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Getting Perspective

And maybe the big picture [is] amazing,
but if you're standing with your face pressed up
against a bunch of black dots, it's really hard to tell.

—REBECCA STEAD, *American author*

Living with dementia is hard, for everyone involved. Yet it is possible to have healthy relationships, even when living with this illness. It's possible to have what I call a dementia relationship that is full of life, despite the dementia. And healthy relationships create well-being for both people in the relationship. However, many people who have been directly or indirectly affected by dementia find that an ill state of being is far more common than well-functioning relationships. There is a person with dementia, and a person close to them—two disconnected and mistrustful parties in the same relationship, trying to deal with, manage, and troubleshoot the real challenges of life with dementia. Close, yet so painfully apart.

This book is about seeing the possibility of reconnection. It offers new perspectives on living with dementia. It does not promise easy solutions, but instead simple solutions that make life more wholesome and far more meaningful.

There is a way to look at things which makes things simpler, without simplifying the problems. Seeing new possibilities is not only a matter of *what* we see and don't see, but also *how* we see—the perspective we have. When we gain greater perspective, it is easier to see how things are connected, and hence how we can connect with each other.

In everyday life, it's common for dementia caregivers to get lost in endless to-do tasks, demands, and newly emerging problems. In the midst of all this, it's easy to lose perspective on what really matters. Everyone gets confused: the person with dementia may not possess the mental faculty to comprehend clearly, and the caregiver may be under so much pressure, they find it hard to think, or even feel, clearly. And when we are confused, we forget about the bigger picture.

A BIGGER PICTURE

Marshall B. Rosenberg, the founder of Nonviolent Communication, liked to use the giraffe as a symbol of the bigger perspective that Nonviolent Communication brings. The giraffe is gentle but strong. It possesses the biggest heart among all land animals, making it a suitable image for a discipline that can help you grow your heart bigger, both in strength and in gentleness. And of course, we all associate giraffes with their long, long necks—which enables them to reach higher, to the very tops of the trees, and see farther than their short-necked companions on the savanna. Giraffes have a more all-encompassing view.

Similarly, by practicing Nonviolent Communication, we can access a bigger picture of every situation. We can even, in a sense, see into the future—because it is easier to foresee the outcomes of our interactions with others. We can imagine what will happen when we are skillful in communication, and what is likely to take place when we are not skillful. Like someone who sees dark clouds heading their way and says, “Close the windows. The storm is coming,” we can become not fortune-tellers, but damage-preventers.

To prevent damage in any relationship, it is good to have a look around and see how we can make it stronger. This is why it is worth seeking ways to connect with one another—because being together strengthens each person.

Dementia affects both people in a relationship, even if only one has the illness. And each person affects the other. Examining what causes disconnection will give us a better sense of what leads to connection. Learning how to connect will put us in a better position to get more out of our relationships, including those with someone who has dementia. Connection makes compassionate giving effortless and makes empathic receiving inevitable. To get there, it’s important to acknowledge that both parties contribute—to the relationship, and to the difficulties of living with dementia.

THE DEMENTIA RELATIONSHIP

Dementia caregivers often talk about the illness as a problem which belongs to *them*. It is they who need to be dealt with, looked after, managed, or protected. This way of looking at the situation makes an assumption that *they*—those with dementia—are the source of the problem.

Consequently, *we*—those without dementia who “know better”—have a problem with *them*. As Tom Kitwood and Kathleen Bredin wrote:

Here there is a clear division between *us* (members of the "normal" population), and *them* (the dementia sufferers). *We* are basically sound, undamaged, competent, kind. *They* are in a bad way, for they are afflicted. . . . So there is a need for training to give us knowledge about *their* illness, and to develop skills, especially in managing *their* "challenging behaviours."

Kitwood and Bredin then point out another way of looking at the situation with dementia, which is to consider this question: Whose problem is it?

Or, in my situation, if someone with dementia decides to pee into the sink instead of the toilet, who has more of a problem with it, him or me?

Gordon was affected by dementia in a way that made it difficult for him to orient himself spatially. On one hand, he saw holes in the ground that weren't there. On the other hand, he was frequently unable to locate objects that were actually there: Where was the door handle? How does one find a light switch? Where could one find a toilet to pee into?

