

Active Living

An Environment not just an Event

“You matter to the last moment of your life, and we will do all we can, not only to help you die peacefully, but to **live** until you die.”

- Dame Cicely Saunders

That quote from the founder of Hospice is generally associated with physical care and pain control. But for us, the last four words seem to paint another picture...live until you die.

Perhaps less prophetic but carrying a similar thought is a quote that recently made a tour on the Internet:

“Life's not a journey to the grave intending to arrive safely in a pretty and well-preserved body, but rather to slide in broadside, thoroughly used up, totally worn out proclaiming, “WOW what a ride!”

There are clearly two sides to the coin of life for elders in care communities:

- An environment can be alive with positive energy...full of people truly living
- Or a hollow space full of people who are technically alive but just passing time--waiting for life here on earth to end

The number of residents in a care community doesn't seem to be the issue. Lots of folks or very few can share a space in which the environment is lifeless. All the brass and glass of some gorgeous facilities can't hide the haunting sense of “nothing is happening.”

Our little company cares deeply about teaching caregivers how to engage elders (particularly those who have dementia). Our past few years of experiences in speaking at major conferences and small workshops; visiting dozens of homes;

working directly with elders; talking candidly with both family and professional caregivers has brought us to some opinions about the quality of life for elders and what their days, weeks and months are like.

Retooling mindsets

We think, mostly, the concept of “activities” is misunderstood. We have repeatedly seen (in the US, Canada, Europe and the South Pacific) that the word “activity” (in conjunction with elder care) is associated with group events--mostly involving a craft of some kind...or bingo. “Activities” seldom has a positive connotation.

So, we think the first step in creating an Active Living Environment is retooling mindsets. The story of Pygmalion from Greek mythology is interesting, but the practical implications of the underlying theory have been proven in many well-documented studies. The best of these were conducted by Dr. Robert Rosenthal. Repeatedly, he showed that expectations shape outcomes. If people are told they are skilled and can accomplish...they will.

This concept blends nicely with the landmark book by Dr. Maxwell Maltz, Psycho Cybernetics. Maltz, a plastic surgeon rather than a psychologist, noticed that patients whose appearance had been transformed from unattractive to beautiful often continued to see themselves as unattractive following surgery. This observation led to his books and belief that when the subconscious mind is loaded with negative information, it is very difficult to see things positively.

World famous motivational speaker Zig Ziglar talks of doing a quick “check up from the neck up to get rid of that stinkin’ thinkin’.” But, changing long held beliefs is not a fast or simple process.

If most of the staff, residents and family members think “activities” are a waste of time, orchestrating group events often isn’t enough to significantly change the environment.

In a deceptively simple statement, Dr. Peter Drucker captured the essence of creating culture change. He said, “Things which do not change, tend to remain the same.” Perhaps even more familiar and on the same subject:

“The definition of insanity is continuing to do the same things over and over, and expecting different results.”

We often hear health care professionals say, “Everything a person does is an activity.” That includes brushing teeth, taking a bath, and dining. True enough. Those are all perhaps activities of daily living...but most do not meet the psychosocial needs of elders (described later).

Simply put, although just about everything that happens during a day can be considered an activity, we think the focus should be on things that are personally meaningful and of interest to elders.

Some believe games and craft making are childish, humiliating, and a waste of potentially meaningful time. We agree that many poorly organized gatherings do little to stimulate creative thinking and seldom produce the sense of community...or inclusion...so needed by elders. But, to broadly label certain types of interactions as “childish” misses a major conceptual principle. There is a huge difference between “childish” and “child-like” especially when dementia is part of the equation. The quality of an activity should be measured by outcomes.

Without trying to list all possible reactions of elders, simply ask, “Was there active (even slight) participation and visual signs they felt included?”

Active Living meets important, on-going needs of elders

In the book DEMENTIA RECONSIDERED, Dr. Tom Kitwood describes six needs of those with dementia. We feel the following applies to all elders regardless of the presence of memory loss:

- ***Attachment***
- ***Comfort***
- ***Identity***
- ***Inclusion***
- ***Occupation (participation)***
- ***Love***

It is imperative that we attempt to meet the fundamental emotional needs of those in our care.

