Nonpharmacological treatment for Alzheimer's disease: A mind-brain approach

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Abstract

A new paradigm is needed that focuses on minimizing the symptoms of Alzheimer's disease and related dementias rather than focusing only on a search for a cure. To include Alzheimer's in the same class of diseases as cancer, multiple sclerosis, diabetes, congestive heart failure, and degenerative arthritis places Alzheimer's in the realm of the medically and psychosocially understandable and manageable. A critical first step toward making this shift is to examine carefully the way in which we define the disease. An approach to care for people with Alzheimer's results in treatment when it systematically compensates for functional losses of dementia by linking caregiving actions and environments to specific brain dysfunctions; namely, the neuropathology of the disease. The ultimate measures of success of such a treatment approach are improved quality of life, delayed institutionalization, slowed rate of progression of the disease, people who achieve their potential, and reduced need for medication.

A new paradigm

Over a decade ago, Jarvik and Winograd, in their aptly named book, *Treatment for the Alzheimer Patient: The Long Haul*,¹ questioned the widely held assumption that Alzheimer's disease is a hopeless and untreatable condition. "The unrelenting downward spiral of Alzheimer's disease," they wrote, "frequently leads to a sense of pessimism and therapeutic nihilism among physicians and other health care professionals." In their holistic approach toward Alzheimer's disease (AD)—a disease which then was, and now still is, incurable—lies a sound basis for taking a new approach to treating dementias. Emphasizing nonpharmacological treatments linked to our growing understanding of neuroscience, this new vision appears to be sparking the imagination of caregivers, clinicians, designers, and others concerned with people living with dementia. Common sense and a knowledge of the history of other diseases demonstrates that "...physicians routinely treat people with diseases for which there are no cures. People with cancer, multiple sclerosis, or Lou Gehrig's disease receive treatment and medical attention even though there is no cure for their maladies. Alzheimer's patients deserve no less."

A new paradigm is needed that focuses on minimizing the symptoms of Alzheimer's disease and related dementias rather than focusing only on a search for a cure. From Jarvik and Winograd,

...[D]espite lack of medications to reverse the underlying etiology, physicians need not feel helpless or hopeless, because management strategies do exist that can help treat the manifestations of this disease. Incurable does not mean untreatable. As with other chronic diseases, such as diabetes mellitus, congestive heart failure, or degenerative arthritis, curative remedies for the underlying disorder do not exist. Treatment is often symptomatic rather than pathology-specific.

To include Alzheimer's in the same class of diseases as cancer, multiple sclerosis, diabetes, congestive heart failure, and degenerative arthritis places Alzheimer's in the realm of the medically and psychosocially understandable and manageable. Making this link turns Alzheimer's into a treatable, although incurable, disease rather than the hopeless condition that it and these other diseases were thought

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to be a century ago. This seemingly simple shift can bring tens of millions of people worldwide back to the realm of the living, who our limited thinking has condemned to a limbo in which they are merely waiting to die.

Labels and definitions control our behavior

A critical first step toward making this shift is to examine carefully the way in which we define the disease. This step is necessary because we tend to gather and organize knowledge according to the way we define the world around us, then act and behave according to what we think we know. Ancient astronomers, who believed the sun revolved around the earth, found "scientific" facts that supported this definition—creating a generally accepted, but incorrect, earth-centered theory to explain the cosmos

Over the years, Alzheimer's disease has been culturally defined in different ways and each label resulted in a dramatically different approach to care. First, there was no definition at all; memory loss, confusion, and disorientation that occurred later in life were labeled "senility" and considered just a facet of normal aging. With dementia symptoms seen as "normal," no specific approach to care was needed. This nihilistic view is reflected in the "one size fits all" model of residential elder care that is still ubiquitous today.

Over time, a second, equally disturbing, definition emerged: Alzheimer's care as a "low-tech" backwater area of medical science and professional caregiving with minimal challenges and scant rewards. This label led to emphasizing the palliative, hospice-like dimension of dementia care—basic comfort measures as patients wait to die.

At the same time, a closely related third definition emerged. With little hope seen for people with Alzheimer's except to alleviate the pain and suffering associated with the disease, society's resources were dedicated to biomedical research. In the context of a vigorous and well funded search for an ultimate cure, people with the disease today are still written off. Biomedical research, it is thought, can offer them very little. They are seen as too early in the long-term research process to benefit from the "magic pill," which, although years away, is being held out as a promise.