Since all of these objects were hiding from his perception, he had found ways to do without them. The door to the bathroom attached to his bedroom was left permanently open, the light switched on at all times, day and night, whether he needed it or not. And as the toilet was never to be found, he developed a habit of using the sink to urinate into. The sink was much easier to locate, as it stood at a height that allowed him to feel it without needing to bend. The sink was so much easier!

So he peed in the sink, and with the stopper in place, the urine stayed there overnight, permeating the air of his bedroom such that I was attacked by a piercing smell every morning as I entered his room. As if Gordon himself was attacking me with his secret weapon. And the secret to this weapon was that it was neither sharp nor shooting, it neither hurt my skin nor fired bullets. Instead, it was disgusting. I sighed silently to myself. Why are you doing this to me, Gordon?

This unhygienic and smelly habit did not bother Gordon, a man keen on wearing clean clothes every day—a spotless, freshly ironed shirt and perfectly matching cardigan and trousers. He was clean and neat, *and* he didn't mind urine in the sink.

I did, though. I had a problem with it. I would be so embarrassed if someone walked into my bathroom and saw my bladder fluid. But Gordon wasn't embarrassed. It didn't affect him. And I assumed he didn't care whether it affected me or not—hence I judged him as inconsiderate and filthy. Sometimes I even thought to myself that he had "lost it altogether." These judgments only contributed to the problem. In a sense, I made the situation worse for both of us.

I thought I had to continue living with Gordon's disgusting habit, and perhaps more painfully, with my judgmental and disconnecting thoughts. Then one day I found out from his other caregiver that it was she who requested that he urinate in the sink!

She had known him longer than I had, and apparently, because Gordon was unable to locate the toilet in the middle of the night, he had frequently urinated all over the bathroom floor. So his caregiver requested that he at least aim for the sink, and thus save her a lot of work in the morning. I never considered that he was trying to collaborate, but instead I interpreted it as a nuisance. I assumed that he was being uncooperative, whereas all this time he was trying his very best.

After adjusting to this new perspective, the only thing that still bothered me about using the sink as a toilet bowl was that the stopper was in place, leaving the urine to sit all night. All I had to do was request that Gordon does not use the stopper and lets the fluid go down the drain.

This Gordon was willing to do. In his case, dementia didn't seem to prevent him from remembering the caregiver's instruction. Once I made my request, he was glad he could contribute to my well-being. And what a change that made in my judgment of him! I no longer thought of him as inconsiderate, but instead I perceived him as cooperative and caring.

Gordon had no problems with urine in the sink, nor all over the floor. It was I who had the problem. And I was contributing to the problem by judging him for his habit. I've learned to appreciate how I, the caregiver, contribute, and in a sense co-create "the problem," even though I do not have dementia.

We all are set in our ways, bound by social norms and personal habits. And through this lens we add to what we see as the *problem* in our own way. We contribute by blaming and judging the other person and by denying personal responsibility for our connection, for the relationship we both have with each other.

Must the problem be about me or them, exclusively? When the subject matter is caregiving, perhaps one could say that every problem is ours, in the sense that it affects our relationship, the way we are together. Dementia affects our relationship, and since one needs two to tango, we are both affected—we are both dealing with it. Difficulties associated with dementia, as Kitwood suggested, are located in the interpersonal. There is you, and there is the other person. But there is also your relationship.

Rumi, a Sufi mystic and poet, pointed out: "You think because you understand 'one' you must also understand 'two,' because one and one make two. But you must also understand 'and.'" The problem with dementia isn't necessarily in any one of us, per se: it is in the "and." It is in the way we relate to one another, in our relationship. Hence the answer is to be looked for "between" us. An ability to see this clearly, to own the difficulties that are associated with dementia, is a steppingstone in building a more satisfying relationship for both parties. Because dementia always affects more than the person who has been diagnosed with the condition.

When you take into account both the person and their dementia, yourself, and the relationship between you two—there is a dementia relationship.

