

## Tuning In to Anger and Confusion

You know, one of the tragedies of real life is that there is no background music.

-ANNIE PROULX, American author

utbursts of anger accompany some of the tragic events of almost everyone's life. Anger, anguish, and confusion are loud emotions, which scream and howl to the point that no one can hear the music. When it's not you but a person you care for who is angry, it's very difficult to take in, unless you tune in to what's behind the feelings.

Anger, despair, and anguish are emotions that are inflamed. Any emotion left ignored for long enough will desperately seek attention. It will do what it must to get someone to notice that some needs have gone painfully empty and unfulfilled. An emotion that is ignored long enough will set itself on fire.

Unfulfilled needs are often painful. And we all make the mistake of looking outward for someone or something to blame for our pain. But doing so doesn't fulfill our needs. It doesn't

bring us any closer to the real cause of our despair. People angry at dementia proclaim war, and gear themselves up against it. Projecting anger outward—at scientists for not coming up with a cure, at the government for not offering more support, at care services for being inadequate—may prompt you to take collective political action.

But until we address the real cause of our feelings, the suffering will continue to consume us from within. And it will be counterproductive: anger saps rather than strengthens our resources and abilities to do something about dementia.

Blaming ourselves doesn't help in the slightest either. It usually makes things even worse. Angry people who turn their pain inside or attack themselves with self-hatred will slide into the darkness of depression. Directing anger inward in self-hatred is a dead end. Often literally.

When you have your own anger to deal with, the tools in Part Two of this book can help. But what will help you deal with the anger, despair, and confusion expressed by someone with dementia?

## UNCOVERING THE NEEDS BEHIND ANGER

Yvonne went in for a general checkup and ended up staying in the hospital much longer than expected. She had encountered very friendly staff, you see, all telling her, "Now be a good girl and sit still" or "Stand up for me, love." Well, Yvonne wouldn't have any of that. After all, she was a lady, she had her pride, and she found this kind of speech that "we're all mates here" infantilizing. She got really, really angry, and then tried to kick the nurse who was helping her. She kicked hard, but blindly, and instead of reaching the person she was aiming for, each time the nurse approached, she kicked out and her leg hit the side of the hospital bed.

She must have done it several times, and with all her force, stoked by anger. This violent expression of anger and anguish left Yvonne with a deep, bleeding wound on her leg. A wound that required even more interactions with nurses and a much longer stay at the hospital, where she continued to be referred to as "love" by strangers.

How often do we hurt ourselves when we express anger unskillfully? When someone expresses explosive emotions violently, both parties get hurt. Often the attacker is in as much pain as the person whom they attack. Indeed, they must be in pain already to have become so angry in the first place.

There is only one reason people with dementia experience anger and other explosive emotions, and it's a very good reason. They are angry because they have beautiful values inside them that demand to be acknowledged, not because they have a short temper.

When their needs aren't being met, their anger will remind you. It is your wake-up call.

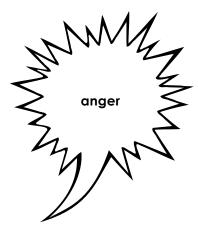
When Yvonne expressed her anger at the nurses for doing things to her that she couldn't comprehend, or talking to her in a manner she found condescending, she

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was longing—deeply—for clarity and respect. These are needs she had been missing terribly since dementia began to change her cognitive abilities, since she had to rely more and more on others. I am sure the nurses tried to explain what was happening to Yvonne and did not mean to be disrespectful. They knew about her dementia, and to put things plainly, I expect they turned on the childlike speech I have heard so often among medical professionals.

None of that landed well with Yvonne. And so no one's needs were met—not Yvonne's and not the nurses. Needs can't be met if neither party is able to acknowledge them. Fortunately, it's not necessary for both parties to be capable of acknowledging their needs—it's enough if you are able to guess imaginatively what matters to the other person.

Fran's friend Diamantina lived in a residential home, where staff reported her to be "difficult" and to exhibit "challenging behavior." And isn't this exactly what they expect from someone who has Alzheimer's? "Difficult behavior" and "outbursts of anger" are often associated with the illness, in a way that seems to suggest that dementia is the source of the explosive emotions.



