



## **Whose Life is it Anyway? ©**

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During Christmas 1992, just over 20 years ago, my family was in crisis. My father, age 80, was in the hospital with a serious infection. My mother, who was disabled from multiple sclerosis, was home alone. Six adult children from six states rallied. Five of us met in Billings, Montana. We feared my father would die. We knew my mother could not live at home alone; and we knew that none of us could move back home to provide full-time care for either of them; and we knew that we would have to move our mother to a nursing home; and we were not quite sure how to accomplish the tasks at hand.

The tasks before us were difficult. Although we were actually adults, we children were exhausted, worried, and scared. Our work was made more difficult by sub-zero weather, snow packed streets, and the “happiness” of Christmas holidays that we did not feel. Yet...within just a few hours after arriving we children received unexpected gifts from our parents. We received unexpected acts of love that made our work with our parents and for our parents immensely less stressful.

The gifts? The first gift was their gift of trust in us that we would care for them. This gift of trust came wrapped in a briefcase that held the tools that we were required to do everything...and I mean everything...that needed to be done. That briefcase was actually a toolbox that held the legal documents or tools such as Powers of Attorney, health care surrogate, phone numbers of bankers and attorneys, estate planning documents, a check books and cash. Our parents trusted us to care for them and gave us the tools to do the work to care for them.

The second gift was our parent’s willingness to change. Yes...their willingness to change. None of us wanted to move our mother to a nursing home...especially our mother! It was one of the most difficult things I’ve done. But my mother loved us as much as we loved her. Her willingness to change, even if she did not want to do so...her willingness to move to a nursing home with minimal fuss or argument was an act of love for us because she knew we couldn’t move back home to care for her.

I am a community minister whose ministry is elder-care; that is dealing with old people. Yes, old people and their families. I am on a mission to bring back the work and dignity to the word old...so I say 'old' because I don't think it is a bad word. I am on a mission to start a new vision of what it means to engage in family planning! *We need to plan to be old.* Yet planning for ageing disability is not a one-sided issue. Throughout this homily you will hear me repeat: We do not live in isolation. Planning for aging and disability involves family and the community at large. I've come to believe that planning to be old is an act of love.

In the past twenty years I have shared a multitude of experiences with families as they have transitioned into dealing with issues of ageing. My experience with my own parents helped shape my ministry. But my ministry has also been shaped by working with families who do not get along or who for whatever reason have not planned well. The polar opposite of my experience was the experience of one of my first client's. I recall the day when a new client came to my office. No sooner did she sit in the chair that she burst into tears and said, "I hate my mother." Then she told me why. She told me of the child abuse she suffered from her mother and her mother's boyfriends. She sobbed as she explained that at that time her mother lived with her. She wanted to know how to get her mother to move out but that her mother had no place to go. This adult child was 68 years old and continued to work full time a minimum wage job to earn money to care for a 86 year old mother whom she had grown to hate. What was she to do?

As part of my assessment I always ask my clients if they are associated with a church or if they have discussed their problems with their minister. This woman's response broke my heart. She said, "Yes, I told my minister. He said I have to take care of her because I have to honor my mother." It was if her minister told her that her ageing mother was her cross to bear. Then the crying started again. I was angry. In fact, there was one particular incident that catalyzed my decision to develop an eldercare ministry because I knew there was a better way to address the issues of ageing.

All too frequently the issues related to caring for an aging parent are discussed under sterile conditions such as attorneys' offices or worse yet...planning documents, such as advanced directives, are pushed across the counter in a hospital or emergency room where there is little or no time for thoughtful discussion. The problem is that these plans and the use of these documents are played out in the complex world fraught with many barriers. Transitions during ageing are rarely smooth or linear. More often transitions are more like a roller coaster ride.

While legal documents (for as vitally important as they are) serve as a guide, they are written in black and white. The reality is that life is lived out in Technicolor. There are some easy answers. It was easy to explain to my tearful client what services are available to mother, that is what nursing home to recommend or how to apply for various insurance benefits. Yet this woman was in deep pain and required a different combination of answers. Indeed, the all too frequent dilemma is how to deal with the spiritual and emotional issues such as guilt, grief, anger, sadness, and fear, that surface in family life during the ageing process. How do we as families and communities plan deal with issues of ageing? Families are but a microcosm of the greater community. Church is a good place to learn how to be family and to support families through various transitions. We are a youth oriented culture, so it's time to talk about growing old and relationships during the ageing process.

Think about this: We grow old together. We are not the same age at the same time, but indeed we grow old together. I recall being stunned seeing my 80 year old father in his hospital bed and thinking, “Good gracious! How did he get to be 80 years old?” I’d forgotten that I’d aged 40 years at the same time he did and throughout that continuum our relationship changed. So today we’ll talk about ageing together and how to support each other through this process.

First, let’s consider some realities about ageing.

□ **First: *We will get old if we don’t die first.*** The ‘silver tsunami’ has arrived. In just a few short years there will be more old people on earth than young people! Albeit today’s elderly are healthier, more active, better educated, and more adequately financed than ever before, *it is a fact* that the older one gets a problem *something will happen that results in the need for care*. Further, it’s possible and perhaps even likely that we will require care for *a long time*.