Like any relationship, whether it is romantic, family, or professional, each dementia relationship is one of a kind. It may overlap with other types of relationships when it is a beloved, a relative, or a business partner who has dementia. Nonetheless, the dementia relationship requires us to make adjustments and establish new boundaries—as if we were running a family business or entering a working relationship with a spouse. We relate to each other according to context, to where and who we are, whether we are at home or at the workplace. In this case, we need to relate to each other while taking the context of dementia into account. Dementia will affect both parties in the relationship, perhaps in different ways, and to greater or lesser degrees, but nonetheless every person in a dementia relationship will be influenced in some way.

Dementia manifests in individuals so differently, one could almost say that dementia is custom-made, one of a kind. Each person differs both in their emotional reaction to the diagnosis and in the symptoms of their illness. Dementia can have a hugely varied range of symptoms, because it can affect different functions of the brain—language, memory, mobility, orientation in time and space, and perception. Whenever a caregiver turned over care of a client to me, I asked this crucial question: How does dementia affect this particular person? There are so many symptoms that one may not identify immediately. My intention is always to assume someone has their full capacity, and to support their independence as much as possible. Unless I had spent time with them before, I can’t know whether someone is safe on their own. I can't know whether they can see accurately, whether what they see is real or part of their world only, or whether they know their limits and current capacities.

My next questions were: How does the illness affect the people around the person with dementia? How do they react to the symptoms? Which do they find challenging? Will I be able to sleep at night? Can I trust they will be okay making themselves a cup of coffee?

I asked these questions because dementia affects both parties. Dementia is a condition that two people share, even though only one may be carrying the symptoms of the illness. Yet we share its impact on our lives. Both of us must build a new relationship, with dementia in the picture. This is what I call a dementia relationship: it is *us*, with and without dementia.

Marshall B. Rosenberg said that "our survival as a species depends on our ability to recognize that our well-being and the well-being of others are one and the same." The well-being of a relationship affects two beings. A relationship can serve, nourish, and enrich. Relationships that are strong enough and occur between two connected individuals can be literally a survival strategy. Relationships can protect what's precious and human about us.

Humans as sentient beings have the capacity to feel, perceive, know and understand, respond, react, and be aware. Dementia affects all of these capacities, and hence it affects a person's state of being. I believe that it does not predetermine whether we experience well-being or ill-being, though. Ill-ness does not automatically imply ill-being. Rather, the state of our being is an indicator of our connection with other human beings.

Ill-ness does not automatically imply ill-being.

JUDGMENTS THAT BREAK RELATIONSHIP

The way we relate to one another can be empowering, or equally, it can be weakening. The more I bought into disconnecting thoughts and judgments, as if they were facts about the other person, the further away I was from the real them. Instead I was dealing with their caricature, a poor representation of the person who was in a dementia relationship with me.

This kind of thinking caused me suffering whenever Dory inquired about her concert tickets.

"Dear, we need to buy tickets for the performance this weekend. Good job, I just remembered! As usual, no one cared to remind me," Dory would say.

"No worries, Dory. I got the tickets for us already."

"Why didn't you tell me? Why did you keep it from me? It's only fair that I should know."

Inside, I felt rather aggrieved. Why does she always assume it was me who did something wrong? Why can't she see the fault in herself for once?

Feelings of hopelessness overcame me. What was the point? What was the point of telling her I'd already told her about the tickets three times? What was the point of reminding her about the tickets in the first place, as she would certainly forget to buy them herself? Then she would be annoyed that I didn't buy them for her. This went around and around in circles. Whichever way I went, whatever clever solution I came up with, we both lost. We both ended up disconnected.

What prevented us from connecting wasn't the tickets or the lack of memory, but the assumptions and judgments. It was each of us assuming that someone was wrong and to be blamed. Dory assumed I was mean and either hadn't reminded her about the tickets or had bought them behind her back. I thought she was unfair for always accusing me of bad intentions. I thought she was difficult or—in a more sophisticated form of blame that pretends it isn't blame at all—that it was her dementia that was difficult.

I was denying both my own and Dory's responsibility for the way we related to each other.

