

Getting Ready For the Biggest Change

Life events cause you to think of things – even the inevitable – in different ways. Intellectually, we all know that death will become part of our lives sooner, but hopefully later. Emotionally, most humans follow Scarlett O’Hara’s philosophy, “I’ll think about this tomorrow.” Then without warning, tomorrow arrives.

The phone rang and it was my mother’s sister, my Aunt Elsie calling from Arkansas. “Chris it’s time to tell you something. I’ve been living with a cancer diagnosis for some time and it has become quite aggressive. Your uncle and I have discussed all the possibilities and I’ve decided to forgo further medical treatment and have signed-up for Hospice care. Since you have Medical Power of Attorney for both Uncle Charles and me, I wanted to keep you informed.”

A quick trip to Arkansas to continue the conversation in person started a change journey for our family that continues today. Over the last 6 months, my 93-year-old Mother moved out of her house and sold it to cover the cost of her new home in an Assisted Living facility. My Aunt passed under the loving care of Caring Bridges Hospice in Bentonville, AK. I moved in with my Uncle for 60 days as he settled their affairs and made decisions about his future. After losing his wife of 66 years, my 93-year-old Uncle decided to move up to Northern Wisconsin to be closer to family. His new home, an apartment in another Assisted Living facility is a far cry from his beautifully decorated, memory-filled home.

Working with my brother and his wife, my husband and daughter, as well as an exceptionally insightful team of attorneys, I’ve project managed clearing out of two households, sales of personal property, homes, changes in insurance policies, settling in with new physicians, two hospital admissions, and other new experiences too numerous to mention. The common thread in all these events was the reactions of the outsiders who became part of our activities. When I’d explain what we, as a family, had decided or easily produced the proper documentation, the universal reaction was “You talked about this? You all agree on your plan of action? Wow, I don’t think I’ve ever encountered a family that actually worked through all these issues together.”

How could they not? I wondered.

After experiencing this reaction multiple times and hearing what seemed to be endless tales of families involved in conflict, disarray, and epic dramas, I realized either ignorance or denial was to blame. Action can offset both. What knowledge, I wondered, was necessary? Upon reflection (idle time in a hospital waiting room gives you plenty of thinking time) here are five things you and your loved ones need to tackle.

Read the Book

I always travel with several books to read. The Kindle app on my iPad carries a library of mysteries, books on change, writing, and leadership, and science fiction - something to satisfy any reading impulse. On my trip to Arkansas, I found a physical copy of *Being Mortal: Medicine and What Matters At the End* by Atul Gawande tucked in my suitcase. (Gawande is a compassionate neurologist and talented writer. A unique combination.) It became my anchor and a rational link to reality during the surreal days of waiting for a loved one to die. As I read:

“This is the consequence of a society that faces the final phase of the human life cycle by trying not to think about it. We end up with institutions that address any number of societal goals—from freeing up hospital beds to taking burdens off families’ hands to coping with poverty among the elderly—but never the goal that matters to the people who reside in them: how to make life worth living when we’re weak and frail and can’t fend for ourselves anymore.”

Gawande’s words helped me see the value of applying the insights from his writing in more than just end-of-life decision-making. How one perceives if their life is worth living is a critical question at all stages of life. It has translated to “What makes your life happy?” as a question for my grandchildren. “What’s working for you in our relationship?” for my husband. “What part of your work feeds your soul?” for co-workers. “What gives your day’s value?” for my Mom and Uncle.

Each page in *Being Mortal* provides equal food for thought and has remained with me as perhaps the most significant book about life I’ve ever read. Get your own copy and read. It’s an important first step. If you plan to go on to the next step and reading books isn’t your thing, do a Google search for Atul Gawande and read/watch a few of the interviews he did when the book came out.

Gather the Family and Start the Conversations

If you’re lucky you and your family members have had discussions about life’s end in the past. In my family, talking about death and choices has been occasional dinner table conversation for as long as I can remember. Matter of fact and grounded in faith, these death-related conversations were not a big deal. I credit my parents for giving us this, what I now know to be, unique gift. If this hasn’t been your experience and the thought of a conversation like this fills you with apprehension, identify an ally, and plan an occasion to launch the dialogue.

If you’ve convinced others in your family to read *Being Mortal* or provided Google suggestions, you’re well positioned to start the conversations. Time and place is important. Conversations that happen as naturally as possible during other family gatherings can be the best place to start. Conversations that are on going and build upon each other will be the easiest. Conversations that

are held before they are demanded by a crisis will produce more successful results. Conversations held in pleasant, mostly private places with minimum distractions will produce more successful outcomes. Conversations with a commonly understood goal will be most productive.

A few opening lines you might consider.

