

January 6, 2008
Alzheimer's and Oblivion

Readings

Adrienne Rich writes:

My heart is moved by all I cannot save:
So much has been destroyed
I have to cast my lot with those who, age after age,
Perversely, with no extraordinary power, reconstitute the world.
"Natural Resources"
Hymnbook, #463

In Judith McCann-Beranger's Caregiver's Guide for Alzheimer and Related Diseases, one woman writes:

"One day my husband suggested that
I check with
the other guy
about going for a walk.
I didn't know whom he meant. A few nights later
he got up from his chair in the living room, and said
it was time to go home
as that other guy
might not like him staying over.
I realized then that
the other guy was
the one he saw in the mirror, and
he no longer recognized himself
or our home as his home."

Sermon

Alzheimer's and Oblivion

Let's begin with a survey, to gauge the scope of our topic.
Could I please see a show of hands, from all of us who have either:
 Wondered, even fleetingly, if we ourselves had Alzheimer's Disease, or
 Known someone whom we have cared about who has had it?

[Two-thirds to three-quarters!]

Thank you.

Let's have a talkaround after the service.

It's a widespread disease. Numbers tell part, but only part, of the story. Researchers at McGill University estimate that about 300,000 people in Canada have it. South of the border, the numbers run about five million. Around the world, 24 to 30 million. Those numbers are expected to quadruple by the year 2050. The costs are staggering. All dementias together cost about \$315 billion dollars in 2005. Alzheimer's appears to be responsible for slightly more than half of all dementia cases. It has the potential to bankrupt whole health care systems. Victims, and their families and friends, are not the only ones devastated by this terrible disease.

This morning we look first at warning signs for Alzheimer's Disease, with a disclaimer. Then briefly some history, and current medical responses to Alzheimer's. Then, some effects of the disease. Finally, some constructive strategies for coping, including spirituality.

Before we examine warning signs, a disclaimer, on the phenomenon called "Medical Students' Disease." Medical students who study a particular disease sometimes come down with apparent symptoms of -- that disease. The phenomenon was noted as early as 1651, by Robert Burton in *The Anatomy of Melancholy*. When students are told to look for symptom X, they find symptom X -- or think they do.

Medical Students' Disease is not confined to medical students. Many years ago, I became convinced I was having a heart attack, and saw a doctor. After a battery of tests, he told me that I had -- indigestion. We then traded mistakes. I asked him what the true symptoms of a true heart attack were -- a mistake. And he told me -- big mistake. I, the good patient, went home and promptly had -- all the true symptoms of a true heart attack. Did I call him? I would rather have died!

So, hearing these warning signs, some of you may make a wildly inaccurate but totally sincere self-diagnosis -- that you personally have Alzheimer's. It's very human. Every time I can't find my keys, I go there. Please -- try not to do this. But, if you find yourself genuinely worried, by all means do check it out. How, in a moment.

Jacqueline Marcell, who turned her experience of caring for her parents into a career, lists ten warning signs for Alzheimer's:

- Memory loss affecting job skills
- Difficulty in performing familiar tasks
- Language problems
- Time and space disorientation
- Poor judgment, or decreased judgment
- Misplacing things
- Mood or behaviour changes
- Personality changes, and
- Loss of initiative.

What can you do, if you are convinced that you, or someone you know, might qualify? First, don't panic.

Learn more. See a doctor who knows something about Alzheimer's. Check in with the local Alzheimer Society, at 180 Park Avenue, Park and Water, where our own Emily Harris-McLeod is the family support counsellor, and has recently become acting executive director. She has supplied us with a whole box of good books, free, from the Alzheimer Society, and she will be at a table after the service (over there) if you want more information. Thank you, Emily.