According to Nonviolent Communication, anger is always about desperation to meet needs. Dementia merely makes it harder for someone to communicate those needs.

What needs might have prompted Diamantina's "difficult behavior"? On several occasions Fran witnessed her friend at the table for a meal, and when bits of food remained on her face, one of the staff came around and mechanically wiped Diamantina's face. They did this merely to keep up their care standards, but without any communication. This left Diamantina looking spotless but

feeling resentful. She did not welcome people—strangers as far as she was concerned!—keeping up *their* standards by using *her* face! As the situation repeated itself, her resentment grew bigger and bigger, along with her needs for consideration, privacy, and choice.

It was no surprise to Fran that her friend's feelings exploded and resulted in incidents of outburst and conflict. The same staff who labeled Diamantina "uncooperative" were not building a sense of partnership with her, but the exact opposite. This is another example of choosing a strategy whose results are the exact opposite of what is wanted. The staff members who longed for cooperation went about wiping Diamantina's face without her collaboration. How should that bring about any sense of partnership?

It is very common in the human species to confuse a wholesome need in us with the things we want to do to meet that need. In this confusion, this gap between *what* we need and *how* we fulfill that same need, we all—with and without dementia—go seeking things that won't give us what we truly long for.

Professional care providers often try to *make* someone with dementia cooperate. Aggressive solutions such as using restraints or sedatives on patients with dementia—though discouraged in many countries—are still common practice. I see it as a sign of how helpless many dementia care professionals feel. We come up with these unfortunate, misguided ideas when we are not listening to needs carefully enough—our needs or the other person's.

Any caregiver can probably relate to the sense of helplessness when faced with anger from someone they care for. They want the person to be at ease and to calm down. But whether the caregiver achieves this outcome depends on how they go about it.

Strategies such as restraining and sedating, which are meant to be effective, are counterproductive in the end. People with dementia often respond to these strategies by becoming more violent or withdrawing to such an extent that they require even more direct personal assistance and staff time. This violent pacification is a sad contradiction in terms, where "violence" and "peace" appear together. I believe there is no peace where there is violence.

To find more imaginative solutions than violent pacification, it is worth considering that dementia is not responsible for anger or aggression. None of the distress and despair is ever caused by Alzheimer's, nor is any other dementia responsible for someone's cry of anguish. A person who has dementia may have more difficulty expressing their own needs clearly, but their ability to value personal choice and consideration isn't affected by the illness, not even a little bit. People have needs, with or without dementia.

Expressing our needs skillfully means expressing them nonviolently. Nonviolent Communication teaches us to hold on to the awareness that anger and other explosive feelings are caused by our human needs. If someone's language or communication skills are compromised, and we cannot rely on them to clearly recognize and express their needs, we can help by receiving anger skillfully. Because communication is never just what people say, it is also *how* people hear what is said. And the ability to hear anger empathically may be our most powerful nonviolent tool. No one gets hurt.

Of course, we should handle explosive substances with great care, and take the precautions of self-empathy.

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And we should take extra special care when handling someone who's holding anger in their heart and a sharp tool in their hand.

I once found myself confronted with someone's anger, and though I did not fear for my own safety, I did suspect potential injury. I had found Clare in danger of hurting herself by doing her favorite activity—gardening. We were in the garden, Clare's kingdom, when I saw her holding a pair of pruning shears she had somehow managed to get hold of. I knew that Clare's vision was seriously compromised, and it wasn't often that she was able to zoom in on an object and recognize it for what it was or discern how far it was from her. She had also lost some of her physical coordination skills. So when I saw her with the shears, I was alarmed. I feared for her safety because yes, I questioned her ability to prune plants without harming herself.

I explained this to her and asked whether it would work if I cut the plants for her. Ideally, I tried to encourage Clare's independence as much as possible. But this situation was beyond my comfort zone, so I objected again when I saw Clare leaning forward to give it a go, to try cutting the plants herself before deciding whether to hand the task over to me.

