

LOOKS CAN BE DECEIVING - DEMENTIA, THE INVISIBLE DISEASE

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The question of how we look versus how we are inside was asked of me by Carol Bowlby Sifton, the editor of Alzheimer's Care Quarterly. Carol invited me to write an article for her journal and explore this topic. The talk I am giving today is taken from my article, which will shortly be appearing in an upcoming issue of Alzheimer's Care Quarterly. I have Carol to thank for this topic. And I have Barbara Snelgrove and Kaori Lochoy from the Alzheimer Society of Canada, for turning my scraps of paper into pretty, readable overheads for you. And thanks to my husband Bill for his invaluable help with discussions and editing.

This Invisible Illness

I walk the halls, streets, garden paths
My near-silent mind my quiet companion
A blank canvas
Waiting, hoping pictures will stay
My mental camera on stall
I struggle to capture the present
For my future
My notepad kept handy
To jot down fleet thoughts,
Meetings, moments
To save my past.
Confusion, like a veil, a fog
A zone where I travel in and out
That passage I can not control
Language eludes me
And words slip through gaping chasms
In my fractured mind
Sputtering, short-circuiting,
Pieces of ideas caught
Inside a labyrinth, no escape
Phantom gremlins overtake my house
And move and steal my possessions
I look in the mirrors

And I am me, unchanged
I walk, move, smile
And I am me, nearly unchanged
This invisible illness
That overtakes the brain
Thief of thoughts and words
Leaves little outward mark
I look the same
How do YOU see me?

“You look so well. There can’t possibly be anything wrong with you”. How many of us in the early stages of Alzheimer Disease or a related dementia have heard this from friends, acquaintances and even family members, when we tell them about our difficulties with our diagnosed illness. How wonderful that we should look so well! Our outer skin may show the ravages of time, but it does not reflect the ravages of our brain disease. Truly, we have an “invisible illness”, and our outward “normality” can mask our inner difficulties from the outside world.

Anne Swift, Psychogeriatric Consultant for the Alzheimer Society of Hamilton and Halton, told me that if we used a white cane or were in a wheelchair, the people around us would automatically recognize our disabilities and understand and make allowances for our problems. They would have a learned basis from which to offer us assistance. But with dementia, we have no outer mark to distinguish us, and consequently, our difficulties are too often underrated and too often minimized.

Perhaps people only intend to be kind and perk up our spirits by saying that we look and act so well (so “normal”?). But our feeling is that generally they do not understand what lies behind our “normal” façade”. They may not understand the struggle it may take to appear “normal” or “mainstream” to the outside world, to maintain correct civility and social decorum, to bathe and groom and dress to a manner that is acceptable in society let alone to our past standards. They may not understand that the trivial superficiality of casual social conversation is a long-learned habit, and people can talk for quite a while (cocktail party language) without saying much or revealing intellectual failings. “I’m just fine, thanks; yes it’s a lovely day; how is your family; I like your dress”. We say these learned responses very well after 40, 50, 60, or 70 years of practice! But the real

test comes when someone asks us for answers that are outside of this well-rehearsed routine, requiring more complex information, thinking and recall.

I find now that nothing I wear matches; something is always off-kilter, in colour or style; the jewelry choice is wrong, the style isn't quite right for the occasion, my hair looks a little unkempt, face without makeup. I buy inappropriate clothing (my dear husband is not much help in this!). My judgment on clothing has changed, and I now have a closet of ill-fitting, mismatched clothes. I realize that this doesn't matter at all in the world-wide scheme of things. But it does matter on a personal level. My standard of dress has changed (downwards), and now at times I look eccentric rather than just interesting. If this were by my choice, that would be fine! But it is not my choice, it is my fate. I am no longer the well-groomed, neat person I had been and used to take pride in being. A recent friend or acquaintance would not know this about me, and would not understand that this change could privately upset me. Or that this change was a signal of many other problems. The "invisible illness" is not invisible, if you know what clues to look for.

And inside my house a general disorganization rules, so much in disarray that I was prompted to write a poem, "Housework Never Ends".

Housework Never Ends

Our dust-bunnies do not quake in fear
 As heavy footsteps round the bed
 They grow steadily, larger
 Inviting friends to stay.
 At night in the quiet middle hours
 I think I hear them whisper to their friends
 As they rustle along the floor.
 They are unpaying tenants and remain
 Quietly raising their families
 In the safety of my inaction
 At times I ineffectually reach
 With a broom or stick
 To test where they rest
 On the still floor
 They might huddle together
 To make themselves small

Waiting until I forget
What I meant to do
As I move on to try
Some other task

“Water me”, my plants call out
In silent plant-talk
As past I walk
In hopes I’ll give a drink
But if I forget and move on
They will wait and wait
Until by their wilting fronds
They signal my watchman.

Do outsiders see this household disorganization as a sign of my decline, or my cognitive difficulties? I don’t think they would, if they had not noticed my previous standards. And they might not understand whether this would cause me distress.

And what about our problems preparing meals? If friends are no longer invited in for a meal or even tea, that is a big clue to our difficulties. We might be embarrassed about the decline in our housekeeping, and too disorganized or lacking in mental energy to plan entertaining, or make even a simple offering of tea or coffee, and so we stop inviting people in. Patterns that change, standards that decline. Yes, these illnesses aren’t really invisible if you know what to observe.

When friends and family tell us we look so well, we can’t possibly have a problem, we want to invite them to come and live with us for awhile, or walk in our shoes. To help our spouses or children or parents who live with us, or to help us if we’re trying to remain living alone independently.

We’re not sure whether people mean to be reassuring, or are using a subtle way of telling us to pick up our socks and just try harder! Since we know our diagnosis and our prognosis, coming as a result of many arduous months of complex tests from experts in this field of medicine, the reassurances from lay people don’t really do much to allay our fears. Instead, they make us sad that we are not being validated, and that our problems are being minimized. They may mean well, but it leaves us feeling rebuffed and negated.

