



## Focusing Imagination

*You can't depend on your eyes when  
your imagination is out of focus.*

—MARK TWAIN, *American author*

What's the first step to making something happen? The very first step is to picture it as a possibility. In this way you set your eyes on the destination: a satisfying relationship with someone who has dementia. A relationship which keeps your connection alive.

Such a relationship requires both imagination and compassion. With imagination, we consider how others might experience the world. With compassion, we focus on how their experience of the world affects them. If imagination is the mind's eye, then compassion is the heart's eye. In a relationship with someone who has dementia, we need both.

Indeed, when dealing with dementia, we often need to draw on all resources available.

## IMAGINATIVE COMMUNICATION

Starting with a pinch of imagination can be very helpful when trying to decipher some of the unusual behaviors associated with dementia. In fact, imagination might be one of our mind's best tools for reaching out to others, for understanding what appears to be beyond understanding.

You cannot assume that a person affected by dementia perceives the world the same way you do. You might see a bath filled with bubbles. They might see a boiling volcano. Imagine that. When it's hard to get your head around what's happening, focus your imagination. For clues about how dementia is affecting the person in front of you, pay attention to how they relate to the world around them.

Both of you will be affected by what you perceive in different ways. That warm bath full of bubbles may appear very comfy to you, but very scary to someone with dementia who fears losing control and wants to guard their intimacy and autonomy. Besides, who would want to get into a volcano naked? That would be rather uncomfortable.

Yet the very same person may be perfectly comfortable wearing their underwear not underneath all their other clothes, but on top, whereas you would find such a situation embarrassing and might long for a bit of consideration.

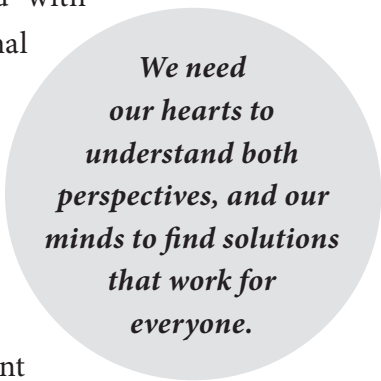
Dare to imagine how another person might be feeling, what they might be needing, and how you might be able to contribute to their well-being. Without forgetting yourself either. You're growing a heart big enough to understand both perspectives, and a mind resourceful enough to find solutions that would work for both you and the person you care for.

In this chapter, I will tell you some stories that come from my

relationships with four people who have dementia. Each one of them required full-time care, due to their dementia and often to other accompanying conditions. I stayed with them in their homes, as a professional caregiver, for several weeks at a time. As I shared their lives for that time, in a sense I shared a life with dementia. And I learned how it can affect everyone involved.

Each person I cared for was affected by the disease in a different way. I have learned that there is no “standard” or “by the book” case of dementia. Dementia occurs in people over age sixty-five, and in younger people too. It can disable someone from recalling what happened only five minutes ago, while they have no problem describing in detail something that happened fifty years ago. One person with dementia may be unable to hear what you say to them right in their ear, while another may be disturbed by the distant noise of a plane eight thousand feet above them. Dementia is full of paradoxes. Nobody who has it seems to feel obliged to follow any “rules” of the disease—as if there were any in the first place! Instead, each person might as well be saying: I will do this illness my way, thank you very much.

One very important characteristic of dementia is that its symptoms are likely to be inconsistent even in one person alone. Some of my clients had severe memory or perception problems one moment, only to be entirely clear-minded the very next moment. For a caregiver, this is both unsettling and lifesaving. It is unsettling because it keeps you on your toes: you can never know quite what ability or disability to expect. Yet this inconsistency also gives you many second chances to approach a scenario more



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skillfully. If things didn't go well the first time you tried, you can try, try again.

Using your imagination on a daily basis could make your care routine more exciting, leaving room for some unpredictability.

It is unimaginative to assume that because someone can't make a decision one day, they will never be able to make that decision, or that they have lost the ability altogether. Yet too often, tragically, people try to treat someone with dementia "equally," where "equal treatment" means treating someone in each case as if it were their worst day. Approaching someone with dementia from this perspective can be both debilitating and deeply depressing. This chapter explores how to approach someone with imaginative openness instead.

