Keeping Curiosity Alive
How an Expressive and Therapeutic Art Program Worked with a Man Named R

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“The Struggle to Move Forward”

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R’s Illness
R was a man, diagnosed in his early 60’s, with a degenerative neurological condition called Cortical Basal Ganglionic Degeneration (CBGD) also known as Cortical Basal Syndrome (CBS). The illness is characterized by marked disorders in movement and cognitive dysfunction. Clinical diagnosis is difficult, as symptoms of the disease are often similar to those of other diseases, such as Parkinson’s disease (PD) and progressive supranuclear palsy (PSP). Other specific symptoms are: alien hand syndrome, which results in the sensation that the limb feels foreign; apraxia, the inability to repeat or mimic particular movements; and aphasia, a disorder revealed through disconnected speech patterns and omissions of words. (Reference: The Association for Frontotemporal Degeneration, www.theaftd.org)

R’s Life History (excerpt written by his son)
In high school, R was known for being the school’s resident artist. He designed logos and banners for the school’s sports teams. R took a great interest in computers and electronics. In 1965 he won an award for a home made computer. R’s interest turned to cars and motorcycles. He operated an auto enthusiasts club customizing cars and bikes. According to friends, he had the best bike in town which he built and painted himself.

R took a position as a welder and painter at the Portsmouth, RI Naval Ship Yard. He later attended a technical academy for computer science. After graduation he toured Europe where he met his first wife and the mother of his child.

As a computer programmer at the Naval Surface Warfare Center, R designed the computer code for the Trident Submarine torpedo launch systems.

R became a world traveler after his first travel experience to Europe and became an expert tradesman of art and artifacts. As always he continued to be industrious. R built two houses and continued his interest in artwork. He also developed a strong interest in sailing. R retired from the Naval Surface Warfare Center in 2004 with many accreditations. The following year he was diagnosed with CBGD. His abilities slowly disappeared over the
following years. Eventually his brain was unable to command eating and breathing functions. He died in August of 2011 at age 64.

**A Medical Directive**

R’s family was advised by Dr. Grafman, Chief of NeuroScience and Cognition at the National Institute of Health (NIH), that "connectivity treatment was crucial: doing as many things as possible - in particular around people - that stimulated neuronal activity and regeneration".

With this medical directive, the goals formulated with R and his family, were essentially to keep him actively involved, using the six areas of wellness (physical, social, intellectual, emotional, productive and spiritual). With a creative flair, ongoing efforts were made by a team of family, friends, and hired staff to keep a vibrant and meaningful lifestyle in place for R.

At the family’s request, I designed an art as therapy treatment plan using a reminiscence approach, incorporating R’s old slides and photographs, his collections and interests, his memories and family traditions. The therapeutic relationship between my self and R began with reviewing the travel slides, observing his illness, and making an assessment of his physical, mental, and emotional ability to function as an artist.

R chose slides to work from that showed his interest in the architecture of Germany and France, and the architecture of a mansion he lived as a caretaker. Ideas were also generated from art history books. Artist, Henri de Toulouse-Lautrec provided a good French connection to the language he loved.

R’s first painting - a German Villa

Sea Fair, a mansion in Newport, Rhode Island

A painting with French words

R had an interest in antique cars so arrangements were made for a trip to an antique car show.

R at an antique car show.

Antique Car Drawing

Painting of the Spitfire
A Combined Approach - Art, Music and Other Interests

I combined a person-centered, expressive and holistic approach with cognitive directives and applications. Besides art, sessions involved reading the New York Times for current events, and music and dance, to sustain, stimulate, and enhance his mind, his daily functioning, and his life. To keep the process light and fun we whistled, listened to music and sang the lyrics. With hand over hand assistance R played a key board and sang the scales and simple songs. He loved the outdoors so walks around the premises where he lived, and at the beach, became part of the routine. R was a funny man and loved to laugh and at times a good comedy show provided an option in the routine. R’s humor was vibrant and engaging. There was ongoing laughter in all of the sessions, often with a ritual of eating the chocolate. R was continually sustained within the creative midst of new activities that allowed him personal choice and expression.

The Time Frame
Work progressed with R steadily for over two years as his body and mind declined. Initially, in the first year, sessions with R were held once a week for two hours, then twice a week for ninety minutes. As R’s stamina lessened with his illness, the schedule was adjusted again, to sessions of one hour, three times a week.

