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Saying hello to Mum[1]

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Abstract
Writing was used as a method of inquiry in an autoethnographic study of the way Alzheimer's shapes my relationship with my mother. Poems and day-book reflective writing document aspects of the effects of the condition and of my response to it. In particular, I was interested in evoking an experience of ways in which the dynamics of the relationship are changed and renegotiated. A common view of Alzheimer's focuses on what has been lost. Following practices of Narrative Therapy for maintaining relationship with those who are no longer here, my intention has been to keep saying hello to Mum, as what is possible for our relationship is changed by her condition. In this article, poems are presented, accompanied by commentary, to speak into public conversations about Alzheimer's, standing alongside and disturbing the notion that Alzheimer's is a long goodbye.

Keywords: Alzheimer's, autoethnography, poetry, family relationships, narrative therapy

Holes in the memory
The first time it was an egg.
What is this?
what do I do with it?
The worried laugh signalling
a step up from everyone else's sillyoldme-ness
when you lost yourself
walking home from church.

All the dropped stitches—
fairisle, cable, purl,
plain.
You carried the needles with you

long after the ending of a row stopped you
dead in your tracks.

All ledgers are closed now.
The father you had come to despise
is simply Daddy.

The daylong list of things whose uses you have forgotten—
a chocolate, a fork,
a daughter.

My mother has Alzheimer's disease. Approximately 50,000 other New Zealanders experience some form of dementia. By 2030, when I will be 72, this number is predicted to rise to 88,000 (Alzheimers New Zealand, 2014). My genetic inheritance predicts that I may well be one of them. But until the disease showed up in my family, it was not something to which I'd given much thought. It was out there, on the edges of my consciousness as something that happened to really old people. My grandmother lived into her 101st year and was proud that she hadn't lost many of her marbles. So when my father admitted they needed help, as well as all the practicalities—the negotiations of the social and clinical assessments and the elder care scene, and the emotional journey of "putting Mum in a home"—there was a whole other journey. Dementia changes people, and it changes relationships.

Inter regnum

1.
Making the Christmas cake falls to me,
hardly the family baker.
Not a natural succession, this is
rather a usurping or an abdication.
You soon clear that one up.
"Stir the bloody thing yourself," you say.
"And get that woman out of my kitchen."

2.
Halfway down the ramp
you ask again.
We stand,
halted by the news that
he died.

Explanation is futile.
We explain anyway.
“Why didn’t you tell me?” you ask.

3.
Moving you to the other island so
you will have visitors at least,
the long day gets longer when the flight is cancelled.
A harried man at the desk suggests we go home.
Easy for him to say, there is
no home here for any of us.
We settle into the calmer ambience of international departures
and practise the future.
You in a wheelchair, clutching your toy dog,
Your voice too loud, your top food stained.
Our love strains to make it all right,
cajoling you out of querulousness, grateful when you fall asleep.
You are waiting for Maurice to sort it out,
just like he did when he was our father and he came home.

When she first went into care in the dementia unit, Mum was one of the more lucid residents, able to carry on a conversation, to joke, to join in activities, to sing (she had a fantastic memory for song lyrics). Able to protest being in a dementia care unit. As time has progressed, so has the disease. Mum has lost mobility; she has lost language; she has lost the capacity to feed herself. She still has a twinkle in her eye sometimes. She still protests.

There’s a word for it
The words used to be waiting

hanging about so you could pluck one from the air,
place it, just so,
roll it round your mouth
spit it, snarl it, sing it, smile it.

There’s got to be a word for it,
for the whirling flight like starlings that won’t settle.
A name for that blank

when you've snuck up on it,
right there it was
and now, gone.

Everything has a name.
Lethologica is a word's temporary absence.
I can't find what you call it
when a word is gone for good.

Quicksand

1.
Sunday afternoons are full of worries
Things are not where they should be
A whole class of children is missing
The garden needs digging over
There is something amiss with the tablecloth
And you can't get a taxi round here for love nor money

2.
A woman is carrying on a three-part conversation
by herself.
It could be one of those interminable radio plays,
droning its way through Sunday afternoon.
Real kitchen sink drama—
everyone gets their say.
She can keep it up for days.