"I will take these shears out of your hand now," I said, "because I don't know how else to protect your health." And I reached out and took the shears away.

Clare's face went white and red at the same time, if you can picture that. I thought I could see anger beaming out of her eyes. She probably wished she could tell me what she thought of me, tell me that I should mind my own business, but when she got emotional her words didn't come easily. As you might imagine, being unable to respond only intensified the heat of the anger she was pouring onto me.

I could have chosen to admit that I was to blame, or to explain to her in many sophisticated words what my reasons were. Instead, in my care that no one should get hurt, I tried my best to guess what was going on for Clare at that very moment. Slowly.

"It looks like you are angry right now," I said. "And I'm guessing

that's because you are longing to enjoy activity in the garden." I paused.

"Or maybe you are longing to be able to decide for yourself and choose what you do?"

I did not suggest that she was angry because I took the garden shears out of her hand, nor that she wished I would give the tool back.

Clare looked at me intensely, processing what I said, and then turned around and went into the house. I didn't know what to make of that. I thought the memory of the event had disappeared soon enough, but I also wasn't surprised when Clare gave me the cold shoulder for the rest of the day. Feelings linger, and I could tell I wasn't welcome to inquire about what bothered her.

The next day in the garden, Clare turned to me as if she had just remembered something important. "It is so good what you did the other day," she said.

"You mean taking the pruning shears away?" I asked. "I thought you had been rather irked."

"No, I have been thinking . . ." Claire shook her head. "I love gardening . . . but I need reminding what I can handle."

Dementia makes it impossible for people to do lots of tasks single-handedly anymore. The helping hand of a caregiver is not always welcomed straightaway. At those times the best help you can offer is an attentive ear.

## FINDING CLARITY INSIDE CONFUSION

For people living with dementia, confusion is a state even more common than anger. Those with dementia sometimes seem to live in a world from decades ago. They may perceive objects or voices that aren't visible or audible to us, or converse with people we know are long dead. To those of us without dementia, they may seem to have lost touch with reality. Hence some approaches to dementia care emphasize "reorienting them to reality." For example, correcting someone with dementia by saying, There is no alligator in the room, so don't be scared. Or, Now calm down, your father died fifty years ago. He is certainly not shouting at you. These attempts at "reorienting to reality" often feed a person facts from our own sensible world, and they manipulate feelings through commands such as Don't worry, Calm down, or There's no reason to cry.

Reorienting people to reality sounds good to me but what reality are we going to prioritize?

I'm not saying I believe each of us lives in different worlds that are separate and disconnected. I am saying we can choose to reorient ourselves to the reality that is the closest to us and most alive—the reality of our feelings and needs. Most of us—with dementia and without—have lost touch with this reality, with this inner, most immediate world of ours. Instead of demanding that others change their outlook, we could reorient ourselves to our own world of experience.

From this perspective, people with dementia are often way ahead of us. Though they may appear to have lost touch with reality, they often have quite tangible contact with their own inner reality. The sphere that occupies most people—social conventions, facts, figures, and world affairs—means less and less to those with dementia. Their focus changes from being outward-oriented to inward-oriented.

Now, coming into fresh contact with the inner world isn't always the easiest experience. Some people with dementia freak out when they face their own inner land. That's only because it is unfamiliar and they lose their bearings. But with help, they can find their way through this difficult, and at times scary, territory. Empathic communication can be deeply connecting, across any two worlds.

Yvonne didn't take it lightly when she started seeing ghosts. On the nights when these phantoms visited her bedroom, she called for me at the top of her lungs, and frantically shared her worries with me while I held her hand.

"There is something wrong with this house. I'm telling you," she would say. "Go and ring the neighbor. Ask them who lived here before we moved in. I want to know who these people are, these ghostly figures! Can you make them go away?"

Yvonne had never previously believed in ghosts or anything paranormal. But what was normal to her anymore? Now she was convinced the house was cursed. It seemed to be all about the house, that the house was the problem. Or was it? Something was alive for Yvonne that was the reality of her experience.

