emotions that came along with them. Eventually, the stacks grew too large to ignore, and now I'm not afraid to deal with them. Now, there is a lot of hope."

To learn more about the CREST program and how you can support their efforts, contact Catherine Ayers, at (619) 543-6904 or cayers@ucsd.edu

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