When we blame or accuse the other person of blaming us, we end up judging each other, which prevents connection from taking place. We disable our relationship. We fall out and our relationship becomes fragmented and disconnected. Each person in a relationship may be both contributing to this disconnection and be affected by it. It is a vicious circle which, once set in motion, carries on by force of habit. Was it the disconnection that came first and caused us to start blaming and judging each other? Or was it our blameful accusations that caused us to end up disconnected? Like with the chicken and the egg, we may never know which came first.

Dory and I habitually fell out over the purchase of her concert tickets and other arrangements that slipped her mind. For her part, I suspect she mistrusted my intentions.

This suspicion and distrust isn't uncommon among those living with dementia, and it doesn't come from nowhere. They have perfectly good reasons to be worried. The scenarios may differ from one person to the next, but from their point of view, some very suspicious things have been happening: a kettle has set itself on fire, their dressing gown turns up in the car, the parakeet is found motionless in its cage. From the perspective of the person with dementia, something isn't right.

As far as they are concerned, they had nothing to do with any of it, because they have no recollection of how these things came about. So it must be the fault of someone else—the spouse, the caregiver, the child, the neighbor. They might think: You are doing all of this deliberately to make me look stupid. You're plotting behind my back. And what the heck have you done to my parakeet!

Those on the outside may be blamed, judged to be wicked and insensitive, and labeled a bad husband, stupid caregiver, uncaring son, or vicious neighbor.

Whatever may be happening, the person with dementia has an underlying intuition that it is not good. Something is wrong. And whenever something is wrong, we tend to blame someone or something for it.

A person with dementia may judge themselves as the problem, rather than mistrusting others. They might think, I've become worthless now! They might turn against themselves, assuming that life is not worth living if one is not in full command of one's memory. Such self-judgment can have truly devastating effects. It can kill. The downward spiral of this thought pattern can lead people to contemplate suicide . . . until they forget all about it again. Ironically, this is how memory loss can save lives.

The worries never end, and they are just as concerning for those who care for someone with dementia: There is almost a fire in the house because an electric kettle is on the gas stove. Someone loses their way home at one in the morning after getting into the car to drive around in the middle of the night. They can't find the bathroom door, or forget how to open it, so they urinate by the wall. They stop feeding their parakeet, and it dies. And on top of it all, they forget your name. Again.

It's very easy to feel disconnected from someone judged as "making trouble" or "not trying hard enough." As if they are careless or insensitive. Because how else can we explain their behavior? Then one day we have a diagnosis, and we have a convenient label: dementia is to be blamed for all of it. We might say, Dementia has eaten up their brain, but what can I do about it? Yet we can take personal responsibility for the connection within our relationship.

The question is how do we take responsibility without blaming *someone* or *something*? We often assume that taking responsibility means also taking the blame. And then on one of those difficult nights, we may find ourselves absorbing the blame for not being patient enough, loving enough, skillful enough, understanding enough, foreseeing, preventing, or protective enough. Always falling short of "enough." No matter how much time we devote to caregiving, how much training we've done, how many self-help books we've read, and how many arrangements we've put in place to deal with this *problem*, during sleepless nights this sense of inadequacy and hopelessness may haunt us.

Self-criticism is as much a sign of disconnection as finding fault with someone else. Whether we judge ourselves or the other person is utterly irrelevant in this context. Both people in a dementia relationship can contribute to the disintegration of the relationship by blaming, judging, labeling, and denying responsibility.

ATTITUDES THAT DISABLE CONNECTION

Blaming: You plot behind my back. I'm not patient enough.
Judging: You're a bad husband. I'm such a horrible son.
Labeling: Dementia sufferer. Thickheaded caregiver.
Denying responsibility: The wretched illness has stolen my wife. This marriage is over.

When I was caught and imprisoned in this way of thinking, I saw Dory as lacking understanding. I saw her as failing, because she was unable to recognize that she had forgotten about the concert tickets. I saw my role as someone who had to be forgiving and to endure her deficits. In my mind, she was incomplete and incapable—that's why she needed me as her caregiver.

In conversations I had with her friends and other caregivers, we often discussed what Dory was losing, how her illness had progressed, and how there was less and less of Dory. “She’s deteriorated since you were last here,” I was told on a return to my caregiving role after a break.

