

The reader embarks on a journey through the factual neuroscience of dementia into an exploration of the metaphysical spirituality the soul travels during dementia progression. Included are practical tips on care, first person narratives and exercises designed to enable the reader to step into the shoes of a person with dementia.

**Journey through the Infinite Mind:
The Science and Spirituality of Dementia**
by Katya De Luisa

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JOURNEY THROUGH THE INFINITE MIND

The Science and Spirituality of Dementia



KATYA DE LUISA

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CHAPTER 8

Mind & Consciousness

*“When you realize the difference between the tool and the user,
you will have knowledge.
-Indrie Shah-*

WHAT IS THE MIND?

When we talk about the mind, most people are usually referring to brain-generated thoughts. However, as we learned in previous chapters, conscious thinking is but a small percentage of what the brain does. Even when we include the subconscious--the automatic physical functions and the bulk of our experiential programming--it seems there must be more to the mind.

Is the mind really just a part of brain function?

During my workshops I begin with the question, “Are the mind and the brain the same?” Most participants usually indicate that they aren’t. However, neither the workshop participants nor medical science can define what mind is, where it’s located, or what it actually does.

The Oxford Dictionary defines “mind” as the faculty of conscious thought; the element of a person enabling them to be aware of their environment and their experiences, and to think and feel. It includes ability to reason, memory, attention, will and determination, as well as thinking influenced by outside influences.

Another definition of mind is that it’s the totality of conscious and subconscious mental processes and activities. Basically, both definitions concur that mind is a function of the brain.

Medical science defines mind as what the brain does--a result of electrochemical activity in the brain. We learned in a previous chapter that electrical energy flows through the axon of the neuron and converts to chemical energy at the synapses.

According to Daniel J. Siegal, a research pioneer in interpersonal neurobiology, *“The brain is a set of interconnected cells that allow energy to flow.”*

Siegal says the mind experience is threefold: brain, relationship and mind. The brain includes all the mental and physical processes. It is an energy and information flow traveling through our nervous system. He has come up with a very viable definition of mind when he states, *“The mind is the emergent process regulating information flow.”*

INNER VOICE

We seem to have an inner voice that sometimes speaks out. “Don’t have that second piece of cake!” it says...“But just this time, it’s my birthday,” replies the rationalizing self.

Who are these voices in our heads?

My inner voice is quite distinct. For instance, when I’m angry, my inner voice tries to calm my angry self down; or not.

First voice: “Katya, you know he doesn’t realize this hurt you.”

Second voice: “He is so full of himself and doesn’t care about anyone else’s feelings!”

First voice: “Don’t take it personally. It’s his problem, not yours.”

Second Voice: “Oh shut up!”

THE OBSERVER

Metacognition is the part inside our mind which thinks about our thoughts and can objectively watch what is going on around us. Quantum mechanics calls this the observer.

In *The Biology of Transcendence*, Joseph Chilton Pearce says, “*I am consciously aware of what is happening inside of me while I observe what is happening outside me*”.

We have the capacity to observe our thoughts while they are happening. We can consciously witness our emotions and control our responses and can consciously cancel out a negative thought replacing it with a positive one. The practice of using positive affirmations helps people to change not only how they think, but how they perceive what they think about.

Our witness self can consciously observe our thinking and interactions with people and our environment. It can act as our higher self, trying to lead us out of the primal cycle of unconscious action and reaction.

The “observer” helps facilitate introspection. Because of it, we gain a better understanding of ourselves and make more mindful decisions in our lives. This witness self observes, assesses, and counsels. It is a higher consciousness everyone has access to, but most people, unfortunately, seldom use it.

SPIRITUALITY AND SCIENCE

Historically, spirituality and science have been separate, but now they seem to be merging. For centuries, spiritual knowledge has been based on what science presently seems to be delving into.

The Greek and Hebrew bibles refer to the mind as the spirit or soul. Most religions believe the soul connects us to an infinite

consciousness--God, Jehovah, Universal Mind, Great Spirit, etc. Today's scientists are researching an infinite field of energy and information. Maybe what they are actually researching is God.

