

# Alzheimer's and Authenticity: A Person-Centered Framework that Promotes Mutuality and Reciprocity

Claudia J. Strauss  
Albright College

I would like to address two aspects of engagement between people with diagnoses of dementia and people without such diagnoses.

The first includes the following observations:

- that conversations that satisfy both participants are conversations that flow
- that relationships are evolutionary in nature, not prescriptive
- that meetings of minds are best achieved when there are meetings of hearts
- that a sense of the other's essence, and the sense of valuing that essence, needs to be reciprocal for any of the first three to take place

The second sets forth these principles:

- that our *desire* to do the best we can often impedes our *ability* to do the best we can
- that setting limits tends to limit...and ricochet

This paper discusses how these two aspects intersect....and interfere with the efforts of those of us who lack diagnoses of dementia to sustain relationships with those of us who struggle with them—depriving each of us of joy, meaning, and deeper exchanges.

And the corollary—when these qualities of life are missing, we lose dignity, patience, peace, energy, which can lead us to lose will,

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disengage, become less effective at filtering, and less able to control impulses.

It is thus that the whole person sustains the whole person, and thus that *each* must experience *the other* as a whole person in order to experience being whole persons themselves.

Here are some examples of how this works and what we can do to participate in simpler, richer, and more easy-going interactions...and help others do the same. Though what follows is couched in terms of friend/family/co-worker interactions, principles and practice hold true for therapeutic interactions. As will become evident, planning these interactions to be therapeutic, even *conceiving* of them as therapeutic, can lessen the therapeutic outcome.

## **REACTIONS THAT RICOCHET**

### **Clinging to Shifting Sands**

A diagnosis of Alzheimer's tends to crystallize our need to hold on to what we have. This isn't true just for the person who has been diagnosed; it is true for friends and relatives. The sense of impending loss throws people off balance and makes them hold on tighter. This generates a set of behaviors that undermine the very goal those behaviors are directed toward: supporting the person with the diagnosis and continuing to enjoy a mutually rewarding relationship.

How does this happen? By confusing the extrinsic nature of the things we want most with their intrinsic nature. By trying to control everything that happens rather than adjusting to flow in accustomed ways. By taking on so much of the responsibility for a relationship that the other person no longer has a role.

### **Taking the Level out of the Playing Field**

The need for purpose and control is universal. Without them, life loses meaning. In order to feel those things and be able to act on them, we also need self-respect and the respect of those around us. When their foundation rests on shaky ground, we are in trouble. That foundation depends on our sense of self and our connection with

others. These four elements—purpose, control, sense of self, feeling connected to other people—form the cornerstone of a healthy inner life and give life meaning.

Alzheimer's threatens that. When those of us *without* the diagnosis hold on too tight, we threaten it, too. The more level we can keep that playing field in our relationships with those struggling with that diagnosis, the more helpful we are to them and, paradoxically, the more we keep of the relationship we cherish.

How does this work?

### **Tangling Manner, Matter, and Mode**

Change is the stepsister of Alzheimer's. It comes with the territory. When it comes to communication and relationships, though, we tend to change what we should keep constant, and keep what we should change.

We change the manner in which we present ourselves; we keep the matter and mode the same.

Here is why it should be the other way around...and how reversing that approach produces both better—and happier—results.

### **Manner**

Manner conveys information without words. It includes body language, tone of voice, pitch of voice, rhythm of voice, intensity of voice, mood of voice, facial expression, posture, position of eyebrows, use of eyes. Most of us absorb these messages to a far greater degree than we do any words that are spoken; we give them greater weight, and the feelings they evoke stay in our memory longer.

Manner lets us know we are respected (or not), cared for (or not), seen as equals (or not), welcomed and appreciated (or not), giving mutually to the relationship (or not).

When manner and words are not in sync, we know something is off and we tend to listen to the nonverbal cues. With dementia, as language processing skills diminish, dependence on these cues not only

becomes much greater, it continues to increase. Those of us lucky enough not to have dementia need to keep that in mind.

Lack of respect is painful: it destroys trust; it hurts relationships; it depletes, disables, and damages. Lack of respect and parity go hand in hand. And this lack makes it so much more difficult to provide support because the essence of the person—that part that most needs support—can no longer accept it from those offering it. On the other hand, respect and mutuality are life-affirming; they promote positive feelings, energy, patience, activity, and self-actualization. When it feels right for the person with Alzheimer's, it feels right for the person without it. And there is the potential for connection, laughter, joy—the easing of burdens for both.

We don't change our manner when someone has a condition that is temporary (a broken leg, mono) or a disease that is chronic (arthritis, diabetes). We're matter-of-fact, supportive, joke around, maybe even pushy—but we still see them as peers, adult-to-adult, and that comes through.

If we adjust our perceptions, our manner will follow.

### **Matter**

Matter is what we talk about. The best conversations leave both participants happy. They work because each is listening as well as talking, listening to the whole person and not just to the words. Sometimes we introduce a topic; sometimes the other person does. As in any successful interaction, we're guided by the person and the give and take.

We can do that and still keep the challenges of dementia in mind. When the topic is not about some business that needs to be transacted, the immediate goal for both parties is to find the interaction rewarding and pleasurable. The long term goal is for both parties to want to repeat the experience.

This means the matter doesn't matter. It's a device to create engagement, a means to connect two people in a meaningful way, a hook to hang the conversation on.

And matter doesn't have to be articulated. If what really matters is feeling one is worth talking to, and that the other person

enjoys one's company, it's no longer about the words. It's about spending time together.