It’s no wonder we think this way. When our view of the person becomes all about their illness, we end up discussing the dementia more often than we discuss the actual person who has it.

Oliver Sacks has said that “neurology’s favorite term is ‘deficit,’ denoting an impairment or incapacity of neurological function: loss of speech, loss of language, loss of memory, loss of vision, loss of dexterity, loss of identity, and a myriad of other lacks and losses of specific functions (or faculties). Everything that patients aren’t and nothing that they are.”

I am not a neurologist, but don’t we all at times get fixated on what’s wrong with someone? And we forget all about what’s wholesome in them? We even do it to ourselves—though not diagnosed with any brain disease, we can still see all sorts of lacks and shortcomings in ourselves. With Dory, I saw myself as falling short of being patient and tolerant, not because of any neurological dysfunction but because, as I told myself, I wasn’t a good enough person. There was never enough patience, care, time . . .

This scarcity perspective—thinking that there isn’t enough of something or that we are lacking in quality—is equally limited. It contributes only to a sense of inadequacy. Caregivers of people with dementia are frequently reported to be at high risk for deterioration of their own mental health. And often the support that is available for caregivers, if any, focuses on troubleshooting specific symptoms, such as high blood pressure or an eating disorder. When caregivers get stressed or burned out, they are given medication or encouraged to develop coping mechanisms. Addressing the problem by tackling the physical and mental symptoms is one way that can help, but caregivers can also do something for themselves that is far more fundamental. They can focus on well-being by taking a bigger perspective. A new perspective can help them develop wellness through reconnecting with the person they care for.

As the American psychologists Christopher Peterson and Martin Seligman point out: “When psychiatrists and psychologists talk about mental health, wellness, or well-being, they mean little more than the absence of disease, distress, and disorder. It is as if falling short of diagnostic criteria should be the goal for which we all should strive.”

Instead of striving for the absence of disease or illness, we could be striving for well-being—which is not an absence of illness or disability but actual fulfillment. Feeling fulfilled and satisfied is how well-being is experienced. It doesn’t mean we will be happy ever after, but that we are feeling strong enough to face anything that life puts in front of us, including illness or disability, and that we can turn it into something that brings us together.

By contrast, when we focus on lacking capacity—such as not remembering, not being patient, not comprehending, or not being able to cope—and other potential flaws and faults of the cared for and the caregiver, both parties end up disconnected and dissatisfied. So even when there’s only one person with an illness, when the relationship becomes ill, both people are, in a sense, unwell.

When we are stuck on ill-being, we focus on what we can’t do or can’t have. On the other hand, changing our perspective to focus on well-being enables us to see all the things we can do: the little skills, the things we like, the small bites of knowledge. These are the kinds of fundamentals we share as humans, regardless of our individual level of neurological fitness.

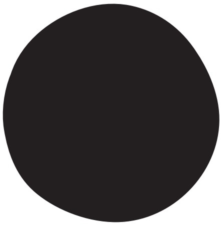
People with dementia can still laugh at a joke, dislike olives, be nutty about chocolate, cry over a broken cup, and admire a sunset. And through all of this, they can fulfill their need for fun and companionship, choice, pleasure, security, and beauty. And I say whoever can play, cry, or laugh wholeheartedly is whole.

A VISION OF WHOLENESS

When we adopt a bigger perspective, and we find ourselves in the bigger picture rather than losing ourselves in a list of lacks and losses, a whole new chapter in dementia relationship can open to us. Everyday life with dementia may appear lacking, impoverished, and incomplete, but it's a matter of how much light we are shining on the whole picture.

Someone with dementia, like Dory, who can't remember whether she bought the concert tickets, may appear lacking and incapable. Especially when she tried to make *me* responsible for any inconvenience her lack of memory caused. At the time, I heard blame. I saw Dory as incapable and confused, and I was resentful at not being trusted. Seeing things this way made us both miserable and grim. It felt like a dead end. When we feel stuck, we don't see things clearly, which is a sign that we're not recognizing things for what they really are.

But what happens when we, metaphorically, shine more light on the situation? Expand our narrow perspective? For example, look at this drawing.