Quantum mechanics is the latest evolution in modern physics and is a forerunner of the union of science and spirituality. Quantum research supports the hypothesis that the field is a vast network of flowing information that's infinite and immensely powerful.

Humans can perceive only minuscule parts of the field's immeasurable potential. Whatever part we focus on becomes the material of our life. We create our life from the infinite probabilities from that field, or, as most religions maintain, we pray for our prayers to be answered.

Renowned physicist, the late Dr. Stephen Hawking is considered our modern-day Einstein. He was disabled with Lou Gehrig's disease (amyotrophic lateral sclerosis), which causes the brain to eventually lose control of all of the muscles in the body, yet leaves cognitive brain function intact. He lost the muscles controlling speech, so he communicated through a cheek-muscle-generated computer.

Hawking stated that *"The Field is invisible, all encompassing, without space and time, forever and always present, the infinite. The human mind cannot conceive it. It is exquisitely gentle and powerful."*

"This field is infinitely powerful, like a giant electromagnetic field with no ending. The field is so powerful that it includes all potentialities."

"Within the field, potentiality is actualized by intention...If you continuously hold a thought, it will become a happening. Otherwise no one would become enlightened."

Hawking's statement seems like a scientific description of God. Most religions describe God as omnipresent (*present everywhere*),

omnipotent (*all-powerful*), omniscient (*all-knowing*), benevolent, eternal and necessary for all existence. His statement “*hold a thought and it becomes a happening*” could be interpreted as our prayers become answered by God, aka the Field.

TAPPING THE FIELD

Carly Fleishman was diagnosed with severe autism and mental retardation. Her physical movements were out of control and she was nonverbal. Her parents hired several therapists who provided her with 40 hours weekly of intensive therapy.

There seemed to be minimal progress, until she was eleven. Then she typed on a computer keyboard, “*Hurt, help*” and threw up: she was sick. Eventually she learned to fully communicate using a computer.

Surprisingly, her writings have been exceptionally articulate, even though her earlier therapy never included reading and writing. She presently uses a computer to further her activism for autistics and has written a book, *Carly's Voice*.

Where did Carly get her writing ability?

In *Evolution's End*, Joseph Chilton Pearce writes about people labeled “idiot savants”. They were usually institutionalized, having an IQ of around 25, unable to read or write, and requiring assistance with hygiene, dressing and feeding.

Typically, they possessed some kind of extraordinary gift which enabled them to carry out astonishing mental or physical feats in one specific area, without ever having previous exposure to the information. Some expertly played a musical instrument without ever having seen or touched the instrument in the past. Others demonstrated mathematical genius, yet they couldn't read or write, and had never studied math.

Chilton Pearce believes that savants may be tapping into the infinite information field. If medical science has proven that the heart and brain generate electromagnetic fields extending out from the physical body, and it is common knowledge the earth is surrounded by an electromagnetic field, is it too inconceivable to imagine that our personal electromagnetic fields are actually part of a bigger network?

Our brain focuses only on specific frequencies from the information field. The rest is beyond comprehension, so we filter it out. If we lost our filtering ability, we would be engulfed by the immensity of this infinite flow of information, and we might appear demented.

As we've learned, when the brain of a person with dementia begins to lose its environmental filters, they experience sensory overload. Could many of the symptoms typical of dementia actually be information-field overload?

If the brain is a receiver and sender of frequencies, wouldn't dementia be like the static a radio produces when it can't tune in properly to a station? If the radio can't tune in to the right frequency, does that mean no broadcasting station exists?

Again--if the brain can't tune in to the right frequency in the infinite information field, does this mean there is no mind?

The neuroscientist, Sir John Eccles says, "The human mind and consciousness may constitute a separate undiscovered entity apart from the brain."

