

DEMENTIA TOGETHER

How to Communicate
to Connect



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Acknowledging What's There

But what am I going to see? I don't know.

In a certain sense, it depends on you.

—STANISŁAW LEM, *Polish writer*

Lucia is a friend of mine who emigrated from South America at a young age. Now living and working in Europe, she sees her mother only once a year. On one visit, she arrived to find that her mother was showing signs of dementia.

“Where are you? Are you there?”

“Yes, Mum, I’m right here.”

“I can’t see you.”

“That’s because your eyes are closed. To see me you need to open your eyes.”

Lucia’s mother forgot that she has to lift her eyelids to be able to see. Due to dementia she has lost this basic knowledge.

Dementia is a word that describes a group of symptoms that result from damage to the brain caused by disease. Dementia can be caused by several different factors affecting the brain. The symptoms

are progressive, usually beginning slowly and imperceptibly, with the effects getting more pronounced over time, sometimes gradually and sometimes rapidly depending on the cause.

Many people experience the illness as losing a loved one bit by bit, with the loved one withdrawing as the people who care about them give up. We associate dementia with parting ways, moving away, leaving for good.

You wouldn't abandon your loved one, but you may feel as if your loved one has left you already. You may feel lonely when you lose a connection that you once shared, or a connection you always hoped for. It may feel like it's too late. This is one way of seeing the situation—but it's like seeing it with your eyes closed. Or filled with tears.

Eyes are windows to your soul. A pained soul keeps the blinds down. But if you don't open your eyes, you won't let the light in. You won't notice that the person you care about is still there, and so is your relationship with them. But the first step is to acknowledge their dementia.

WHAT OFTEN GOES UNSEEN

We often do not see four essential elements:

First, dementia itself. It is an invisible sort of illness; it does not reveal itself through bandages, wheelchairs, or walking aids. It starts slowly. It is subtle. It is a different experience for each person it affects. We don't necessarily know if someone has dementia by looking at them. That's how invisible dementia is.

Second, the person behind dementia. Because once dementia is diagnosed, it is all too easy to pay more attention to the disease than to the person who has it.

Third, the caregiver behind the person behind dementia.

Fourth, the relationship between those two people. There is still, always, a relationship between a person with dementia and a person who cares for them.

Dementia itself is difficult to spot in the wild. It affects people subtly, even in its advanced stages. But eventually, things start disappearing. Almost imperceptibly, particular skills, words, and knowledge may start to vanish. Even so, which skills a person loses, and to what extent, differs from person to person. This means there is no “standard” form of dementia. However, loss of memory and loss of words are two ways that people commonly recognize dementia.

An average adult knows about thirty thousand words. What difference does it make if someone forgets a couple of hundred of them? It is not immediately obvious—neither to the person who has dementia nor to the people around them. Work by famous authors such as Agatha Christie, Iris Murdoch, and Terry Pratchett showed symptoms of language deterioration before the authors themselves were aware of the disease. Not even their most faithful fans noticed, at the time. The study of these writers’ novels did not take place until after they were diagnosed with dementia, or in some cases even after their deaths.

Time is another subtle clue. Saint Augustine famously stated, “What then is time? If no one asks me, I know what it is. If I wish to explain it to him who asks, I do not know.” No wonder people with dementia get confused about time—time of year, time of day, or time of their life. They aren’t quite sure what year it is. They get day and night mixed up. And like most of us, they feel younger on the inside than they appear on the outside. Unlike the rest of us, they may believe that if they feel twenty, they must *be* twenty.

A person who seems to be losing things more and more often—words, keys, and sometimes their temper—will at some point be

taken to the doctor. As they enter, they are treated like a regular person, though perhaps as a person who's a little forgetful. They are addressed directly, in first person: Take a seat, Mr. Jones. But after they have been diagnosed, they are discussed in third person, as if they are not there: We are afraid that Mr. Jones is showing signs of Alzheimer's. Once dementia has been acknowledged, it takes over the show. The diagnosis often marks the transition between not seeing dementia to seeing *only* dementia.

Why have you started talking about me as if I weren't in the room? Mr. Jones might ask. This is the moment when a person seems to disappear behind dementia. Like one person I used to know.

A PERSON HIDDEN BEHIND DEMENTIA

Dementia can act like a cap of invisibility: whoever has it turns invisible. Indeed, someone who has had dementia for a while can mysteriously go unnoticed in the midst of their family's everyday life. A person with dementia is unable to contribute much in terms of housework, is incapable of following conversations in the usual way, and is often deprived of their personal friendships, leading them to retreat into the background. In my family, that person was my great-grandmother, known in my family as Grandma Maria.