So now I have the pleasure of introducing you to my unpredictable clients: Gordon, Clare, Dory, and Yvonne. Four people with dementia with whom I formed dementia relationships. I spent more time with some than others, and some relationships felt more personal than others, but in each case my client and I figured out how to relate to each other in a way that created a meaningful connection. Sometimes quite unexpectedly.

Ultimately, these four people were my best trainers in imaginative communication skills. They taught me how dementia can affect people's ability to remember, view, observe, and foresee reality, as well as how it indirectly affects caregivers—in this case, how their dementia affected me.

## THE MAN WHO FOCUSED MY IMAGINATION

Gordon had worked for half a century as a village vet, and along with his wife, Jenny, he shared a dislike of the city lifestyle. They had both been very hands-on country people, managing their land

and their household together until Gordon's health deteriorated after a stroke that resulted in early onset of Alzheimer's and reduced mobility. Since that time, Gordon needed company whenever Jenny could not be with him.

He walked slowly, and I had to walk with him and watch his steps, as he had fallen several times in the past. Also, when walking, he often stopped abruptly and watched the floor very attentively.

The first time I noted this, we were on our way to his bedroom, both rather tired at the end of the day. He stopped for no apparent reason, and I tried to be patient and encouraging. "Gordon, we're nearly there," I said. "We just need to cross the hall."

He did not respond, but maintained his attentive gaze on the mosaic of the corridor floor. I wondered whether he had suddenly felt some pain, or maybe he had stopped to remember something, because I couldn't see anything on the floor he might be staring at.

In other words, I couldn't see what he was seeing.

So I reminded myself: When my eyes are of no use, let me try my imagination. And instead of hurrying him up, I paid attention. I became interested. I focused my eyes right where he was looking.

Paying close attention to someone is like paying a visit to their world.

Perhaps this focused attention encouraged Gordon to explore further, because he then moved his right leg forward, tapping the area under analysis with his foot, as if double-checking the surface. Then he suddenly remarked, "You know, for whatever reason, my brain wants me to believe there is a hole in front of me. Right here, you see? But I can feel with my foot that it is a solid surface. How very odd!"

Gordon found the way that his senses presented the world to him to be very amusing, and he began to share these observations with me. Each time was a discovery for him and an amazement to

me that he had this double perspective. On one hand, he saw black holes all around him, but on the other hand, he was able to question whether they were truly there. He was relaxed, not disturbed by it. Just a little bemused each time.

What I learned from this experience is that a person's observation is less important than their response to it. Gordon was amused. Everyone needs fun in their life, and Gordon's study of the holes in his floor met this need for him.

When he shared this amusement with me, he also met a need for companionship. I wouldn't, on my own, have conceived that a perfectly even floor could be taken for a bottomless black hole. But I could imagine that this was surprising and even in some way fascinating. I could also imagine that to someone who did not have Gordon's curiosity and confidence, such faithlessness on the part of the floor might be frightening—something worth bearing in mind the next time you witness someone hesitating to cross a black doormat or a patterned carpet. Their stuckness may not be a matter of stubbornness but an inner battle between reason and perception. Is the abyss real? Should I fear it, or have the nerve to walk across it? The answer depends not only on what they see but also on how they see it. Frightening or entertaining? There is only a fine line between the two.

I admit that some days I was not excited at the prospect of examining the floor again. There were always household chores, more or less urgent, that needed doing. And sometimes I was simply worn out. I often chatted with Gordon over supper, and at times I expressed what was on my mind or how I was feeling. After I shared what bothered me, Gordon rarely needed any extra prompting from me. I did not need to hurry him up. If he was aware that I had no extra time that day, he slalomed around the black holes in the floor without discussing the status of their existence. He did not need

to be reassured, calmed down, or convinced that the holes weren't there. It was easier to walk around them.

