

## Praise for *Be With*

‘My heart lodged in my throat and my eyes stayed glassy... It’s a lovely, loving and unflinching work reflecting on an awful, inexorable illness. Physician offices would do well by stocking copies. Mike Barnes shares knowledge (“The truth is, there’s no graceful way to take control of someone’s life away from them”) and he asks questions (“How much room in your own heart?”) any caregiver must consider. He also asserts his primary insight: “But being with in person trumps all else. It’s the one way of caring most likely to be right, and the least likely to be regretted.”’

— *Toronto Star*

‘The particulars of Mary’s dementia give this brief book universal appeal. The author effectively humanizes himself as a man who has made errors, who wishes he had done things differently, and who has his own psychological burdens to bear... A book that tells the reader that you are not alone, whoever you are.’

— *Kirkus Reviews*

'In their simplicity and even-handed tone, the letters achieve their author's difficult aim: they present as a literary Third Man, a friendly, authoritative voice in the dark that will lead its at-the-end-of-their-tether listeners through to the endgame... Barnes has been moved and amazed by his mother's courage and effort, how she has learned to be a new person. What really matters, he concludes, is the hardest thing, being there with her. "For every thousand pages describing how living is shattered by this dread disease, there should be at least one page observing how living goes on within it." *Be With* has 156 pages of them.'

—*Literary Review of Canada*

Mike Barnes is the author of ten books of poetry, short fiction, novels, and memoir. He has won the Danuta Gleed Award and a National Magazine Award Silver Medal for his short fiction, and the Edna Staebler Award for non-fiction. He lives in Toronto.

# Be With

*Letters to a Carer*

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# Be With

*Letters to a Carer*

Dear —

Someone told me that your loved one has been diagnosed with Alzheimer's.

I was sorry to hear that, and also a little frightened for you both.

~

I feel I know a few things about you, even before we meet.

Already you are busy beyond belief. Stretched thin, getting by on meagre sleeps. You are sad, frightened, troubled, confused. Dark waves of these emotions estrange you at times from your normal life. But you are also energized, adrenalized. You push down the sadness and the fear to be there for your loved one. To be a voice for, an ally, a companion. To help in every way into this dark.

You are on Caregiver Time. It's like New Parent Time, Student Crunch Time, Double Overtime—all those other stressed and sleepless zones. But Caregiver Time lasts longer. It can last for years. It's lasted seven years, so far, for me.

That's why I'm composing these the way I am. In short bits. Bits I have the time to write, bits you might find the time to read. In a waiting room. During a loved one's nap.

Over takeout coffee in the parking lot.

Messages in bottles.

Uncork on any beach.

~

I also have in mind those packets of dried food people take on long trips into the wilderness. Compact, lightweight nourishment, high in energy and nutrients. Oat bars. Pemmican strips, in olden days.

*Pemmican posts?*

Read just this. Or, if you like, read several in a row. (It's strange how the over-busy often look for even more to do, from a need for distraction or from the habit of pure speed.) The result may be the same in either case. Your mind crammed and blurry, you'll forget what you read and need to read it again. And that will be a satisfaction, I hope.

Read just this. Put it in your mind like a single pebble in your pocket. Feel it there—small, hard, irregular, with its own peculiar shape—until you have the time to come back for another.

In an hour, a day, a week. A year.

The bits of news, food, stone will still be there.

~

I'm sending you the news I needed to hear myself. Needed and still need often, ransacking confusions to find a clear way forward.

You see, the need for guidance goes back further than my seven years of active caregiving. Since nine years ago, when my mother, Mary, was diagnosed with Alzheimer's—and, really, for some years before that, when something-wrong was obvious but hadn't yet been named—I've had need of the items, soft and hard, that I aim to send here.

Soft: fellowship, solace, understanding.

Hard: facts, clarity, direction.

You need accuracy, but you need kindness too. We all do. Accuracy without kindness is too unfeeling to be true. And kindness without accuracy is too unreal to be felt.

~

“Blah blah blah,” Mary says, when stuck in an activity session involving a speaker or

storyteller. “Doesn't like to share the stage,” says Laura, the activity co-ordinator in her current care home. Partly—and yet, no. Mary transfixes, roots visibly, to a voice speaking; grows intent and still as its currents envelop her. The talk can be about anything, as long as it's just talk. But she has an urchin's antennae for speech designed to edify or placate her.

Forgive me in advance my blah blah blah.

