



A Case Study In Caregiver Engagement

*Improving Outcomes
for Patients with
Dementia and Their
Caregivers*

Executive Summary

Tom has Frontotemporal Dementia, in addition to complicating conditions that include COPD, bipolar disorder, diabetes, hypertension and sleep apnea. Tom is 82-years-old and lives at home with his 80-year-old wife Renee, his primary caregiver. His declining health has resulted in multiple hospitalizations in less than a year.

Renee felt unprepared and alone in coping with her role as Tom's caregiver, causing her to experience a high level of anxiety and burden. To address these issues Renee enrolled in Ceresti's Caregiver Engagement Program, a technology-enabled service that provides caregivers like Renee with personalized coaching, education, and support to provide the best possible care for a loved one living with dementia.

Over the course of twelve weeks, Renee developed a deeper understanding of Tom's conditions and valuable skills for how to effectively manage his care. Renee completed daily tasks and activities on her Ceresti health station, and interacted regularly with her Ceresti health coach, who personalized her program to address the specific challenges she faced.

As she progressed through the customized learning modules and worked with her coach, Renee gained confidence in her ability to address daily challenges as they arose, without the anxiety she had previously experienced. Renee participated in 100% of the daily assessments and completed more than 140 tasks. She became a more effective caregiver and was able to reduce her stress and burden significantly. Her engagement ultimately contributed to better health outcomes for Tom and likely prevented some emergency department visits and hospitalizations.

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"I'm not afraid anymore. The anxiety just isn't there like it used to be..."

It wasn't always that way for Renee. As the primary caregiver for her husband Tom who was diagnosed with multiple chronic conditions, that meant managing his health needs and daily activities in addition to her own. Renee often felt stressed and anxious about the requirements of caring for Tom at home. By working with Ceresti's coaching, education and support program, she was able to develop the skills and confidence needed to provide Tom with the best possible care and alleviate the stress associated with her role as his caregiver.

The Challenge

At 82, Tom was diagnosed with frontotemporal dementia (FTD), a challenging condition on its own, further complicated by the presence of additional conditions including COPD, bipolar disorder, diabetes, hypertension and sleep apnea. In less than a year, Tom had been in the hospital four times for treatment, necessitating prolonged observation and care. His 80-year-old wife Renee became his primary caregiver, helping Tom by managing his conditions at home between care episodes.

Initially, Tom found it difficult to accept his FTD diagnosis and became argumentative and hostile toward Renee, making the process of caring for him more challenging. His mood was often volatile, shifting from aggression to apathy, when he was no longer interested in taking part in the activities he and Renee has previously enjoyed together.

Feeling a great deal of anxiety about the future and how she would manage Tom's health on her own, Renee reached out to his healthcare provider, who referred her to Ceresti. The provider suggested that Renee enroll in Ceresti's Caregiver Engagement Program to provide her with knowledge, skills and confidence and access to personalized support oriented toward caring for Tom and his specific needs.



The Program

Starting the Ceresti Caregiver Engagement Program

The next day, Renee received a call from her Ceresti health coach, Diane, who explained that Ceresti offers a program tailored to the needs of caregivers in Renee's position. During the call, Diane asked Renee a series of questions about her caregiving challenges, Tom's condition and capabilities, and gathered additional family contact information.

Diane explained that a Ceresti health station would be delivered to Renee's home in the next two days, when their work together would officially begin. After some initial concern about using the technology, Renee was comforted by Diane's reassurance that she would be there for her as they navigated the easy-to-use interface together.



Two days later, Diane called Renee to confirm that a package from Ceresti had arrived via USPS. As Renee opened the package, Diane described the contents of the box: a tablet computer-based Ceresti health station, headphones, a charger, styluses and an education binder with start-up guide and additional visual references. The cell-enabled tablet required no WIFI connection, allowing Renee to simply power up the health station without any complicated technical set-up. Once the tablet was on, Renee began describing to Diane the start-up process and picture frame mode that appeared on the screen.