I was in my teens when I realized I knew hardly anything about Grandma Maria, who was at the time in her nineties. She lived with her daughter, my Granny Irena, in an old two-bedroom flat which I visited on a weekly basis, and yet I could not recall seeing Grandma Maria much. She was always quiet, like a shadow. She was used to keeping out of the way, I suppose. I only spotted her moving silently between her bedroom and the neighboring bathroom, and once a year around the Christmas table, where she sat without saying a word.

Everyone in the family seemed to treat Grandma Maria with respect, but silently, from a distance, and without talking to her. I don't recall many interactions I had with her, apart from one meaningful conversation. Later in the book, we will explore the odd mechanics of human memory, one of them being that we tend to remember things that have personal significance for us. The event I'm about to share with you wasn't a particularly big one in the sense that no one can validate it for me; it wasn't a significant part of my family history. But it was meaningful for me, as it illustrates how I lost my great-grandmother even before she died. In a sense, she passed away from my world years before she actually died, and in my personal history, this was an event worth remembering.

At some point in my teens, I began to realize how little I knew about this mysterious ancestor of mine, and I became determined to spend some time in her company. My sudden interest might have been ignited by a family tree project at school. I remember the amazed responses from my friends whenever I mentioned that I had a living great-grandmother who was nearly a hundred. At that time it was very unusual to have such an ancient relative. And mind you, we were only one generation away from those who had lived through the Second World War. In fact, my great-grandmother had lived through two world wars—a dubious privilege.

I decided there was no time to be wasted. Although I already paid regular visits to Granny Irena's house, there was only one occasion when I remember going specifically to see Grandma Maria.

That day I knocked and went into her room, asking politely whether I could join her for a moment. I had a secret mission to claim my heritage. To me, as a teenager, she was the living past. She looked like the past. She behaved, sounded, and even smelled like the past. Walking through the door into her room was almost like time travel, like being teleported into a living, breathing history,

more alive than any old history book, yet smelling the same. This was it, my chance to have a real conversation with my own great-grandmother!

I will never forget her bright face and sheer delight at welcoming me into her room, her kingdom. She seemed attentive and observant, yet there was something passive about her. She didn't say anything as I came in, nor did she offer me a seat. I sat down next to her on the sofa bed.

I started by asking a series of questions about her life and our family. She became engaged, smiling and sitting up a little bit. She told me about some cousins of hers in Poland who had fled to a remote part of the country, in the North, after the Second World War, and how much she wished she had visited them there.

Curious, I asked her more questions. I asked what games children played during her time. I asked whether there was any television back then, and what would she do in the evenings without it? In response she said: "After the war, my cousins fled to the North. All my life I wished I had gone to visit them."

I froze in confusion. Didn't she realize she was repeating herself? I thought maybe she hadn't heard me. Old people tend to go deaf, I thought. So I asked her about the television again, and she retold the whole story about her cousins all over again, as if it were the first time.

I lost interest almost immediately. I was so confused, and embarrassed because I didn't know how to react. The worst thing was that I felt utterly disconnected from her. I felt separate and detached, almost as if we were strangers rather than family. It was an uncomfortable sort of feeling, like when you feel utterly alone despite being with someone.

Grandma Maria and I were in the same room physically, but I felt very distant from her.

She seemed stuck in the past, and although I was interested in her personal history, I couldn't understand why she went around in circles about the same topic. I was interested in comparing the past to the present, but she didn't seem to know anything about the present.

We were so far apart that our sentences could not travel through time to make communication possible. What was the point of talking then?

If she doesn't realize what she's saying, she probably doesn't understand who I am, or where we are, or what any of this means, I thought. I not only withdrew my interest but I also lost any feeling of warmth or closeness. I kept nodding, while looking for any opportunity to leave the room. In a very strange way, I felt as if she had rejected me, simply because she repeated the same story several times.

This repetition, and worse, the fact that she was oblivious to it, made me question everything about our relationship. And the point of it. Tragically, I began to see her as a robot—a machine lacking awareness or any meaning whatsoever, mechanically repeating the same old story. She was simply parroting a story that was etched in her mind as a series of information bytes inherited from the person she used to be, or so I thought. At the time, I felt that her lack of short-term memory meant that she too was gone.

I left the room as politely as I had entered it, but this time I crossed the threshold without hope.

Afterward, I simply glossed over the whole experience with one convenient judgment: Oh, well. She's just old. Little did I know at the time, my great-grandmother was living with dementia, most likely vascular dementia that developed after her stroke. I don't know whether knowledge of a medical condition would have influenced my experience in her room back then. I suspect I would

have glossed over it with only a slightly different understanding: Oh, well. She's got dementia. Meaning, there's nothing I can do about it, so I will continue to politely acknowledge her existence without any hope for connection.

She may have lost her mind, but I was the one who lost heart. And that is how we lost one another.

It doesn't have to be that way.