The most recent and positive view of Alzheimer's and related disorders to emerge defines these diseases as disabilities, albeit caused by a progressive and fatal neurological illness. Caregivers employing a disability model emphasize active treatment of symptoms by focusing on supporting the capacities a person retains, particularly the person's psychological capacity. To develop a better understanding of the psychology of dementia—how a person thinks, feels, communicates, compensates, and responds to change, emotion, and love—can lead to breakthroughs in treatment.

Popular and professional acceptance

One indicator of the success of a new label is its popular acceptance. A recent, broadly distributed pharmaceutical industry health guide reflects this approach:

AD Can be Treated²

Although there is no cure for Alzheimer's disease at this time, there is much that can be done to manage the disease and to treat its symptoms to provide a better quality of life for those afflicted and their caregivers.

In addition to medication to treat the symptoms of AD, physical exercise and social activity are important in maintaining overall good health, as is proper nutrition.

Calm structured surroundings may also help the afflicted person to continue functioning as well as possible for as long as possible. Modifications to the living environment can help the afflicted person maintain comfort and dignity.

Another important indicator of a label's influence is its appearance in scholarly articles by respected researchers and authors. Barry Reisberg and his colleagues at New York University School of Medicine discussed "treatment" for Alzheimer's disease in a 1998 article:³

A stage 6 AD patient who is frustrated or mistreated will frequently respond with what has been termed a "catastrophic reaction"...A stage 5 or 6 AD patient who is insecure, whose pride has been wounded, or who experiences their current life as intolerable, will frequently develop delusions. We might consider *treating* the AD patient's catastrophic reactions by removing the sources of frustration or mistreatment [and] we might use "delusion therapy" in AD to explore and *treat* the source of the AD patient's insecurity, wounded pride, etc.

This shift in the paradigm, prophetically predicted by Winograd and Jarvik over a decade ago, is now taking form as a distinct treatment.

An ethical dilemma with practical implications

Alzheimer's disease poses a significant ethical and practical dilemma for those who care for people with the disease. Because Alzheimer's is a terminal illness, people



Figure 1. A higher quality of life as long as we live.

with the disease face a death sentence. It is as if someone has said to them: "You have only a certain time to live." If that time were two days, we would clearly treat that person as if he or she were dying. If that time were 75 years, we would clearly treat that person as if they were going to live and provide them with the highest possible quality of life. However, for those with Alzheimer's disease, the term lies somewhere in between—closer to 12 years. The question is whether to provide care for these people as if they were dying or living.

When people with Alzheimer's disease are seen as dying, it is reasonable to focus on making them as comfortable as possible in a custodial environment. If those with the disease are seen as people who are living, we need to think differently; we need to concern ourselves with their treatment and quality of life.

In the 20th century, significant diseases have posed the medical and nonmedical professions with this same dilemma: diabetes, manic depression, and now AIDS. Each was first thought to be a hopeless condition, a plague from which there was no way out. However, each has become a treatable disease through the use of proper medication, life style changes, diet, and environmental design. Alzheimer's is now at the cusp of this shift from hopeless condition to treatable disease.

In order to frame a treatment approach, caregivers, clinicians, environmental designers, and others need a coherent way to envision the quality of the lives of those with the disease so that they can maintain their quality of life. (See Figure 1.) For Alzheimer's disease, treatment must also take into account the quality of life of family members and professional caregivers, not only of patients and residents.

Quality of life and treatment outcome levels

Abraham Maslow⁴ defined the components of life quality for cognitively intact people half a century ago as physiological, security, social, self-esteem, and self-actualization. For those with Alzheimer's disease, a similar model can be constructed, with three levels of needs necessary for them to experience life quality; the highest level representing the highest quality. (See Figure 2.)

The first two levels of needs that caregivers must meet to provide quality of life require only brief explanation. The most basic set of needs is physiological: the need for safety, health, nourishment, and shelter. Meeting these basic needs comes first because doing so forms the foundation for meeting the others. The next set comprises behavioral needs for appropriate functioning and use of the environment. Help is required to meet these needs because damage to the brain of people with dementia specifically affects those areas that control social behaviors, impulse control, and environmental cognition.