If Pinter had written it, something would happen soon.
Exploring complex ambiguities, elegiac mysteries, comic vagaries,
his fascination with the past in the present.
Well, that's what Google says.

The relationships my sisters and brothers and I had with Mum were changing. Dementia meant we couldn't carry on as before. But it also meant we didn't quite know how to go on. How to have a relationship with someone who is not how they were, whose life you remember more about than they do themselves, is not discussed much at morning tea or dinner parties, or in the "How's your Mum?" conversations you have in the supermarket. We were making it up as we went along. Of course, we weren't making it up in a vacuum: there were ways to be informed. We watched out for what seemed to work in interactions we observed in the dementia units. We read the brochures for caregivers. We talked to other families. We Googled it.

We have not been alone in facing this renegotiation, finding our way in a relationship shaped by Alzheimer's. In a submission to a Senate hearing on Alzheimer's research, American actor Seth Rogen said, "So few people share their personal stories; so few people have something to relate to" (C-SPAN, 2014). He added that stories of caring for someone with Alzheimer's tend to be whispered, but "they need to be yelled and screamed."

When I began writing poems about the way Alzheimer's shapes and changes my relationship with my mother, I thought they were just for me. The many conversations I have had about the effects of Alzheimer's, and my experience of renegotiating the shifting dynamics of my relationship with Mum, have changed my mind about that.

> *Mum was in no position to say if she was ok with the story being told, though I did tell her my plans. As holder of Enduring Power of Attorney, I was sure that no harm would come to Mum from this activity, but I could hardly give consent on her behalf to my own project. With no clear notion of where I might end up, I sought my siblings' approval to make my writing about family matters public, as part of a research project. The EIT Ethics Approval Committee then received and endorsed my notification of a research project, 'How Alzheimer's changes things: A poetic auto-ethnographic exploration of the effects of Alzheimer's on family relationships'. I kept writing.*

The general population doesn't turn to research and academic literature to figure out how to do the tricky things in life. Popular culture is a much more likely source of the material from which we fashion our identities: the media, movies, and bedtime reading shape our ideas about and performance of identity (Barker, 2000). Just as my teenage daughters and their friends, purposefully or by osmosis, learnt something of how to "do" relationships from *Friends*, *Grey's Anatomy* and *Gilmore Girls*, we were learning how to "do" this changed relationship with Mum from sources all around us. I didn't deliberately set out to find material from popular culture that features Alzheimer's, there just seemed to be a lot of it about suddenly. On television, in fiction I was reading, all over the internet. Typing Alzheimer's into Google will give you about 11,700,000 results. Okay, you get 159,000,000 for Beyoncé, but still…the volume knob is being turned up. The stories, both personal and fictional, *are* being spoken into public spaces. They contribute to the shaping of values and practices, producing images and symbols which cannot be separated from individual ideas about how to conduct ourselves (Tilsen & Nylund, 2009).

The changed nature of relationships when Alzheimer's enters them certainly features in contemporary fiction. Here is the voice of Fiona's husband, in Alice Munro's story *The Bear Came Over the Mountain*:

> *Day by day. But things really didn't change back and forth and he didn't get used to the way they were. Fiona was the one who seemed to get used to him, but only as some persistent visitor who took a special interest in her. Or perhaps even as a nuisance who must be prevented, according to her old rules of courtesy, from realising that he was one. She treated him with a distracted, social sort of kindness that was successful in keeping him from asking the most obvious, the most necessary question: did she remember him as her husband of nearly fifty years? He got the impression that she would be embarrassed by such a question—embarrassed not for herself, but for him.* (Munro, 1999, p. 9)

And Sue Miller's character Frankie in *The Arsonist*, describing her father:

> *In any case, she kept talking, she would have said anything to keep the sense of friendly chatter going, to give him time.*
>
> *Time for what?*
>
> *To remember her? It was the first time this idea had occurred to her, that he might not recognise her, and it struck her how far she'd come in her thinking about her father since her arrival. The many small things she'd noticed and talked about with Liz: his absenteeism in any group. His repetitive returning to the few things that compelled him…His confusion, his occasional* lostness. *Most of all, the way he looked a good deal of the time, the frequent deadness behind his eyes.* (Miller, 2014, p. 105)