To connect with Gordon, I had to meet him in his world. I had to visit him there, through the power of my imagination. My mind's eye then allowed my heart's eye to hear his feelings of amusement and wonder. I was imagining, he was seeing, and through this connection, both of us were able to enjoy a sense of companionship.

With Gordon I learned that connection is possible even between people who are not necessarily the best of friends. We two had our differences, in worldviews and life philosophies. His favorite hobby had been shooting animals for sport, whereas I was horrified by the idea of killing a sentient being. But we had a good time together. A friendly relationship is not the same as a friendship, and yet both can connect two people in peaceful companionship.

## THE WOMAN WHO MISTOOK ME FOR A PHONE

Clare's natural environment was her garden. It was her creation, and something that kept her alive in return. After many years of a demanding career in banking, she changed gears and chose to retire in a secluded area. She thrived on being surrounded by greenery and beautifully kept grounds, which made it even more unfortunate that her vascular dementia affected her vision. She was still able to encompass the view over her carefully designed flower beds and rows of bushes, but smaller details had become more difficult to comprehend.

She lived alone, and I stayed with her for several different periods over the course of a year, witnessing all four seasons of her garden. I learned that Clare's ability to see individual objects clearly, and to recognize them for what they were, was more changeable than the weather.

One day as we sat in the living room doing crosswords, Clare dozed off as usual. I continued doing crosswords in my book on the table, with Clare drowsing next to me in her armchair. Suddenly she woke up and looked around. She looked at me but right through me—she didn't seem to see me at all, even though I was only an arm's length away from her.

She grabbed my left hand from the table and lifted it.

I froze, not knowing what was going on. But I didn't make any sudden moves, not wanting to scare her. Judging from the look on her face, she wasn't aware I was even in the room.

She put my hand next to her ear and said, "Hello?"

Once I realized that she had mistaken my hand for a telephone, I said, as gently as I could, "Clare, I am here."

She continued talking to the phone. "What? Where are you? Speak louder!" In her own quiet manner, she was, in fact, shouting at my hand.

"I am right here," I said, and I moved toward the center of her field of vision. (I later learned her vision was better on her left side, while I had been sitting on her right side that day.)

When Clare saw my face, and that there was a hand attached to it, she was not amused. She hid her face in her own hands in resignation and gave a deep sigh. She may have felt stupid, or indignant. Instead of laughing it away, or trying to convince her that nothing had happened, I tried to imagine what it might have felt like for Clare and empathized the best I could. "You seem dismayed . . . Is that because you would like to understand what just happened?"

While Clare may have lost some of her visual skills, she never lost sight of her own needs. On many occasions, I heard her mourn her loss of vision and long for clarity and understanding. We went to medical doctors and optometrists, and she explained to them



and to me that “the objects around me keep moving; they don’t stay the same.” A phone suddenly becomes a person, for example. Many other times she mistook me for a hairbrush or a chair to sit on. My arms were mistaken for a belt to put around her waist. To me this proved a point made by Gerald Edelman, an American biologist, who said that every act of perception is to some degree an act of creation, because it depends so much on both what we see and also how we interpret what we see. In his book *The Man Who Mistook His Wife for a Hat*, Oliver Sacks describes neurological cases of patients who misinterpreted people for objects, and vice versa, similar to how Clare confused my hand for something else entirely.

Clare was worried and perplexed, as anyone might be in such circumstances. After several conversations, together, we guessed that her worry arose from her need for safety and dignity. Understanding her unmet need was important. I had to do more than imagine her feelings of confusion, perplexity, and fear. It was when we recognized that she longed to feel safe in the world—“which moves around a lot”—that we were able to come up with ideas to make this world safer and more stable for her.

One strategy was for me to say, “Hi, Clare. I’m here, by the window”—or wherever I was at the time—as soon as she entered a room where I was. Before I was mistaken for a phone, I hadn’t imagined that I would not be visible to someone who wasn’t blind. I had assumed she would see me for herself.

I also moved my armchair to sit on her left, where she could see me more clearly. And whenever I addressed her, I held her hand. This provided her with a sense of support, an arm she could lean on, something stable and reliable.

