

# Passing Thoughts



The Newsletter of The Twilight Brigade, *Compassion In Action*

Volume 6, Issue 1, Spring 2004

## Letter from the Chairman

*This Passing Thoughts is dedicated to the memory of my father, James Carlisle Brinkley, who passed from this world on Memorial Day, 2004. My Dad was a disabled WWII veteran, and one of the finest men who ever lived.*

As spring turns to summer, I want you to know that 2004 will be an excellent year for the Twilight Brigade! In 2003, we were recognized in many fields of palliative and end-of-life care. We were also chosen to participate in programs and studies researching the various methods of improving the quality of end-of-life care. Several of our volunteers received recognition on local, state and national levels for their contributions at the bedside. I congratulate each one of them, and I encourage you to read more about them later in this newsletter.

As we are mid-way through 2004, the state of the world appears to be tenuous. In an election year, the issues that confront us everyday filter to the surface to be dealt with. The factors controlling the formation of our

personal and professional priorities are, at very best, stressed. A climate of unpredictability and instability is inevitable with our national security stretched to its limits both financially and emotionally, the economy totally unstable, public education ever increasing in cost, and lastly, healthcare spiraling out of control. All of this combined dominates our decision making processes as we strive to make the proper choices for ourselves, our aging parents, our children and our country. Therefore, there can be no greater time than now to become a volunteer. In times like these the pooling of our talents, along with the use of our ability to help one another, are the national treasures we possess that can help to change the future. Volunteerism is an act of spiritual activism that allows us to look deep inside ourselves as we serve as guardian of the ever evolving qualities of humanitarianism and the American experience. We of the Twilight Brigade have chosen to volunteer to defend and protect the rights of those who have fought to build this great country and are willing to die to keep it free.

As volunteers in the Twilight Brigade, it is our primary obligation to encourage those in transition to identify and clarify the unique imprint their lives and service will leave upon their families and this great nation. There are more than forty-five thousand veterans leaving this world every thirty days. So, with this in mind, the need for your time, effort and financial contributions could never have a greater impact than now. I



Dannion Brinkley, Chairman of the Board for The Twilight Brigade (L), and Anthony J. Principi, Secretary of Veteran Affairs (R), at the kick off to increase national awareness at the Library of Congress' Veterans History Project.

personally became a volunteer because I saw the need. I remained a volunteer for over 27 years because I saw I could make a difference. It has taken 60 years for the people of the United States to honor our WWII veterans. They were there when we needed them. We must be there when they need us.

Please join me, please help me help them...

With purpose,

Dannion H. Brinkley

*Volunteering Inspires  
Self Appreciation!*



**THE  
TWILIGHT  
BRIGADE**

*Compassion in Action*

### MISSION STATEMENT

The Twilight Brigade is committed to raising society's consciousness about the needs of the dying through community and professional education, advocacy and service to the terminally ill and their loved ones so that no one need die alone.

# The Twilight Brigade

## Compassion In Action



### WHO WE ARE

*According to the Department of Veterans Affairs, America's Military veterans are dying at an alarming rate - the majority being World War II veterans. Recognizing an unmet need, **The Twilight Brigade** made their highest priority establishing chapters across the country to assist the VA's by providing volunteers specifically trained for end-of-life care service.*

The dying are one of society's most unrecognized and under-served minorities. As individuals near the end of life, they are often ignored, discounted, misunderstood and forgotten. In 1997, a small group dedicated individuals, under the leadership of best selling author, Dannion Brinkley, came together to form a very special organization named COMPASSION IN ACTION.

The Twilight Brigade, Compassion In Action (CIA) is a national 501 c (3) non-profit service organization committed to raising society's consciousness about the needs of the dying through community and professional education, advocacy, and direct service to the terminally ill and their loved ones, ensuring that *no one need die alone*.

We believe that with compassionate care and reassurance, the end of life can be a time of personal growth and healing for the dying and their loved ones. We are committed to the active practice of compassionate service through the

worldwide mobilization and training of volunteers to provide a loving presence for those approaching death.

### PROGRAM DESCRIPTION

Twilight Brigade volunteers provide reassurance and caring human companionship to the dying. Where applicable, volunteers provide respite relief and support to loved ones and caregivers. When possible, we provide 24-hour attention during the final hours allowing people to die in peace and with dignity.