This book exists to share what I've learned and practiced about how to maintain heart, connection, and communication with someone one who has dementia. To do it, you need to see the person behind dementia and see another person too: yourself.

A CAREGIVER OUT OF SIGHT

Dementia caregivers can be just as invisible to people around them as those with dementia are invisible, because it is not immediately obvious that someone with dementia requires care.

Unlike a small child who cannot be separated from their caregiver. If we see a small child alone in a public place, we wonder where their parent is. Where is their mother, father, or any caregiver for that matter? We expect them to be visible. Children need caregivers for food and shelter, to keep them safe. Just as fundamentally, children need adults for companionship—to hear their needs, and to laugh, play, and fight with them. Every child needs someone to communicate with, and to connect with. When we see a child alone, we assume something is missing—or rather someone.

Caregivers to those with dementia are so invisible to the public that people wouldn't even notice if they are missing. And yet they are no less essential. People with dementia are not children. Yet behind every person with dementia, there is a caregiver. If we see

someone who has advance dementia unaccompanied in a public place, would we ask ourselves: Where is their caregiver?

We probably wouldn't. Unless we had some experience of how dementia can disable someone's abilities, we wouldn't be alarmed to see them alone, would we? Not in the same way as if we saw a child on their own.

And yet, the caregiver of a person with dementia is an essential component of their life—just as a parent is an essential component of childhood. Except that caregivers of people with dementia have the added difficulty of being invisible to the world, and even the person they care for. Their job is not obvious to people who don't realize what dementia care requires.

Caregivers are life-enablers. And yet most of the time this caregiving role is as invisible as the disease itself. Do we wonder how someone with dementia gets through the day, every day? Do we wonder who prepared their food when they forgot how to open the refrigerator, or when they forgot they needed to eat food in the first place? Who answers one question after another, often the same question all day long?

People don't demonstrate dementia in any obvious way, and therefore they do not appear disabled. Not even, or maybe especially not, to their own eyes. I'm fine, Mr. Jones might say—I do all these things on my own. Having forgotten that bills have to be paid, and pets need feeding, they may not comprehend why they wouldn't be able to cope by themselves. And indeed, in early stages of the disease, many people who have dementia can manage well on their own and won't need a caregiver for daily personal care or to keep them safe. But this won't last.

Sooner or later, people with dementia lose the ability to do daily tasks like cooking a meal, doing laundry, driving, or handling money. They may not be aware of it because along with the skill

goes their sense of necessity for daily tasks. But their caregiver will be aware. Their caregiver will notice and be able to help in more than one way.

Caregiving can mean hands-on work helping another with everything that everyday life involves. It can also, just as importantly, mean organizing and masterminding direct care providers while managing everything else in a person's modern life, from paying bills to answering emails. When I talk about caregivers in this book, I mean not only those who deliver care but also those who simply care about someone who has dementia—in this book I use “care for” to mean both types of caregiving. Either of these forms of care involve a to-do list that is longer than the hours in the day.

Did I ever notice the caregiver of Grandma Maria? Did I ever wonder who listened to her repetitive story about her family's venture to the North? Who made sure she had everything she needed from morning till night? Did I ever realize Granny Irena was her sole caregiver? I knew Granny Irena well, and I loved her with all my heart, but I did not recognize the caregiving she devoted so much time to. It was invisible, in the background. The caregiving involved smooth and continuous hours of care—around the clock.

So on top of the endless tasks that care itself involves, a caregiver has to deal with being invisible—to the world at large, to passersby, and even friends and family who do not notice dementia happening at all. Invisible even to the very person they are caring for, since people are often unaware of their own dementia, and therefore also unaware of the role of the person who was “just” their husband or wife, son or daughter, friend or neighbor. They may not realize that now they are caregivers too.

Caregiving can happen so invisibly that a caregiver may even be invisible to themselves. They may not realize they have taken on this additional role, with its additional cost. When a caregiver ignores

their own needs and the things that matter to them personally—perhaps unaware of how they could possibly meet everyone's needs in the situation—they end up burned out and downhearted. And, perhaps most painfully, they become disconnected from the very people they do all of this work for.

Care describes something that happens between two people, yet for many people, caregiving feels solitary. Expectations are high on all sides. People expect a caregiver to be compassionate, resourceful, and have an endless supply of patience—under any circumstances, always. Is that what you expect of yourself?

The job of caregiving is, as the word implies, all about giving. Giving time, effort, and attention. It may seem like you're giving much more than you're receiving, and that your lonely one-way street gets only steeper and more winding over time.

What I hope you learn while reading this book is to open your eyes not only to what you need yourself, but to how much you are, or could be, *receiving*. In other words, to learn not only how to be more efficient at giving love and care, but also how to receive something precious from the people you care for. How to enrich *your* life.