These strategies helped, but the primary building block contributing to Clare’s sense of safety was our communication, and the trust that we built over time. Communication and trust

made it possible for us to come up with doable solutions that we could introduce straightaway. They were specific, as in, “When I talk to you, I will hold your hand so that you know where I am, and that I am next to you.” These little things created a bond between us, on many levels. And they helped me realize that Clare was good at growing many kinds of things, including our professional relationship, which grew into friendship.

This relationship met my need for contribution and mutuality so deeply that often I felt more uplifted and replenished after spending time at Clare’s than when I had my time off. Many times we switched roles in a sense. If I confided in her that I was suffering from period pain or was in a low mood, she expressed genuine empathy and care. She cared about me, though of course she did not care *for* me. If Clare offered me a cup of tea for comfort, I was the one who made the tea. Did that matter? I had more physical ability and more trustworthy eyesight, but care went both ways between us. We cared about each other.

When two people connect through communication and trust, both people are more likely to be flexible, imaginative with solutions, and willing to stretch a little. But sometimes you hit a boundary, a situation you are not willing to go along with. This is a time to say no.

## THE WOMAN WHO HEARD MUSIC IN MY NO

Dory was a retired music teacher whose passion for music led her to live a short distance from a concert hall. As close as it was, it wasn’t within walking distance, and public transport wasn’t conveniently available. She needed a car to get there.

Although Dory was the fittest of all my clients, both physically and mentally, she was also the least aware of her dementia.

Her mental abilities, such as understanding her surroundings, multitasking, problem-solving, and decision-making, were seriously compromised, and Dory herself was almost utterly unaware of her brain condition. She was very well aware of her other health problems, such as sensitive skin and heart arrhythmia, but she appeared to know nothing about her Alzheimer's. She would even forget she had forgotten about it.

But her family and friends (of whom she had many) were aware of her condition. They also recalled the story of a man with dementia who drove into a group of people crossing the street, because he confused the accelerator for the brake.

When Dory's trusted friends got together with her to discuss her declining ability to drive, she eventually made the sensible decision to sell her car. At the time, with everyone present and with all facts on the table, Dory, I was told, had been perfectly okay with making this decision, which was documented in writing with her signature on it.

After a very short time, all these facts had left Dory's head for good. The absence of her car was highly upsetting, and any attempt to present her with the written documentation of the circumstances and reasons for selling the car unnerved her. Family and friends made all the necessary arrangements for Dory to be able to attend her weekly concerts, and this was regularly erased from her memory.

When I met Dory, she was still very tormented about the car, which she noticed missing on a daily basis. "You see now that I don't have a car, I can't go to concerts anymore," she would say. "I haven't listened to live music for months now. Would you help me get my car back?"

Her observation wasn't factually accurate: she had not missed any concerts since the car was sold. The loss of her own vehicle was

not preventing her from going to the events. Furthermore, getting the car back was practically impossible and something I wasn't willing to help her do anyway. I shared her family's concern for her safety and the safety of others around her.

So far, the situation seemed impossible to solve because it was based on a false assumption and an inaccurate observation, and it involved a demand I didn't want to fulfill.

Assumption: "Now that I don't have a car, I can't go to the concerts." (Not accurate.)

Observation: "I haven't listened to live music for months now." (Not accurate.)

Demand: "Help me get my car back." (I said no.)

I was unable to make Dory see the inaccurate assumptions and observations she was making without confronting her, or questioning her sanity. I felt frustrated that there was no reasonable way to explain to Dory why she could not drive again. How I wished for some understanding on her part! I was stuck, and annoyed—until I realized that instead of trying to convince Dory about how mistaken she was, I could simply listen to what mattered to her the most.

What I learned from Dory was that to be on the same page with her, I needed to address directly the very thing she cared about the most. Safety wasn't Dory's primary interest. What mattered to Dory was that she could trust there would be a way to get to her concerts.

In other words, I didn't need to get stuck in my own false assumption that the only way forward was for Dory to understand *my* reasons and observations. Instead, her ability to reason could be replaced with her ability to connect.