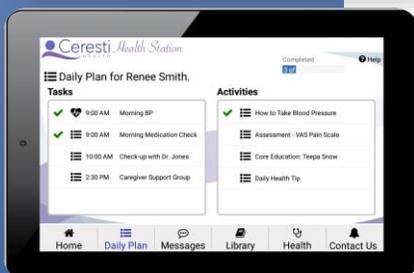
Diane showed Renee how to navigate the touch screen interface and move through the various screens while explaining the functionality of each section.

The Ceresti Health Station

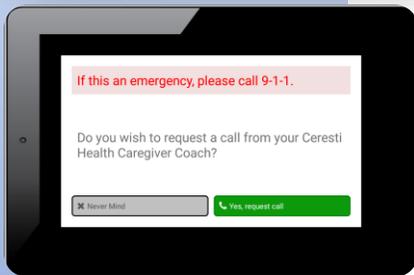
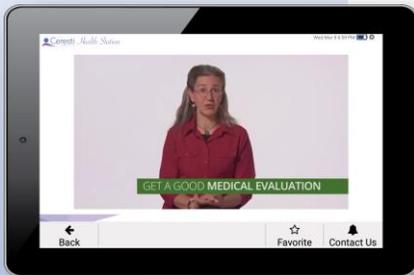
As Renee gained comfort moving around the Ceresti health station interface, Diane guided her to the "Press Here" button on the welcome page, the entry point to Renee's personalized daily plan.



When Renee pressed the button, a new screen appeared with two columns, one listing specific "tasks," and the other "activities." Diane explained that Renee would spend about 15 minutes each day going through the assigned tasks and activities and complete a daily assessment to track her progress. Today, the tasks listed included reminders to take Tom's blood pressure in the morning, to read a synopsis about diabetes, and to speak with his doctor. There was even a caregiver support group meeting scheduled for that afternoon, should Renee be able to attend.



Each day featured a new list of tasks and activities for Renee to complete, personalized to address the specific challenges associated with Tom's conditions and to educate her on managing his care.



Renee found the curriculum extremely relevant and helpful, providing tips and brief videos on topics like how to assess Tom's pain and manage his chronic conditions. Her favorite part of the day was the core education, a daily series of videos featuring Teepa Snow, a leading educator on dementia. Teepa's dynamic lessons helped Renee feel empowered and less alone in dealing with her husband's dementia.

Renee continued to gain comfort with her health station, working with Diane who explained additional functions like the "Messages," "Library," and "Health" buttons. Diane showed her how to use the "Messages" button to send text messages not only to her coach, but also to other family members who were connected to the health station remotely. Diane then emailed directions on downloading the Ceresti smartphone app to Renee's daughter, so she could send messages and family pictures for Renee and Tom to view in picture frame mode on their health station.

Diane also noted that there was a "Contact Us" button located prominently in the lower right-hand corner of every screen allowing Renee to request that Diane call her directly for any immediate needs or questions. The next day, Renee used the "Contact Us" button to speak with Diane about helping her add physician names to her medical resources list. Knowing she could reach her coach at any time made Renee feel even more at ease as she continued to learn new skills.

Renee continued with the lessons and video tutorials and completed the daily assessments for herself and for Tom. Diane would regularly ask questions about her progress, using Renee's feedback to further personalize the program.

With each passing week, Renee strengthened her ability to care for Tom, learning more about his chronic conditions as she progressed through the learning modules customized specifically for their personal circumstances. She felt more educated about Tom's health conditions and more confident in her ability to effectively address daily challenges as they arose, without the anxiety she had previously experienced.

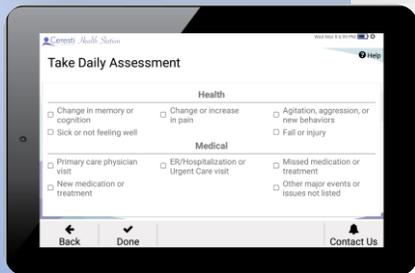
Renee also noticed that her ability to communicate with Tom was improving as she utilized new interpersonal skills and techniques for how to engage someone with dementia. Tom was generally in a more positive and receptive mood now, which made things easier to manage and each day more enjoyable.

