Hospice Patient Stories

by Michelle Traub

When I first began working with Regional Hospice and Palliative Care (formerly Regional Hospice and Home Care) they only had 5 patient stories. Working with the Volunteer Coordinator, I sourced, wrote, and edited an additional 13 stories over 9 months. In addition, I put together sample questions and helped to train a volunteer writer.

Following are the original stories that I wrote:

The Trip of a Lifetime for Sara Samaha



Crispin Baynes, Sara Samaha, Tom Kamber at the MET

(Danbury, CT) When Sara Samaha made the trip to *Regional Hospice and Home Care Center for Comfort Care & Healing* in August of 2015, she believed it would be her last. The 66-year-old had accepted that after two years of battling Amyotrophic Lateral Sclerosis (ALS) her treatment options near her home in Tennessee were limited. The former ICU nurse of 40 years worried about her ability to care for herself, and after careful consideration decided to make the 700+ mile drive to Danbury, CT to be closer to family. She never imagined that the journey she was taking was just the beginning, or that the family she was joining was about to grow.

The staff and volunteers at Regional Hospice and Home Care (RHHC) welcomed Sara with open arms, as they've done for the more than 774 patients they have cared for in the past year since the Center opened. Samaha appreciated her new home telling Center volunteer, Deborah "Deb" Pointon that, "the only door that opened for me was this in-patient hospice facility. This decision turned out to be a blessing in disguise for all involved."

Sara was introduced to Deb upon requesting a volunteer to help write her obituary. The two became fast friends, and their time together took a different turn as Sara's life progressed in unexpected ways. Although she only expected to live three months, after seven months in the Center's care, she continued to flourish. At that point, with Deb's help, Samaha wrote an article detailing the value of hospice care in hopes of helping other patients.

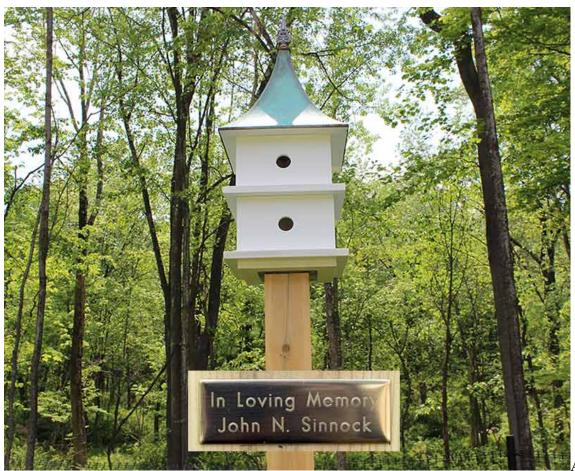
The article stressed that, "the reason hospice works so well is because of all the people who are involved." It went on to praise the caring group of <u>volunteers</u> who offer everything from personal assistance, to <u>reiki and massage</u>, as well as the dedicated clinicians who attend to a patient's every physical, emotional and spiritual need. Sara concluded with, "...my quality of life was better maintained and has definitely been prolonged because of hospice. I could not have made a better choice."

Many Center volunteers and staff were like family to Sara. When asked about her close relationship with Deb Pointon in particular, Sara expressed disbelief in her new friend's dedication. "I don't know why she's continued – I think because – we both love one another...She has become my hands, and my feet, and my communicator."

There were other unexpected helpers as well, including Tom Kamber, Executive Director of Older Adults Technology Services (OATS) and Crispin Baynes. The two New Yorkers met Sara while visiting RHHC to learn more about legacy journaling and end-of-life decision-making. In speaking with her they learned that she wanted to see the *Fabergé* eggs at The Met (The Metropolitan Museum of Art). Although her health was worsening, through the assistance of a family member, along with Kamber and Baynes, Sara was able to visit New York City last Thursday.

It was her final trip, as Sara Samaha passed away peacefully six days later. The loss is an especially difficult one for the many people who she touched while at the Center. In a message to staff, RHCC President & CEO, Cynthia Emiry Roy shared, "She said such beautiful things to me about your care. I could not be prouder of all of you. The love and attention you have shown Sara and her family has been so generous. One thing I know for sure – her life, struggle, and time here with us has been a gift. Her indomitable spirit will stay with us now and always."