Listening to Dory made me realize that live music was so important because it was, in a sense, keeping her alive. Without

music, there was no point to her life; that's how meaningful music was to her. The car was simply the strategy that she associated with the thing she lived for—music.

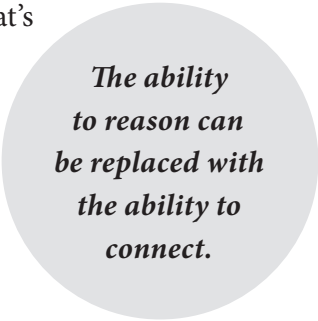
This made sense to me. I was able to understand what was beneath her anxiety about the car and her longing to attend musical events.

The first conversation with Dory in which I expressed genuine interest in the importance of music seemed to settle her a lot. She felt heard and understood. But she then made the assumption that because I understood, I was therefore going to get her car back. It is so easy to jump to the conclusion that someone who understands us will do what we want.

But Dory's need for feeling alive and uplifted wasn't the whole picture. I also had my own needs, such as for ease and safety. And I was going to say no to Dory's wish for her old car.

I once watched a television program about hotel services, and how staff members were trained to never say no to a client. One receptionist said it was his personal ambition to never refuse his client anything, whatever they wanted. I thought to myself: What is so frightening, or offensive, about saying no? I suppose people may think that saying no can imply a lack of respect, or lack of consideration to someone's needs. The lesson I learned was that if I am not prepared to go along with someone's request or demand, ensuring the person knows I care about their needs will help our relationship. If I acknowledge my own needs too, we become partners in our relationship.

So I said no to Dory. I said no, I would not help her get her car back. I stressed that I cared about Dory's needs as well as mine. That I wanted to support her in getting to the musical concerts, and



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that I would be so much more relaxed if we drove in my car. Saying no to helping her get the old car back was my way of saying yes to a relaxed time together, when we could both enjoy the beauty of live music. “How does that sound?” I asked her.

Upon hearing this, Dory seemed touched. “Would you really enjoy taking me? It would be wonderful to share the time together, and it would free me of the trouble of getting my old car back,” she said. Hearing the pleasure I took in supporting her to stay connected to her musical passions was in itself music to her ears. In truth, she didn’t care about the car at all. Once we were able to get to the bottom of this—her passion and my need for safety—we found a solution in no time.

This solution was not a new one. In a sense, we reinvented the wheel because it wasn’t the first time Dory had been driven to a concert by her caregiver. But this time, she was easy about it. And she stopped mentioning her car so often afterward. Connecting to both of our needs kept us on the same page even when facts and assumptions were unreliable and fleeting. Our connection was, in a sense, unforgettable.

Dory didn’t remember my name, nor did she know who I was or what I was doing in her house. She didn’t think I was her caregiver, because to her best knowledge, she didn’t require any care. However, because of the connection we made with each other, she assumed I was a friend. In her mind, why else would she feel warm toward me, and why would I be staying at her house? People tend to be kind to their friends, cooperative and easygoing, and open to discussion and different solutions. They care what their friends need. She wasn’t thinking of herself as a customer at a posh hotel where every wish was a command. Rather, we were friends. At home. Together.

In this way, I and other friends involved in caring for Dory

met her needs while also fulfilling our own values of contribution, collaboration, and friendship.

## THE WOMAN WHO PUT MY IMAGINATION TO THE TEST

“You’re being thrown in the deep end with this client,” I was told when assigned to work as a caregiver to Yvonne. “Your soft approach won’t work with this one. You have to make sure you follow the procedures to cover your ass in case there’s a complaint. This client has made complaints against caregivers in the past, so watch yourself.”

Yvonne was once an owner of a highly rated beauty salon, but since living with dementia she was better known for her “challenging behavior.” This judgment was based on the numerous occasions when she had expressed her agitation by hitting, or at least trying to hit, the people around her. During her latest stay at the hospital, Yvonne had been aggressive toward staff members and had often been tamed with drugs. Now back at home, still bedridden, she was getting her strength back. But she had not yet recovered from her fury.