Technology Enabled Coaching

As a trained Ceresti health coach, Diane knows that relating to caregivers like Renee is an important element of the Ceresti Caregiver Engagement Program. Many spousal caregivers are older and thus unfamiliar with using tablet technology, so they gain confidence knowing their coaches are there to guide them through the learning process.

The caregivers feelings of loneliness and isolation are alleviated by the daily touch these coaching interactions provide, while creating an open and welcoming educational environment.

When Diane began working with Renee, she was sensitive to Renee's lack of confidence in knowing how to care for Tom at home, as well as Renee's feelings of being overwhelmed by the responsibility of caring for him on her own. Diane utilized data from the personal preference assessments Renee completed early in her program on her health station to identify her social style, activation and personality attributes to tailor their interactions and optimize Renee's experience.



At the end of one day during their third week on the program, Renee reported that Tom was "sick or not feeling well" in the daily assessment. This prompted a follow-up call from Diane the next day to enquire about his condition.

Renee said that after going for a walk with Tom the day before, he seemed tired and was more quiet than usual, even resisting Renee's suggestion to drink some water. Diane picked up on these signals and asked if Tom might be dehydrated, a common problem in patients living with dementia as they often forget to drink enough water throughout the day. Diane added an information page with a tutorial and tips on hydration to Renee's daily plan for the next day.

Diane monitored Renee's comfort and satisfaction with her personalized program as they moved through the educational modules, taking time to answer her questions and address concerns as they arose. Diane frequently employed established techniques to encourage feedback and ensure clarity and understanding between them.

Personal Coaching Interaction

Over the course of the program, Diane and Renee built a personal relationship that provided comfort for Renee and helped Diane to tailor the program specifically to her needs with regular personalized adjustments and updates. When Renee expressed concern about Tom's coughing and mentioned he felt warmer than usual, Diane asked Renee about her understanding of COPD and the associated signs and symptoms. Renee didn't have familiarity with the disease, so Diane accessed Renee's health station remotely to update her daily plan and provide information about Tom's COPD.

In one instance when Tom was refusing to engage, Diane encouraged Renee to use a proven technique called "reminiscence therapy" to relate to the old memories he could more easily recall, a common trait in those with dementia. Together, Renee and Diane developed approaches to engage with Tom, with plans to build a scrapbook of old photos and visit familiar places. This strategy worked well for Renee, and she continued to employ this approach when needed to draw Tom out and encourage interaction with others.



The Outcome

Each interaction gave Diane greater insight into how best to support Renee in her new role as Tom's caregiver. As a result of Diane's personalized coaching, Renee felt more supported and less alone.

Outcome Following Graduation

Patients with chronic conditions often find their health issues are exacerbated by the presence of dementia, as communication with their family caregivers is limited or incomplete. A primary task of those caring for their loved ones is to interpret behaviors and address health issues as they arise, before they become serious enough to require medical intervention or even a hospital visit.

Renee is now able to recognize changes in Tom's behavior. Before the Ceresti program, Renee wouldn't know what to do when Tom would get agitated due to his painful arthritis and would often take him to the urgent care facility for treatment. Now she can identify these concerns on her own, noticing when Tom shows discomfort and is better able to better manage his arthritis pain at home.

Other members of Renee's family were also participating in Tom's care more so than they had before. Renee was regularly communicating with them through her health station, receiving new pictures and support from family members using Ceresti's smartphone app daily.

An unexpected benefit of Renee's participation in the program was recognizing the importance of self-care. She hadn't realized before how important it was for Tom that she take care of herself too.

Renee developed a deeper understanding of Tom's dementia and its impact on his health. She was now aware that Tom's inability to manage his other conditions, like COPD and diabetes, would require additional care from Renee. She felt more confident in her ability to monitor his health and to be proactive in seeking medical attention when needed.

Renee completed more than 140 different activities and tasks and 100% of her daily assessments and felt fully engaged in her role as Tom's family caregiver. She was able to reduce her own burden (measured via the Zarit caregiver burden assessment) by 25%. Most importantly, her engagement ultimately contributed to better health outcomes for Tom and provided the knowledge and support necessary for his optimal care.