The highest quality of life level deserves further explanation because popular misconception holds people with dementias cannot feel the way cognitively intact people can. However, one of the last parts of the brain affected by this disease, the amygdala, receives, reacts to, and expresses mood and emotion. Mood and emotion are therefore readily accessible to caregivers until very late in the disease. Nevertheless it remains difficult to maintain positive mood and emotion for this population because the amygdala equally processes both negative and positive emotions. Many people with Alzheimer's disease feel negative feelings as readily as positive ones. In addition, people with dementia face many real frustrations and experience many losses.

The goal of quality-of-life treatment is not only to maintain positive mood, but also to maintain emotional stability around social norms (*i.e.*, recognizing and dealing with other people) and personal norms (*i.e.*, maintaining a sense of self).

Even those with Alzheimer's disease can achieve higher emotional levels when treated consistently in specially planned environments. These people can develop both a sense of self and belonging to a larger community of residents.

Treatment, not random care

An approach to care for people with Alzheimer's results in treatment when it systematically compensates for functional losses of dementia by linking caregiving actions and environments to specific brain dysfunctions; namely, the neuropathology of the disease. In other words, treatment for Alzheimer's employs environment, activities, communication, and programs to maximize use of cognitive capacities that remain intact while compensating for those cognitive capacities which decline. As neuropsychologist Marilyn Albert⁵ points out, the more fine-tuned treatment approaches are to an individual's specific configuration of



Figure 2. Quality-of-life treatment outcomes.

brain dysfunctions, the more effective treatment is likely to be. Knowing, or at least thinking about, the links between a person's cognitive strengths and weaknesses and his or her brain function is particularly helpful for caregivers who might otherwise treat the person with Alzheimer's disease as globally dysfunctional rather than as a person with certain strengths and other weaknesses:

To make [neurological assessment] information useful to family members, one must explain the practical consequences of the cognitive profile one sees and, whenever possible, relate it to the function of the brain...A simplified explanation of brain function tends to allow family members to better visualize the changes caused by the disease...For example, if a patient is inappropriate, it may be useful to explain that the frontal lobes of the brain enable people to monitor and inhibit their behavior...While the suggestion that the frontal lobes are involved may only be an educated guess on the part of the neuropsychologist, this explanation will help the family to think about behavior as caused by the brain...This may prevent them from blaming themselves or the patient unnecessarily for the development of the troubling behavior and also help them to change their expectations of the patient.

The brain works as an integrated whole, making it difficult to link specific functions to single areas or lobes of the brain. Nevertheless, because researchers over the years have mapped where alterations occur in the brains of people with Alzheimer's and have begun to associate locations of changes with clinical symptoms, schematic associations between brain function and functional capacity are possible. Making such schematic associations is useful for diagnosis, family counseling, and treatment planning, even though Alzheimer's disease is generally caused by nonuniformly distributed changes that evolve over time in many areas of the brain.

Alzheimer's disease tends to begin in the medial temporal lobe, then spreads to other regions of the brain. Alzheimer's tends to affect most severely the association cortex of the parietal, temporal, and



Figure 3. Parts of the brain. (From Fishbach GD: Mind and brain. *Scientific American*. September 1992. Reprinted with permission.)

frontal lobes and the cingulate cortex of the brain. By contrast, the motor cortex and major sensory areas are less affected. Memory dysfunction and emotional and personality changes tend to arise from damage to the limbic system—the hippocampus and amygdala while damage to the temporo-parieto-occipital association cortex results in different forms of language, visual, and movement disorders. Social graces and habitual personality traits are relatively preserved until late in the disease. In this context, it may be easier to accept the simplification presented here to explicate the nature and organization of a nonpharmacological approach. (See Figure 3.)

The temporal lobe

The temporal lobe may be the first part of the brain affected by Alzheimer's disease. Grossly speaking, the temporal lobe controls new learning, short-term memory, and, in conjunction with other parts of the brain, language and perception of music and rhythm—all of which may be profoundly impaired by mid-stage of the disease. The hippocampus, a key structure in the limbic system, located in this area of the brain, can be seen as a computer chip with the following functions: recording new information, partially processing that information, and sending the newly learned information to other parts of the brain to be further processed and eventually stored in memory. By mid-stage of Alzheimer's disease, the person will have almost no capacity to learn new information or to hold onto experience. Because these connections between new learning and response cannot be made, traditional forms of treatment such as behavior modification do not work with this population.