Bird Houses – A Fitting Tribute to John Sinnock



Sinnock recalls her brother-in-law, John Sinnock, as a nature lover with a particular affinity for birds. While John was at the <u>Center for Comfort Care & Healing</u>, Ann spent time in the Memorial Gardens and noticed the numerous pavers and benches <u>honoring loved ones</u>. They inspired her and her family to pay tribute to John in a way that would bring joy and comfort to other patients – two bird houses to attract the feathered friends John loved.

A Teacher with a Love of Nature

John Sinnock had a long career as a math teacher, first in Massachusetts, then at Litchfield High School, and finally at Central Connecticut State University. His brother James shared that following John's passing the outpouring of support from former students made it clear he was loved and appreciated. "He had a gentle nature and really touched many lives," James stated. Ann agreed, further detailing John's love of nature and

animals, reflecting on how he had taught her to feed the ducks by sprinkling corn around the pond where John and his wife, Dianne Lastoria, lived.

Bluebirds of Happiness

At their Bridgewater, CT home, John and Dianne had beautiful gardens including a wood duck house and a bluebird house sitting atop a long pole. Ann noted that John was tall, so he had a great view of the birds as they'd come and go. "The birds were a great source of pleasure for him," she said. This was especially true as John's mobility became limited due to Parkinson's disease.

Finding Peace & Paying It Forward

As John's disease progressed he was in and out of hospitals, a circumstance that caused great distress for him and his loved ones. James Sinnock reflected on his family's experience with the *Center for Comfort Care & Healing*:

"We all felt relaxed and at peace once we made the transition from the hospital. Just a big sigh of relief that he was somewhere peaceful and restful. I have been in other facilities but they were nowhere near as well planned out. In retrospect we wished we were able to get there sooner."

A Place for Family

Dianne Lastoria was also grateful for the short time that her family was able to spend together at the Center. "We have a large family – 5 sons and their wives. There was enough room for everyone to spend comfortable time with him [John]. We used the living rooms to relax and loved being able to get food from the kitchen. All of the needs of the family were met without having to go anywhere," she explained. "It is a wonderful place. It is a great thing that we have it here."

A New View

Ann remembers John being wheeled onto the patio of his room where he could watch the sky and the trees from the comfort of his bed. Now, due to the generosity of the Sinnock family, that same beautiful view is accented by two regal bird houses – a fitting tribute to a special man.

If you would like to honor a loved one, please visit the <u>Make a Gift</u> page or contact us at **203.702.9130**.

A Wonderful Life for Edwin Alward



Edwin Alward and RHHC Volunteer, Bob Sweeney

Edwin Alward grew up in Erie, Pennsylvania. It was there that he met the love of his life, Katherine, with whom he enjoyed 61 beautiful years of marriage. With a chuckle that beams with pride, Edwin explained how together the couple raised four children who, "are the smartest, best looking children ever born." Although Edwin admits, "I have a lot of problems — Parkinson's, diabetes, cancer and a few other things in between," his steadfast sense-of-humor and infectious love of life make him seem invincible. Still, at 83 years of age Edwin understands that his life is nearing an end, and he embraces the additional joy that hospice care brings to his final days.

A Life of Quality

"I have had a wonderful life. What I have done I will never regret," Edwin proclaims. A vocal proponent of living a life of quality vs. quantity, Alward has chosen to forgo chemotherapy and other curative measures for treating his melanoma, which returned after a surgery 10 years ago. He understands the challenges of aging after having cared for his beloved Katherine before she passed away from Alzheimer's disease nearly 3 years ago.

Embracing Life's Changes

Edwin's life speaks of an ability to transform change and loss into beauty. He was raised with two brothers, one who died from Leukemia and the other who had gone to West Point. Edwin served in the Air Force for four years, after which he worked at Travelers in marketing for 30 years before he was let go in 1986. He then served as a Financial Consultant for a few years. Upon reading a book that suggested if you lose a job you should try something that you've never done before, Edwin took a leap and began working in education.

The Highlight of His Career

Teaching as a substitute at a technical school became the unexpected highlight of Alward's career. Although he taught at a difficult school where drugs and gangs were prevalent, Edwin embraced his role, dressing up every day, sometimes wearing a boutonniere. He wanted to expose the kids to sophistication and teach them the importance of respect by serving as a disciplinarian. The experience was very rewarding for Edwin who was able to help countless kids over the 9 years he served in that role, even inspiring some to get off of drugs.

