

# Keeping it Good 'Till the End

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A Message for the First Unitarian Church by Jay Johnson, Kathleen Rhoad, Mara Hoffman, Barb Free and the Rev. Christine Robinson October 23, 2016

## Introduction -Christine

We UU's pride ourselves on looking at life with clear eyes and a rational bent of mind, and on thinking that the spiritual life encompasses ALL of our lives. Since we live, learn, cope, grow, make meaning, and love from the moment of our birth until we take our last breath, the last years of our lives with adjustments, difficulties, and blessings are important to us. Last week we talked about choices in dying, and I know that many of you were glad to hear this issue raised and frankly discussed. This morning, some of our members who have been digging into issues of aging will speak about the important issues of how we live and make our lives significant until it comes our time to die.

## Jay Johnson

When the Sunday Explorations meeting decided to discuss Atul Gawandi's book BEING MORTAL, I knew I wanted to join the conversation. I had read Dr. Gawandi's book, and found it to be spot-on in so many ways. First of all, during my long career as a hospital pharmacist I have often seen the outrageous waste of money, resources, and even dignity that has been, and still is a big part of the healthcare industry. You might even call it the institutionalization of death and dying. Over the centuries since the renaissance we in western culture have become more and more enamored with the rational and scientific way of doing things, so much so that we often forget that technology must be shepherded by good judgment. There is a tendency to expect life to be repeatedly prolonged until that last gasp when technology, not life, has reached its limit. The time has come to put our values about what is a good life and what is a good death back into the equation. Ultimately, I believe this can result in better quality of life, less suffering, better goodbyes, and more cost savings than anyone can imagine. That is why, when we decided to pursue the topic of what we came to call "Self-Directed Aging" I thought "I'm in!!"

What is meant by Self-Directed Aging? It includes researching housing options, healthcare and legal matters, finding ways for maintaining positive attitudes and staying engaged in life. It means developing the means to exercise freedom and autonomy so as to live life on our own terms.

We soon realized that aging is not something one should try to do alone. Living and dying is a normal cycle. We are, all of us, “TERMINAL.” Our job, then, is to make the most of it—to Keep it Good Till the End. Exactly what that means is very personal and ultimately spiritual for each individual. But we need a lot of help with this from friends, family, professionals, and our own institutions.

Our church can be a lot of help by feeding the spirit, accompanying us on the journey—helping us with spiritual crises and marking life's milestones. This is a big part of why we form congregations—spiritual communities. However, there are times when the church can also be the key to a very practical problem such as transportation to and from church events. Many of the larger U.U. Churches have developed a network of volunteer drivers who provide rides to church for members who can no longer drive due to medical or age-related inability. Are we willing to do that here? Another very practical measure that is already being discussed is placing an A.E.D. (Automatic External Defibrillator) on the church campus and training as many members as possible in its use and in the CPR technique called Compression-only CPR. You will hear more about this project soon. I hope that today's presentations will get you thinking about how we, our families, and our church can work to empower each of us to navigate the later stages of life in ways that enhance the experience and reflect our deepest values.

### **Kathleen: Retaining Autonomy**

I moved to Albuquerque 6 years ago when I retired from Florida. This required an adventure-some spirit and many investigative trips to the region for about 10 years before I retired. I'm 71, single with no children and my family lives in Pennsylvania and New York. And I hike: I coordinate the UU hiking group and I want you to know that I'm good for a six mile hike of moderate difficulty. Sometimes people look at me and think I'm frail, and I want to tell them that I just-completed the Fourth of July Canyon Loop. To make sure I can continue to hike, I wear orthotics and do special ankle exercises every morning.

Here's another way I'm taking care of myself. I'm researching options for housing as I get older. Now what I hope is that I can stay in my home as long as possible, ideally until my “home-going” as Zen teacher Peter Matthiessen called his dying. I have been participating in the Self-Directed Aging group to learn more about Albuquerque housing options in the event I need them. Visiting and learning about alternative housing arrangements and their cost from independent to assisted has been a sort of warm up activity should I need to move out of my home down the road. This has helped me to feel more confident that I'll be able to make informed and autonomous choices about my living arrangements.

Another way I'm taking care of myself is that I have a Durable Power of Attorney for Health Care document and an Advance Directive. I have designated my nephew as my agent to carry out my instructions in the event of an incurable and irreversible condition, in which case, I do not want my life prolonged. I also specify that I do not want artificial nutrition or hydration at the end. I would want Hospice if I need it.

An Advance Directive or Living Will is a critical document for every one of us to have because accidents and sudden illnesses have no respect for age. Search for NM Living Will and download one for yourself. For those who do not have family or who don't trust their family with end of life instructions, a great deal of anxiety can result about who to trust. There are organizations to help. One in Albuquerque is Decades which offers elder care services and acts in good faith under a court appointed conservatorship. One friend in our UU lunch bunch died recently. She was an only child without family. She had made all of the necessary decisions and arrangements with Decades. She carefully and thoughtfully exercised her autonomy regarding her end of life decisions before peacefully dying alone in her bed. Her preparations were appreciated and comforting to her friends.