Emotional
Working with R was a pleasure because he was so good natured and funny. R was also very emotionally sensitive and expressive of his feelings. R’s self awareness about his own declining condition was evident to him. Attending to him in his times of sadness and grief helped him to feel supported. Whenever he cried he said it was a family trait and very much a part of him. It was always from this point that he was able to move forward. He worked on acceptance and his support team helped him with his coping skills, to help him keep a positive focus so he would not sink into deep depression. R’s medications helped to stabilize him and enabled him to work through positive focus, using the strength of his personality traits like his humor, his highly social nature and his awareness of others, and his tenacious desire to have fun and to always be productive.

R's Chinese Symbol for Patience
Purpose
Much of the group effort was focused on keeping R engaged in purposeful daily living activities, like watering his plants, buying fish food and bird seed, filling the bird feeder and feeding the fish. For the art sessions he helped in shopping for art supplies and helped carry supplies to the work areas.

Connectivity
Sessions also included field trips going to art exhibits and gallery openings since new experiences are known to stimulate new growth in brain cells. Connectivity was evident during winter, 2010, from these excursions, as R pointed to similar content in paintings, indicating that he understood some of the repeating elements present from piece to piece. He was also able to connect as an artist, by infusing into his observations, his personal involvement and experiences in the art making process. When going out was not an option similar results were achieved viewing art history books. Through his own art making experiences and art appreciation R was able to maintain functioning and connections to his emotions, memories, choices and preferences, relationships, and mental processing. He experienced happiness, contentment, and growth, despite his degenerating condition.

Motor Functioning
Due to neurological impairments almost all art work and activities that were done by R were accomplished by our hand-over-hand team work. Initially R did do some drawing on his own but on a very limited basis due to limb-kinetic apraxia affecting precise movements in his hands. He was able though to paint large and small partitioned areas on his own and experienced an immediate sense of accomplishment, laughing as he did.

R's large motor movements were also effected by apraxia. He experienced reduced stamina and tolerance to exertion and involuntary spasms. His gait became unsteady and his "alien hand" was always clenched into a fist. At times it was positioned to give him physical support. Collectively, his sensorimotor functioning was at an active level. Successful coordination was achieved involving the use of large and small motor movements, including eye-hand coordination to visually track his hand movements, observe an image or object, and then paint and copy it. He held the tools and manipulated the media. He followed directives including: remove the cap from the paint tube, dip the brush into the paint, mix the colors, and move your hand in a horizontal, vertical, or diagonal direction.
Attention, Process, Cognition and Expression

In helping to promote R's attention the initial goals remained constant, to work with his interests, his preferences, his photos, and his extensive collections. Producing art provided R with many hands on activities and gave him a creative and expressive outlet. He produced paintings on canvas and paper, using acrylic paints, pastels, watercolors, markers, pencil, and collage.

Creating line drawings and paintings, working with clay, and doing assemblage art, gave R opportunities to be involved with a variety of sensory and tactile experiences, and make cognitive and emotional connections. In making the assemblage piece pictured below R formed a connection to past experiences. He had the opportunity to use the familiar tools he built his houses with, a drill, a screwdriver, and sandpaper. And in the process of framing his artwork, he sanded and stained the frames. Working with clay he got his hands wet and dirty.

The painting of the outdoor dining scene below reinforced cognition through a visual spatial planning process involving placement of design elements. The composition was created using a spatial arrangement of shapes, colors, patterns, and strong directional lines that are vertical, horizontal, diagonal, parallel to each other and also perpendicular.

The two to three times a week routine of applying these tasks kept R engaged. We followed the original directive of Dr. Grafman, to “stimulate neuronal activity and regeneration of new brain pathways, by doing as many things as possible”. R repeatedly made connections
between the application of process, and the end result of those actions, to a cognitive understanding of what he had achieved. R was very challenged in his ability to communicate, and experienced hesitant and halting speech due to the verbal aphasia, but he knew what was being said to him, as evidenced by how he could follow the directives of an art process that he was engaged in. He listened and focused his mind, then followed with his hands, his eyes, and his enthusiasm to create art that had meaning to him. R loved process. It was how his mind had always worked. Keeping it active effectively helped to maintain some continuation of his cognitive functioning, his life goals, personal expression, and quality of life.