Silence can be comforting, non-threatening, safe, even enjoyable. As Alzheimer's progresses, silent companionship can be relaxing, too. No need to negotiate all the pitfalls of language and memory; no need to risk messing up or trying the patience of the other person; no need to worry that the other person isn't having a good time. Both people in the conversation feel these things and worry about them. What if they didn't have to?

Don't be afraid of silence. When one person is comfortable with it, the other person will be, too.

### **Mode**

Mode is how we put our sentences together. How we get the conversation going. How we keep it going. How we change direction. How we deepen it. How we end it. It's about the process we follow and the techniques we use. For most of us, it's set on automatic pilot.

Because of continuing changes in how someone with Alzheimer's is able to manage language and memory—both a big part of managing conversations—those of us without Alzheimer's need to take our conversational process off automatic and revert to manual.

We need to become aware of how much of the time we ask questions rather than make comments. And we need to examine the type of questions we ask. As dementia progresses, first the type of question and, eventually, just the presence of a question, can present problems and wound dignity.

The challenge of questions is that they demand a response. It doesn't matter who asks or how the question is constructed, or if one understands the question or not. We all recognize a question and hear the question mark at the end. We know that we are expected to answer. Not answering would be inappropriate, outside cultural norms, and embarrassing. Misunderstanding, and answering the wrong way, would be humiliating, too. If we have trouble processing language, accessing memory, or forming our own sentences, we will realize we are stuck. That's a horrible position to be in. How do we ensure we don't put someone else in it?

The key thing is to ask questions that don't require memory retrieval, are so commonplace that the answer is automatic, refer to a suggested activity and can be answered with a yes or a no, or don't require an answer at all.

Comments, for example, don't require a response. It is up to us whether we make a comment in return, pose a question, or just nod or smile.

By untangling the threads of manner, matter and mode, we enhance the possibility of entangling the bonds of connection, essence, and meaning, in all the best embodiments of that word.

### **Reorienting What Can't be Oriented**

Clarifying confusion is engrained in us. We all need to make sense of where we are, what is happening, and how it affects us. It's the way we figured out how the world works, what we could expect to happen next, and how we might be able to control some of it. It was our primary job when we were babies and it's pretty compelling still. And we find it disorienting when the people around us aren't sharing the same present we occupy.

It is incredibly difficult not to wade in and *insist* that those around us acknowledge the same time and place we're living in.

If reorienting *once* were all it took, go for it. Sometimes that's the case. If it can be done without embarrassing or frightening the person, it's all good. However, if the information can't be retained for more than a few minutes, if the person is only going to be embarrassed and frightened and maybe even hurt again, it's not worth it. These emotions take energy, energy better used elsewhere. And sometimes the attempt to reorient only makes the person hold on tighter to their perceptions, to fight what you are trying to do, and it ends up taking longer to move out of that place.

Often, it is counterproductive. Sometimes it is damaging. Who among us wants to relive those moments when we first heard of the death of someone important to us, such as a parent? Who wants to relive it as if we had never lived it before, because we are living in a time before it happened?

Be prepared for the present to be *their* present. Joining them is validating and reassuring. How would we feel if the most basic of beliefs—our understanding of where we are and when we are—were challenged? How could we trust the person who insisted we were wrong? What would be easier: giving up what we know to be true or giving up our trust in the messenger?

## REACTIONS THAT RESTORE

Keep in mind that:

- the more we try to control, the less control we have
- the more we feel respected, the healthier we feel
- the more our relationships feel reciprocal, the more we welcome them
- the more we concentrate on essence, the stronger the connection

The person with the diagnosis may not be able to articulate, engineer, or live by these principles. Those without the diagnosis, though, can make them inform their manner, their matter, and their mode. And everyone's lives will be made both easier and richer, even sweeter, in so doing.

This means being open to where an interaction goes, and not trying to push it in a planned direction. It means expecting the interaction to feel good and letting the other person feel that expectation. It means setting aside all distractions and creating a moment not bounded by time. It means thinking of the other person as an equal, so that voice, body language, and facial expression will all convey that. It means sharing the control of the conversation and, as much as possible, ceding control in whatever areas possible.

Doing otherwise gets in the way. *Thinking* otherwise gets in the way. Thinking is reflected in the doing. Rather than focus on what you do, the key is to focus on what you are thinking. Perception is everything. If you see a patient, a case, a resident—you are not seeing a person. A unique individual whose responses matter and who is seeing *you* as well as the *way you see him*. Perhaps the label is different—

perhaps the label is creative and new and still resonates as respectful, compassionate, and individualizing—in time all codifiers—all shortcuts—become labels. And labels generalize, collectivize, and, without meaning to, dehumanize. The category, in itself, *by* itself, distances you from the other person (and thereby distances the other person from you). Thinking of the person by name, as person first, disease process second, can change everything.

It can make it possible for us to give as well as to receive—for both the person without the diagnosis and the person with the diagnosis to give as well as to receive. When all the flow is one way, the recipient is diminished. One of the best ways to give—to provide support—is to welcome being the receiver. And to recognize all the opportunities for that as they arise. And then to express gratitude for the gift.

This levels the playing field, restores reciprocity, reverberates with the rhythms of strong relationships, and helps us join forces in walking shifting sands as we have other vicissitudes of life—with flexibility, mutual respect, and a come-what-may insouciance.

If we are not authentic, we will not be perceived as authentic. And if we are not authentic, our support will not bring healing.

NOTE: This paper grew out of a talk presented at the 24th Annual Conference of the Association for the Development of the Person-Centered Approach, held in June, 2009. It is based on extensive experience with and numerous observations of interactions between people living with diagnoses of dementia and people struggling to maintain relationships and be supportive. The writer is the author of *Talking to Alzheimer's* (New Harbinger, 2001).

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