

Still Here
Rev. Ken Read-Brown
First Parish in Hingham (Old Ship Church)
Unitarian Universalist
April 26, 2015

Readings

from the poetry of the 13th century Sufi poet Jelaluddin Rumi

A moment of happiness,
you and I sitting on the verandah,
apparently two, but one in soul, you and I.
We feel the flowing water of life here,
you and I, with the garden's beauty
and the birds singing.
The stars will be watching us,
and we will show them
what it is to be a thin crescent moon.
You and I unselfed, will be together,
indifferent to idle speculation, you and I.
The parrots of heaven will be cracking sugar
as we laugh together, you and I.
In one form upon this earth,
and in another form in a timeless sweet land.

from *Where Two Worlds Touch: A Spiritual Journey Through Alzheimer's Disease*, by
Unitarian Universalist minister Rev. Jade Angelica:

Everything that's real in our lives is right here, right now. Sometimes we'd rather forget, deny, or avoid the importance of now, especially when the current experiences of our lives are difficult to embrace. Feelings of loss, grief, anger, abandonment, rejection, fear, loneliness, disappointment, and sadness often send us searching for distractions, of which there are many in our busy lives. If we instead choose to accept the present moment, our hearts, minds, and spirits will awaken to the wisdom of putting the past and the future into perspective. Then we can focus our attention, accordingly, on the right now.

"Do not dwell in the past, do not dream of the future," the Buddha tells us. "Concentrate the mind on the present moment."... The present moment is the one that calls for and merits our attention. Now is where we will find reality, connection, meaning, joy, and, ultimately, love. For those seeking to find spiritual meaning on the journey through Alzheimer's, it's important to mention that *this* moment at hand, the only thing we truly own, is most often where we will experience true meetings with ourselves, others, and God. (p. 158)

Sermon

As most of you know, I ran the Boston Marathon last week, part of a team of thirty-four runners raising funds for the Alzheimer's Association of Massachusetts and New Hampshire – as I've done now for the past three Marathons.

As you *all* know, the weather was, shall we say, a bit wet and windy.

But the enthusiasm of both runners and supporters along the way was undiminished.

For me one of the most emotional moments in the race came a little after mile 16. Mile 16 itself was great because it was there that I was given some water by my colleague from across the street, Rev. Gary Ludwig; and it was there that two of our own members, Ellen and Eric, cheered me on – just as at mile 12 Old Ship members Jane and Chuck Malme and their son Bob cheered me as they waited as well for their daughter Karen. All wonderful boosts!

But mile 16.5...

You run up and over Route 128 just before that point. The road then slopes downward, and a hundred yards away, on the left, is the cheering station for the Alzheimer's Team. The Alzheimer's color is purple, and I could see their banner – and they could see me, wearing the Alzheimer's singlet we all had been given (wearing it over several other layers!).

"Ken Read-Brown!" And the cheer went up. And tears came to my eyes. I thought of my mother. I thought of all those affected by Alzheimer's. High fives all down the row of supporters – including the Association CEO Jim Wessler – and off I continued (to an even better moment, my wife Susan and our daughter Eliza just past mile 19!); then up and over Heartbreak (encouraged by our Alzheimer's Team coach Gail, at the foot of the hill), Cleveland Circle, Beacon Street, Kenmore Square, right on Hereford, left on Boylston, to the finish.

If you've never run the Boston Marathon, it is hard to describe the elation of it – a combination of the achievement itself and the support of all those along the way. (I don't call those who line the roads "spectators" – for they truly are participants too in this celebration we call the Boston Marathon.)

Then, adding to the satisfaction for me – and joy, poignant joy, but joy – was being part of a team that raised over \$340,000 for the Alzheimer's Association to fund their contributions to research and family support.

And each member of this team, ranging in age from 20s and 30s to one runner in his 60s... each has a story and most with a family member close to their hearts who had or has Alzheimer's:

father and grandmother
grandfather
grandmother and mother
mother, father-in-law, sister
mother
father
grandmother
grandfather
father
mother
grandmother

mother
grandmother
mother
grandfather
grandfather...

And on the team web site, we learn little bits about these treasured family members:

The way a grandmother was still warm and bright when her grandchildren visited, even deep into her Alzheimer's.

The way a father would introduce his son as his nephew; or how another father didn't recognize his son at all.

Memories of lessons learned from or gifts given by a grandparent or parent in years gone by.

Challenges of caring for that grandparent or parent as they progressively lost their ability to care for themselves.

And each of us on the running team had supporters, dozens, altogether hundreds, who contributed to our efforts, most of whom had also been in one way or another deeply touched by Alzheimer's – and so were making their contributions in honor or memory of a friend, grandparent, parent, spouse.

In other words, I'm describing a bond that transcends any differences in politics or religion or age or pretty much anything else – a bond forged from the simple knowledge that we each really do know what the other has been through or is going through. So... I have no idea, for example, whether my running teammates were Democrats or Republicans! (In this hyper-politicized era of ours, what a relief!)

My own story most of you here at Old Ship know, at least in outline. My mother, who many of you knew, died in December of 2012 at the end of some fifteen years or so of the progressive journey with Alzheimer's.

Well, I had already qualified for and entered the 2013 Boston Marathon; but as December turned to January I realized I didn't want to run just for my own personal satisfaction. So after a little searching I found the Alzheimer's Team, who warmly welcomed me aboard (many thanks to the development staff leader, Angela Floro!).