History. Although general dementia goes back to ancient times, Alzheimer's itself made a relatively recent appearance on the medical scene. In 1901, a German psychiatrist named Aloysius Alzheimer noticed that a patient of his, a woman identified as Auguste D., 51 years old, was suffering from a combination of memory loss, confusion, and difficulty answering questions. When she died five years later, he performed an autopsy on her brain. It showed a unique combination of plaque and tangles, which have characterized Alzheimer's Disease ever since.

Incidentally, a definitive diagnosis still requires a patient's death and an autopsy, although living diagnoses are considered 90 to 95% accurate.

The causes of Alzheimer's are not understood, and there is no known cure. Drugs can minimize the appearance of symptoms of the disease, but so far, that's about it. However, because the societal costs are enormous, many drugs are now in the trial stage.

Alzheimer's has succeeded AIDS, and cancer, and polio, and other terrifying diseases down through the ages, and no doubt it will be succeeded by another apocalyptic disease. Polio of course has a vaccine, discovered by Dr. Jonas Salk. But for cancer, AIDS, and especially Alzheimer's, in spite of progress, the great corporations and researchers have a distance to go.

Unlike AIDS or cancer, Alzheimer's is considered a mental disease as well as physical, in this odd, mind-body duality that we have inherited. It certainly affects the brain and personality and, some would say, even the soul. It carries a stigma that encourages affected people and families to deny, to hide, even -- to lie. You cannot get a mild case of it; all cases are progressive and terminal.

Alzheimer's has a totalitarian quality that other diseases seem to lack. With many diseases, the victim can fight back, sometimes even win. Alzheimer's seems to subvert, or redirect, these human fighting skills. Some victims fight the people they have loved the most during their lives. And just living with the disease can be so difficult, that caregivers too sometimes fight with those they care for.

Alzheimer's claims its victims' lives even while they are, technically, still alive. It is a kind of death in life. Family and friends must begin to mourn, prematurely. Mourning is hard enough as it is. It doesn't need to be made any harder. Caregivers sometimes find themselves speaking in the past tense of those they have loved, because the past is so much safer than the jittery present or the grim future.

"So much has been destroyed,"

Adrienne Rich writes.

Wayne Ewing, who took care of his wife in the three years she lived with the disease, calls Alzheimer's a "thief of time and personality," because it stole not only his wife's memory of him, but also his shareable memories of their life together.

It's also a thief of independence, and exacerbates the common fear of becoming a burden. It threatens the

inherent worth and dignity of both the person afflicted, and those who care for them. If you have to rely on others for simple things like everyday memory – where did I put the car keys, dear? – the experience can, if repeated often enough, become humiliating. All the joy a teenager feels on getting that first driver’s license, may boomerang at the other end of life, with the forced surrender of the precious freedom to come and go at will, and the unexpected return of dependence on others. But all the freedom in the world does you little good, when you keep getting lost, like Grandmother Sachiko, in your own neighbourhood.

Memory loss creates un-right-relationships with others, especially family. Verbal tics enter the conversation, like “I may have told you . . .” or “Stop me if I’ve told you this one before.” A friend endeared herself once, when I asked if I had told her a certain story, and she said, “Probably, but if you did, I’ve forgotten it, so -- tell me again.”

Memory loss makes people both more honest, and less. Truth-telling becomes simpler than trying to piece together what you told A, and B, and C, and D. On the other hand, sometimes it’s hard to remember what is actually true and what you only wished, once upon a time, were true.

Our children’s story, *Sachiko Means Happiness*, shows how a child might come to accept, and even to understand, a grandparent’s extreme forgetfulness. That acceptance can be a great gift – destruction, followed by creation.

No matter how much Alzheimer’s destroys – and we are just skimming the surface here – caregivers can still choose how to respond. Arranging for good medical help is important, of course, but early books on Alzheimer’s often noted how hard it was to find competent medical help. That situation has improved, but it is still a tough diagnosis, in part because its progression takes place over time, and there can be terrific fluctuations in conditions.