An Open Mind and Open Heart

Last year Edwin's illnesses had him in the hospital and several nursing homes for over 100 days. It was at that point that he was <u>referred to</u> Regional Hospice and Home Care (RHHC). Edwin fully embraced the assistance stating, "I take advantage of all the wonderful services offered to me." Those services have included visits to the <u>Center for Comfort Care and Healing</u> and inhome <u>Art Therapy</u> with RHHC's Art Therapist, <u>Briah Luckey</u>. He has also been regularly receiving <u>Reiki and Therapeutic Touch</u> treatments from RHHC volunteer, Jean Handler. Edwin explained, "It really works. There is something between Jean and me – the energy," further detailing that following the energy treatments he is able to sleep soundly for hours.

New Forever Friends

One hospice service that has been particularly rewarding to Alward is the friendship he has received from his <u>Family Support Volunteer</u>, Bob Sweeney. The feeling is mutual as Bob indicates, "We have a real bond. It's been great." When asked what they do during their time together, both men said with an air of mischief in their voices, "We sit and tell each other lies." Truth is, the two friends banter as though they have known each other for years. They are both quick-witted and well-read with an ability to talk freely on any topic from sports to politics. One of their favorite activities is to sit on a bench in Kent where they "watch the world go by."

Unexpected Gifts



Photos of Katherine Alward

They have met a variety of interesting people from that post including hikers making their way to Maine via the Appalachian Trail. One afternoon they started chatting with a woman who turned out to be a local artist. Edwin mentioned that he had hoped to have a replica of Katherine's engagement photo created. Much to his surprise his new acquaintance completed the request as a gift – proof not only of the kindness of strangers, but also of Alward's ability to inspire such acts.

Praise for Hospice

Edwin greatly appreciates the care he's received from Regional Hospice stating, "I have nothing but praise. I have a fond feeling for everyone I have been associated with," further emphasizing, "and I have never been more pleased to be associated with an organization." When asked what he would tell anyone considering hospice care, he said, "Anyone who has any feeling for themselves and their family needs to take advantage of the opportunity [of hospice]. They need to understand how lovely and accommodating they are. The facility is wonderful."

We are so blessed to care for Edwin Alward. His enthusiasm for life and gracious nature uplifts all of us at Regional Hospice and Home Care.

A Life That Inspires Giving – Richard Neptune



Lindsay Neptune with her Father, Rich Neptune

"Rich was a great husband, a great friend and a great father," Debbie Neptune, his wife of 39 years recalls. When their daughter, Lindsay found herself facing her first half marathon alone after a friend had to back out, Rich jumped into action. It didn't matter that the event was a "Princess Half Marathon" – he still ran right alongside his little girl, making sure she made it to the finish line. That was the kind of person Richard Neptune was.

That love and support for his family was not unlike that which he expressed for his friends and colleagues. It was so great that for the past two years those friends and former Chrysler Capital co-workers have gathered together in Rich's name for the <u>Circle of Friends Golf Outing</u>.

A Man of Character

Organized by Rich's dear friend, Kevin Corbett, the "Circle of Friends" honored Rich's joyful spirit and generous nature while raising over \$10,000 for patient care at Regional Hospice and Home Care. As Kevin put it, "You can tell a lot about the character of a man by the way he plays golf." For Kevin and Rich's other friends, some of whom travelled long distances to honor his memory, Rich Neptune played golf the way he lived life – with dedication and heart.

Doing Things Right

In addition to playing golf, Rich loved running. He had participated in the Boston Marathon and in Disney Marathons too. In addition, he also ate well and took care of himself. "He did everything right," Debbie Neptune explained. That is why when Rich began having trouble walking in July of 2014, the couple immediately sought medical care. Rich was in and out of hospitals for several weeks before a tumor was identified on his spinal cord. The tumor was surgically removed, giving the Neptunes a sense of relief as it was believed to be benign. However, a month later the family received devastating news – the tumor was a malignant melanoma. On 9/11/14 Rich started the fight for his life at Memorial Sloan Kettering Cancer Center.