Retaining autonomy does not mean that one is alone in making health care and other important decisions. One is fortunate indeed to have an advocate or advocates. Ideally one has a close friend or friends or family members near-by in addition to one's distant family and physician who wants to be an advocate. They can offer emotional support and serve as a sounding board when decisions are being considered and choices made. They are available to accompany one to important doctor appointments or to visit during hospitalizations.

Social connections nurture and support one's autonomy. They can be formed in community groups, with neighbors and in various small group opportunities within the First Unitarian community. My six years participating in the lunch bunch after church many Sundays and the monthly hiking group have fostered friendships. I have gotten to know people I can reach out to who care about me.

One area where retaining autonomy might be compromised is if one can no longer drive. Many people cannot drive the last 10 years of their lives. I discuss this with age peers occasionally and say "Well, hiring a taxi or a regular driver is less expensive than maintaining an auto." Choices to be made in the future.

I feel very grateful, happy and immensely fortunate to have envisioned my life in the North Valley of Albuquerque and to be living it. Plus to be able to travel about to see and enjoy the com-

elling landscapes and activities of New Mexico and the region, often with visitors from the Northeast. This is a joyous approach to my homegoing.

## **Mara:**

As an Elder, I can and should be a person of influence, but for this exercise of influence to be felt, **I must be connected** to the people around me.

In past years, no one had to think about “fostering inter-generational relationships”, because such relationships were exquisitely normal,... as the dense family clusters that remained, ...were ties to a single community for many generation which retained an important place in American iconography,...many of us don’t live... in this way today.

As a result of unending discussions with my Self-Directed Aging co-hearts, with Angela Merkert’s able assistance, and many conversations with my partner Peggy and other family members, I’ve decided to stay in my own home in Albuquerque,....and connect more with the people in my surroundings.

In 1987, I came out to my husband as a Lesbian, and that changed both of our lives. Our grown children and their families live in Virginia, along with their Father, who just recently moved to join them.

I purchased my home in 1989, and since then, I’ve been busy at work, reshaping this home to fit my present needs. I dearly love being connected to my xeriscape,... which was initially ably designed by Jim Lewis, (one of 1<sup>st</sup> Unitairan’s early xeriscape creators,...where we now immerse ourselves during an Easter sunrise)

At home,....my surroundings to the East, allow me to observe hummingbirds flitting over the meadow of Blue Gramma,...as they approach & argue as to who will have access to the feeder. The bees at the newly created pollinator garden, with many other species flying in & out of my Apricot & 70foot Arizona Cyprus tree.

The workshop I created, . . . flanks the meadow, & allows me to view Mother Nature thru it’s wide opened door. The walking path that surrounds the meadow has been a blessing, whether as a path to recovering from surgeries, .... or simply viewing the rosy glow of the Sandia at Sunset,.... or, perhaps a moon rising.

I can also hear & view the Albuquerque transit bus on San Mateo, just beyond my backdoor neighbors..

The view to the West I have from my front window lets me connect with the Curved Beak Thrasher Parents, creating their nest and eventually feeding their offspring. An occasional Roadrunner loves to taunt the Thrasher, but the local cat keeps the Roadrunner in check.

This view captures my neighbors walking by, ...many are accompanying students on their way to Whittier Elementary School, at the end of my block. A new term to identify this activity is "Peidibus", meaning "footbus".

This view of **multi-generations**,.... reflects my present realization that in past years, no one had to think about "fostering inter-generational relationships", because such relationships were exquisitely normal, as the dense family clusters that remained were ties to a single community for many generations, which retained an important place in American iconography,.... few of us live this way today.

When confronted with the **facts regarding our society's** radical and destructive practice of age segregation, most people respond with nostalgia. "It used to be," we say, "that older people were respected, as families took care of their own. This appeal to kinfolk and tradition might feel good,.... but it also disregards the realities of contemporary American Life."

Dr Bill Thomas, the author of Chapter 5 in "Being Mortal", has been exceedingly helpful in educating me, & others, about how ones community can help us connect with everyone, whether it be by staying in your own home, Co-housing, Retirement/Assisted Living, or Skilled & Nursing Homes. The community we create is a result of our having a "Purpose in Life!"

Because the transition into our elder years can be so invigorately simple, I've reaffirmed that my purpose and intension, is to stay in my home, and to become less isolated, by connecting more with those in my neighborhood.

I've just recently become a "Block Captain". **AND**, just this past Tuesday evening, I was one of about 60 neighbors, who took part in a stimulating discussion at our Parkland Hills Neighborhood Association Bi Annual Meeting,... a Community Outreach Coordinator at APD/Community Policing Councils, the Principal & newly appointed Vice Principal of Whittier E S, the contact person for North Campus Community & our City Councilor were ALL presenting & taking part of the Q&A.

Just this month, founding members of the "Village in a Village" in Corrales, NM, joined in with our Self-Directed Aging discussion.

I refer to such happenings as "Goose Bump Times". (I would suggest leaving this out. It is a distraction from your focus unless you want to talk about that project, which you don't have time to do.)