For family, friends, and caregivers especially, there is an almost universal desire to grieve. That too is a choice. But it is weird grief. Some call Alzheimer’s “the funeral that never ends.” Nowhere is human uniqueness more poignantly demonstrated, than in the uniqueness of our individual approaches to grief. Grief blindsides people. There is no one right way to grieve. Ten years ago, when Princess Diana was killed in a car wreck in Paris, you may recall how the royal family was criticized for keeping a stiff upper lip.

My faculty advisor in seminary, a dark-skinned, ordinarily droll gentleman from Oklahoma named Yielbonzie, kept his silence as long as he could, and then one day he just exploded with indignation. “How the Queen and the royal family grieve the loss of Diana -- is their business,” he said. “Their business, and nobody else’s.”

Judith McCann-Beranger, who has written *A Caregiver’s Guide for Alzheimer and Related Diseases*, a short, marvellous book included in Emily’s Care package, says this about grief: “Grieving involves the reactions and responses to loss, and is necessary and healthy. . . .

The grieving process is unique to each person, but will conjure up many similar feelings and symptoms.

[She lists some:]

“Guilt, . . .

Sadness, . . .

Anger, . . .

Restlessness, . . .
Loneliness, and
Apathy . . .”

[She adds some common behaviours around grieving:]

“Crying,
Sleepless nights,
Weight loss,
Knots in the stomach,
Headaches . . .”

And she suggests some ways to work through grief, with – yes, another list! (I don’t know why lists are so spiritual, but they are.) Among her suggestions:

Seek help
Accept all feelings
Talk with someone you trust
Remember who your friends are, and use them,
Try counselling, or
Spiritual direction, or
Peer support systems.
Read good stuff (Susan Tiura loaned me Alice Munro’s haunting story, *Away From Her*, which Sarah Polley turned into a film)
[You can] Journal [she adds],
Take a course,
Forgive yourself, and forgive others, . . .
Help a newcomer along the same path, and, if all else fails,
Call your local Alzheimer Society.
At: 807 345-9556.
807 345-9556

Encouragement toward forgiveness, of self and others, suggests the spiritual value of lowered expectations. Twelve-Step programs have been preaching lowered expectations for decades now -- one day at a time (which itself is a lowered expectation).

Over the years I’ve developed lowered expectations about 12-Step meetings. Now, if someone asks, How was the meeting, I sometimes say, “Good. Nobody drank.” Lowering expectations is a good coping skill. Education is too. Locating and using support is another. Providing support – that’s even better.

Caregivers are encouraged to focus on who is still there, and what is still there, rather than on whatever has gone away, or may never have been there in the first place. That’s good practical and spiritual advice. When someone comes to my office to talk about Uncle Joe and his drinking problem, it’s all too easy to focus the attention on Joe.

But the most significant fact about Joe is – he’s not here. (Like that bar in Chapel Hill, North Carolina, with the fabulous name: [MAKE TELEPHONE] “He’s Not Here.”) The truly hurting person, the person who might

actually be helped -- is not old Joe, but rather the tender human being sitting right here, right now, right in front of me. So, please don't come asking advice about Uncle Joe and his drinking problem. I'll just ask you about you, and how you're doing -- which, by the way, is not so hot, otherwise you wouldn't be coming to see me --, and I'll probably eventually send you to Al-Anon, for friends and families of problem drinkers.

When it is time for Uncle Joe to show up in person, he will. The universe is extremely reliable about that.

One consistent recommendation to caregivers is to be concrete and clear. There can be unexpected side benefits. When I was 19, I lived with my Aunt Margaret and Uncle Chuck in San Francisco. Chuck was stone deaf. Because he read lips, I learned how to [SHOW] enunciate more clearly, using my lips; to moderate my pacing; to use more concrete language (or at least to knock off the fancy vocabulary!); to coordinate facial expressions and body language with the spoken words; and to telegraph important words -- like punch lines. Chuck loved to laugh, and you could hear that man laugh, halfway down the street. But to make sure he would get the joke, and not be embarrassed, you had to let him know, that the punch line was coming, and coming -- pretty soon. A twinkle in the eye, or a smile, sufficed.