A Strong Spirit

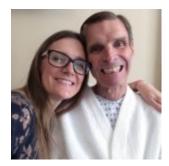


Rich Neptune with his Disney Marathon medals

With Debbie and Lindsay by his side, Rich began receiving immunotherapy treatments. In spite of those efforts, his prognosis continued to be grim. Still, Neptune's spirit remained strong. "He had two goals; completing the Disney Marathons in January of 2015, and turning 65," shared Debbie. Defying the odds, and doctor's recommendations, Rich ran a half marathon and a full marathon as part of the *Walt Disney World®* Marathon Weekend. A little more than two months later, on March 15th he blew out 65 candles on his birthday cake.

A Daughter Once Again

Not long after, Rich was admitted to the hospital with complications due to the advancing cancer. It was an especially difficult time for Debbie and Lindsay, who is a Pediatric Nurse. In April, Rich Neptune was transferred to the *Center for Comfort Care and Healing*. Debbie stressed, "Regional was the best thing that ever happened to us." Since she and Lindsay had been serving as Rich's vigilant caregivers, once he was at the Center they were finally able to find some peace. Later that year in a speech bravely delivered at the Bethel Chapter Breakfast,



Lindsay reflected that being at the Center where all of Rich's needs were attended to, she was able to just be his daughter again. Rich and the Neptune family received care at the Center for 3 ½ weeks, a period in which they developed a close bond with their nurses and other staff members. On May 13th they had to say their final good-byes as Rich Neptune's cancer battle came to a peaceful end.

A Day to Remember

Having experienced firsthand how powerful the love and care the Neptunes received, Kevin Corbett knew he wanted to support Regional Hospice and Home Care in extending care to other families in need. Just a few months after Rich's passing he organized the first annual *Circle of Friends Golf Outing*. Shortly afterwards, with the assistance of State Representative David Arconti Jr., August 31st, 2015 was officially declared *Rich Neptune Day* honoring not only Rich's memory, but recognizing the outpouring of community support that his life inspired.



Kevin Corbett, Lindsay & Debbie Neptune, and Ginger Corbett with the CT citation for "Rich Neptune Day"

The Memory Lives On

That support lived on in the <u>2016 Circle of Friends Golf Outing</u>. Prior to the event, Rich's friend Bob Madar created the following video tribute detailing some of the most beautiful moments of Rich's life: https://www.youtube.com/watch?v=ags3MllH5Fw

It is evidence that a life like Rich's lives on in the memories and hearts of those he touched.



Lindsay & Debbie Neptune wearing orange in support of RHHC at the 2016 Circle of Friends Golf Outing

For more information on Rich's legacy, see <u>The Circle of Friends Grows</u>.

Stephen Bergeron – Embracing Life's Gifts

He was beginning the 2nd semester of his junior year at Champlain College in Vermont when he got the devastating diagnosis – cancer. While it may have derailed his plans, 20-year-old Stephen Bergeron didn't let it dim his spirit. Stephen continues to embrace life, living by the philosophy, "Yesterday is history. Tomorrow is a mystery. Today is a gift. That's why it's called the present."

A Leap of Faith

When Stephen told his Regional Hospice Social Worker, Ed Schwartz, that he had always wanted to go skydiving, Regional Hospice worked to make that dream a reality. On a clear day in September, Stephen experienced the world from 10,000 feet. From that breathtaking vantage point, he could see as far as Providence and Boston.



"It's a Rush!"

Bergeron's eyes lit up as he explained the rush of being able to skydive. "I had always wanted to do it – my entire life." Still, he admitted, "I was terrified." Contrary to what he imagined, it got easier the closer he came to jumping. "I was most calm right before the jump...The feeling of falling is just indescribable. Everything was so fast...You wear goggles. So I was just trying to

look around and see as much as I could. Everything looked so small. It was incredible," Stephen recalled with great joy. "At the landing you keep your feet out and you slide a bit. When we were on land again I thought, 'I'm alive. That was awesome!"

A Team Player - Boston's Biggest Fan

Born and raised a Boston sports fan, Bergeron recently had the opportunity, thanks to a generous Regional Hospice supporter, to attend a New England Patriots game and sit on the field with his father and uncle. Reflecting on the experience of being able to watch the team warm up, Stephen said with a laugh, "The guys are so big! I mean, they are massive." Stephen enjoys the strategy involved in sports. He is grateful to have witnessed the last game of the 2016 World Series explaining, "It was a privilege to watch, since the Cubs haven't won a series in 108 years...They deserved it." His appreciation for teamwork and a well-played game comes from years of sportsmanship – first as a little leaguer, then as a wrestler at Cheshire High School, and finally as a scrum half on his college's rugby team. "I have always been on a team," Stephen explained. He enjoys the comradery, with some of his greatest friendships developing through sports.