Active Living (an environment that nurtures a person’s physical, mental, spiritual and emotional well-being) creates a nourishing atmosphere where these needs will be met on a consistent rather than sporadic basis.

Recently we watched an elder wrestle with the delicious dilemma of wanting to be two places at the same time...big dollar bingo or a big band dance party. In the end, he made it back for the swingin’ good time and showed off his winnings. He had more than one choice about what to do with the day...and the freedom to choose!

Sometimes, care communities suffer from what the world of business calls “paralysis by analysis.” Far too much time is spent trying to nail down answers to questions like: Will this be successful? Do we have the materials to do it? How much time is needed? Is the gathering place large enough?

We like an action plan prescribed in the book IN SEARCH OF EXCELLENCE...Ready, Fire, Aim. If you have an idea that you think might work, try it. Then make adjustments to correct flaws from the first round attempt.

So if you're interested in facilitating a rhythm circle with elders, don't search and wait for the perfect Remo hand drum. Grab some 'kitchen' instruments like a pot and spoon to try something today.

Prioritizing Active Living

To accomplish the goal of injecting something (more than physical or medical attention) into the hours and days of residents, the concept of Active Living must be woven into the culture of care, and the position of Activity Director must undergo changes.

In the widely criticized "medical model of care," daily chores such as 'feeding' and 'toileting' progressed in a systematic, staff-centered, military-like manner. The task-oriented work completely trumped elders' preferences...whether that meant their desire to sleep late or enjoy a particular activity.

This begs a question. At your building, "If elders are enjoying an activity and want to stay, can they?" Attending to physical care tends to live at the top of daily priorities. Activities often are at the bottom--something that can be done if time permits and doesn't disrupt the orderly flow of "important" tasks.

The list of needs to build an Active Living environment is relatively short. It includes: (1) people who are willing to try new ideas and learn, (2) a giving mindset, (3) schedules that have enough time built in to allow activities to take place.

When positive cultures take root, amazing things begin to happen

Southwest Airline is one of America's most written about companies...and for good reason. In addition to 40 years of unbroken profits, they work steadily at having fun and showing sincere appreciation for their customers. The current

president, Colleen Barrett, was asked to explain what makes Southwest different.

She said, "We want our team to treat others as they would like to be treated; and smile at customers...because they want to." It's the last four words that make the difference.

The legendary Herb Keleher (previous Southwest CEO for almost 30 years) had a way of inspiring this positive attitude in his staff...even when times got rough.

He once asked employees to take a steep pay cut during a budgeting crisis...and took one himself. It cost him about \$100 million dollars.

He costumed on Halloween every year, and, as a result, so did all employees at Southwest.

He practiced what he preached about everyone pitching in to get the work done. To keep things on schedule, he would help baggage handlers load and unload planes.

Today you'll notice Southwest pilots helping disabled passengers get on and off flights.

Off-duty flight attendants flying home get up and help the on-duty crew serve peanuts. Southwest even has what they call "Hokies." It's a surprise crew of flight attendants who periodically meet incoming flights and help the on-duty crew clean the plane...some have done this on their day off.

Passengers still remember those goofy safety announcements like:

"For those of you have never ridden in a car built since 1954, we need to show you how to use a seat belt."

If the cabin should lose pressure, four yellow masks will drop from the panel above you. Stop screaming, grab one, and put it over your nose and mouth like this." Or a favorite after a hard landing, "While we're waiting for Captain Kangaroo to bounce us up to the gate, please remain in your seat with your seatbelt fastened."

Teamwork is the key

There are similar stories about other employee groups...and wonderfully many come from elder communities where the care team “gets it.”

When the environment is alive, people volunteer...and they do it because they want to. And, the work they do is magnificent.

One thing remains constant. Leaders must be a part of the culture. Staff members who watch team leaders consistently interact one-on-one with residents see immediately that “person-centered care” is more than another hot doin’ phrase picked up at a recent conference.

Care communities that “get it”

We’ve witnessed CNA’s work straight through their lunch break to facilitate a meaningful activity for elders...a maintenance man ask for a hand while repairing the heater...a master chef spread out flowers for elders to arrange at each table...a housekeeper lend a listening ear to a troubled family member.