DEMENTIA & THE MIND

"Demented" is derived from the Latin *de mente*; of mind. In this age of increased cases of Alzheimer's and other neurodegenerative conditions, it has become the most commonly used word related to cognitive disease.

People with dementia seem out of their minds. But are they?

“Have you lost your mind?” is a common expression when we’re talking to someone about to do something considered crazy or irrational. But which mind are we referring to? Is it just the conscious rational mind that thinks and reasons, or does it also include greater consciousness?

When someone is “out of their mind”, could their awareness still exist? After all my friend Frank, in the last months of Alzheimer’s, chose that phrase from the magazine “Sometimes you are most in touch with the world when you are out of touch.”

During earlier stages of dementia, the person can still express what they are thinking and perceiving, no matter how irrational it may seem. But in the later stages they become incapable of articulating feelings, thoughts or perceptions.

Might people in the nonverbal later stages of dementia retain a type of consciousness, with access to that infinite field of information, but be unable to communicate it? Because advanced dementia damages the brain, interfering with control over their bodies, perceptions and responses, we can’t tell what they are aware of. If that awareness is different from what we experience, how would we know?

Consciousness is an information flow; something moving, an action. Our brain, like a book, is a physical object containing information.

The information in the book comes from its creator, the writer. But if the book is never opened, the information goes nowhere. It is the experience of the reader that creates the transfer of information. The flowing information is separate from the physical aspects of the book.

Our nervous system receives the information from the field (the writer), and sends it to the brain (the book). Then the mind (the reader) converts it to consciousness.

If the brain malfunctions, is the mind also damaged? Isn't the brain basically an organic vehicle designed to carry us through our mental and physical environment, like an automobile transporting us through our daily world?

What happens when the automobile's motor won't run? Does the driver also malfunction? If the brain is a vehicle, then the mind must be the driver. When the brain is damaged, does this mean the mind is too?

What if the mind (not brain-generated thinking) remains aware? What if the observer is still witnessing? Maybe the observer mind simply has a different way of processing the information than our physiological brain's electrical/chemical system.

If the mind is not simply what the brain does, there could be a different way "knowing". If so, the person in later dementia might be more conscious of what's going on than we imagine.

MIND, BRAIN, CONSCIOUSNESS & DISABILITIES

Throughout history, people with disabilities severe enough to interfere with motor control and communication have been given up on or institutionalized. When there were no outer signs of cognitive abilities, they were usually diagnosed as mentally deficient.

Luckily for Stephen Hawking, medical science is very familiar with amyotrophic lateral sclerosis. He could have been considered mentally damaged when his condition progressed. Imagine the hell he would have lived if technology hadn't provided him with the speech computer he uses to communicate.

Martin Pistorius was born in Johannesburg, South Africa in 1975. He was a bright, normal twelve-year-old until he inexplicably began losing motor control and speech. He was diagnosed with an unknown degenerative disease, and when he slipped into a coma, doctors gave him two years to live.

When he was sixteen, he began regaining awareness. At nineteen, he was fully conscious, but still completely paralyzed. He was imprisoned in his own body.

No one suspected this until his caregiver noticed his eyes responded to her talking to him. He was tested at the University of Pretoria, where doctors confirmed he was consciously aware.

He eventually regained control over his head and arms, and his parents provided him with a speech computer. He married in 2009 and works as a professional web designer. His autobiography, *Ghost Boy*, was published in 2011.

It was also commonly believed that people with severe cerebral palsy were mentally impaired. The Academy Award-winning movie, *My Left Foot*, was about the life of a famous Irish artist and author, Christy Brown, who had severe cerebral Palsy and diagnosed as mentally deficient.

Christy's parents were advised to institutionalize him, but they decided to keep him at home with his other siblings. He had no control over his involuntary physical movements and was unable to speak.

But one day, using the toes of his left foot, he snatched a piece of chalk from his sister and drew a symbol several times on her slate. He couldn't communicate until he discovered he could control and use his left foot.