The occipital lobe

The occipital lobe, the rearmost part of the brain, controls vision and other functions related to visual performance. Depth perception, acuity for objects, recognition of faces and objects, and what environmental psychologists call a "cognitive map"—that is, holding a picture of an environment in mind that enables a person to make his or her way from one place to another—are occipital lobe capacities affected by the disease. Because of deficits in processing and holding visual information as well as hippocampal deficits that lead to an inability to hold other information about the recent past, the person with Alzheimer's lives in the present moment. What a person sees at any moment makes up his or her reality.

The parietal lobe

The parietal lobe, together with the temporal lobe, is involved in understanding written and spoken language and processing spatial relations. The progressive loss of these capacities with advancing Alzheimer's typically means that the person with the disease has difficulty making himself or herself understood as well as understanding written or spoken language. Because of this, many people with Alzheimer's become extraordinarily dependent on body language to understand meaning.

The frontal lobe

The frontal lobe is the site of judgment, reasoning, decision-making, and sequencing tasks. The frontal lobe also controls our ability to look inward to understand our own and others' deepest motives. Planning and carrying out a task and understanding how others feel are capacities dependent on this part of the brain. By mid-stage or sometimes even the early stage of Alzheimer's disease, many of these capacities are seriously compromised. Overall, people with frontal lobe damage in mid-stages of Alzheimer's disease have difficulty with personal care and the everyday tasks of life.

Other parts of the brain

As the disease progresses, psychiatric symptoms such as hallucinations, delusions, paranoia, agitation, panic, and denial are seen in some people. Toward its end stage, other, more primitive parts of the brain are affected. Changes in the cerebellum lead to impaired coordination of voluntary movements, such as sitting, standing, opening a door, and walking. Changes in the pons and medulla areas of the brain late in the disease even affect basic functions such as breathing, heart rate, temperature control, digestion, swallowing, and blinking.

Why treatment can still be effective

After looking at all the neurological damage caused by Alzheimer's, one might logically ask how treatment can take place. Traditional forms of treatment, such as reality orientation, behavior modification, and talking therapies, require at least some memory and introspective capacities. Alzheimer's caregivers have none of these with which to work. What neurologically based capacity remains for treatment?

The amygdala in the brain's limbic system gives us the ability to respond to emotion, to evoke or hold emotion, and to perceive emotion. Remaining relatively intact late into the disease, the amygdala retains enough function so that those with Alzheimer's disease continue to relate emotionally to others. What is lost is the personal insight into what may have triggered a particular emotion and how to control it. Treatment ultimately targets the person's ability to hold and respond to emotion.

Two treatment modalities are available to maintain quality of life for those with Alzheimer's disease and related dementias. They are environmental design and staffing and programming. However, before either of these treatments can be effectively employed or evaluated, medical intervention must be taken into account.

Specifically, when other illnesses are present, symptoms associated with dementia can be exacerbated.^{6,7} Such additional symptoms are one type of "excess disability" labeled this way because they are not strictly symptoms of the dementia itself. For example, a person with Alzheimer's disease who is also clinically depressed is likely to appear more demented than an Alzheimer's patient whose depression has been medically and psychiatrically treated. For this reason, the first steps need to include thorough diagnosis and treatment of those illnesses that may be present, but are not integral to dementia.