RELATIONSHIP AS A TWO-WAY STREET

This book, and all of my work with people who have dementia, is based on the discipline of Nonviolent Communication. Nonviolent Communication teaches people to connect with each other by learning not only how to give compassionately, but also how to receive gracefully. In communication, this translates into honestly expressing and empathically receiving.

If you already offer care, love, or respect to another person, do you also know how to receive it from them? In a relationship with a person who has dementia, there may be many blocks in

communication, like barriers in language or perception, but that doesn't mean they have nothing to offer you.

Communication is at the heart of every relationship, and in its very essence, communication is a two-way street. If I have one hope for this book, it is to help you learn how to get more out of your relationship with someone who has dementia.

People with dementia, though they require care, are not children. They can be partners in caregiving, helping you help them and supporting you in many ways. People with dementia so often long to contribute in a meaningful way. Anthony de Mello, a Jesuit priest, said that old people are often lonely not because they have no one to share their burden, but because they have only their own burden to share. To me this explains why so many people with dementia feel useless and alone: because they wish they could contribute meaningfully.

Even when someone can't realistically *do* much to contribute in the household, they can still *be* in relationship with you. Meaningful contribution can be delivered with their heart, not only with their hands.

I wish I had been able to see my own great-grandmother behind her dementia. I wish we'd been able to have the type of relationship I've had since then with other people who have dementia. Instead I was told that "she's out of her mind" and "she's not all there." So where was she then? I didn't know where to look for her, how to meet her where she was. I was lost. And because of that, I lost Grandma Maria. My inability to communicate caused the untimely death of our connection. She became even more absent from my life after our memorable conversation than before, as if she had died to me, even though she lived on in her body for another two years.

Dementia didn't kill our connection, however. It was my own disconnection that had such deadly consequences for our

relationship. Once we acknowledge the disconnection that sets us apart from other people, we can do something about it.

DISHEARTENING DISCONNECTION

Dementia can affect thinking and memory in a range of ways. It can affect day-to-day, recent memory. It can cause difficulties with planning, concentrating, or organizing. It can affect use of language. It can affect visuospatial skills. It can affect orientation to time or place. Sometimes it causes visual hallucinations or delusions. Dementia can also lead to changes in mood, but *dementia does not cause disconnection*.

Disconnection is a state of having a closed heart and a disengaged mind.

The various symptoms of dementia, such as emotional withdrawal, volatility, or decreased attention and motivation, are often associated with disconnection. But disconnection is not an inevitable part of dementia.

Disconnection means disengagement that can lead to loosening of bonds with people. In contrast to the sense of life that a meaningful connection with another person can bring about, disconnection cuts off these bonds. It robs people of the aliveness that comes with connectedness in life, and they eventually drift away from others. Although they may be spending a lot of time physically close to other people, they are not necessarily present in their spirit. For those who feel disconnected there isn't much "closeness" about the quality of that time.

It is disheartening when disconnection happens. Disconnection can occur equally on the part of the person who has dementia as well as anyone around them. It can take place in any relationship and between any two people, with or without dementia. It is

disconnection, not dementia itself, that leads to the sense of isolation, loneliness, and separation that many people living with dementia experience. In many cases disconnection is the most painful factor in living with dementia. And this pain can lead to making dementia even worse than it has to be. The worse off someone is in their heart and spirit, the more dependent they become, and the more care they require, and the less cooperation there will be. Eventually, disconnection costs everyone more time, effort, money, and heartache. Who pays these costs? In most cases the caregiver pays the price for disconnection, making their work and their relationship even more painful. It isn't in anyone's interest to ignore disconnection.

Acknowledging disconnection when it occurs can reveal options that would stay closed otherwise. Like a question that never gets answered unless someone asks it.

Asking how you can connect with the person who has dementia can spark imagination. I am not asking you to imagine impossible things—on the contrary, I invite you to dream of the possible, the actual and genuine. Dream with your eyes wide open and feet firmly on the ground. There is a way into a satisfying and deeply connecting relationship between two people, even when one of them has dementia. In the next chapter I will share four stories from my life about such connections. The rest of this book will explain how you can communicate to connect with the person you care for.

Lucia and her mother managed to save their relationship despite the challenges of dementia, geographical distance, and the different lifestyles and cultures they ended up living in. Lucia knew that her ability to save their relationship was not a matter of being lucky. She used the discipline of Nonviolent Communication and her spiritual practice to see through the illness and maintain a

quality of connection with her mother. It was a matter of skills and a bigger perspective. A little bit of imagination helped too.

Dementia can deprive one of many skills, abilities, and memories, but it does not have to deprive us of connection. “It is true what they say, you know—that connection never dies,” Lucia said to me. “In a sense, I have never really lost my mother.”