His mother began teaching him to read and write, and he eventually learned to use a typewriter and hold a paintbrush with his toes. He became one of Ireland's most celebrated artists and writers.

These examples depict functional minds in damaged bodies. Some might argue that people with dementia have physical impairment because of their damaged brains. Their minds would also be damaged, especially during the last stages, when motor control, cognition and communication abilities are gone.

However, could it be that what are impaired are the brain's processes of perception, thinking and reasoning? The mind could be more than mental processes; it could have an observer than might not be contained only in the brain.

Couldn't it be possible that these people might actually be trapped inside dementia-ravaged brains, but still retain an element of awareness?

MIND, COMMUNICATION & DEMENTIA

Often people talk about the person with dementia while in their presence, assuming they can't hear or understand what is being said. This happens especially if the person is in later stages, or seems to be asleep or unconscious. Doctors discuss the person's health issues with his or her family, ignoring the fact that the person is present in the room.

One family was so distraught over their mother's dementia that they held a memorial service—even though the mother was still alive and a resident in the dementia unit of one of the facilities where I gave workshops. The family perceived her to be a hollow shell; they felt she had already died. Worse yet, I was shocked to hear them talking about the service in her presence.

Marilyn Hears Everything

Marilyn, in mid-stage Alzheimer's, was declining fast. She would doze off unexpectedly throughout the day, and I would often wonder whether this was the result of too much stimulation and she just had to close her eyes, whether she was slipping away into the dementia, or whether she was simply sleeping.

Her son lived in the same town, but visited very seldom. When he did, he would spend most of his time with his father, rarely having much to do with Marilyn.

One day he tried to have a conversation with her, and she nodded off in the middle of it. He took this opportunity to tell me that he and his father had discussed placing her in a care facility. He went on to say that it wouldn't matter, because her condition was deteriorating so quickly he doubted she had any awareness of her surroundings anyway.

I whispered that it was best not to say anything upsetting in front of her. He pointed out that she was asleep or unconscious, and couldn't hear what he was saying.

I turned to Marilyn and in a normal voice, asked if she understood. Without opening her eyes, she immediately replied, "Sure did."

It is not easy to know how much a person with dementia comprehends. The best policy is to assume they can hear everything, and on some level, understand what's being said.

Include them when the doctor is giving a diagnosis. Ask the doctor to talk to the patient as well as you. Explain whatever requires their cooperation: "Mom, let's go to the table, lunch is ready." Don't just start moving her. "Henry, we have a doctor's appointment today. I'm going to help you dress." Tell him where you are going.

Treat them with the same respect you would if they didn't have dementia. Include them in a conversation with the family or visitors. Even just a short comment directed to them is better than talking about them or ignoring them: *"I love roses! Mom always did too. Isn't that right, Mom?"*

Always assume they know what you are saying, even in the nonverbal stages, and never say anything in front of them as though they don't exist.

They are neither ghosts nor hollow shells. They are people who are still alive and worthy of respect, recognition and love, even when they are not able to respond.

DURING MY WORKSHOPS

Throughout my years of working with dementia, the people who intrigued me most were those in the later stages. Their families and the facility staff usually concurred that these people weren't capable of doing anything anymore.

I didn't believe this.

I conducted weekly workshops at a number of facilities where many of the residents in later stages of dementia wandered incessantly, mumbled to themselves, sat in chairs staring into space, or obsessively repeated movements or sounds. Outwardly it seemed they were not cognitive, yet I was haunted by the sense that they still might possess awareness. I felt it was the damage to their brains that was preventing them from communicating what remained inside their minds.

Some of these residents participated in my picture-communication workshops with the help of a volunteer companion or a family member. Their image selections represented elements from their past, and often revealed an awareness of their present environment.

The mental and sensory damage caused by dementia creates a different kind of perception, so in order to communicate, it was necessary for both parties to be on “the same page”.

Pictures are a universal language both companion and resident understood. The imagery became a bridge whereby both individuals could communicate, using the same pictorial language. Even the nonverbal now had a way to communicate. As with the other disabled people mentioned in this chapter, the driver found a way.

