



## Isabel de Sousa

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In meeting Isabel, you are immediately struck by her fierce determination, advocacy and boundless love for her husband Joseph, and their beloved daughter, Ana.

For over forty years, Isabel has been relentless in her quest to give her daughter the best care and quality of life. It's with this unwavering devotion and compassion that Isabel is able to provide in-depth, around-the-clock care to Ana, who at 56, is now confined to a bed due to an undefined progressive neurodegenerative condition.


As Ana approached her teenage years, she began to show signs of cognitive and mobility issues, which led to a diagnosis of scoliosis. At 13, Ana had an operation to attempt to correct her scoliosis, but sadly, her condition continued to worsen as she faced ongoing challenges. Frustratingly, doctors and specialists have been unable to confirm the root cause of Ana's condition, and she has continued along a slow path of regression that would eventually lead to the loss of all motor and mobility functions.

As you can imagine, this means the type and complexity of care that Ana requires has continued to shift and evolve over the last several decades, but Isabel and Joseph have remained steadfast in their duties as Ana's loving parents, caregivers, protectors and advocates.

While they did everything they could to find answers and supports for Ana, Isabel and Joseph were also balancing frequent appointments, tests, and work. Following their move from Portugal - Isabel and Joseph settled in Canada and established busy and successful careers that took them around the world, including to the United States, France, and England. Ana loved to travel and would often join one or both of her parents until her needs became too high. With Ana's care, comfort and safety always top of mind - they adjusted their routines and workloads, with Joseph taking on primary care duties.

As Ana's care needs grew, Isabel recognized that additional support was needed and would come to be connected with her longstanding care coordinator, Jill, who has remained with the family for more than 14 years. Jill shared that what sets Isabel apart is her exceptional ability to collaborate with Ontario Health atHome's multidisciplinary team of health care professionals, always welcoming their expertise so that she could learn the skills to provide all the direct and necessary care for her daughter.

When Joseph began experiencing his own health challenges and was diagnosed with Parkinson's disease, Isabel stepped away from her career to become the full-time caregiver for both Ana and



Joseph, who is now mostly confined to a bed. With her longstanding experience, she was prepared to advocate for the same array of supports. Together - Isabel and Jill, worked to ensure the community care services were in place, and adapted to meet his ever-changing needs. Isabel credits her partnership with Jill, who oversees care for both Ana and Joseph, and her deep knowledge of their family, for making an incredibly difficult time a little easier.

At 5'1, Isabel is small, but mighty. With true grit and resolve, around the clock she tackles challenging caregiving tasks such as suctioning, turning and transfers, management of Ana's G-tube, nutrition, and exceptional skin care to avoid wounds. Often back and forth – Isabel is always at the ready – responding quickly to ensure her daughter and husband are safe and comfortable.

Although Ana and Joseph are much taller, and due to their loss of mobility require full support to move – Isabel has not let this faze her. She has outfitted their home with equipment and tracks so that she can move Ana from one room to another using a variety of ceiling and chair lifts to maneuver up and down the stairs. Isabel also helped design a custom-built hospital bed in Ana's room to ensure it was large enough for her to snuggle in – so they could watch movies or simply be together.

With Isabel and Joseph, their love and respect for one another is so evident. Married for over 50 years, it takes only a few moments in their presence to see how devoted they are to one another. Amongst the many challenges they've faced they continue to be one another's greatest strength. Despite Joseph's health challenges, with a gleam in his eye his sense of humour still shines through.

In preparing their story and telling Joseph about Isabel's special acknowledgement, he teased her and cautioned that all this attention and recognition was going to "go to her head". Isabel takes this all in stride, as he then looked to her with total admiration and told us, "She does it all. She helps everyone." If you ask Isabel, she brushes it off stating it's "normal" and that this is how she was raised in Portugal - "We look after one another".

Care coordinator, Jill, sees it differently. She shares, "despite the immense physical and emotional demands of her caregiving role, she approaches each day with remarkable strength, ensuring her husband and daughter's comfort, dignity and quality of life remain the top priority." In thinking back over the 14 years, Jill continued to share, "I have had the privilege of knowing and supporting Isabel and her family. She is, without question, a truly outstanding caregiver whose unwavering dedication deserves the fullest recognition and gratitude."

**Thank you for going Above and Beyond!**