Or, from a less exalted plane in the world of fiction writing, this scene from Yvonne Cassidy's novel *What Might Have Been Me*, when Carla's mother launches into a story for the umpteenth time:

> *"Jesus Christ! We know! You were meant to be going to Madrid, only you swapped and you came home and you made the party and Suzanne was delighted and you all lived happily ever after. We know."*
>
> *Mum looked from Lily-Anne to me. She was upset, confused, but I didn't care.*

> I *was upset.* I *was confused. Why was it always about* her*?*
>
> *"Carla," Lily-Anne said, her hand reaching out for me again. I jerked my arm away before she could touch me.*
>
> *"What? Don't act like I'm the only one who's driven crazy by her repeating this crap over and over. You've had it all day—you must be fit to swing for someone by now."*
>
> *I knew I'd gone too far. Even as I was saying the words I knew I was going too far.* (Cassidy, 2012, p. 315)

Writing in *The Guardian*, Libby Brooks (2011) proposed that the increasing incidence of dementia as the population ages means it is suddenly in our faces in popular culture.

> *I don't think it's glib to impute real significance from the fact that Alzheimer's is now turning up as a plot device in Hollywood blockbusters, albeit one loaded with as much desolation as hope. Privately, thousands of families in Britain—including my own—are affected by dementia each year, an ineluctable consequence of living longer. That it should leak into popular culture is no surprise: over the past decade dementia has been the subject of chick-lit and literary memoir, as well as storylines in* Coronation Street *and the* Archers.

In her introduction to *Beyond Forgetting: Poetry and Prose about Alzheimer's Disease*, Holly Hughes (2009) might have been speaking of my experience when she wrote:

> *Now, because it is touching so many lives, Alzheimer's disease forces us to acknowledge it. I looked for other writing that might help me through this uncharted terrain. Each time I found a poem in which it was clear the writer also knew this territory I felt less alone. When I began to share the poems I had written about my mother at readings, I came to realise how prevalent this disease is by the fact that a knot of people always gathered afterward to tell the story of their mother, father, wife, sister, brother.*

Alongside the sense of comfort I experienced in discovering this new aspect of my life—this journey in uncharted territory—that was reflected in my recreational reading, I began to sort my way through the ideas that lay behind what I was reading and hearing, performing an on-the-hoof discourse analysis. What lessons about how to be with people with dementia are transmitted by these texts? What is it these stories are communicating?

Message number one: Fear

A recent British survey found that dementia is the thing most feared by the elderly: more than cancer, more than death (Donnelley, 2014). In this country, it seems we haven't quite reached the same degree of fear. Alzheimers New Zealand (2014) reported that for one-third of New Zealanders, Alzheimer's is one of the things they most fear about ageing, and that 15% fear it more than they fear cancer. Philip Larkin's poem "The Old Fools" (1973) captures the horror:

> What do they think has happened, the old fools,
> To make them like this? Do they somehow suppose
> It's more grown-up when your mouth hangs open and drools,
> And you keep on pissing yourself, and can't remember
> Who called this morning? Or that, if they only chose,
> They could alter things back to when they danced all night,
> Or went to their wedding, or sloped arms some September?
> Or do they fancy there's really been no change,
> And they've always behaved as if they were crippled or tight,
> Or sat through days of thin, continuous dreaming
> Watching the light move? If they don't (and they can't), it's strange;
> Why aren't they screaming?
>
> …Can they never tell
> What is dragging them back and how it will end? Not at night?
> Not when the strangers come? Never, throughout
> The whole hideous inverted childhood? Well,
> We shall find out.