When our problems are minimized in the above ways, I believe that we are unlikely to invite the other person (acquaintance, friend, family member) to discuss our illness or to tell them how they can be of help or of real reassurance to us. After a few experiences of hearing, “You look so well, there can’t possibly be anything wrong with you”, people with dementia often simply stop talking to their friends or families about their ongoing problems and fears. This can lead to isolation and perpetuate the stigma of having dementia.

Some friends and family seem to fear coming close to us to touch our true spirits. Perhaps they are uncomfortable, since they know instinctively that we are now different and they believe that their relationship with us has changed. But the result is that they won’t allow themselves to get in close and continue to develop an ongoing relationship with us. If we’re not allowed or encouraged to tell the truth about ourselves, then we surely will be isolated on private, individual, lonely islands.

See Me Today, Love Me Today

I hurt inside
 Silently
 When you do not understand
 When you forget
 And expect too much
 Demand too much
 Remind me again in anger
 How can you not see
 There is a clear window
 Into my mind’s failings
 Are there shutters over your eyes
 Or over your own mind
 My invisible disease
 So concrete inside
 Leaves little outward sign
 But look through my window
 See me as I am today
 Love me as I am today

How would I like to see changes to help me and my friends in the early stages of these “invisible” diseases?

If we tell someone that we have Alzheimer Disease or a related dementia, we would like the response to be something like this: “I’m so sorry to hear that. You are looking very well and I’m glad to see that. But you must have many ongoing difficulties. Would you like to tell me about them? And how can I be of help to you?” With this kind of response, we will all have been given “PERMISSION TO SPEAK” about our disease, not just for **today**, but also for the **future**, and not just with us, but with our spouses or caregivers, and close family, who also might need emotional support and physical assistance. Wouldn’t it be wonderful if we could educate friends, family and the public, bank tellers, bus and taxi drivers, waitresses, and the public that deals with us daily, to watch for signs and ways to provide assistance for us, and to make allowances for our difficulties, the way they would if we had an outward obvious sign of our disease (such as a blind person using a white cane, or a person in a wheelchair)?

Anne Swift suggested to me that the public should use the “Brown Bag” approach in order to validate and support people with dementia. This means suspending their own old attitudes and preconceptions towards the person or illness (i.e. temporarily putting these unhelpful attitudes away in a figurative “brown bag”) in favour of just listening and not judging the person. Perhaps outsiders simply want to fix our problem and make us feel better; they do not hear the pain or the difficulties behind the diagnosis. The best support outsiders can give at times is simply just to listen and validate our feelings and our experiences.

There are so many ways that our friends, family and the public at large can help us. They can reassure us that they want to continue with our friendships as before and ask how that can be facilitated, given our current difficulties. Would it help us to meet in quieter settings, have shorter meetings, different activities that we can enjoy together? Do we want them to phone us more often? Should they assume that if we don’t call, it is not because we don’t want to talk, but because we are having difficulty using the phone, or remembering to keep in contact?

If our speech is now a problem, they could ask how our communication can be aided. Do we want them to fill in the blanks when we hesitate and have difficulty, or do we want them to let us slowly find our words on our own? What works best to preserve our independence and dignity? Do we need their speech patterns to change to help our comprehension, for example,

shorter, less complex sentences, letting us deal with one subject and one answer before adding in the next subject.

If the friend or family member has time and interest in being of more help, do we now need assistance getting to appointments, and/or going inside to the doctor, dentist, optometrist, shoe store, etc. with us? Do we need help practicing new tasks, such as taking an easy bus route or the DARTS system (when we have to give up driving a car)? Can they see or suggest ways to simplify and help with our housecleaning and cooking problems, get church groups and other volunteers to help with occasional assistance?

Each person with dementia may want these questions answered differently, and the answers may change through time, so friends and family should not assume that we are all the same, and ideally checking on how best to help us will be an ongoing process.

Dementia can at times seem to be “invisible” to care-givers also, even though they have been involved in the diagnosis process and have watched the cognitive changes while having to cope daily with the resulting problems. But sometimes perhaps we “look so well” and even “seem so well”, that our care-giver temporarily suspends the knowledge that we have dementia, and expects us to perform once again like our old selves. “How could you forget that? I already told you more than once!” “You didn’t write down the phone message! Why didn’t you write it down? How could you forget not to write it down!” We are not helped by being reprimanded when we are forgetful, and being forgetful is a main characteristic of our brain disease! Sometimes our care-giver might forget that we get overwhelmed by a certain type of situation, and inadvertently put us in it again, and then wonder why we are having trouble coping. I suppose it must be very trying for care-givers at times, to have to yield so much, give so much leeway, hold their impatience, but we hope they will always keep the following statements in mind.

Do not be embarrassed or ashamed about our disease. We are not to blame for our illness, and neither are you. We have nothing to apologize for having our disease. Accept us as we are. We are still the same person inside, but now with new and changing challenges. If we act differently, please focus on blaming the disease and not blaming us. Continue to love us and respect us, and show others that this is the model to which they should aspire. Do not speak for us unless we give you permission to do so; please reinforce

that others give us the same respect. Help us to maintain our sense of identity and our self-respect. Do not smother us, but enable us to continue to be independent persons, to the best of our ability and our choice.

Hope

Daily changes
Daily challenges
We look for opportunities
And possibilities
In this evolution
This now simplified life
Seizing each present moment
In this there is hope

By Marilyn Truscott, presented at A.D.I. Conference, Kyoto, Japan, Oct. 15, 2004 (with permission of Alzheimer's Care Quarterly Journal)