



# Conversations of Dementia

## Real Stories of the Journey



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## Juliana Marquez: A Resilient Journey with Huntington's Disease

Juliana Marquez, a 42-year-old woman with a bright, bubbly, and cheerful demeanor, had a special place in the assisted living community she called home. Active and full of life, she enthusiastically participated in all the available activities alongside her fellow residents. Juliana was adored by residents and staff, engaging them in conversations about her weekend trips with her husband and outings with her family.

Despite her usually vibrant nature, there were times when Juliana returned to the assisted living community feeling a little down, possibly due to a disagreement with her husband or disappointing news. She did her best to conceal her sadness, but the discerning staff could see through her facade and offered their support during such moments.

Juliana's husband deeply cared for her and ensured to meet her needs. However, there was a complicated aspect to their relationship - he had a girlfriend whom Juliana knew about. Surprisingly, she befriended this woman and appreciated her visits, yet moments of jealousy, resentment, and anger surfaced when she spent time alone with her husband.

The staff was aware of the situation, but understanding the intricacies of Juliana's emotions was challenging due to her diagnosis of Huntington's disease. Cognitively aware of her feelings and prognosis, Juliana desired her husband's happiness and wished him to be with someone she approved. However, conflicting feelings of loss and anger were natural for her, given the circumstances.

Living with Huntington's disease presented many physical challenges for Juliana. She relied on a four-wheeled walker with a seat to move around, and her body's jerky movements made emotional distress risky, as it could exacerbate her condition and lead to falls. Despite her cognitive struggles, the supportive staff worked diligently to help her maintain a sense of autonomy, assisting her in using any cognitive skills she still possessed.

Juliana's resilience and strength shone throughout her journey, inspiring those around her. The staff remained steadfast in their care, providing a loving environment for Juliana to navigate the complexities of her emotions and life with Huntington's disease.



## Huntington's Disease: Unraveling the Link with Dementia

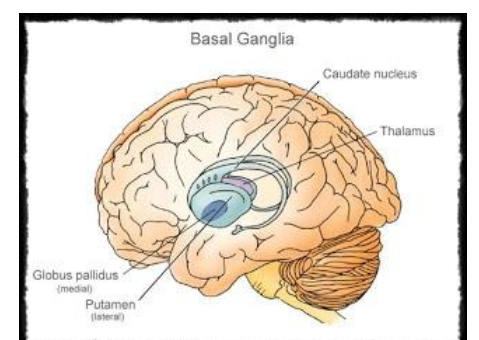
Huntington's disease is a rare, progressive neurological disorder classified as a form of dementia, specifically a "movement disorder dementia." It typically develops in adulthood, usually between the ages of 30 and 50, and

is caused by a genetic mutation in the huntingtin gene. This genetic mutation leads to the progressive degeneration of nerve cells in specific regions of the brain, particularly the Basal Ganglia, resulting in various physical and cognitive symptoms.

The disease is inherited in an autosomal dominant manner, meaning that a child of an affected parent has a 50% chance of inheriting the mutated gene. While some individuals may experience symptoms earlier in life, genetic testing is often deferred until 18 unless signs are evident.

Some typical symptoms of Huntington's disease include involuntary movements, known as chorea, which worsen as the disease progresses. Cognitive decline is also standard, leading to difficulties in memory, concentration, problem-solving, and decision-making. Emotional disturbances, such as depression, anxiety, irritability, apathy, and social withdrawal, can also occur.

As the disease advances, individuals may experience impaired voluntary movement, speech difficulties, difficulty swallowing, weight loss, and a decline in fine motor skills.



Individuals may exhibit cognitive rigidity when they have trouble shifting focus or adapting to changes.

The progression and severity of symptoms can vary significantly between individuals. Over time, affected individuals may become increasingly dependent on others for daily activities and care, eventually requiring total assistance. It's important to note that individuals with Huntington's disease are at an increased risk of choking and may experience mental health challenges.

Currently, there is no cure for Huntington's disease, but supportive therapies and medications can help manage symptoms and improve the quality of life for affected individuals. Individuals with Huntington's disease must receive appropriate care and support from healthcare professionals, caregivers, and support groups.

## Guiding Care for Huntington's Disease: Practical Advice for Caregivers



Huntington's disease is a progressive neurological condition affecting individuals physically and cognitively. As a caregiver for someone with Huntington's, you play a vital role in supporting and maintaining their quality of life. Here are some practical tips to help you navigate the challenges of caregiving:

**Educate Yourself:** Gain a comprehensive understanding of Huntington's disease, its symptoms, progression, and how it affects the individual. Knowledge will empower you to provide the best care and anticipate potential challenges.

**Prioritize Safety:** Due to the risk of falls and accidents, ensure a safe living environment. Make necessary modifications to the home and use assistive devices as needed.

**Create a Routine:** Establish a daily schedule that provides structure while allowing flexibility. Routine can bring a sense of stability to both the caregiver and the person with Huntington's.

**Communicate with Compassion:** Be patient and understanding during mood swings and cognitive challenges. Maintain open and supportive communication, giving them sufficient time to process information and respond.

**Engage in Physical Activities:** Encourage appropriate physical activities to maintain muscle strength and balance. Gentle exercises can promote overall well-being.

**Adapt Activities:** Adjust activities to match the individual's current abilities and interests. Engaging in meaningful activities can uplift their mood and sense of purpose.

**Manage Medications:** Stay organized with medication schedules and medical appointments. Work closely with healthcare professionals to manage symptoms effectively.