□ **Second: *There is no such thing as being independent.*** I hear time and time again that our goal is to maintain our independence as we age. I have had many old clients who have their heels dug in, you know, the person who says, “but I don’t need any help! I just want to be independent! There is nothing wrong with me!” We have misinterpreted what independence means! Too often we think that independence means we want things to happen as we choose or that we have the right to have our own way. I say give it up! None of us have been independent since we took our first breath! So to those old folks who “just want to be independent,” I teach this paradox: You remain independent when you accept some help!

□ **Third: *There is a difference between being independent and being autonomous.*** Maintaining autonomy means we get to make choices for ourselves. It’s important to remember that choices are made in context of community, so indeed sometimes are choices are limited...hence, reality #4:

□ **Fourth: *We cannot always have our own way.*** Sometimes we must change whether we want to or not. One of my favorite clients was Jeffy. At age 97 she had to move from her little apartment to a nursing home. I loathed having to move her, especially to a much different place where she didn’t know anyone. I was apologetic as I explained the need for the move. I will never forget Jeffy’s response. She said, “Esther. I’m 97 years old. All I have been doing my entire life is change. I can change again.” Indeed, change happens.

□ **Fifth and most important: *We do not live in isolation.*** We live in the context of community and family life where we care for ourselves and care for each other. *Caring is relational*. So... community is affected by how we choose and plan to care for each other. It’s true! Think for a minute. If your mother has a massive stroke and moves to a nursing home, not only does her life change, but your life changes...AND...the lives of the people you work with change because your life changed.

So now let’s place this idea in the context of ageing, particularly ageing in family life. This is important: *The Waltons existed only on television* yet we strive to be the ideal family where two generations live happily under one roof. Many families are at a disadvantage because the stereotypes of the ideal parent- adult child relationships are stronger than the reality at hand.

Many families do not get along well, and child abuse is not restricted to young children and the wounds of child abuse may linger indefinitely.

Old people are not unlike any other group of folks. Some old folks are nice, others are mean, some are flexible, and others are stubborn. Not everyone's parents are easy to deal with. Therefore, caution is warranted particularly in regard to what it means to honor your mother, father, or elders. This concept is most clearly evident in the fifth of the Ten Commandments: "Honor your father and your mother, so that your days may be long in the land that the Lord your God is giving you." Honor, like love and forgiveness, is a relational term with profound theological meaning. The edict to honor parents is found in all three major world religions (Islam, Judaism, and Christianity). The edict to honor one's parents is solidly embedded in the consciousness of American society, particularly because of the strong influence of the Jewish and Christian religions.

I stress the concept of honoring because many adult children have been indoctrinated that honor means giving parents what they want rather than what the parent may need or what may be good for the family as a whole. This misunderstanding of honor means leaves adult children like my tearful client feeling isolated, exhausted, and guilty. I would be a rich woman if I had a dollar for every time a client told me she feels guilty ... or worse, feels like a bad person, because she cannot or has to unwillingly give the parent something the parent wants.

The problem is that the concept of honor is misunderstood if it is not taught always in context of *modern* society. So it is important to reframe what honor means. In today's culture, honor does not mean total self sacrifice on behalf of a parent; rather *honor requires thoughtful and respectful care*. It is acceptable, if not actually healthy, for adult children and their parents to separate if they do not get along well. Yet the question remains: How do adult children or care-givers learn to honor and respect their parents or elders while at the same time maintain a sense of their own integrity and self worth? How can we honor our elders' autonomy while at the same time give consideration to the burden the adult child faces, showing our concern no less to the adult child than to the parent?

Remember, we grow old *as a community*. So we must ask: *Whose life is it anyway?* In my twenty years of experience in geriatric case management, the most important thing I have learned which I will now preach from any pulpit or soapbox is this: We must give up the notion that the care-receiver is the *sole* focus of our concern. Care-givers' needs are every bit as important as the needs of care-receivers because care-giving is nothing short of hard work. A relationship between care-giver and care-receiver can last for years. In fact, data prove it. There are many data based studies that show that primary caregivers have as much as a 63% greater chance of death or disability compared to non-primary caregivers of the same age secondary to caregiver stress. Spouses that are primary care-givers often die before the care-receiver. We must honor the care-giver every bit as much as the care-receiver. If I had another dollar for every time I heard, "Oh mom takes care of Dad. She's a little tired but she's doing okay," I'd be even richer! My response is, "Take care of your mother first because if you do not your father will be the first to suffer." That's right! Be sure to take very good care of the primary caregiver(s) because if something happens to the primary caregiver(s) the care-receiver is the first person to suffer.