That night, as I was about to take over from the previous caregiver, I heard her screaming, “Take me home at once! Can you hear me?! Get me out of here! You wretched, stupid woman!”

Yvonne was in a state of anguish, which she was expressing through violence and verbal abuse toward the caregiver who was desperately trying to calm her down in her bedroom. I made my way in to investigate, and I witnessed a conversation in which any attempt to make a clear observation failed tragically.

“But you *are* in your own bedroom. Look around,” said the caregiver in a loving voice, trying not to contradict the woman

who could not recognize the bedroom in which she had slept for the last thirty years. “Look at the picture of your late husband. You recognize him, don’t you?”

“You stupid woman! This is *not* my bedroom!”

At this point Yvonne’s tantrum reached its peak as she tried her best to be aggressive, even while her weak, ninety-seven-year-old hands failed to succeed at what she intended: to hit her caregiver. She was ready to persuade the caregiver by force that her own perception of the room was correct.

Whatever Yvonne was observing was not being acknowledged. But even if the caregiver played along with Yvonne’s delusion, how could she do what Yvonne was demanding? How could she take Yvonne “home” when they were home already?

I exchanged looks with the caregiver. I could see she was at the end of her wits; she’d had a long day. And Yvonne’s demand was simply impossible to satisfy. But let’s try it anyway, I thought.

After pausing for a few minutes, I approached Yvonne, who was helplessly waiting to be saved from the bed in which she had spent countless nights over the last few decades. Pausing usually helps to cool the heat of the moment, helps the storyline to fade a little. But the anger was still there, smoldering.

“Are you upset, Yvonne, because you feel you are not being heard?” I asked.

“I just want to be taken home. At once.”

“I would like to help you do this—but I need your help, as I don’t know how to get you home. I don’t know where it is.”

“That’s all right, I know how to get there,” she said. “Will you take me?”

The tone of her voice changed immediately. She had gone from seeing me as a caregiver—since she was unable to differentiate faces, we represented a function—to seeing me as an ally. Simply



engaging with her about what made sense to her, without confronting her with facts, made her relax. She felt understood, and so already there was a certain level of connection. That's how our cooperation began.

"Let's get you in the wheelchair so that you can show me how to find your home," I said.

Now she was acting as if we were setting off on an adventure, sailing off into unknown waters, with me turning the wheel and her setting the direction. Her power and sense of self-governance was back with her. She was at home with feeling in charge.

We headed through the corridor and out the front door. Looking back at the house from the garden outside, she said to me, "That's my house, you see!" As if all this time she had been kept elsewhere, in some other, unfriendly place where she was powerless and useless. Now, feeling empowered and useful, she also felt at home. It was right there. As the novelist Cecelia Ahern has said, home isn't really a place, it's a feeling.

Yvonne wanted to show me around her newly discovered family home, where I was treated more like a guest. We went back through the same front door we'd left several minutes earlier, except this time Yvonne guided me through the corridor—she knew the place well—and back to the bedroom, which not long ago had felt like an unfamiliar place. But now it felt like home.

She became thankful, warm, and calm, treating me like a friend. Although in many ways I still remained a function to her, at least I was a useful, friendly function. A function she treated more like a human than a robot performing tasks.

Yvonne went to sleep within minutes of me putting her to bed. I was relieved and astonished and, admittedly, I giggled to myself. What a way to meet a need for autonomy! I would have never imagined!

Since then, Yvonne astonished me many more times. Gradually, she began to recognize me as a person, and became very attentive to my needs. “Go and rest your legs, dear. You must be tired,” she would say after we came back from a stroll in her wheelchair through the neighborhood. She frequently offered me gifts, which I later put back in her jewelry box, so that she could offer them again soon after, without any recollection that we had done this exchange before. I never kept any of these objects; instead, I confess, I kept something far more precious—our connection.

I kept that connection close, right through the outbursts of anger or fear we experienced again and again, the periods of constipation and diarrhea, the bed falls and hallucination highs, the expressions of love and hate. It was rarely easy. And yet, from a bigger perspective, it was so worth it.