The fear of dementia is expressed in contemporary literature, be it at the more literary end, such as in Larkin's poem, or in popular fiction: Deidre Purcell's (2013) characters in *The Winter Gathering* visit their mother in a dementia home:

> *"I can't stand this ---" Mary bolts from the room.*
>
> *…she, like me, like any one of us, could belong inside that room. Youth and health, I think, are mere cloaks worn over the constantly ageing selves waiting to emerge. I'm shaken at the thought and out of the blue a memory blast from my childhood culture bursts through. Dear God, I supplicate over Mary's head, dear God and Your Holy Mother, let me not end up like that. Let Mary not end up like*

> *that either. Sacred Heart, St. Joseph and St. Jude, please take us before that happens.* (as cited in Heltemes, p. 321).

Fear of ending up like that, of losing memories, the core of identity—if that's a primary response to watching what is happening to your partner, or your parent, or your friend, how will that shape a relationship? What positions are made available for both parties when interacting with someone whose condition you fear?

> *I read a death notice in the local paper that says "released from the prison that is Alzheimer's disease." My neighbour tells me that she had lost her husband long before he died. "He didn't know me. He was gone, just a shell," she said. "It's a cruel disease. It wasn't him. He was gone." While I acknowledge the grief, anger, despair of that loss, I also want to say, "Well, who was he then? If he wasn't himself, who was he?"*

Message number 2: The long goodbye

Patti Davis, Ronald Reagan's daughter, made popular the conceptualising of Alzheimer's as the long goodbye, using this as the title of her memoir of her father's decline with this disease. "Alzheimer's," she wrote, "snips away at the threads, a slow unravelling, a steady retreat; as a witness all you can do is watch, cry, and whisper a soft stream of goodbyes" (cited in Heltemes, 2011).

Debra Dean, in her 2006 novel *The Madonnas of Leningrad*, wrote:

> *She is leaving him, not all at once, which would be painful enough, but in a wrenching succession of separations. One moment she is here, and then she is gone again, and each journey takes her a little farther from his reach. He cannot follow her, and he wonders where she goes when she leaves.* (as cited in Helburn, 2007).

And you can find plenty of heartbroken long goodbyes on the internet:

> *Alzheimer's is truly the 'Long Goodbye'. I lost my mother eight years ago and have had to be a witness to the deterioration of an intelligent and vital human being.* (Alzheimers: The long goodbye, *n.d.)*
>
> *And while I know, both professionally and personally, what to expect with Alzheimer's, and I can rationalize that 'she had a great life' and 'she was ready,' my heart still feels so heavy about it. We lost the matriarch of the family piece by piece,*

> *memory by memory…Alzheimer's is truly a long goodbye and although I felt like I lost her long before she was actually gone, I'm still not fully over it. I'm not sure I ever will be.* (Jordan, 2013)

The long goodbye troubled me. How can you be there, be with a person, while thinking of them as leaving—even as having left, gone? How can you be present with an absence?

Message number 3: Keep saying hello

Dementia consumer advocate Richard Taylor has a pretty simple message: Stop trying to have the relationship you used to have. "'Say hello, not goodbye', he preaches. He wants family members to accept and love dementia sufferers as they are today, not how they were" (Laugeson, 2011, p. 18). To keep saying hello sits for me alongside the re-membering practices of Narrative Therapy, conversations which allow for re-establishing connection with "an experience of the voices of, and the touch of, the lost loved ones" (White, 1997, p. 25), who have been significant shapers of a person's preferred identity. In this case, the lost loved one is also the loved one right here.

Alongside the "long goodbye" discourse, there is a body of fictional writing producing a "hello" discourse. In one paragraph, Ian McEwan's character Henry in *Saturday* offers a way through "the empty visit" the long-goodbye discourse of memory loss produces, to a relationship of companionship in the moment:

> *His mother no longer possesses the faculties to anticipate his arrival, recognise him when he's with her, or remember him when he's left. An empty visit. She doesn't expect him and she wouldn't be disappointed if he failed to show up. It's like taking flowers to a graveside—the true business is with the past. But she can raise a cup of tea to her mouth, and though she can't put a name to his face, or conjure any association, she's content with him sitting there, listening to her ramble.* (McEwan, 2005, p. 125)

Richard Taylor's advice is to "start by saying hello. And then wait and see what they say back" (Laugeson, 2011, p. 19). While some material out there in popular culture supports the "saying hello" positioning, there is also acknowledgement of the unpredictability of what may be said next. In her magnificent poem "The Glass Essay", Anne Carson (1994) presents what happens when you say hello:

> Father sits strapped in a chair which is tied to the wall
> in a room of other tied people tilting at various angles.