This is what I believe and teach every time I'm given opportunity. The ideal relationship between care-giver and care-receiver is grounded in our Unitarian Universalist theology of

interdependence. Interdependence means more than being connected. Indeed, the best definition of inter-dependence I have encountered is “a love of mutual regard.”<sup>i</sup> An interdependent relationship calls for mutual accountability and mutual responsibility for each other in order to *help each other not only survive, but also thrive.*

A theology of interdependence helps families figure out a way to help each other meet their needs through loving tone and intent and with careful and thoughtful care. Interdependence promotes human dignity by encouraging autonomy; however, interdependence also requires us to make choices within the *context of community rather than clinging to the false concept that the world revolves around the any one individual.*

So...whose life is it anyway? In reality, our lives are not our own. Living is not only about you or only about me; rather life is about us. *Interdependence is a process.* It is an *on-going ritual* of giving and receiving. This reciprocity is not necessarily sharing equally, not tit for tat; rather it is giving and receiving to the best of a person’s ability at any given moment. We are interdependent when we claim our own needs while at the same time we honor and respect of the needs of others. We engage in that love of mutual regard, requiring both the care-receivers and the care givers to be active in process. Caregivers need not adopt the martyr mentality of thinking that caring means total self sacrifice. Care-receivers need not adopt a mentality of thinking they must be totally dependent. We know this! “From you I receive, to you I give, together we share, and from this we live.”

So what does an interdependent relationship look like? Here are a few examples:

- We engage in love of mutual regard when we accept help we need it. Digging in your heels and “maintaining independence” is worrisome and can be harmful. It is not helpful to refuse care because you “do not want to be a burden.” The reality is that you become more of a burden when you harm yourself or make family and friends worry that you will harm yourself. I recall begging my mother to ask for help when she walked because every time she fell she hurt herself resulting in more work and angst for my father. Accepting help is an act of love so others do not worry about you.
- We engage a love of mutual regard when we help others help us. Care-receivers can reciprocate to the best of their ability and respond with grateful and gracious hearts. Sometimes the only thing a care-receiver can do is be kind or say ‘thank you.’ I recall hearing from a old woman who acknowledged that the only thing she could do was be nice. Her willingness to be nice in spite of her situation made caring for her easier. Being grateful and gracious are acts of love.
- We engage in love of mutual regard when we tell the truth and listen with open hearts and open minds. Sometime ago, a woman in a congregation where I regularly preach stood up during joys and concerns and said, “Oh dear. My beloved husband has been diagnosed with Alzheimer’s disease. I am so afraid. I do not know what to do. It is your responsibility to help me.” There were an audible gasps throughout the sanctuary.

I admired this woman’s courage to tell her story...to ask for help. She did not whine. She did not beg. She simply stated her need. Her admonition took great courage...to acknowledge her needs and place them right up front.

In yesterday's workshop about life care-planning we talked at length about how families can plan to grow old and the relationship between caregivers and care-receivers. Yet our mission as a "church family" is to realize we are part of the community that supports the family because we are an extension of the family.

Indeed, the silver tsunami hit our shores. We have to help each as we grow old. It is time we re-frame what it means to care for the elderly. One of the most important things we as church can do is support the primary caregivers whether be they the spouse or adult children. Remember: If something happens to the primary care-giver then the care-receiver is the first to suffer. Therefore...and this is important...there should not be a sole caregiver. Rather, our function as church is to be the ecclesia...an assembly of caregivers...to work within our interdependent web to share the work so that no one caregiver is responsible to carry the entire load.

My family was not the Waltons. There were things my parents did that drove me nuts and that scared me. Yet, they did what was right for themselves and their children. They planned well. They realized change was coming and prepared to change. They considered their children's needs and gave us the tools to help them. We operated interdependently because *my parents helped us help them*. And indeed the church helped. When I was at my wits end and when my heart broke moving my mother, my mother's church came to my rescue. I was not served a big helping of guilt; rather I was served, literally served a helping of hope when other hands came to support me.

My heart aches each time I recall the pain of my client who said her minister told her she had to honor her mother and take care of her. That woman's church failed her through harmful theology. So how could Unitarian Universalist theology help her? First, we could tell her that her mother need not be an extra burden for her to bear alone because in our interdependent web all of us are responsible for caring for her mother. When we are faithful to a theology of interdependence, we care for both mother and daughter. The most helpful outcome would be that the daughter would come to believe that honor does not mean that she has to care for her mother all by herself. Ideally, the daughter would come to truly believe that her needs are important and that she too is worthy of love and support even if love and support does not come from her mother. And, by giving compassionate care to the elderly mother who abused her own daughter, we send a message to the elders themselves that they, despite their infirmities or previous sinful behavior, remain worthy of attention and love. And such attention might come in the form of ensure appropriate care in a nursing home in the absence of the daughter's care.

Each family has its own story. Each family has its particular needs. It is here that families learn how to get along through the ethic of love of mutual regard. I encourage you to share those stories and needs here...right here in church. We are growing old together and we must help each other do so. Elder care is a global issue that the Church must address. May we grow old together with courage, honesty, and hope so that no hearts ache in silence and no hands work alone.

Amen.

1 Don S. Browning and others, "A Practical Theology for Families," in *From Culture Wars to Common Ground: Religion and the American Family Debate*, (Louisville: Westminster John Knox Press: 2000), 271-305.