Another interesting occurrence took place during the workshops. I was told that several residents would not be able to see the images in the magazines, because their glasses had been taken away. (It was common in later stages of dementia for people to fiddle with their glasses, usually breaking them.) Yet even without their glasses, they were able to see the pictures in the magazines and make their selections known.

I’d used multi-focus glasses for two decades until I developed cataracts, which commonly cause close-up vision to return, so I was able to read without glasses. But my distance vision and depth perception got worse. I tripped a lot when walking and couldn’t tell how fast something was coming at me when driving.

Maybe some of these seniors with dementia had untreated cataracts.

An old wives’ tale says elderly people develop “second sight”. Maybe there’s validity to this. It remains a mystery to me how all of those workshop participants could select images obviously significant to their past when they supposedly couldn’t see them!

Could they have been seeing the images because their minds were connected to the field and the perception of “seeing” was coming not from the brain’s sensory input, but from some other process outside the brain?

Jean's husband Ben was in the last stages of Alzheimer's. He was nonverbal and spent his days in a lounge chair, staring into space. Each day Jean visited, trying to find ways to get him to interact with her, with few results.

Jean Wrote

“When I first took Katya's picture-communication workshop, I thought it wouldn't work with my husband. He had severe dementia and had been in a nursing home six years in a Special Care Unit. His speech was limited to one or two words, and there wasn't much he could do anymore.”

“To my amazement, when I visited him with several magazines and we went through the pages, he would point to a picture and nod his head when I asked if he liked it. His selections were not random choices, but things meaningful to him. Many pictures resembled past events we shared together.”

“We often looked over the collages we had previously made and he would become animated, reaching for the collage or spending extended time gazing at the pictures. If we looked through a magazine he had previously selected from, he wouldn't choose anything. I had to mark those so as not to repeat going through them.”

“Ben became more alert when I visited, and the staff said they were noticing that he seemed more aware. He and I continued to make collages and completed over 200 in that last year of his life.”

“A diagnosis of Alzheimer's does not mean the individual is gone. The essence of that person is still there. Although there are many changes, there is much they still have to offer. The joy of a smile, a caress or a response from your loved one makes all the effort worthwhile.”

“Ben died 7/31/02, and to the end of his life these collages brought pleasure to both of us. They were a means of expressing himself when he could no longer verbalize his thoughts or feelings. And most important, they gave me meaningful memories of our last days together. I saved all of them.”



In this collage of Ben’s the couple was an image from an advertisement for Alzheimer’s medication. The text in blue box reads: *“I’m not who you think I am. I am who I know I am.”*

The images in Ben’s collage showed he retained aware of his mental condition. He chose a couple from an Aricept ad: he had been given this medication in the earlier stage of dementia. The significance of the text to his situation seemed more than just some random coincidence.

Jean was not the only family member of people in later stages of dementia who found through using the collage-communication process that their loved one could communicate and interact with them. When families discovered their loved ones retained an awareness of shared past experiences, they emotionally reunited, even if their loved ones couldn’t communicate verbally.

What most families desperately needed was some assurance that the person they presumed lost was still with them.

ARE THEY CONSCIOUS OR NOT?

Testing cognitive abilities usually relies on patients' ability to intellectually or physically respond in some way. Christy Brown proved he was still conscious by using his left foot; Martin Pistorius responded with his eyes. If they had not been able to respond by controlling parts of their bodies, would their intact mental processes have ever been acknowledged?

How can a person with dementia ever communicate what level of consciousness or intact mental processes might still remain? How would we test the consciousness of people with cognitive diseases and conditions, when their severe physical disabilities and impaired intellect impede their response?

Magnetic resonance imaging (MRI) scans brain activity, and some researchers have used it to test for consciousness in persons in vegetative comas. But these machines are very expensive and require the patient to remain totally immobile. During the scan, the machine emits a very loud mechanical thumping sound.