Can you tell what it is? A tunnel with no light at the end of it? A black hole?

It's rather hard to tell. Let me shed some light on it.

This is the same drawing, except now you can see it more clearly.

It is a moon.

The difference between them is that the first drawing depicts a new moon, an astronomical object in darkness, whereas the second picture depicts a full moon, the same object but fully illuminated. The first drawing looks like a hole, but in fact a whole moon is there. They're different phases of the same thing, with more or less light applied.

I once saw a cartoon that made a similar point. It showed the new moon walking into the doctor's office and saying, "I feel so empty." The doctor responded, "Don't worry, it's just a phase."

Like this new moon, Dory was only seemingly flawed. Despite her dementia, she had not lost her sense of fairness, and she cared about being included in the process of buying her concert tickets. She was afraid of being excluded, because it mattered so much to her to be seen and acknowledged. How can someone who cares so much be said to have lost their mind? What does it mean to say that she's not really there? As far as Dory was concerned, she certainly was very much there, with her needs and values that were alive for her, despite her dementia. Don't we all care about being acknowledged and taken into consideration?

Everyone, with or without dementia, has these universal needs. They are needs because we all need them for our well-being. They are also values because we value them in ourselves and others. They are principles because they are fundamental to who we are. And they are qualities because we can embody them in our actions and the way we express ourselves. Nonviolent Communication puts all wholesome human values, principles, and qualities under one umbrella name: universal human needs.

Universal human needs include connection, acceptance, affection, appreciation, belonging, respect, safety, trust, warmth, honesty, humor, celebration, beauty, ease, inspiration, order, autonomy, choice, challenge, clarity, competence, and more.

connection, acceptance, affection, appreciation, belonging, compassion, consideration, inclusion, intimacy, love, mutuality, nurturing, respect/self-respect, safety, security, stability, support, to know and be known, trust, warmth, sexual expression, honesty, authenticity, integrity, presence, joy, humor, celebration, peace, beauty, communion, ease, equality, harmony, inspiration, order, autonomy, choice, freedom, independence, space, spontaneity, challenge, clarity, competence, consciousness

We value qualities such as these because they make our lives brighter.

Sometimes we feel that someone is lacking in certain qualities, not living up to certain values, or not fulfilling certain needs. Sometimes we ourselves feel like the new moon from the cartoon: empty, downhearted, and lacking. We can identify with this hollow state, as if that is who we really are in our core. But how we choose to view ourselves depends on our perspective—how we position ourselves in relation to the sun, and how much light, or attention, we shine on our world.

Regardless of whether we feel empty or full, we do continue to care. At least deep down. These universal human needs matter to us. The very longing of the new moon to be full again is a sign that those needs are hidden and unattended to, but not absent. We can strive to fulfill our needs, to shine the light of our attention on ourselves or others like the new moon, to reveal our wholeness, and to recognize our wholesome needs and values. Because when our needs are fulfilled, we feel like the full moon: glowing and full of radiance.

On days when I was able to hold this perspective, I never heard Dory complain. I never heard an accusation, and I didn't feel blamed for anything. In whatever words she used, I understood her to be expressing her needs. I heard how much she cared about being part of it all when she said things like "You bought those tickets without even telling me." Hearing someone say (or imply underneath it all) that they care about the same things we do is connecting. It brings us together. I find this perspective much more fulfilling than fixating on accusations. By bringing her needs to my attention, Dory was enriching our relationship with these qualities. Calling for our needs or values is like a call for life, for growth and maturity.

Originally I was missing trust and wanting Dory to have more faith in me. When I became aware that trust was what I cared about, I was able to become more trusting myself. I trusted that in her heart of hearts, Dory simply wanted her needs to matter too. We can embody the very things we wish for, and that's how we light up the darkness. Seeing ourselves and others in light of universal human needs makes connection inevitable—this was Marshall B. Rosenberg's message to the world.

Rosenberg's principles of Nonviolent Communication help us focus on what we value and find meaningful. They offer a bigger perspective on how to enrich one another's lives by discovering what motivates us, and what needs we are striving to fulfill. By illuminating our needs, we highlight their positive value. In relating to those with dementia, we can focus on skills they have and qualities they display, always striving to assume their wholeness.