Once when a resident (scheduled for therapy) was having a ball at one of our spontaneous group gatherings, an OT smiled and said, “I’ll come back later.” The decision to shuffle her schedule (and prioritize Active Living) was an excellent example of person-centered care...allowing him additional moments of joy.

When we see and make adjustments to meet the needs of the situation, everyone wins.

If leaders encourage this kind of group effort, the environment becomes even more caring...and active.

The glue that holds it together

All who come in contact with elders should be equipped with good communication skills for personalizing care.

But, are the skills of effectively communicating with elders taught to all staff members?

Does everyone on the team know:

(1) how to establish eye contact (on an equal level)

(2) why “baby talk” is demeaning and becomes a communication roadblock

(3) how to use questions with attentive silence to stimulate responses

(4) good techniques like using non-committal replies to encourage communication attempts by elders

Is communication with elders a central part of “important” daily duties? Does the staff know three or four simple one-on-one techniques they can use to engage residents?

Much of Active Living happens at times when elders would otherwise feel alone for long hours.

Story telling rather than interrogating

During the years the matriarch of our family lived in an assisted living facility, we “stopped by and visited.” But, one day we hit upon a gold mine of an idea that ultimately led to a change in communication style.

Mildred and her husband, Jack (whose death preceded her stroke), owned a small farm about 45 minutes’ drive east from Kansas City. It was a “get away place” that had little in the way of buildings and equipment but tons in beauty, quiet, and memories of summers when she and Jack took their grandkids there many summers and spent weeks fishing, hiking and bonding.

One day we asked Mildred, “Would you like to drive to the farm?” You probably know the answer. She lit up and looked for a sweater!

That first drive to the farm was a huge learning experience. Telling stories to a person with dementia is relaxing and enjoyable compared to trying to maintain a “normal” conversation...where people bounce opinions back and forth, ask questions, and reminisce.

The drive from Kansas City to “the farm” has a virtually endless number of landmarks to observe...or point out. They aren’t, by the

world's standards, comparable to the Golden Gate Bridge or The Great Wall of China (which, incidentally, Mildred had seen), but they were breathtaking to someone who grew up on a farm and remembers the colors and smells of fields of corn and soybeans...and livestock.

Story telling began when Mildred said, "What's that?" pointing to the smoke stack of a small electric power generating plant that serves a tiny farming community along the drive. The short answer would be, "That's a chimney."

The story telling answer would be, "That's the big smoke stack for an electric plant. They bring carloads of coal in...see them over there...and they burn the coal to heat water to make steam..."

Only a short distance from the little electric plant, the road climbs a hill, and ahead is an awesome vista down into a huge valley that is prime farming land. Every year it is planted with corn or soybeans. The rows are perfectly straight and seem to go at least 100 miles.

When we crested that hill, Mildred said, "Isn't that beautiful!?"

The short reply could have been, "Yep." The story telling reply pointed out that it was late spring "and the corn was really starting to get tall. See over there, there's a tractor in the field. Isn't it amazing how they make all those rows such straight lines?"

The trip was an event that hit the emotional buttons of every person in the car. Granny (Mildred) was having a stunning moment, and we all knew it. We used about a half box of Kleenex that day.

We decided to do the trip again the next Sunday...and the Sunday after that...and...

As time passed the number of landmarks pointed out and about which comments were made became lengthy. The list was helped by the fact that we learned she particularly liked trains and rivers.

As it turns out, the highway runs parallel to a major train track and the Missouri River. We had

the ever-changing appearance and natural beauty of the crops, the colors of treetops on the hillsides...clouds in the sky...birds flying by. There seemed to be no end to things upon which to admire.

That reoccurring 45 minutes of magic could easily have been killed, though, the second week (and every week thereafter) if Mildred had asked, "What's that?" and the answer had been, "You know what that is. It's a chimney. Remember me telling you about that last week?"

Instead, I appreciated the silver lining to her dementia. Short-term memory loss made the trip brand new each week. It was a "first" every time.

Familiar music opened closed doors

One Sunday, we plugged in a cassette tape of old and very familiar hymns sung by a variety of country music stars...Amazing Grace...In The Garden...Church In the Wildwood, etc. Since our family is one that sings in the car, it was a natural that everyone joined in singing as we drove...including Mildred.