- *A friend of mine has just gone through some stressful times dealing with end-of-life issues with her mother and I realized we've never talked about your wishes. (Or I've never told you what I'd like to happen if/when I get ill.)*
- *I recently read a very interesting book/article about how people take control of their medical care when they face serious illness. It's gotten me thinking...*
- *At a recent Doctor's appointment, the Dr. asked me if I had a living will and when I said no, she gave me a source for the forms. I wanted you to know that I've completed mine and they're in my bottom desk drawer/filed with my medical records at the clinic/in this envelope that I'd like you to keep for me. I wondered if you'd ever signed one?*
- *My friend explained that her father wanted all possible treatments at the end of his life and that her mother didn't want any invasive medical treatments. Because they talked about it she was able to do what they each wanted. What do you want?*

Don't fool yourself. A single conversation won't be enough, but starting the process is what counts and subsequent conversations will be easier.

Research Legal and Medical Resources

There is a practical aspect to all of this. The greatest gift my Aunt and Uncle gave to us was having all the proper legal documents signed, discussed, and available to us as we worked together to deal with the process of her passing. This section is not intended to be legal advice, but it will help you begin the process of getting your affairs in order for those who will be handling your affairs. It will be in your best interests to find and consult an attorney for help in understanding and securing these important documents. Know that any of these documents can be rescinded or changed at any time.

- Location of your important papers
- Contact information of your attorney and financial team
- A will
- In order for someone to access your medical records and make decisions on your behalf, they need a Durable Power of Attorney for Healthcare
- In order for someone to access and use your financial resources on your behalf, they'll need a Durable Power of Attorney for Finances and Other Property
- Copies or lists of insurance policies, bank accounts, other financial holdings

- Medical insurance cards and contact information
- Information describing your wishes about body disposition and funeral arrangements
- Contact information for your spiritual advisor and religious home

Research the Services of Hospice

“All I know about hospice is that they give people drugs until they die,” is a limited view that began a helpful article by hospice nurse Joy Eastridge. Misconceptions abound when it comes to hospice. Hospice actually provides broad education, in-patient and in-home medical services, and heart-felt compassion. It is covered by most insurance plans and is filled with medical, psychosocial, and spiritual professionals who have a view of healing that encompasses entire families. Most services are available on an as needed and as wanted basis.

Eastridge goes on to write, “Hospice doesn’t do anything to shorten life or to prolong life. We simply accompany people on their journeys and work to relieve troubling symptoms that might come up along the way such as pain, shortness of breath, restlessness, anxiety, etc. ...Hospice is not about giving up. It is about changing goals. Being in hospice does not mean that a patient cannot be healed. Occasionally, some patients live on and are discharged by hospice as their condition improves.”

You don’t need to be in need of the actual hospice service to start the educational process they offer. Understanding the resources from hospice will help you prepare for the issues you’ll undoubtedly face in the future. Learning about the hospice services available in your community or the community in which your loved ones lives, will give you access to a tremendous resource and be great comfort when the time comes.

Make Time to Discover, Capture, and Share Your Stories

So far my suggestions have been pretty intense, possibly difficult, and therefore easy to put off. Let me end with one that, in the life of your family, maybe the most important assignment of all. Everyone I know who has lost a loved one can recount the moment when they thought of a question they wanted the answer to and simultaneously realized that they’d never know that answer because they’d missed the opportunity to ask.

I grew up in a family of storytellers. The longer and more involved the better. But still, there are gaps in our knowledge of family history and traditions. Why does creamed herring get a more prominent place on the smorgasbord table than the regular kind? Who originally taught us the Swedish Birthday song? Was Dad scared during World War Two? Did Ivan really leave Sweden to avoid the draft? Did Aunt Vera have three different husbands or did she have four because she

married one twice? Some are facts that time on Ancestry.com could uncover, but the stories and feelings behind the facts are gone. These unanswered questions pile up into regret.

As you look and find opportunities to talk about the serious stuff, make room for storytelling. This applies and works for all ages in a family. Even semi-sullen teenagers will become engrossed in their Great Uncle's stories about learning to drive without having to worry about passing a drivers test. Tweens find Baby Boomers descriptions of high school life in the 60s beyond belief when they learn that their grandparents were dancing to the same Beatles songs that they know and like. Little ones are excited to hear about their parent's vacations – especially the ones where mom or dad got into trouble. And the magic really happens when the story ends with a question – how is that like/different from what you're doing? Children of all ages are nurtured by learning and understanding all the threads that are woven into their identity and that their stories count, too. If the worst happens and the loss you have to deal with is death of a younger generation member, you'll have the comfort of knowing that their stories will live on in your family's history.

These conversations can be prompted by old photographs, everyday meals peppered with family comfort food, holiday celebrations, or just moments presented when you're fully present in a relationship. No matter how they occur, seize them and look for more. You will never use time in a more worthwhile way. Trust me on this one.

As long as I can remember, there was a highly polished silver tea service on the sideboard in my Aunt Elsie's dining room. I can see it as I sit and write this. The silver was a gift of value that pales next to the model of end-of-life behavior she gave me. This article is my attempt to pay-it-forward – sharing and keeping her example of a unique combination of pragmatic actions tied with time for loving conversations. This is, of course, her real legacy.

How is this like or different from what you're doing?