

Getting Our Affairs in Order

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It was an odd thing to enter into my calendar.

I had the date and the time, as well as a Zoom link.
But I hesitated, trying to figure out
what exactly to call this particular appointment.

I eventually typed:
“End-of-life planning with Becky”.

And, then, a few weeks ago,
there it was in my schedule,
tucked in between other meetings—
a time to sit with Bob and our friend Becky
to review our final wishes.

This wasn't the first time we had had such a chat.

We discussed all of this several years ago,
when we prepared our wills
and named each other as our medical power of attorney.

But as the Covid-19 pandemic began to unfold,
and it started to become clear that men
were at a greater risk of poor outcomes,
and being a couple of middle-aged men,
it felt prudent to revisit our conversation with Becky
about what mattered most to each of us
when it came to decisions about how
we would want and would not want to die.

And so we talked about ventilators
and the potential for long-term organ damage;
we talked about what “quality of life” really means to us both;
we talked about pain management and sedation,
and our hope to be able to say goodbye

should the end come sooner than expected.

Statistically, our risk of death in this pandemic is quite low.

But it exists, and, so we heeded the pleas
that have come from doctors on the front lines:
To get our affairs in order.

Specifically, with Covid,
medical teams have most needed to know
if patients wished to be intubated and put on a ventilator.

While the impulse is often to take whatever measures
are necessary to save and prolong life,
the decision can be more complicated than it would seem.

As one doctor put it in an article in *The Star* on Friday,
these are horrible decisions to be making,
often with loved ones over the phone,
in the space of a very few critical and chaotic minutes.¹

So, my first charge to you this morning
is to spend time in the coming days
putting your medical affairs in order.

Reflect on what matters most to you.

If you feel you need to know more, do some research.
(Some helpful links are posted down below!)

And, most importantly, have a brave conversation
with the loved ones in your life
who may be called upon to speak for you,
if you cannot speak for yourself.

One of the kindest things you can ever do
for those who may be asked to care for you
is to ensure they aren't left to wonder about your wishes.

¹ Bruce Arthur, "Intubate or give palliative care? ER doctors wish they knew what residents and families wanted," *The Toronto Star*, 24 April 2020.

When I worked as a chaplain in a trauma hospital
as part of my training for ministry,
I would come home
from my overnight shifts in Emerge
to present Bob with a new list of things
that I did or did not want to have done to me,
should I ever be in critical condition myself.

That experience left me
with mixed feelings about heroic measures;
though they can sometimes make all the difference,
they can also be incredibly invasive.

Which is why it's so important
that your beloveds understand
what quality of life means to you.

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I know these may not be
the easiest conversations to have.

It can be deeply uncomfortable
to reflect on the decisions
that may surround our death and our dying.

It is okay, if it helps to get through it,
to keep it a pretty abstract, intellectual exercise.

But I promise you there is life,
and life more abundant,
to be found by going deeper into all of this.

One day, for us all,
the abstract will become reality.

It's been said that
"life is a sexually transmitted condition
with a terminal prognosis."

That our lives will end
is the hardest fact of life.

Forrest Church, the UU minister,
often said that religion itself is our
“human response to the dual reality
of being alive and having to die.”²

It is our way of making sense of life’s fragility,
even as we fill our lungs with the breath of life.

In our tradition, we often say
during memorial services that a life is sacred,
in its being born, in its living, and in its dying.

I have witnessed enough deaths
to know that that is true.

Much about how our final moments play out
may be beyond our control,
given the many ways in which we humans die.

But more often than not,
our wishes can be honoured to the end,
if they are known.

I hope those of you who took my course,
“Living for a Good Death”
a few years ago remember the take-away:
that “good deaths” don’t happen by accident;
they require intention, planning,
and heartfelt conversations with our loved ones—
as well as a bit of luck.

Dr. Atul Gawande, the medical doctor
who wrote a powerful book on death and dying
called *Being Mortal*, through the course of his research,
discovered there are four questions to be asked

² Forrest Church, *Lifecraft: The Art of Meaning in the Everyday*, Beacon Press: Boston, 2000, p. 3.

of a person nearing the end.³

- 1) What do they understand about the condition of their health?
- 2) What goals do they have, if their health worsens?
- 3) What are they feeling afraid of?
- 4) And, finally, what trade-offs are they willing to make and not willing to make?

These can be powerful questions to ask, because the answers can transform the time a person has left.

Because it becomes clear to all what a person's highest priorities are.

These questions can and should be revisited, as the answers can and do change.

But when loved ones and medical teams join the person dying for these conversations, everyone can work together to respect these priorities to the end.

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Now, most of what I've said, thus far, concerns the physical aspects of our dying, the logistical details of life's end.

Having clarity about all of this is incredibly important to dying well.

But there is more to consider.

There is also often emotional and spiritual work to be done in order to truly put our affairs in order.

³ Atul Gawande, "The Best Possible Day," *The New York Times*, 5 October 2014.

Often people reach the end
with some part of this work left undone—
and while living out their final days,
find themselves contending with regret,
and hurt over things left unsaid.

Such distress is never helpful at life's end.

While a medical team can help a patient manage pain,
they cannot relieve the suffering
of the work we've left undone.