She looked at me with pleading eyes, waiting for me to rush off and call the neighbor. (It was two o'clock in the morning.)

"Are you scared, Yvonne? Is that why you want to inquire about the house?" I asked.

"I need to know who lived here before us. I wondered why they were selling the house so cheaply at the time, you know . . ."

"So you are anxious because you would like to be able to feel safe here?"

"I want to know whether things will get worse if I stay here any longer."

"Ah, so you would like reassurance that it's safe to stay? Is that right?"

"Yes." She took a breath. "Am I going to be okay?"

"Would you like to hear how I feel in this house?" I asked.

With this question, I asked Yvonne for permission to shift her attention to hearing something from my world. When she nodded, I reoriented myself to my own reality.

"I feel safe and out of harm's way while I'm in this house."

Upon hearing this, Yvonne stroked my hand. She took a deep breath. Perhaps her need for reassurance was fulfilled now, or maybe trust played a bigger part in bringing Yvonne peace of mind. For me, it brought a good night's sleep afterward.

Having dementia brings some people to confront their inner land more closely, perhaps for the first time in a lifetime. Some people find their inner experience to be unfamiliar territory, and at first they lose their bearings.

The awareness, perspective, and skills you are learning in this book, and the dementia relationship you are learning to build, can help provide enough context for people with dementia to make themselves at home. What you have learned can also help them overcome the sense of loneliness they might experience when realizing that each of us has our own world to inhabit.

A dementia relationship, like any other meaningful companionship, is all about meeting each other at the threshold of our worlds. If we stubbornly insist on one reality only, meeting others there may be difficult. If your world has no room for other perceived worlds, you may miss out on the joy of contributing to each other's well-being. I believe that no other person can make us happy, but that happiness comes from fulfilling another's needs and having our needs fulfilled. This is the joy of giving and receiving empathically. The joy of communicating between worlds.

You don't need to believe in anything paranormal to connect with someone who has dementia. You don't have to buy into someone else's idea of the afterlife or believe the stories you hear about ghosts. There is certainly no point in trying to convince someone who may experience hallucinations that they are deluded or wrong in their experience.

You can connect with the authenticity of feelings and needs

instead. As long as you can focus on the reality of needs alive in your heart and the heart of the person you care for, you will have a meeting place. The heart's reality is a genuine reality you can rely on.

This reality is precisely where Kathleen, a Nonviolent Communication trainer, met up with her father. She met him at the doorstep of his world and listened to his needs. "I never felt that I lost my father," said Kathleen. "Despite his dementia."

When he stopped making sense, she understood that he was sens-ing instead. Once he told her that he had recently moved back to Kansas, even though she knew he remained in Colorado, where their conversation was taking place. But she knew he associated Kansas with his family roots, so she sens-itively asked, "Are you excited about moving back to Kansas because that's where your family roots are? Does reconnecting with your family matter to you? Is that what's on your mind? "And he said, "Yes! Yes!" His daughter's empathic presence left him feeling understood and encouraged to share the most meaningful things that took place in his world.

The other person's world isn't so far away that you can't reach them. On the contrary, if you sense what's important for them, you can meet them right there, in that moment. When you listen to what they share with you, focus on what matters to them at that place, at that very moment. What is it that they care about, what is it that feels meaningful right then?

You may not only avoid losing a loved one, but also gain a friend. Melanie Sears, who worked as a nurse at a dementia care home, quickly learned that "reorienting people to reality" wasn't the way to make friends. The routine questions—today's date, the president's name, one's actual age—were obviously too boring to engage with. Some folks choose more fun things to do. One day

Melanie walked into a patient's room and was invited to a private tea party, with imaginary cups, saucers, and cakes. It was rather fun. As Melanie got into her role, she made an excellent guest. The interaction certainly made the patient feel very content, as Melanie's care met their need for companionship and celebration.

Can you imagine this scenario if Melanie had reoriented her patient to the reality of the care home instead? Well, it's clear they would have missed out on a jolly good party.