For me it all began 2009. My mother had recently been diagnosed with hypertrophic cardiomyopathy and refused to take the medicine she had been prescribed. Unfortunately, no amount of yelling, screaming, or cajoling convinced her to heed the doctor’s orders. On July 22, 2009, one day after meeting with the surgeon who was going to repair her heart, she passed away.
My mother’s sudden passing was hard enough to cope with, but on top of everything, my father completely lost it. He had been acting strangely for months prior to her death, forgetting dates and events and seeming out of it and I later found out he had been diagnosed with early onset dementia four months prior to my mother’s death. My mother, not wanting anyone to know, had attributed this odd behavior to a variety of causes including the side-effects of medication and hearing loss. Her sudden death sent my father into a state of shock and accelerated his dementia. In an instant, I became a member of the “sandwich generation” – a generation of people who are taking care of ailing parents while also raising a family.

I’m not alone in the sandwich generation. Almost half (47%) of adults in their 40s and 50s have a parent over 66 and are raising or financially supporting a child. 15% of middle-aged adults are providing financial support to both a parent and a child. While the first statistic has not really changed over the years, the financial burden of caring for multiple generations of family members is growing. One in five of middle-aged adults provide financial support to a parent aged 65 or older.(1)

At the time of my mother’s death my children were 15 and 13 and I was working full-time. While my husband and children tried to help, I still bore the brunt of the driving, cooking, laundry and cleaning at home. With my mother’s passing, I added caring for my father to the load. It was a rough road initially, and at every crossroad with my father’s health today, it still is. Here are a few tips if you find yourself in my shoes.

Prepare. There is a good chance one of you reading this will find yourself taking care of an ailing parent or loved one in the next few years. There is no way to be prepared for the emotional shock of a sudden illness or disability, but you can be prepared.

According to a MetLife Institute study in 2011, women who take time off or quit work to care for a loved one lose an average of $324,044 in lifetime wages, pension and Social Security. Not having a long-term strategy can be costly for your family and affect your own retirement plans.

What type of insurance policies do they have? Do they have long-term care? If they don’t, see how much it will cost to get it. Long-term insurance has been a life-saver for my family. Make sure you have a list of the policies somewhere.

How do they feel about nursing homes? Do they have enough money to cover a nursing home if it’s ever necessary? Research what expenses Medicare will cover. You may want to talk to them about setting up some type of account to cover expenses as expenses add up very quickly.

Make sure they have a Durable Power of Attorney and a will. Having Power of Attorney has been very important in dealing with my father’s declining mental state. Even if the person you care for has full cognitive function today, that can change suddenly, or over time, and you want to be prepared regardless of the situation. There are a lot of scam artists who prey on senior citizens, and if your parent or loved one is in a state of mental decline you want to have some control over their finances.

What type of funeral would they want? Under what circumstances, if any, would they want a DNR (Do Not Resuscitate) order?

If they are in a retirement community in another state, what will your plan be if one, or both of them need help. Will you need to move them closer to you or a sibling?

It’s never an easy conversation to have, but have the discussion and make sure you know where they keep their papers, and other critical information. I knew what my parents wanted and what they didn’t want and it made some hard choices a bit easier.

Research. There are lots of organizations out there that can help you. I know that the Alzheimer’s Association helped me tremendously while I was researching my father’s Lewy Body Dementia. Here are a few helpful sites you should consult:

- www.eldercare.gov – connects you to community services that can help
- www.benefitscheckup.org – helps you find benefit programs for medication, food, etc..
- www.medicare.gov – official site for all things Medicare

Don’t try it on your own. I was the executor of my mother’s estate, and because my father was unable to do much, I had a lot of responsibilities. Initially I felt as though I had to pay all of the bills, go grocery shopping, take my father to all of his doctor’s appointments, submit insurance papers, do taxes, etc… on my own. It was exhausting. The Elder Care website (www.eldercare.gov) has a lot of resources and can help you find the services you need – from meal delivery, transportation to doctor’s offices, and legal assistance.

I am lucky to have a good network of support between friends and family, but there are also lots of caregiver support groups.
Everyone’s situation is unique to their family and we each need to do what works best for us. I’ve made mistakes along the way, sometimes I’ve learned from them, sometimes I’ve made them twice. But I do the best I can, and that’s all anyone can do.

also for caregivers. In the first few years, I visited my Dad two to three times a week. I was lucky that I was able to come in an hour or two early to make up time when I needed to take my father to appointments or go to his house at lunch time to deal with the crisis of the day. Having that kind of flexibility at work was very important to me. That being said, when I got home I still had to drive children to practices, make a dinner etc. I was frequently emotionally exhausted and on more than one occasion, short-tempered (add a few hot flashes to the mix and it wasn’t too hard to have a menopausal meltdown). It is hard. There is no way for it not to be, and it’s okay to have a meltdown (or two) in the process.

Make time for yourself. This is easier said than done, but it’s important to practice. Don’t let your situation define who you are.

Home Care versus Nursing Home Care. It’s a very tough decision. We kept my father at home as long as we could using an elder care group that came to his house and did light cleaning and cooking for him. We had two women who came to the house in shifts – one spent the bulk of the day with him, and one spent the evening with him. It gave us piece of mind that he was looked after throughout the day, and was receiving care and nutritious meals. It was a great alternative for us and was financially manageable as well.

The decision to move him to a nursing home was made about a year and a half ago when my dad started wandering outside in-between the caregiver’s visits. It was amazing how much trouble he could get into in an hour! Once he even escaped from a doctor’s office. We were lucky that he had long-term care insurance and a government pension, so we were able to put him in a facility that specializes in dementia and Alzheimer’s care and is set up to keep patients until the “end of life” (an important distinction: some facilities will force you to move your loved one to another facility as they physically decline, sometimes even weeks before death). I also felt guilty about not having him live with me, but I made the choice that worked best for my family. I have the utmost respect for those who move their parents into their own homes to provide care.

Everyone’s situation is unique to their family and we each need to do what works best for us. I’ve made mistakes along the way, sometimes I’ve learned from them, sometimes I’ve made them twice. But I do the best I can, and that’s all anyone can do. My father is safe, clean and comfortable. He laughs when we visit and I will miss him tremendously when he’s gone from this earth.