This meant I was able to run to honor my mother as I contributed (with the huge help of my supporters) to the effort to end Alzheimer's and meanwhile to support families and caregivers struggling to be companions to their loved ones on this Alzheimer's journey – which as many of you know firsthand can be a very hard journey indeed.

By then I had already learned quite a lot about this disease (or collection of diseases – primarily Alzheimer's, but including other forms of so-called dementias). Learned not just about the symptoms and stages and underlying brain changes of the disease. Learned also a good deal about how to be with someone who is slowly but inexorably losing her cognitive abilities.

I had grown in patience, learning to respond to the same question or comment from my mother multiple times as if it was the first time.

I had learned to introduce myself every time I visited her, just in case. And on a couple of occasions – blessedly only a couple – I simply had to take a deep breath when she clearly did not at first know who I was.

In short, I – really Susan (without whom I don't know how I would have managed) and I and all our family – had gradually learned to enter Mom's world, not

correcting her, not reminding her that she was repeating herself or forgetting this or that, just present. Susan's and my mantra became simply "it is what it is" – not always the same day to day, progressively more challenging, but no changing the inevitable decline, and so in response at every step of the way just learning to be present and to try to make the best decisions possible amid the various turnings in her condition... and (hardest of all for me) to try to be forgiving of myself when in retrospect I felt I may have made some sort of wrong turn in those decisions.

Finally, and maybe most importantly, I had learned that though Mom had lost much in the way of memory – almost no short term memory during the last months or couple of years, and long-term memories eventually fading as well – but I had learned that she, the essence of her if that's the right word, was still here, that she was still herself at heart, still kind, still a shining light for everyone.

I know this isn't always the experience for everyone who is a companion to a dear one with Alzheimer's. But I do believe that however clouded, and whatever occasional or even frequent disruptions or eruptions of anger or frustration... the person, the essence, is never entirely gone.

To put it another way: I felt I experienced through this journey with my mother that a soul is a soul is a soul, "still here" with as much a "spark of divinity" as anyone else (as Jade Angelica puts it in her book), even if and when the outer shell cannot remember family members, cannot remember what she had for lunch five minutes ago, cannot remember I was there five minutes ago, cannot eventually even speak much or at all.

And whether one has this experience or not, we, caregivers, companions, loved ones, volunteers... can be compassionately fully present – still here – knowing that the value of a human being does not diminish even as brain cells are destroyed and neural connections increasingly tangled.

Further still, as I learned all this, and as I tried my best to be present every day, my experience during the last months of my mother's life was heart-opening. My experience was that this was all about love.

I experienced the hospital as Susan and I waited during my mother's hip surgeries as a house of love.

I experienced the movers, who moved my mother's belongings from one residence to another (her outward life in some ways shrinking and shrinking again) as conveyors of love.

I experienced the nurses and aides at Allerton House, Sunrise, and finally Harbor House nursing home as loving companions.

I felt your loving support all along the way.

Yes, all about love.

Love also still here – indeed more manifest than ever.

Of course I hope, as we all do, that a time comes, and comes sooner than later, when Alzheimer's Disease does not have to be one of the ways in which we learn patience and wisdom and love. I hope that our children will not have to share the Alzheimer's journey with us. I hope that for our grandchildren (our first will be joining us in August!) Alzheimer's will be only, to put it ironically, a memory, a story from the past.

But meanwhile, there is work to do to end Alzheimer's, and there is work for many – and spiritual work it is – to be present as caregivers and friends.

To aid this work, Jade Angelica crafted a version of the Serenity Prayer, in which the prayer is to accept all that cannot be changed about Alzheimer's – which is a great deal; yet at the same time to have the courage to change what can be changed – which mostly means, she writes, such things as our own attitudes, reactions, expectations, and priorities; and to learn the wisdom to know the difference. She concludes her prayer with these words:

God, may I open my heart to the peace
that passes all understanding.
May I care for and comfort my loved one
with patience and compassion.
May I be hope.
Amen.

None of this is easy. Which is why we need a prayer, or something like a prayer. Which is why we need each other, listening ears and helping hands.

But while none of it is easy, the gifts – *yes, the gifts* – can be many: the gift of deeper connection with someone we love, the gift of hearts more and more open to love, the gift of learning greater patience, learning to be just in the present moment – which is the only moment, after all, that we ever have.

In the introduction to *Where Two Worlds Touch*, Jade Angelica affirms that her purpose is:

..to remind us of the inherent dignity and worth of all persons – even persons with cognitive decline – and to remind us that interconnectedness is a central aspect of being human. We are not separate from persons with Alzheimer's. Our lives are woven together, and we are on this journey together. (p. xx)

Elsewhere she affirms, as I've been suggesting this morning, that “people with Alzheimer's and dementia could be our most important teachers in the school of life and love.” (p. 76)

Indeed, spiritual meaning on our shared journey with Alzheimer's *is* as close at hand as the present moment, which is, as Jade Angelica puts it, “most often where we will experience true meetings with ourselves, others, and God.” (p. 158)

To put all of this quite simply:

The Alzheimer's journey is often a hard one – there is no use denying the suffering and sadness and loss.

But if we pay attention, give our full presence to the journey and above all to our dear one (still here)... there is also joy, and there is surely love (still here)... another way of saying there is surely the Divine by whatever name (still and always here).

So may it be. Amen.