VtV began in 2001 in the Boston neighborhood of Beacon Hill, in the form of a self-governing, grassroots, community-based organization focused on the sole purpose of enabling people to remain living in their homes and communities as they age. In 2010 the Beacon Hill Village partnered with the community development organization NCB Capital Impact to help replicate the Village model nationwide through the Village to Village Network North Campus Community has been helped thru the years by 1<sup>st</sup> Congregational Church (at the corner of Lomas & Girard)

...semi-annual/Spring & Fall, let's help the elderly neighbor groom their yards,

...sign-up to help those needing to have transportation, small home repairs,

...created a community garden with the help of County Commissioner Stebbins,

...installed Stations for libraries on a pedestal,

...website & monthly newsletters for additional/enhanced communication.

A viable community of neighbors helping neighbors is where & what I am about.

In recent conversations with my neighbors, I've become very aware of the need we all have to connect & share stories. My sharing my story here this morning will help you understand my hope & present purpose in life, to see if I and others can create a village within my neighborhood. And, by having all I've mentioned previously, will allow me to continue pursuing how a neighborhood could possibly be a village.

## **LIVE YOUR WHOLE LIFE! -Barbara**

When the Sunday Explorations group decided, after studying Being Mortal, to do further research, under the umbrella of "Self-Directed Aging," three of us decided we wanted to emphasize the importance of attitudes and staying involved in life despite challenges of various disabilities or restrictions. It happens that all three of us acquired significant disabilities fairly early in life and learned to acknowledge and accept them, and to adapt our lives accordingly, without either giving up or denying reality. We're here today as proof of those decisions.

Janelle Campbell was diagnosed with Multiple Sclerosis at age 23, and was told that she'd be in a wheelchair within a year, that 90% of women with MS would have that immediate outcome. She said she'd be in the 10%. The doctor said "What 10%?" Janelle replied, "Well, if 90% are in a wheelchair, that means that 10% are not, and I'm going to be in that 10%."

Many years later, she is still not in a wheelchair. She completed her education, married, and had a long and successful career as a teacher and tutor. She has always been involved in serving others and social justice issues. Now that she's retired, she continues to volunteer in our After School Tutoring Program, and many other activities, including traveling and learning French!

Christine Hall, who is usually accompanied by her service dog, Tessa, began to lose her sight in her early 20's, regained some, was legally blind by her 30's, and lost all sight in 1986, thirty years ago. Not letting vision loss at such an early age stop her, she went to college, completed her degree, and had a long career of teaching blind skills to other blind people. She is now retired but still serves on the Board of Regents of the New Mexico School for the Blind, among other things. She successfully raised a family and still leads a full and independent life, including hobbies, social activities, and travel. She enjoys life.

My own story is not as dramatic as Janelle's or Christine's. I knew that I might get age-related macular degeneration by my 80's, due to family history, but I had a positive role model in my great aunt and knew that it was important to stay positive and involved. I did not expect, however, to lose the central vision in my left eye at 52, in the middle of my career as an addiction therapist. It did change some aspects of my life and career, including restricting my driving, but it got me involved in blind issues and a focus on various acquired disabilities. Being able to maintain a positive attitude, enjoy life,

and accept the limitations I do have, especially as I get older, is an important part of my identity and spirituality.

As we explored our own life experiences, and the possibilities for involvement in life in our community, we found that there are endless opportunities in Albuquerque. There are many senior centers, multiple- generational centers, and countless community groups, churches, and volunteer opportunities, as well as ways to travel despite physical disabilities.

There are some barriers to remaining involved, such as physical mobility, lack of personal connections as friends die or move away, safety concerns about night driving, going out at night or to unfamiliar places, and inaccessibility such as steps, poor lighting, and transportation. The biggest barrier of all is difficulty asking for help. This is a cultural as well as personal trait. Sometime others would be glad to help, and even offer, but people are reluctant to ask. There is also a need for non-disabled people to become informed about various disabilities, because anything can happen to anyone at any age. Sometimes well-meaning friends or family urge a person to become less involved in certain thing, especially if it involves inconvenience on their part, or they may urge a person to continue activities in which they are no longer interested or with which they need assistance.

Older people should not be expected to adapt their lives for someone else's peace of mind. Because transportation is such a big issue, it deserves a special study, and that's our next challenge.

However, it's important to examine one's attitudes about taking risks, being willing to try new things, and learn new ways, adapting our lives to new situations, and developing a strong sense of humor, so that we do live our whole lives.

## Closing Christine

That's a lot of things to think about. But for many of us, our "elder years are going to be something like 20% of our lives. This is a new thing in this society. It took our parent's generation by surprise, but there's no excuse for that any more. This generation of elders gets to plan, not only for their active retirement, but for their truly elderly years, which can be rich with growth, love, friendship, and activities way into the time in which we will need help with our affairs, with advancing technology, and with our aging bodies. These brave folks have started the conversation. May it continue in good health!

Now, at the request of the group, we will sing "Let it Be a Dance" , #311, as our closing song.