There was a chorus of off key voices surrounding her, the sounds of big orchestration coming out of the speakers, words to hymns so deeply engrained in her memory that she could and did join in singing songs she hadn't sung for years.

So, what's the point? Music is a powerful tool and one of the fastest and simplest ways to stimulate the environment. Most types (classical, jazz, country, big band, religious) may enhance the mood.

One-on-one activities help

In separate articles, we have chronicled how the use of simple bean bags can prompt trigger/flash moments as well as keep conversation at a pace comfortable for people who have dementia.

We have heart-stopping letters from family members who needed a way to "talk" to Mom or Dad when words were limited or gone. After only a few minutes of instruction, bean bags opened lines of communication again.

Though often used in small and large group settings, tossing bean bags is a great way to enter a one-on-one interaction with a resident.

Because language abilities vary from elder to elder, “conversation substitutes” or “props” often break down barriers, spark interest and highlight an elder’s interests or strengths.

Short (sometimes spontaneous) exchanges are of equal importance to orchestrated large group activities.

Validate Activity Directors

We’re not talking about creating a new, more impressive title (although titles can sometimes spark a new way of thinking). We’re focused on changing mindsets about the essential work Activity Directors do in relation to other equally important caregivers.

Even though some Activity Directors have advanced degrees and many hours of specialized study, their position in the “pecking order” among the staff is too low to be impactful. This may change when boomers arrive, but until it does, many large group events will be short and ineffectual in their ability to address major needs of residents.

Group activities provide a sense of community and connectedness. There are many productive interactions that can happen among elders and caregivers that don’t require heavy expenditures for props nor more than a very few minutes to orchestrate.

Activity programs on a budget

How do you build group activities that are alive and meaningful? First, keep it simple.

Most large group gatherings should (1) require little time to set up or clean up, (2) not require buying expensive equipment or supplies, and (3) allow for flexibility and spontaneity.

If the budget only allows simple activities that don’t include expensive equipment and props, don’t hide behind “We don’t have the money to _____.”

We have seen gales of laughter and joyful interactions produced with bargain basement items...things that cost \$5.00 or less and were mostly found at thrift stores. Many times the simpler the supporting props, the easier to start and end the activity.

We’ve also seen spectacular computer based applications and very elaborate karaoke machines with sing-along devices that replicate what used to happen on the Mitch Miller TV program (when a white ball bounced from word to word).

Great ideas already in use

We modified one of our favorite activities after visiting a day center on Prince Edward Island. We’ve always found tea parties to be fantastic small or large group events that work every time.

The very best of social behavior rises from this group setting. With only gentle cues, enjoyable light conversation escalates. And, it doesn’t cost an arm and a leg.

The PEI day center reminded us that a collection of mismatched china cups, a ceramic tea pot, creamer, sugar bowl and just about any kind of cookie or cracker (that won’t create medical problems for those attending) is about all that’s needed to create a feeling of community...family, if you will.

Jane Verity, an Australian dementia care consultant, describes a more advanced version of these gatherings as clubs.

She teaches care communities (with her Spark of Life program) how to create groupings like a gentlemen’s club where “the boys” might get together for a non-alcoholic beer, or, in some cases, a cigar. The concept applies equally well to gardening clubs, art clubs, reminiscence clubs, etc. There is no limit to the number of creative possibilities.

And if one of the outcomes is laughter ...GOOD!

Laughter is good for you

“Do we laugh because we are happy and healthy, or are we happy and healthy because we laugh?” This question was put to the test by Norman Cousins in the 1960’s when he was diagnosed

with ankylosing spondylitis, a collagen illness that attacks the body's connective tissues.

Questioning the prognosis of irreversible and continued decline of his body, Cousins decided to take on his disease with a little humor.

He watched *Candid Camera*, Laurel and Hardy, Marx Brothers movies and listened to humorous stories. His fifteen minute investment of time spent laughing each day provided up to two hours of pain relief and sleep.

His adamant belief that belly laughing improves overall health was not embraced until 1989 when the Journal of the American Medical Association acknowledged laughter therapy. Today, it is widely accepted that laughter creates positive emotions enhancing—not necessarily replacing—conventional treatments.