**Visual and Spatial Perception**
Promoting clarity for R about environment was a priority since the disease was compromising his visual perception and orientation. But so was keeping curiosity alive and having fun. So many of the tasks I engaged R with, to help orient him, were light hearted. Providing him with hand-over-hand assistance we drew and painted his fish, the plant he nurtured for years, and the other people that lived in his community. As we did we observed closely and noted how every object or person filled and interacted with the space it occupied.

**Brain Function and Color, Shapes, Symbols, and Design**
In working with R two levels of brain processing were stimulated, the sensory system (bottom level), and cognition (top level). A bottom’s up approach involves the use of color, abstract shapes, and spatial arrangements of the elements. They are drawn and painted to decode information at a sensory level. This is an approach used in neuro art therapy and academic design curriculums. When changes are made with new arrangements and include the addition of more colors, shapes, and lines, then access is created to enter the top level of cognition.

The neuro art therapy modality uses this developmental process by including writing, naming colors, using metaphors and symbols, giving verbal directives, and requires answering questions. Art students begin their curriculum using basic design elements, and improve their skills with increased variables, and through practice and problem solving, find solutions.

In creating a program for R, my personal childhood academic experiences and my later art training, provided a course of action. My poor grade school academic comprehension drastically improved when I began studying art. Visual and developmental assignments opened a window that changed and improved my perception and my thinking process. I wanted to exercise R’s brain the way I experienced changes in mine. I began by referring to the book, “Drawing with Children” by Mona Brookes. In my classes with the children I used the line and shape drawings for routine exercises, as they were designed to be a cognitive developmental process. I determined the same process would be the place to start with R.
Positive and Negative Spaces

From “Drawing with Children”

The drawing exercise to the left shows both positive and negative spaces and three different shapes. I used the black and white exercise with R to stimulate cognition. Drawing exercises from The Del Giacco Neuro Art Therapy curriculum stress the use of color as a tool for stimulating attention. R and I repeated the process a year later using color. Using color with the image added impact to the exercise.

Color was used in all of R’s art projects because he was very stimulated by it. I increased our use of it after completing the neuro art therapy curriculum.

The mandala painting to the right is more advanced employing symbols within a complex design. It is a collage painting on an 18x24 canvas. It was meant to keep R’s mind active by moving back and forth between the sensory and cognitive levels of the brain. The symbols represented things that were important to him in his life. R and I started it together. We began with the colored symbol in the center and always meant to finish it by adding color to the small symbols. After he died I added the colors. You can see how color draws attention to the shapes.

Some other tasks used to exercise R’s brain were:
- located the EXIT sign, drew it, and put it on his door
- used colored blocks to make architectural structures
- played Tic-Tac-Toe
- drew or copied the symbols for staircases and cross walks and then compared them by walking on them.

The following paintings by R demonstrate varying effects using:
- repeating shapes and equal proximity
- high contrast colors compared to low contrast
- repeating patterns
- alternating shapes and patterns
- echoed shapes and form
High and low contrast, repetition, and equal proximity.

Basic shapes using 3 colors.

Design and added patterns increase interest and attention.

Engagement
R's work covered a large wall section in his room and there were other pieces placed around the room. Through his continued efforts R created his legacy. There are many more pieces that make up his portfolio. Whenever he was in his room he would spend time looking at all of his work. It was rewarding to witness him being engaged by it. His newly made collection of art and artifacts was something that had meaning because it was produced during the most trying times of his life, and it was also a continuation of the lifestyle he had always lived. His art work was a constant vehicle for conversation and involvement with others long after he had completed it.

Outcome of R’s Treatment
The goals of my therapeutic art treatment for R had been to act as a mentor to provide him with guidance and companionship, and keep him engaged in a positive and expressive lifestyle. R had always wanted to paint and that became his goal. The weekly scheduled appointments gave him something to look forward to, provided him with a means to engage in an aesthetic practice, exercised his brain, relieved stress, and gave him a sense of purpose. He had always been a person of purpose and action, and always building something.

R knew that new brain cells and pathways could be developing through his productivity and his positive life experiences, as his doctor had said, yet he also knew that they could not abate the progression of the disease. He went with the flow of his life path with acceptance, making the best of his foreboding situation. He still always managed to laugh. He had laughter in his heart.

The outcome for my self, is the realization that having the attitude of acceptance of life on life’s terms, reduces the struggle, and makes room to recognize what’s good, and to see possibilities. Potential and growth do not have to be lost due to oppressive setbacks and road blocks. The human spirit can break through to make a difference, and instill a sense of well being.