Table 1. Nonpharmacological Alzheimer's treatment matrix			
Brain dysfunction	Functional loss	Treatment approach	Treatment actions
Naturally mapped environment			
Parietal and occipital lobes ⁴³	Lack of cognitive map and vision	How environment communicates to residents by speaking for itself and cueing	 speaks for itself directs cognition (cueing) archetypal spaces links into what is lost last
Accepting residents' frame of reference			
Hippocampal complex	Being in the present, with no past or future	How we communicate to residents by participating in their definition of the situation	 never say no participate in patient's reality reduce fear
Activities of Daily Living (ADL) success assistance			
Frontal lobe ⁴⁵	Loss of executive function —ability to sequence tasks—and motor function	How we approach ADLs to create independence and enhance mood. The way they are done is as important as getting them accom- plished	 use ADL to bring about a positive emotion—participate in daily life routine limit excess disability—do not do too much for residents
Therapeutic activities			
Frontal lobe ⁴⁵	Loss of impulse control and social norms	How we therapeutically structure activities to increase relationships, belonging to the group, and indi- viduation	 the main treatment therapy use activities to keep cognition that still remains from being lost
Multiple communication modalities			
Anterior and medial temporal lobes	Loss of language and detailed memory	How we link into the way resi- dents perceive, feel, and process information to enhance whatever types of memory are preserved	 verbally and physically structure things so residents can "see" them employ music, art, visual objects, and hugs
Self-control behaviors			
Frontal lobe ⁴⁶	Loss of ability to place meaning and reality—no ability to soothe themselves	Strategies to avoid negative behaviors—agitations, confusion, hallucination—to react positively to negative behaviors and to sup- port positive behaviors	 react positively yourself to prevent causing problematic behaviors structure the environment to provide meaning change yourself—you cannot change behavior by words
<i>Note:</i> The amygdala ⁴² in the brain retains the person's ability to sense emotion and mood; therefore, the major treatment goal is to maintain positive emotion.			

Treatment Interventions

The goal of nonpharmacological treatment is deceptively simple: to bring about a positive emotion and to maintain that positive emotion for as long as possible. Clinically, this presents a challenge. It is not simple for a caregiver to increase functional independence, reduce the need for psychoactive medications, prolong life, reduce the need for restraints, reduce acute hospital admissions, reduce depression, and improve morale. Treatment has the potential for improving the quality of life at any stage of the disease⁸⁻¹⁵ early, middle, or late, in home, day care, assisted-living, or long-term care settings—but what are its components?

"Habilitation" therapy¹⁶

An important conceptual stepping stone toward recognizing treatment possibilities and shifting the caregiving paradigm away from hopelessness is called "habilitation" therapy. The term reflects the realization that the brain of a person with Alzheimer's and its function cannot be restored to its prior condition—hence, therapy is not *re*-habilitative. The term also implies that effective treatment aims to help people "live and work through every day life," namely, it is "habilitative." In the definition of this unique and pioneering therapy, "using mood to bring about a person's ability to live and work to their full potential" is a central feature.

Six treatment domains

Naturally mapped physical environment¹⁷

Treatment can be a physical environment that promotes safety and reduces fear by directing cognition, even without the person's awareness. (See Table 1.) The literature is replete with environmental intervention strategies that have proven effective in improving resident behavior.¹⁸⁻²¹ The environment is like prosthesis for those who have difficulty carrying a cognitive map. By being self-evident, the environment compensates for neurological losses. It has what Donald Norman calls "natural mapping" in which the environment itself contains the knowledge necessary for its correct use rather than relying on knowledge held in the head of the user.²² Design adaptations and enhancements work by reducing demands on the person's already challenged perception, thus dramatically improving levels of functioning. More importantly, by promoting feelings of security, mastery, and belonging, these adaptations and enhancements lessen the frustrations that often result in behavioral outbursts.

Accepting residents' frame of reference

How we help the person to make himself or herself

understood and how we make ourselves understood to the person forms the cornerstone of nonpharmacological treatment. Communication is where this treatment departs most dramatically from traditional forms of therapy with older adults. Communication with people who have limited word recognition starts with the premise that a person's behavior is not changed by words alone; rather, to change behavior, caregivers must change either their behavior or the environment. Another tenet of treatment communication is never to try to bring the person-especially with mid-stage or laterstage dementia-back to our sense of reality, but rather to move into their sense of the world. A third principle is to reduce fear by using validation therapy and limiting the range of options for the person to a number he or she can manage. A fourth strategy is to use distraction, refocusing, and redirection to change goal-oriented behavior. The success of specific treatment techniques such as validation therapy has been demonstrated in previous research.²³⁻²⁵

Maintaining positive emotion while assisting with activities of daily living

All too frequently, caregivers take away the opportunity a person with Alzheimer's may have to perform life's routine everyday tasks. Rather than helping the person with what he or she still can do for themselves, the caregiver carries out the entire task. People cared for in this way feel frustrated, dependent, and helpless, often losing the drive and ability to care for themselves. Such dysfunction is a type of "excess disability" because it is caused by a caregiver's well meaning actions, the person's own emotional reaction to his or her disease, or the lack of environmental support rather than in response to brain damage. For example, if we present a person with a large plate of food and feed her by hand when she can still eat finger food by herself, that person is likely to lose the ability to eat by herself.