Francis Brennan and Carl Charnetski explain in Feeling Good is Good for You, “If you force yourself to act in ways that are out of sync with how you actually feel, your brain will change your attitude to come into accord with your behavior.”

Good for your heart

The idea that laughter is linked to good health has been recently supported by research conducted at the University of Maryland School of Medicine in Baltimore. In March 2005 Dr. Michael Miller announced the results of a small study involving 20 healthy volunteers. Each person watched two movies, one humorous, one stressful. Researchers carefully measured activity in the lining of the blood vessels.

After watching the movies, results showed a 22% increase of blood flow during laughter and a 35% decrease of mental stress. The study supports the theory that laughter may reduce the risk of cardiovascular disease.

Laughing lowers blood pressure, reduces stress hormones, increases muscle flexion and boosts immune function by raising levels of infection-fighting T cells which produce disease-destroying antibodies.

Some refer to it as “an internal jogging.” In general, laughter has healing powers.

Natural pain killer

Laughter also triggers the release of endorphins, the body's natural pain killers, and provides a general sense of well-being. Obviously, the physiological benefits are huge. But, the positive effects don't stop there.

Psychologically and emotionally, laughter energizes us spiritually, builds friendships, increases communication and increases our sense of safety with one another.

One of the best parts: laughter is free...with no known negative side effects! Perhaps this is why hospitals in ancient Greece were built next to amphitheaters to help “cure” patients or why laughter clubs and associations have formed throughout the world.

Where science and dementia care meet

Dementia is not a laughing matter. Memory loss evokes pain, sadness, frustration and depression. Losing the ability to remember is difficult, but adding the inability to find things at which to laugh makes life bleak for many. Our interactions with people who have dementia can be friendly, positive, good natured, gentle and kind...and often bring the healthy gift of laughter. People with dementia want to laugh, but need others to help initiate the moment.

Laughter is contagious. The TV industry has this figured out—add a laugh track in the background and the audience naturally joins in! People with dementia have similar reactions. Starting with a smile, we may lead the way into a giggle fest or a hearty deep laugh that can bring tears...of joy. Although it is true of most people, when working with those who have dementia, it's especially important that we create situations where they can share a laugh...and not feel laughed at.

Studies at the Rotman Research Institute found it is the right frontal lobe of our brain that comprehends when situations are humorous. Damage to this lobe makes it difficult for a person to catch punch lines or understand sophisticated or

subtle jokes. Instead, they may laugh harder at slapstick humor.

People with dementia may or may not have frontal lobe damage. Regardless, we need to be sensitive to and aware of the possibility that “goofy stuff” has a better chance of bringing a laugh than telling a long joke with a punch line.

A person’s laugh is as distinctive as a fingerprint and we each find humor in different things. What makes Margaret laugh? James? Dorothy? And, what kinds of things seem to “tickle their funny bone”? Enjoy individualizing approaches to humor!

Creating on-going or individualized activities

The 5-7 minute interactions provide instant joy. But, accumulating things learned by caregivers can be pieced together like a jigsaw puzzle.

We were so impressed while watching a heart-warming video of an elder who, staff learned, was a retired newspaper reporter. When they gave him access to a computer, he not only became editor of the newsletter...but he also wrote a letter nominating his caregiver for “CNA of the Year”.

In another example, a resident had been a farmer/gardener all his life. He was given “a wee bit of earth.” You can imagine the rest of the story.

“Wait...wait...I have one better than that!” You probably have a story that needs to be told...and ideas for residents of your community.

This is where “person-centered care” takes on real meaning. The more we learn about an elder and apply that knowledge...the richer the quality of life becomes.

So, what am I supposed to do?

As we have said, Active Living is an environment, not an event. There is no “one size fits all” prescription to creating this nurturing atmosphere.

Like a good soup, a few key ingredients can make for a satisfying meal. However, when the chef adds small pinches of seasoning and spice (Remy in Ratatouille), that good soup turns into something absolutely divine!

Build as you learn. Evaluate what you’re doing now that is working. Polish and refine it. Make it easy for others to repeat. Share successes.

Try a new idea that won’t cost much or take too much time. If it works, refine it. If it doesn’t, dump it...and look for something else.

Regardless of what you try, you will add something meaningful to the lives of those in your care. The possibilities are endless.