Part of living with the hope of having a good death
is ensuring that when you come to die,
all that you have left to do is die.

Dr. Ira Byock, whose work across several decades
has focussed on the process of dying,
speaks of “The Four Things”—
the four statements we need to have said
to our nearest and dearest before we die:⁴

Please forgive me.
I forgive you.
Thank you.
I love you.

These four statements—both simple
and possibly not-so-simple, all at the same time—
come from Byock's observations
of people reaching the end
with this work left undone.

So, my second charge to you this morning,
dearly beloved, is to take up the deeper work
of getting your affairs in order.

To engage with the soul work that may be required

⁴ Ira Byock, *The Four Things that Matter Most: A Book about Living*, Simon & Schuster: New York, 2004, xi.

for you to be able to forgive and be forgiven,
to live from a place of deep gratitude,
and with a heart full of love.

There's no time like the present to get going.

As a certain song from the 50's put it:
"it's later than you think."⁵

Or in the immortal words of Dr. Seuss:

How did it get so late so soon?
It's night before it's afternoon.
December is here before it's June.
My goodness how the time has flown.
How did it get so late so soon?

We humans are prone to thinking
we have more time than we actually do.

More time to do the work
of healing our relationships where they hurt,
and saying every last, loving thing
that should be said, if our beloveds
are to truly know what they mean to us.

Preparing for life's end involves
living deeply into what's left of our lives—
whether it be weeks or months, years or decades.

We need not wait until the end is nigh
to get our proverbial house in order.

This work is the work of life itself.

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Atul Gawande, the doctor who came up with
the four questions to ask a patient

⁵ Guy Lombardo, "Enjoy yourself, it's later than you think," 1949.

near the end of life,
tells the story about how these questions
played into the life of his daughter's piano teacher, Peg.⁶

Gawande had learned from her husband
that Peg was in hospital.

She'd been treated [two years before]
for a rare pelvic cancer requiring chemotherapy,
radiation and radical surgery.

She returned to teaching
and refilled her student roster in no time.

She was in her early 60s, tall,
with a lovely, gentle way...

[But she had now] developed
a leukemia-like malignancy
caused by her [earlier] treatment.

She went back on chemotherapy
[and] somehow kept teaching.

Then for two straight weeks,
she cancelled all of her lessons.

That's when Gawande got the call
that she was in hospital
and learned her treatment wasn't working.

She didn't know what to do.
[And neither did her doctors.]

She [felt] utterly hopeless.

Her condition was incurable by [all]established means.

Gawande asked Peg the four questions.

⁶ Atul Gawande, "The Best Possible Day," *The New York Times*, 5 October 2014.

She said flat out
that she knew she was going to die.

[He] asked what her goals were.
She didn't have any that she could see were possible.

Then [he] asked what her fears for the future were,
and she named a litany: facing more pain,
suffering the humiliation of losing
more of her bodily control,
being unable to leave the hospital.

She choked up as she spoke.

She'd been there for days just getting worse,
and she feared she didn't have many more.

...hearing her fears,
[he] suggested that Peg try hospice.

It'd at least let her get home, ...
and might help her more than she knew.

Hospice's aim, at least in theory, ...
is to give people their best possible day,
however they might define it under the circumstances.

... it had been a while since she'd had a good day.

With her husband's encouragement,
she went home on hospice less than 48 hours later.

Gawande broke the news to [his daughter] Hunter,
then just 13 years old,
that Peg could not teach her anymore,
[and] that she was dying.

[Hunter] asked if she could see Peg one more time.
[Gawande said he] didn't think so...

A few days later, [though,
they] got a surprising call from Peg.

She wanted to resume teaching.

She'd understand if Hunter didn't want to come.
She didn't know how many more lessons
she could manage, but she wanted to try.

That hospice could make teaching
possible for her again
was more than [any of them had] imagined.

But when her hospice nurse arrived,
she asked Peg what she cared most about in her life,
what having the best day possible meant to her.

Then they worked together to make it happen.

Her husband Martin said:
"She came to a clear view of how
she wanted to live the rest of her days.
She was going to be home,
and she was going to teach."

It took planning and great expertise
to make each lesson possible.

She'd had no children;
her students filled that place for her.

And she still had some things
she wanted them to know before she went.

Peg... got to fulfill her final [wish].

She lived six weeks after going [into] hospice.

Hunter had lessons for four of those weeks,
and two final concerts were played.

One featured Peg's current students,
all younger children; the other,
her former students from around the country.

Gathered in her living room,
they played Brahms, Chopin and Beethoven
for their adored teacher.

A week later, she fell into delirium
and, a short time after that,
died peacefully in her bed.

[Gawande's] final [memory] of Peg
is from the end of her last recital with the children.

She'd taken each student away from the crowd
to give [them] a personal gift and say a few words.

When it was Hunter's turn,
Peg gave her a book of music.

Then she put her arm around her.
[And whispered,] "You're special."

It was something
she never wanted her students to forget.

Friends, how we approach the work of our life—
the work of our hands and our hearts—
will be, in the end,
our magnum opus, our life's great work.

Let us then, this day, renew our commitment
to truly putting our affairs in order—
to truly doing our soul work—
that we may live with each moment we are given,
into the fullness of our Best Possible Day.

Blessed Be.