

Elder Options, Inc.

Resource Library

Subject: Determination

A Lesson in Determination

I first met Margaret * **not her real name* during the early years of my practice when I, a social worker by profession was just beginning a new business as a Professional Geriatric Care Manager (PGCM). I was out of the office when she called the first time. "You have a prospective new client," I was told by my part time assistant. "She's direct, kind of grouchy, very concerned about cost and will only talk to you. You need to call her." The description should have given me a forewarning and to some degree it did. This client should we agree to work together, was not going to be easy. I was right.

Several days later, I arrived for the initial home visit. She told me she would be alone and to loudly knock at the front door. I did as she suggested and she responded, "Come in." The door was unlocked. I walked into the small, tidy house to find Margaret in bed, a detail she had neglected to mention. Not only was she in bed, there was a Hoyer lift next to the hospital bed and a wheelchair along side. I didn't see anyone else in the house. Without a word, I knew this woman was bed bound and lived alone. We introduced ourselves and as I sat in her wheelchair next to her in the bed, she told me her story.

Five years earlier Margaret had retired from teaching and shortly thereafter had a massive stroke. She was now in her early 70's. She survived the stroke but was severely disabled as a result. She was moved into a skilled nursing facility. Her adult children sold her home and all of her belongings. She was told she would live in the nursing home from then on. She didn't agree with the decisions being made for her. She began talking about leaving the nursing home and having her own home again. Her doctors, her children, and staff at the nursing home told her it couldn't be done. She disagreed. When one of her children took her to court to declare her incompetent, she hired an attorney to prove otherwise and won. She was determined more than ever to be independent even with her continuing disabilities. Her adult children were angry with her decision, said they would not help and cut off contact with her.

Margaret's sister lived in another part of the state. She agreed to help look for a house nearby that her sister could afford. She did find a small home that with the balance of Margaret's money was remodeled for her special needs. She made the move and once again was in her own home but unable to walk, arms and hands paralyzed and disabled and with a noticeable speech defect, all residual affects from the stroke.

I had to admit looking around that first visit what planning she must have done from her bed in the nursing home hundreds of miles away. She decided what her house needed to have in order to be functional for her. The house with wood floors was remodeled to suit someone in a wheelchair. The hospital bed and Hoyer lift were in the living room with abundant windows for natural light. The kitchen counters, sink and stove were lower for wheelchair access. Her hands and arms had been crippled by the stroke so she had easy to open containers at her reach. The furnishings in the house were sparse. Her belongings were necessities with no room or money for frivolous items without a purpose. The bathroom had a tile floor with a center drain with the sink and mirror lowered. "I designed this." Margaret told me once again. "When I was in that nursing home, I knew I had to get out. I had lots of time to think of what I needed." The house was made to order.

Margaret had called our agency because she needed help finding someone to help a few hours during the day. We agreed to work together. She was explicit that she had limited funds and needed just a bit of help. She knew she could manage on her own. Although she needed 24-hour care, she couldn't afford it. She didn't have the resources for more. There was little money for care management and what there was had to be carefully budgeted. And so, our association began. It would have to work.

As clients go, she was not easy. We'd put requested resources in place and not hear a word from her for weeks at a time. She had a special phone set up; voice activated but was only out of bed and in her wheelchair several

hours a day to be close enough to use it. She would not authorize regular monitoring visits and did not qualify for public services. We knew though that if or when she needed something, she'd call. Sometimes the call was a panicked one with an immediate response necessary when her regular care provider didn't show up and she was alone in bed.

This tenuous client/care manager relationship went on for some time. Winters during the cold, rainy times, we'd get a call from the hospital telling me Margaret had pneumonia, was recovering, and needed help once she went home. I'd go see her only to be told that she only needed one or two hours more a day and she'd be fine. We'd argue about what was safe and not. We'd come to a compromise that we both could live with. Not that she ever really admitted it but I know from our conversations, she was determined to stay out the nursing home; a place she told me was "just awful". I had to admit my respect for this client continued to grow.

Out of the blue, we'd get a call. Someone hadn't shown up or she'd fired another provider. She had a habit of firing people if they didn't toe the line. As a retired teacher, she could be a hard task mistress but then turn around and compliment the provider on the cleanliness of the kitchen floor. Not everyone wanted to work for her particularly when she was known for sending people home early without the hours they were counting on. Our agency became the fall back position. But the determination and will of this client had everyone impressed. She had a sharp tongue and didn't mind giving anyone from the doctor, the home care nurse, the provider or the care manager a piece of her mind. Her determination and pure stubbornness were probably the reasons she did as well as she did for as long as she did and we all admired her for it.

She was on the list for a Christmas food basket that she gratefully accepted. She wrote a handwritten Thank You that we all knew had taken her an hour to write with her crippled hands. The hospital installed a Vital Link system to call in case of emergency and wrote off the costs. We worked with the county when new program money came in to help her receive a little more help. Community agencies got together and bought her a new TV when her old one was unable to be repaired. Her neighbors checked in on her when they got home from work, put her trash can out for pick up, and decorated her house with Christmas lights that she could see from her hospital bed.

Margaret lived in her little house on her own with little help considering her disabilities for almost 8 years before her health declined to such a degree that she had to return to skilled nursing. It was with great reluctance that one of her daughters with whom she had reconciled helped her move into a facility near her. Whenever I have a client that's determined to stay at home, remain independent and struggles with the ability to be independent, I remember Margaret who could not walk, could not dial the phone, and needed someone to transfer her in/out of bed who was absolutely determined to have a life of her own. In that, she was successful for a lot longer than anyone thought possible. To me, she continues to be a great example of determination, stubbornness, and ability to be in charge of one's life.

Carol S. Heape, MSW, CMC is Executive Director of Elder Options, Inc., a company she founded in 1988 with offices in Placerville and South Lake Tahoe, California.

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