People in comas are immobile, but people with later stages of dementia commonly have involuntary physical movements. They can't remain motionless, and the closed space and noise could cause panic. To test them would probably not be viable.

Those with dementia, like those in a coma appear to be asleep or unconscious, yet often hear what's going on around them. The Coma Science Group from the University of Liege in Belgium, led by Professor Steven Laurey, working with partners from Cambridge, England and Ontario, Canada, began testing consciousness in persons in vegetative comas using an electroencephalogram (EEG). Their research results were published in November 2011 by *Science Daily*.

They found that about 40% of vegetative coma patients are incorrectly diagnosed as having no consciousness. When the person in a vegetative coma was asked to move a toe, the EEG registered the brain's motor cortex response, even when the patient couldn't demonstrate muscle response in the toe.

This new line of researching consciousness in severely disabled people has brought a ray of light for inaccurately diagnosed coma patients who still retain consciousness.

Maybe someday something similar it will bring hope to those in later-stage dementia.

OUT-OF-BODY CONSCIOUSNESS

Numerous cases have been documented of patients who, while undergoing surgery, felt they left their bodies and witnessed what was going on during the operation. In 2008 AWARE (Awareness during cardiac arrest) began studying consciousness and the brain. Research subjects had to have met the criteria of being considered clinically dead for between a few minutes and an hour. "Clinical death" meant the heart wasn't beating, the lungs had stopped, and the brain had ceased functioning.

After resuscitation, many subjects were able to recall and describe their out-of-body experiences in precise detail. Supposedly a clinically dead person (no heartbeat, no lung action and no brain waves) should not be able to generate thoughts. Yet hundreds of people interviewed in the AWARE study lucidly remembered every detail of their near-death experiences.

One of the most common descriptions of the near-death experience is that the person felt they were out of their bodies aware that they were dead. A bright light appeared, and they found themselves flying through a tunnel towards it. Some reported encounters with celestial beings.

How could these people recount their experiences and remember every precise detail years later with perfect accuracy?

In 1999 I experienced a near-death experience which I believe changed me. I too found myself traveling the tunnel and had an encounter with otherworldly beings. But we'll look more closely at out-of-body experiences in Chapter 13.

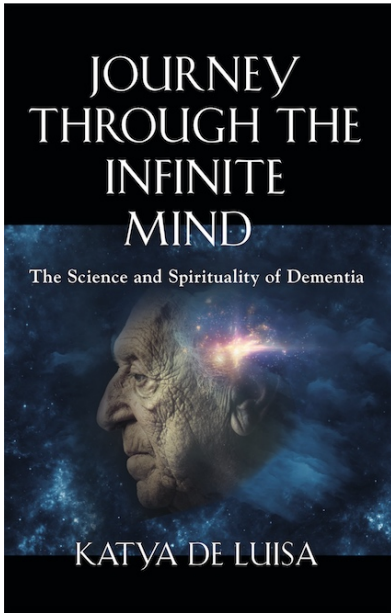
BRAIN VS COMPUTER

In a 2011 interview, Stephen Hawking declared, *"I regard the brain as a computer which will stop working when its components fail."* But no computer yet exists that can equal the human brain. Science has developed artificial organs and transplanted kidneys, livers and hearts, but so far, cannot replace the brain. The brain's neuronal network is far more complex than any computer's electrical circuits.

Hawking also said, *"There is no heaven or afterlife for broken-down computers."*

I agree with him there. The brain is merely part of our physical structure, and like the rest of the body, will eventually turn to dust after death, but what about our consciousness? Is it simply a brain-generated function only existing to enable us to perceive our physical world?

On this point I disagree with Hawking; I believe an afterlife does exist for consciousness.



The reader embarks on a journey through the factual neuroscience of dementia into an exploration of the metaphysical spirituality the soul travels during dementia progression. Included are practical tips on care, first person narratives and exercises designed to enable the reader to step into the shoes of a person with dementia.

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