~

Let's try to get a timeline, first. It may be the last thing you want right now. I resisted clock-talk for years myself. Even hearing the word—*timeline*—made me bristle. It belonged to a world of cold quantities that reduced, I felt, individuals with dementia to a kind of grey goo, deteriorating with predictable uniformity as microscopic proteins accumulate in their brains, just as, in that other end-of-the-world scenario, replicating nano-bots turn the particularized universe into mush. Talk of timelines—of *stages* in

the *course* of a *disease*—not only equated people with their disease, it gave everyone the same disease. One patient, one disease. That offended me greatly. And was just plain wrong besides. When I meet, as I often do, ten or fifteen people with dementia in a row, they seem as various as any other ten or fifteen people. Maybe they are all moving roughly in the same direction—like caribou moving across a plain from east to west, say, on various meandering paths, some pausing, some even reversing course, but all, after a time, closer to the setting sun than when they began—but the same sense of a shared trajectory can be felt in a nursery, a school classroom, a company cafeteria, a retirement party. People are people, and people are persons, you realize—unless you don't.

I still feel that way. With time, however, I see better the overall direction of dementia, its east-to-westness, and even the somewhat distinct (though still messy and overlapping) stages of its passage. I realize, too, that part of the reason I couldn't see this before was that

I was simply overwhelmed. My twenty-hour caregiving days bombarded me with so many urgent particulars, a great many of them brand new and all of them constantly changing, that I simply lost the ability to see beyond getting through this minute, this hour, this day. Self-protectively, I lost my pattern recognition. Now, with things a little quieter, some of it is coming back.

~

One time (early on, forgotten until just this moment), I was sitting in a corridor with another caregiver, a thin, grey-haired woman, telling her of the micro-naps now riddling my days. Micro-comas is more like it. Blacking out for short spells, coming to on the other side. While sitting, while standing. While talking—returning, after sudden dark, a half-sentence or more further on in the conversation. While walking, even—lifting a foot up and putting it down, then noticing I was several steps ahead of where I'd been. Most terribly, while driving.

Gripping the wheel, determined to stay alert—and then popping back, eyes still wide open, further down the highway.

It happened without warning, often when I was unaware of being exceptionally tired. (I was never *not* tired, then.) It was like the gap when a slide projector pushes the current slide out and prepares to push the next slide in. There is a dark interval, which can last for half a second, or be prolonged to a few seconds, or even half a minute or more of oblivion.

This was new to me, and I recounted it with a degree of fascination as well as fright. Perhaps, back then, I was even boasting a little.

The woman sipped her takeout coffee, and said flatly, as of something decided long ago, “You won’t be much help to her if you’re dead.”

~

Mary has moved—I have moved her—four times in seven years. These moves, I see now, map onto the progressive stages of Alzheimer’s as clinically described. From mild

to moderate, moderate to severe, severe to very severe, very severe to late stage. During the roughly year and a half she lived in each place (sometimes a little more, sometimes a little less), she would be in between stages, leaving one for the next, and the move would become unavoidable when, for example, the moderate-severe stage became more severe than moderate; or when severe-very severe became mostly the latter. The stages are never neat: they are taking place in a person, with all her quirks and qualities; different parts of the brain are affected to different degrees; she is as subject to the vicissitudes of mood and physical health and events of the day and even weather as the rest of us; and she is fighting hard against dementia’s encroachments—but in broad outline, especially in retrospect, it is possible to make them out.

And they are the stages, leaving room for digressions, by which I’ll organize what I have to tell you.

~

Alzheimer's' beginnings are mysterious. What eventually becomes a great river sweeping all before it may start as thin rivulets wetting grass or leaves deep in a forest half a continent away—origins never to be seen or even guessed at.

Depression mixes with it, mimics it (some deep depressions are called for good reason pseudodementias). Stresses of all kinds play their part. Sleep, diet, alcohol and other drugs, exercise, other daily habits. Physical illnesses and the natural slowing of the ageing brain...

All of these retard or accelerate whatever genetic propensity for dementia is there.

Dementia, like any illness, works with what it has, when it has it. A *person* develops it.

~

The onset of Alzheimer's is sometimes divided into four subtly overlapping phases. Fittingly, the first of these has *no symptoms*. Yet it is still

a phase. Those rivulets may be rising in the forest.

Mild Alzheimer's is a rich, and sometimes very long, stage comprising three blended gradations. First, the certain but unmeasurable symptoms of subjective cognitive impairment (SCI). Mary had talked on occasion of feeling "something funny" in her head, and throughout her life, more so in middle years, could be a dreamy, abstracted person, sometimes strangely insistent and repetitious in her stories. Next (and as well), mild cognitive impairment (MCI), measurable on tests but not yet dramatically impacting day-to-day activities. On to (and along with) mild dementia, which does clearly impact daily life and of which all not in denial are aware.

Mary's personality for as long as I've known her (she had me, her first child, at age twenty-nine and she's ninety-one now)—including dreamy and depressive spells, well camouflaged within an active life, a tendency to drift away into alien regions that was part of an intense imagination—shaded gradually into, merged with, the Alzheimer's

that was diagnosed when she was eighty-two. There was no definite start, at least not visibly. It was as if those many minute streams accumulated until, obviously, a river was flowing and had been for some time.