All of us long for this full-moon sense of fullness and completeness that makes life worth living. It also makes life worth sharing.

We long for a sense of fullness and completeness that makes life worth living. It also makes life worth sharing.

COMPASSIONATE PARTNERSHIP

Sharing a life with someone who has dementia can enrich your life as well as theirs. People with dementia have full capacity to contribute to our well-being, or to our misery, depending on which perspective we have.

When our perspective is narrow, we generally don't see a person with dementia as someone worth sharing our lives with. I have witnessed many embarrassed, confused, uncomfortable, and at times horrified looks on the faces of people who simply did not know how to engage with someone who has dementia. People generally try to be sympathetic, and nice enough, but they also try to escape as soon as possible. Like I did with my great-grandmother. I left because I didn't know how to relate to her repetitive comments and confused statements. And I'm not alone. Many family members of people with dementia distance themselves, not because they don't care but because they don't know how to relate. I saw my clients' long-awaited visits from family turn into quick, fifteen-minute drop-ins. And the less a family member was able to relate, the greater the distance that grew between the relatives. Even close relatives can become strangers to one another over time.

On the other hand, the more connection we have in a relationship, the less we find differences in each other. We are able to see the person, with all their intact qualities, hidden behind the dementia. If we insist on perceiving a person through what their brains *can't* do, and evaluating them based on cognitive performance only, we may become so fixed on what *isn't* there that we miss altogether what *is* there.

If we become used to talking about and hearing about dementia in the context of suffering, damage, and misery, we will become used to thinking of those who have dementia as helpless, pitiful victims. We are unlikely to see "dementia victims" and "those suffering from dementia" as people with whom we can be in partnership. We will feel sorry for them, endure their company, and pass them by.

These expressions generate pity, not compassion. When we feel pity in a relationship, we categorize one person as pitiful, weak, and somewhat lacking, while in contrast the other person appears capable and "knows better." This sets up a dynamic of patronizing and infantilizing attitudes toward those with dementia, and that only makes our disconnection worse. This dynamic increases the feeling of dependency on the part of the person "suffering" and, in turn, increases the burden felt by the "capable" one, if they come to feel that all responsibility is now on their shoulders.

In these scenarios, those of us who have full mental capacity may experience a sense of having power over those who don't. This often comes with a sense of duty toward the other person, and feeling accountable for their health and physical condition. It's easy to put all that power and responsibility into making sure the person with dementia is in good physical condition—meanwhile, we forget to relate to them and to share the power we both have to make the relationship meaningful. This is another way to treat a person with dementia as pitiful, disabled, and lacking.

Pity is disengaging. People who pity others may attend a fundraising event or donate to a charity, but often they don't pay attention to those they are trying to support. In contrast, compassion is about togetherness. And it comes at a cost: it costs the value of our presence and empathy. Attention and presence are the most expensive, luxurious gifts we can give one another. Even though they don't cost money; they save so much of it! Engaging with another person in partnership not only provides a sense of togetherness, it can heal common symptoms of dementia such as emotional distress and challenging behavior. A content and connected dementia relationship can save nerves, time, and money—all needed to manage the many distressing situations in dementia care. Teaming up with the person you care for will make you both stronger, and you can share the power of your relationship.

But if we don't see someone as a partner, we won't know how to engage with them honestly. Pema Chödrön, author of *The Places That Scare You: A Guide to Fearlessness in Difficult Times*, puts it in the following words: "Compassion is not a relationship between the healer and the wounded. It's a relationship between equals. . . . Compassion becomes real when we recognize our shared humanity."

So calling someone a "dementia sufferer" or saying that someone is "suffering from dementia" harms the relationship by bringing pity and power inequality into play. These are highly inadequate expressions for several other reasons as well. First, none of the medical conditions that fall under the umbrella term *dementia* cause physical pain or emotional hurt for the person with the condition. Second, some people with dementia live well without suffering. The “suffering” that ensues may belong more to the relatives, friends, and care providers than to the person who has dementia. Finally, people with dementia do not want to be described as suffering. “Nothing about us without us” is a message they want people like you and me to understand. Let’s not talk about them as if they can’t enjoy life and personal power.