Scores of specific strategies and skills have been developed to keep the person with Alzheimer's participating in their own care far into the disease.²⁶⁻³⁰ Treatment in this domain requires caregivers to discover and capitalize on remaining skills, to break down tasks into simple, easily sequenced steps, and to know when to provide more or less support.

Therapeutic activities and programming

Structured therapeutic activities are the motor that drives the entire treatment model. A broad range of specific treatment techniques in the literature can be incorporated under this modality.³¹⁻³³ People with dementia who spend long periods doing nothing experience more psychiatric symptoms, such as depression, anxiety, paranoia, delusions, and hallucinations; however, therapeutic

activities should not be considered valuable merely because they fill time. Activities are therapeutic because they quickly change negative emotions and promote feelings of purpose and accomplishment.

From another perspective, activities maintain connections between healthy neurons and may even prevent neuronal connections from being lost. By drawing on a person's remaining skills, as determined by a battery of neuropsychological tests, caregivers can create a plan of success-oriented activities that focuses on the individual's cognitive strengths and avoids the weaknesses, thus slowing the rate of decline of those skills.

Such therapeutic activities also confront an unfortunate but persistent myth that people with Alzheimer's disease, because they may not remember friends or initiate a relationship, no longer have a need for relationships or social interaction. In fact, as people lose the ability to make and hold friends, they increasingly need the social benefits that derive from relationships. Whereas some people with Alzheimer's may not have been very sociable before they developed the disease, group activities that surround them after they have the disease can counteract feelings of alienation and isolation, and support feelings of belonging and safety.

Multiple communication modalities

With Alzheimer's, people's senses do not work as well as they once did and the brain's ability to interpret sensory information becomes impaired. Sensory modalities blend together and one's senses of sight and sound may not be completely separate experiences. As William James observed about infants: "Sensory information is a blooming, buzzing confusion." In some cases, a person may lose proprioceptive memory—that is, memory related to muscle function.

The treatment intervention consists of constantly stimulating the senses at the appropriate level for that person. Familiar music, food smells, touching furry animals, and other nonverbal perceptual inputs replace words in many cases. In addition, because receptive and expressive language abilities are impaired, much of what is communicated to people with dementia is not done with words. Feelings of safety, personal value, and purpose are communicated with a look, a tone, or a hug.³⁴⁻³⁸

Self-control behaviors

Self-control behavior strategies focus on behaviors rather than emotions, striving to prevent difficult behaviors and to react to difficult behaviors positively when they occur. The premise underlying this treatment area is that negative behavior is rarely a random neuroelectric impulse. Instead, it is caused by a triggering event, which, if identified and eliminated, can reduce the problem behavior. Current research in the field addresses various treatment techniques to reduce behavioral disturbances.³⁹⁻

⁴¹ When a negative behavior occurs, caregivers can observe, analyze, and plan interventions that manipulate the triggering event. Caregivers who continuously and vigilantly apply each of the other treatments—particularly, therapeutic activities that focus on the person's sense of self and belonging to the group—can reduce the likelihood of negative behaviors occurring in the first place.

The simultaneous cross-fertilization and interconnected use of all these treatments creates a proactive therapeutic milieu for understanding and treating the needs of people with Alzheimer's disease. This is as much a paradigm shift in our way of thinking about Alzheimer's disease as it is a therapeutic method.

Outcomes

The ultimate measures of success of such a treatment approach are improved quality of life, delayed institutionalization, slowed rate of progression of the disease, people who achieve their potential, and reduced need for medication.

Specific enhancements in quality of life that we can expect to observe when these approaches are consistently employed in a coordinated way include improvements in functional independence, mood, motor skills, happiness, and satisfaction, and reductions in agitation, disease-related behavioral symptoms, depression, and excess disability.

A poignant definition of this approach to treatment may lie in the observation of neurologist, A.R. Luria in a letter he wrote years ago to Dr. Oliver Sacks:⁴⁷

People do not consist of memory alone. They have feeling, will, sensibility, moral being. It is here that you may touch them, and see a profound change.

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