At her diagnosis, she felt, she said, “relieved”. She had known something was “wrong” with her head for a long time, she said, and it was a relief to finally have it named.

It wasn’t her only reaction; typically, she shared only the positive. In an abandoned journal that I found years later in a drawer, she marked that day with just two words.

*Dear God*

When her husband of sixty years, Bill, my father, died of lung cancer in August 2011, I had been her Power of Attorney for several months, and she was already well along dementia’s passage, in the moderate phase that made living alone impossible and made living with others subject to special conditions.

~

I’m saying much more than I planned to. I’m sorry—I can feel your impatience as if by telepathy. Please remember that you can spot-read this in any direction, in any amount. You can, if you dare, practise sortilege, or bibliomancy, by consulting these entries at random.

There’s one more thing I want to say at the outset. To set the tone, to state my view of things unequivocally. And to establish something that it’s best you hear now, nearer to the start of caregiving—though surely you will need to fight your own way to a belief in it.

It will take a few more entries, I expect, and then I think I can progress with fewer delays.

~

Plainly, so it can’t be missed:

All people with dementia, and some of them strikingly, show depths of sensitive awareness, resilience rising to heroism and a capacity for joyful relatedness that is almost

totally missing from public discussions of their condition.

~

I could show you a hundred instances of what I mean. Here is one:

It is the morning after I'd finally agreed, after many tense discussions and postponements, to move Mary into a room on the locked ward of the facility she was living in. (This is years up ahead in her story, though still years from its end.) I'd stayed with her until she fell asleep, very late, and returned early with two of the mocha frappuccinos we liked to drink together. Dark circles ring Mary's eyes. When I ask if she slept well, she says, "Oh yes! Very!" Her mood is bright. Mine is glum at best. Space on the locked floor is tight, this room more crammed than her previous one. I wonder what might be added to the storage locker. *The last room. Last but one*, I think. What snares dismay particularly is the two green dumpsters below her window, one floor down. A warm

spring day, yet the windows must remain shut. I wonder if adhesive frosting on the lower panes might keep her view just sky.

The faint clanks and thuds from below fascinate her. Startle and fascinate. "What's that?" Her hearing still a wonder.

*The garbage truck backing up?*

"No. That chim. Not chimney. Chimp."

*Chime?*

"Yes, chime! Chimp's a monkey!" Her laugh clear and ringing.

She limps over to the window, peers down at the uniformed people pitching bags.

"So many good people. Taking good care . . . of us. Of everything."

Large, new homes stretched away around. Yet I knew that, at that moment, not one of them contained a happier person.

~

I know you are imagining what lies ahead. Seeing pictures of a coming desolation and disintegration. I wish I could tell you your

pictures are untrue. I can tell you only that they are incomplete. Future's gallery is vaster, more lavish in its paradoxes.

We are so much better at imagining the disasters that lie ahead than we are at imagining the joys. And better at foreseeing both than at perceiving what is already here. We are prepared in some deep way for sorrow. Joy, when it arrives, always breaks in. It interrupts.

I was once in hospital for two years. The first of many serious illnesses, forcing long withdrawals from active life. One day, someone brought me a snack and drink. I opened, with difficulty, the plastic apple juice container. I brought it to my lips, sipped, and—*actually tasted it*. I don't know how else to put it. It felt as natural, and astounding, as waking up. As if I'd simply stepped through a door, across a threshold, and there (here?) I was, aware of all the gifts streaming unearned to me, like milkweed floss on a late summer breeze. *I am warm, I am dry, I have a window to look through (clouds, a couple on a bench).*

*Hands, unasked, bring me a mini-muffin and this juice. So sweet, like nectar. Music from a radio down the hall...*

So sanity, as joy, breaks in. Often through the door that insane grief has left ajar.

The taste of apple juice is fleeting. Powerful but delicate, it recedes under a barrage of other tastes and duties. I return to it as often as I can—or *am returned*, since it is not an act of conscious will, but a relaxation of will and a deepening of attention, that takes me back to that place of simple belonging and gratitude.

With Mary, for all that caring for her has cost me, I return to tasting apple juice more often than I do with those who are well, i.e., not suffering from any named impairment. Seeing that she has got there first, ahead of me. Seeing that there is a space cleared in which we may sit together quietly, sipping what is given.

~

Driving to visit Mary the other day, I heard on the car radio an author I admire answering the question, Who is your current hero? My father, she said, who despite advanced dementia still manages to be himself much of the time. (Her words were close to these.)

I felt a surge of agreement, and a trailing need to qualify.

*Hero.* Yes, absolutely. What do heroes do? They enter dark places upright; fight monsters there; get maimed, sometimes killed; emerge with treasure.