These new skills were easy to learn. I have never forgotten them -- as you can tell. They have served me well, in the courtroom, in the classroom, in the pulpit. The larger the crowd, for example, the further away some people are likely to be, and the further away they are, the broader your gestures need to be. [WAVE ARMS]

Many things we take for granted become more important when Alzheimer's enters the picture. Record-keeping, for example -- because Alzheimer's steals memories. Good records can help puncture denial, everyone's denial, and they encourage accurate and early diagnoses.

Humour is important, in part because it's so hard. How hard, you ask? Here is a truly dumb joke. Garrison Keillor tells of the doctor who says to the patient, "You have cancer, and -- Alzheimer's disease." The patient says, "At least I don't have cancer."

Because Alzheimer's so disrupts regular times and schedules, -- habit, custom, and routine become important. But one cruelty of this cruel disease is that, despite routines, caregivers themselves need great flexibility. Many caregivers' accounts are just heart-breaking. You read anecdotes like "The Other Guy," describing things that go on, page after page after page, and you ask yourself, How in God's name did they ever do it?

I suppose the answer is, the same way that relief pitchers in baseball can give up a game-losing home run in the ninth inning, and still show up for work the next day. They say the primary job requirement for a relief pitcher, apart from a strong arm, is -- a really, really short memory. One day at a time.

Since Alzheimer's can play havoc with language skills, non-verbal communication becomes especially important. Respectful touching goes a long way. I often hold hands, when praying with a person or a family. And music, especially familiar music, can work its amazing magic.

Just acting "as if" may have a positive effect. Once, in Seattle, a ministerial colleague named Alex had a terrible car accident on the morning of December 24. Late that night, after our church's last Christmas Eve service, I went down to Harborview Medical Center to visit him. He was so hooked up, by tubes and wires, to every machine in creation, that you could barely discern the wreck of a human being underneath it all. He

was heavily sedated, barely alive. He gave no recognizable sign of – anything at all. Only the monitors blipped, and not very often either.

I felt awkward, and was prepared to leave after a few minutes, but the wise young nurse on duty encouraged me to stay and chat with her for a while, in the presence of Alex, actually across and over him. She said she didn't know if he could hear us talking, but she thought it might help him, just to know that people were physically present, thinking about him, concerned about him. So I stayed and we chatted, before I left for a Christmas Eve party with other colleagues, who were anxious for word of Alex.

Here is the odd part. Alex, as he slowly recovered, thanked me whenever he saw me, for visiting him that horrible night, for sticking around and chatting for a while. I never did figure out whether he had been awake, or present in any meaningful way, during my conversation with the nurse, or whether he just learned about it later. Finally, I decided that it didn't matter. Alex kept on recovering, he chose to feel grateful, and that was enough. Sometimes "as if" packs more punch than reality.

Alzheimer's can teach us about acceptance. In my mother's later years, as she declined, I began to regret that, even though I was now ready for a truer relationship, she was not and probably never would be. Self-pity being what it is, it took me a while to accept this inevitability, but eventually I did – as if there were any choice! -- and it was a good lesson.

Acceptance is always a good lesson.

So what has spirituality to do with Alzheimer's? Plenty.
If you want to test a faith, see how it stands up to Alzheimer's.

Judith McCann-Beranger has another one of her lovely lists, on the therapeutic benefits of spirituality, and with this we will close. Spirituality can help, she says, in Making sense of a situation and assisting with the grieving process.

Providing comfort, courage, and connectedness.
Finding meaning or purpose in our day, our relationships, and our lives.
Making sense of life and framing the past. . . .
Encouraging acceptance of our mortality, and that of our loved ones.
Perceiving life in terms of the values we attribute to our experiences. (And finally)
Knowing we are loved,
can give love,
and hope.
May it be so. Amen.