**Seek Support and Respite:** Take breaks to rest and recharge. Seek help from family, friends, or respite care services to prevent caregiver burnout.

**Focus on Nutrition:** Ensure a balanced diet and adequate hydration. Address any swallowing difficulties by consulting healthcare professionals.

**Address Emotional Challenges:** Caregiving can be emotionally taxing. Don't hesitate to seek emotional support from support groups or counseling.

**Consider Cultural Sensitivity:** Be mindful of cultural differences in caregiving approaches and adapt your care accordingly.

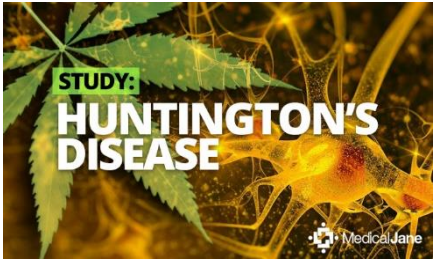
**Prioritize Self-Care:** Your well-being is essential. Engage in self-care activities you enjoy and seek support when needed.

**Plan Legally and Financially:** Consider long-term care needs and plan legal and financial matters early on.

**Seek Professional Assistance:** Don't hesitate to involve healthcare professionals experienced in Huntington's disease care to ensure the best support for your loved one.

Caregiving for someone with Huntington's disease is a significant responsibility, and taking care of yourself while providing compassionate care to your loved one is essential. Seek help, support, and resources to make this journey more manageable and fulfilling.

# Stowers Institute Scientists Uncover Huntington's Disease Initiation and Potential Therapeutic Approach



In an exciting breakthrough, researchers at the Stowers Institute for Medical Research have successfully determined the structure of the initial step in amyloid formation, known as the nucleus, for Huntington's disease. This groundbreaking study, led by Associate Investigator Randal Halfmann, Ph.D., proposes a revolutionary treatment approach for Huntington's disease and other amyloid-related conditions.

Amyloids, protein deposits in the brain, are linked to devastating neurodegenerative diseases like Huntington's, Alzheimer's, and Parkinson's. However, understanding the first step in amyloid formation and developing effective therapies has remained a challenge until now.

The co-first authors, Tej Kandola, Ph.D., and Shriram Venkatesan, Ph.D., successfully identified the amyloid nucleus structure for huntingtin, the protein responsible for Huntington's disease. Remarkably, they found that the nucleus forms within a single protein molecule.

Huntington's and similar diseases, collectively called "PolyQ diseases," occur when specific proteins have a repeat of the amino acid glutamine (Q) that is too long. The researchers discovered that the nucleus consists of four strands, each with three Qs in specific locations within a single protein molecule.

The study revealed that clumping the proteins in cells halted amyloid formation, suggesting a potential therapeutic avenue. The researchers plan to explore this approach further in mice and brain organoids.

The research technique used, Distributed Amphifluoric Förster Resonance Energy Transfer (DAmFRET), provided crucial insights into the rate-limiting amyloid-forming nucleation event. By observing the stochasticity or randomness of the reaction, the team deduced the minimum structure that could form amyloid.

This groundbreaking work provides a molecular model for investigating the structure of any amyloid nucleus and offers hope for potential treatments for individuals with pathologic PolyQ proteins.

The research was funded by the National Institute of General Medical Sciences of the National Institutes of Health (NIH) and supported institutionally by the Stowers Institute for Medical Research.

The findings present a paradigm shift in understanding amyloids and offer potential therapeutic opportunities to combat Huntington's disease and related conditions.

To review the news coverage of the new research, check out Megan Abundis' story: "Scientists at Stowers Institute researching memory diseases find breakthrough" Link: [www.kshb.com/news/local-news/kansas-city-scientists-at-stowers-institute-researching-memory-diseases-find-breakthrough](http://www.kshb.com/news/local-news/kansas-city-scientists-at-stowers-institute-researching-memory-diseases-find-breakthrough).

About the Stowers Institute for Medical Research:

Founded in 1994 by Jim Stowers, founder of American Century Investments, and his wife, Virginia, the Stowers Institute for Medical Research is a non-profit organization focused on foundational biomedical research. It aims to expand our understanding of life's secrets and improve the quality of life by advancing the causes, treatment, and prevention of diseases. To learn more about the Stowers Institute, visit [www.stowers.org](http://www.stowers.org) and [www.stowers.org](http://www.stowers.org).

## About Chasity Robinson Mwangi and Mindful Connection

Chasity Robinson Mwangi is a highly experienced healthcare professional with over 25 years of expertise. She founded Mindful Connection, an organization that offers coaching, training, speaking engagements, and educational resources to families, businesses, and healthcare organizations. One of Mindful Connection's significant initiatives is "Conversations of Dementia," which aims to raise awareness and understanding of this challenging condition and provide practical support to those who need it most.

Chasity's unwavering dedication to caring for humanity and seniors is the driving force behind her work. Currently, she serves as the Senior Community Relations Director and Corporate Sales Trainer for Anthem Memory Care. To inquire about memory support communities, please contact Chasity via email at [Crmwangi@anthemmemorycare.com](mailto:Crmwangi@anthemmemorycare.com) or by phone at 913-901-8500. For general inquiries, consultations, coaching, training, presentations, or any other questions, please contact [MindfulConnectionUs@gmail.com](mailto:MindfulConnectionUs@gmail.com). You can also connect with Chasity on [LinkedIn](#) or follow [Mindful Connection](#) on Facebook or [Instagram](#) for more information.

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## Figures:

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