My father tilts least, I am proud of him.
Hi dad how y'doing?
His face cracks open it could be a grin or rage

and looking past me he issues a stream of vehemence into the air.
My mother lays her hand on his.
Hello love, she says. He jerks his hand away. We sit.

Both my daughters have published writing about their "saying hello" relationships with Mum.

> *Every dog is called Charlie. Some people are just irritating. I'm a good one. These are things I have learnt from my dementing grandmother. She doesn't remember my name but she knows she likes me. Much to my mother's half-comic despair, Nana will always take my side despite not having a clue what she is fighting for. She taught me loyalty.* (Pentecost, 2011)

Nana
we will have this almost-conversation
about tomato sandwiches and
the wind in the trees out there and
tom the ginger cat and
who is that?

while I remind you how
to drink a cup of tea.
(Pentecost, 2012, p. 50)

And this, from my daughter's unpublished poem "What it is":

This is not *isn't it awful*.
I think her life floats by moment by bubbled moment.
We look at picture books, talk about fat dogs and skinny dogs
and dogs she used to have. Like we were there
because we've heard the stories told to her so often now.
Look, we say, doesn't that look like Charlie?

There is a trailing string
of all the things she doesn't say.

I wonder how much isn't, and how much is lost
and how much just doesn't have a word for itself anymore.

She beats the table,
tells me aren't you beautiful, beautiful, beautiful
with such ferocity it hurts.
(Pentecost, 2013)

I used writing as a method of inquiry (Richardson & St Pierre, 2005) to explore and tell the story of my changing relationship with Mum, in poetry and reflective prose. It matters to me that the writing is affectionate and respectful, and that it speaks into that "saying hello" space. As both the writing itself and the writing about the writing construct, rather than reflect, social reality, my understandings of what I was writing about were changed and shaped by the processes of writing. In accordance with Denzin's (2003) criteria for the evaluation of experimental ethnographic text, I hope that readers or hearers of these writings will find themselves invited into my world of experience in a way that engages their emotions. I also hope that they are invited to consider their own beliefs and practices in terms of those who have dementia.

In reading some of the poems to a general audience, I have found that this writing does open spaces for people to speak of their own experiences, and perhaps to consider things a little differently. In sharing them with an audience of counsellors, I wish to contribute to something worthwhile for those, like Mum, who live with dementia, and for those, like me, who love and care for them. In placing my writing in the public arena, I want to speak into the discourses about Alzheimer's. I want to say, with Richard Taylor (and The Beatles): Don't say goodbye. Keep saying hello.

Mothers' day
Facebook greetings from Peru
Ola. Happy mothers' day.
Pink heart emoticon.

I bring you white stock,
straggly supermarket stems,
not the sweet night scented blooms
Dad planted in each garden.
Across the room
Alice's family persuade her with their gift.
Do you remember hyacinths?

You like them, remember.

It’s all on Facebook these days.
My daughter searched the archives, found us
snapped together,
four generations of Faulkner women.
All mothers and daughters—and look,
not a photogenic moment between us!

You smile.

About my sister
Rachel’s coming
                Bang bang bang
to see you soon.
                You pound the chair
You’re cross with her
                I am. I am.

I tell you again.
                Goody, you say.
                She was always
I agree.
She was.

We do it again
The woman over there
has stopped dancing
to remove one red sock.
It is an object to fold and smooth, fold and smooth.
Folding and smoothing interests you
more than her wafty dancing.

Diddle diddle dumpling I say
my son John.

I see you cajoling four kids to bed,
out of your hair for the night.
Who knows what you see?

The second time through you join in,
your hand bouncing mine.
I love this, you say.

Endnotes

1. This article is based on a presentation given at the Contemporary Ethnography Across the Disciplines (CEAD) Conference 2014, Sensual Landscapes of Ethnography, Hamilton, New Zealand, November 2014.

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