One summer when I was staying with Yvonne, her house was undergoing some (very necessary) work on the roof. That meant the house was wrapped in a net of scaffolding, and every now and then, workers’ heads popped up through the windows. The family had warned the workers that it was better to stay out of Yvonne’s sight, but she was rather observant. Besides, how can you hide scaffolding from the eyes of a house dweller?

As it happened, Yvonne was unnerved every time she discovered, to her great astonishment, the scaffolding and the people on it. What were these people doing climbing around her private house as they pleased?

Despite being told about the work on the roof, and having it explained to her on several occasions, Yvonne’s agitation was stimulated again and again whenever she rediscovered the strange happenings outside her house. One day she decided to put an end to it, and she requested that I take her in her wheelchair to speak to these unwelcome guests. Which I did. A couple of workers, a woman and a man, stood there utterly frozen in confusion when Yvonne, firmly and definitively, told them off for intruding on her private property and demanding that they should all leave at once. She shouted, in her slightly throaty voice, “I wish to not see you again! You are to go away as soon as you get this ugly construction of yours from my house!”

The workers did not know what to do, or what to say. As far as they were concerned, they were hired to do a job, which they were dutifully doing. They did not respond to Yvonne's words at all, but she didn't care. I got her back into the house, and she appeared to be very pleased. "Now I've told them!" she said. I do believe that as far as she was concerned, her need to stand up for herself and to be heard was utterly fulfilled.

In a conversation later that day, I realized she did not in actuality want the workers to stop. It was true that she did not understand the necessity of it, but that wasn't what troubled her. It turned out that she wanted to be acknowledged as the owner of the house. To be seen and respected. In the end, she didn't care about the wretched scaffolding.

I went back briefly to explain to the workers about Yvonne's condition, and I told them what I had learned mattered to her. In response, I heard, "Poor lady." They felt pity for her.

This response was inadequate to Yvonne's situation. She wasn't "poor" in any sense of the word. She wasn't suffering, for a start—her health at that stage was pretty good. In terms of her finances, she was living comfortably. Moreover, Yvonne was decidedly not miserable; she was quite pleased with herself that she had told the workers off!

We requested that the workers report to her periodically to explain what they were doing in and around her house. She wasn't quite able to comprehend what was being explained to her, but again, that wasn't what mattered. Being acknowledged mattered. After being acknowledged, despite that she regularly forgot what the scaffolding was doing on her house, as if she had never seen it before, she remained much more settled in her emotional reaction to it. The workers' reports seemed to have truly met her need for recognition.

The fact that Yvonne had needs for recognition and acknowledgment did not make her weak or needy. Expressing her needs was an act of independence that showed how much personal power she was still holding, and that she was not letting it go. Her awareness of the needs and values she cared about had made her stronger and more empowered.

To dissolve the fake division between the “poor sufferers” and the “normal,” we need to consider that dementia affects both parties in a dementia relationship. At times a relative, friend, or caregiver may carry a much heavier burden; they may suffer more than the person with dementia suffers. The person with dementia may be having a good time and feel more content and satisfied with themselves than ever before—which is to be celebrated. At the same time it is important to realize that a happy person with dementia does not necessarily result in a happy dementia relationship. The caregiving spouse, family member, or friend may still be strained. They may still experience overload, overwhelm, and overburden—emotionally, physically, financially, socially, or on several levels at once. This feeling of overload may not be understood by the person they care for, as people with dementia often release themselves from all responsibility for shopping, cleaning, personal care, or feeding.

A happy person with dementia does not necessarily result in a happy dementia relationship.

Thus dementia has an indirect effect on the caregivers of those who are directly affected. The needs of both parties have to be taken into account to build a genuinely fulfilling dementia relationship.

Dementia by itself is not a cause of suffering. Rather, the suffering, or ill-being, is the result of unfulfilled needs—often needs that nobody is aware of. A person’s ability to adequately meet their own needs may be affected, even severely affected, by the disease. But the physical or mental condition of the brain on its own is never the sole cause of unhappiness.