A Hard Worker, Wise Beyond His Years

That sense of teamwork extended into his work. While on summer break from college, Stephen was on a construction and demolition crew for a new building in New Haven. The work was hard, with long days and challenging hours, particularly for a 19-year-old. He often woke at 2:30 a.m. for a 4:00 a.m start and put in 50-hour weeks. Still, Stephen never missed a day, and was never late. Although his crew members were much older, they told him that they enjoyed communicating with him because he was such a level-headed person.

A Gentleman and A Scholar

The maturity his co-workers observed is readily apparent. Stephen is a logical, practical thinker with impeccable manners. He is quick to credit his father, Tom, for raising him to be such a gracious young man. "He's a really good guy," Stephen noted with admiration, "My Mom passed away when I was 5." Careful to choose his words, Bergeron tends to, "Rough draft things in my head before I say them." However, when asked if there is anything he would like to say to his Dad, with little hesitation, he replied, "I would just say, 'I love you."

Still Young at Heart

Stephen's maturity is teamed with a beautiful balance of playfulness. Known by his family as the "Lego Kid," he always enjoyed building something new. Set to turn 21 on Thanksgiving Day, he recently received an anonymous early birthday gift of a Lego architecture set.

Effortless Inspiration

Stephen's story is one that has touched many of us at Regional Hospice as it is such a powerful reminder to embrace life with courage and reverence. Bergeron doesn't see himself as inspirational, as his commitment to living life fully is just his natural inclination. He genuinely appreciates all that he has been able to do in his young life, recollecting stories of whitewater rafting, a camping excursion with friends which led to several bear sightings, and over 20 Boston sporting events. He is very grateful for those experiences and cherishes the friends and family who have made them a



reality, stating, "I couldn't do anything without them." He especially adores his girlfriend, Mimi, whom he met at college. The two text daily and see each other as much as possible.

Grateful for His Regional Team

With regards to his clinical support team with Regional Hospice, Stephen says, "I am so thankful for everything they do. Whether it is coming in and checking on me, or things like Ed helping me to go skydiving." Such gratitude is mutual as Stephen Bergeron is a pleasure to spend time with.

When asked if there was anything else he would like to share, he closed with, "Happy to be here." Simple words we could all live by.

Jane Powell Smith – The Much-Loved Lady Jane

Some people just have a knack for caring for others, for loving people unconditionally and welcoming them into their hearts and homes. Jane Powell Smith had such a gift that she shared with others. In the way she cared for her family, raised funds for the community, and fulfilled her important role as a devoted military wife, there was always much love given and received.

Always a Lady

In a beautiful and fitting tribute to his beloved wife of 43 years, delivered at the prestigious Old Cadet Chapel at West Point Cemetery, Donald Smith, Putnam County Sheriff and U.S. Army Brigadier General (Ret.) explained the many graces that made Jane so very special. Graces that ultimately led Don's Mother to bestow her with a title of fitting admiration, "Lady Jane."



Jane was, as Don recollected, "a wonderful, loving wife, and incredible mother, a terrific grandmother, loving daughter and granddaughter, a sister extraordinaire and an aunt, niece, and cousin whom everyone not only loved, but respected, and wanted to be around as often as they could."

A Loving Start

Jane was born January 15, 1951 to very loving parents, William Powell and Eleanor Powell. According to Don, Jane's mother was her greatest role model. She too bore a title of respect and honor – that of "Saint Eleanor." As a girl Jane loved to spend time with family at Pleasant Lake in Elkins, New Hampshire where her love for crafting and cooking grew through the nurturing of her maternal grandmother, Ruth Holcomb.

Preparing for Flight

William Powell was a teacher and a coach at private schools. As such, his children were provided with a strong educational foundation at Saint Bernard's in Gladstone, NJ; St. Paul's School in Garden City, NY; and Trinity Pawling School in Pawling, NY. Following high school, Jane went on to study Fashion at Virginia Intermont College. Upon graduation, Jane applied to become a stewardess. She was accepted into the Delta Airlines training program which was scheduled to begin a few months later in January of 1972.