Mary's been my hero for a long time, for my whole life perhaps, but never more so than during these years when I've been her caregiver. She's fought this toughest battle with such abundant heart. I would say she's been my teacher, except that I could never emulate the sheer grit, tenacity, grace and humour she's brought to her ordeal. Almost miraculously, she's kept the essence of herself against a withering assault—yes, I agree with the author on that—but, even more miraculously, she's gone beyond maintaining her old self in order to learn to be a new person, with

new and extended abilities—this in her tenth decade, in the teeth of such steep odds.

~

*A new person. New abilities.*

That flies in the face of what we're told about Alzheimer's and other dementias. Loss, loss, loss and loss is how they're usually described—not without reason.

Dementia is spoken of as a terrible tag-end to the real life that came before it. It strips a person, piece by piece, returning nothing of value.

But that is true only in part, and in no part true enough.

Dementia is certainly terrible; and, being invariably fatal, an end as well. But it is no tag-end. "Tag-end" scants the reality and those who live it. Mary has lived with dementia for nine years since her diagnosis, and for who knows how many years before that—three or four for sure, maybe many more. Twelve years at a minimum, say. As long as her school years, kindergarten to Grade 12.

As long as having her five children, until my youngest sister was almost in kindergarten and I was about to enter high school. As long as growing up, then.

A seventh of her life, let's say. And a fifth of mine, beside her.

A big, big part of life; and as real as any other. Filled with momentous changes, close-grained with challenge and response, crowded with new relationships. In short, a lived life.

That life is what can never be conveyed by statistics or by case studies in deprivation.

~

I want to tell you in these pages of some of the wholly unexpected riches Mary found in the cave of dementia. How she brought them out to glitter in the sun.

I told her, years ago (and I hope not just this once): I admire you more than I can say, and couldn't be prouder of what you have accomplished.

Unused to praise, she shot me a timid glance and bowed her head. I believe in that moment she understood.

Knowing what you're embarked on, I can wish for you nothing higher than that you have some moments such as these. And that you share them with your loved one.

Speak them. Give them voice. It's what you have most definitely.

I would have done anything I could have done to have spared her this. But, since it had to be, it's been my privilege to have gone through it by her side. I wouldn't have missed it for the world.

~

Look at the person with dementia before you. See them with honest, open eyes. (It's not easy to do, but no harder than it is to do with anyone else.) See them plainly for the warrior they are. Meeting terrors you can't imagine, and can't try to without a shudder.

And meeting them not only with heart-stopping fortitude, but with a resourcefulness impossible to comprehend.

The bravest, most persevering person you'll meet today? There's a good chance he's trying to dress himself, or tackling the dilemma of a meal. Sitting in a chair surrounded by strangeness, or making her slow way down a hall.

~

None of this—does it need to be said?—is to deny the ravages, the sheer devastation of dementia. That would be impossible to do, and grotesque to try. It is only to correct in a modest way an imbalance. For every thousand pages describing how living is shattered by this dread disease, there should be at least one page observing how living goes on within it, and even—approaching this with all due caution—is, in ways, at moments, enhanced by it.

~

*Am I up to this? Me?* You know best why you ask. Accosted for years by a sense of deep inadequacy, you feel now a preposterousness in your role. Help her? Help him? It's been all I can do, and very often more than I can do, to help myself.

You often find the very sick among the ranks of caregivers. Full-time helpers who are themselves cancer patients, heart sufferers, copers with canes and braces, soldiers of depression, pre- and post-psychotics, disability pensioners, the frail, the elderly... Why us? they may well ask. Why me?

Not from an unwillingness to give care, but from a disbelief that they can. Not *why*, but *how*. How on earth?

I know that *how* well. I've lived inside it like a burrow. My nest of broken twigs. Of soft, twined cast-offs.

Including those two years in hospital, between the ages of twenty-two and forty I

spent seven years entirely disabled—unable to work, often unable to leave my bed. Other crises and periods of impairment stretch before and after those, forcing all manner of cutbacks and curtailments. Changes of plan, foreclosures of hope. Bad health is my oldest adversary—and my oldest ally. Other-self, evil twin, enemy...friend?

And you? You know your own mischance. That faulty, misshapen story arc you struggle to smooth out, conceal, edit, mute.

You give care from your strength, a strength informed by weakness. A strength that *knows*. Respect your frailty if you can't yet love it: it taught you to be tough. It cracked you open. And what good ever flowed from a sealed container?

~

You will meet disaster birds. These soar, shrieking, far above the carnage on the ground, which they see as abstract shapes

called Realism, Practical Necessity, Biology, God's Will, Destiny. Their cries, wind-bent, will tell you disaster is not terrible but only a fact. Or not terrible but a gift.

Here on the ground it is terrible. And a fact. And, sometimes, a gift.