A Love Meant to Be

While waiting for the training program to begin, Jane lived with her parents in Pawling and worked as a hostess at Birch Hill Inn of Patterson. Don recalled the night they met, "As fate would have it, or as I believe, the Holy Spirit, Jane just happened to be working the night of my welcome home party from Vietnam." Don was so taken by Jane's beauty and grace that he asked the Inn's owner for her number. Nervously, he called to ask her out. Their first date was to the movie "Lovers and Other Strangers."

As Don explained, "I didn't really care where we went or what the movie was – I just wanted to be with her." Their love grew quickly. "It was just meant to be, and we both were so sad after the holidays when she went to Atlanta, Georgia and I traveled to Fort Knox, Kentucky to assume my new [military] assignment."

Love Grows Long Distance

Although the couple had to be apart, their love continued to grow, fueled by long distance calls and trips, courtesy of Jane's position with Delta. On one of those visits Jane helped Don organize a party for the Armor School. Attendees were wowed by Jane's attention to detail and many senior officers advised Don not to let her get away. "To this day people still comment on how Lady Jane was an excellent entertainer and hostess," Don explained. While Don was also impressed and appreciative he stressed, "My reasons for liking and loving Jane had absolutely nothing to do with her ability to host a good social function."

A Family Is Born

In April of 1972, Don asked Jane for her hand in marriage. The following June the two were married at Holy Trinity Church in Pawling. Their first dance was to the Carpenters' song, "For all we know" – from that first fateful movie, "Lovers and Other Strangers".

A few years later, the couple was blessed with the birth of their first child, Christopher. Their daughter Cherilynne Whitney arrived three years after. Don stressed that, "Jane was an incredible mother. Her real passion in life was taking care of our family and raising our children." As time went on the couple welcomed 8 precious grandchildren to their loving family: Jonathan, Ellie, Riley, Lindsie, Mitchell, Lillian, Benjamin and Asher Jeremiah.



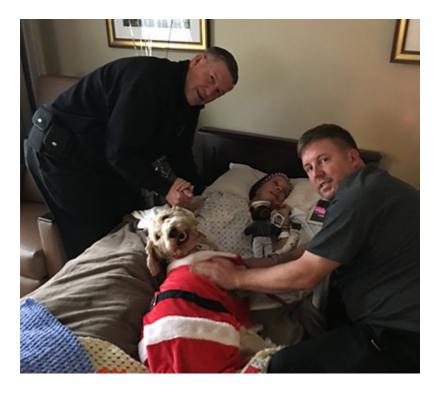
A Special Way

While raising her family, Jane sometimes served as both mother and father since Don had to be away fulfilling his military duties. Jane was in many ways as committed to caring for fellow military families as she was for her own. During Desert Shield and Desert Storm, she established a Family Action Care Team (FACT) aimed at offering information, support and a sense of normalcy for Army family members. As Don's career advanced, Jane was always by his side. Once he had retired from the military and later assumed the role of Putnam County Sheriff, Jane continued to shine. "Jane had a very special way about her that made other people feel good about themselves," said Don. This endearing characteristic made her, "An exceptional Commander's wife and First Lady of the Sheriff's Office who was loved by the Sheriffs and their ladies throughout New York State."

Dedicated to Giving

Jane always looked out for others, and was driven to support many charitable causes. She made a quilt every year for the American Heart Association and crocheted over 80 caps in the form of flowers and animals for the children at Maria Fareri Children's Hospital. Even after becoming ill with cancer and suffering from a stroke, she raised over \$6,000 in the "Scare Away Cancer Scarecrow Campaign."

Gracious Until the End



Jane enjoyed visits from our Pet Partners during her stay at the Center.

Jane battled illness with great strength, and still, "Counted her blessings and looked for the bright side of every situation." That positive energy and strong spirit was evident as she made her final home at the *Center for Comfort Care & Healing* (a journey that Don bravely detailed in a speech delivered at the New Fairfield/Sherman Giving Circle's Breakfast). Her room was a reflection of her love-filled life with family photos, balloons and lovingly-crafted quilts. In her final moments, Don recalls how Jane mouthed "Thank you" to those who were attending to her care, just before passing away peacefully at 4:00 am on December 5th – a Lady until the end.