Although The Twilight Brigade fully embraces the hospice philosophy of care, we are not hospice. We are a volunteer-driven organization *that* provides no medical services. Through our unique service system, our trained volunteers visit terminally ill patients at hospitals, nursing homes, hospice facilities, and assisted living communities. All support services are provided at the request of the patient, family member, clergy, caregiver, doctor, nurse, or any other member of the hospice support team.

### TRAINING

As an educational organization, our 20-hour volunteer training program combines recommendations from the National Hospice and Palliative Care Organization, educates participants about the death and dying process, teaches important Care techniques and methods,

raises awareness about the importance of volunteer service to the dying in their communities, churches, and organizations.

The core of The Twilight Brigade's program involves training volunteers and placing them in service roles to *provide* support and reassurance to those facing terminal illnesses, delivering community and professional education that increases the acceptance of death and dying as a natural life process, and advocating the critical need for quality end-of-life care.

Volunteer service is delivered to individuals, regardless of age, race, or ethnic background. Individuals must be diagnosed with a terminal illness or condition, but is not limited by prognosis or treatment course. Fees are not charged for services provided.

### SUMMARY

What we try and create is a loving family atmosphere. We all need to know that we have a place to turn when facing the end of life. Grief and bereavement are a very important part of this process. The Twilight Brigade's objectives are to expand volunteerism on a global scale and educate the public about the needs of the dying. Our devoted group of over 5,000 volunteers nationwide continues to grow, creating an influential grassroots force for promoting compassionate care at the end of life.



# Why I Became A TB/CIA Volunteer

*What made you join The Twilight Brigade?*

I joined The Twilight Brigade because of the experience I had when I took the TB/CIA training. I have stayed because of the need to provide others the opportunity to have such an experience and to support the mission that no one need die alone. I have witnessed that anyone can provide loving support for another, if they choose, and for many people all it takes is permission to do so. I hope that I have encouraged people to look within, find their true self, and boldly share the unique gem they are with the universe, balanced with the wisdom that it is not about us. I am so thankful for this work and the friends I have made while volunteering.

Keith Jachim



*What made you join The Twilight Brigade?*

I joined TB/CIA after listening to

Dannion Brinkley's interview with Art Bell. His words and compassion for people at this very important transition time made me realize that no one should be alone, and that I need to prepare myself for that time, also.

Ruth Sausman



*What made you join The Twilight Brigade?*

I joined TB/CIA to help myself and others heal from losses through selfless service and dissolution of fears surrounding death and dying.

*Why have you stayed?*

It brings me great joy to lead others to their own self-healing process; for once they have resolved their own issues, they become a source of strength for others.

Jeffrey Pears



*What made you join The Twilight Brigade?*

I joined The Twilight Brigade because I believe in the organization's philosophy that "no one need die alone" and to be surrounded by like-minded individuals who give hugs from the heart. I have stayed to help others experience the loving presence we teach and provide at our trainings. I have learned that both the receiver and giver of compassion receive blessings of love. I believe I've been an example of how to love and connect with another, with a kind and open heart.

Cherisse T. (CT) Bara



*What made you join The Twilight Brigade?*

I joined TB/CIA because I had volunteers help me during my mother's terminal illness, and I wanted to share in their vision.

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On October 2<sup>nd</sup> thru the 5<sup>th</sup> Los Angeles hosted the fifth national **Train the Trainers Workshop** for the Twilight Brigade. Trainer candidates attended from both sides of the country. Seattle and Portland were represented as well as Atlanta and California. The national training committee put on a four day intensive workshop that provided an opportunity to learn and practice facilitation skills, develop an inner awareness of personal resources while making a connection with fellow volunteers throughout the country. It was a memorable weekend of hard work, personal insights, lots of laughter, and especially fun.





# IMPROVING END-OF-LIFE CARE

## The Twilight Brigade On A National Team Whose Focus Is Improving End-of-life Care

Since its inception, the Twilight Brigade- Compassion in Action (CIA) and its Chairman Dannion Brinkley have played an integral role in educating legislators, policymakers and the health care community about the importance of improving end-of-life care, especially for our nation's veterans.

In 2003, Kenneth Rosenfeld, MD and Jennifer Rasmussen, MPH published the findings from a three year study at the Los Angeles, California Veteran's Facility in the *Journal of Palliative Medicine*. This study, funded in part by the Robert Wood Johnson Foundation, evaluated a palliative care management program for patients with inoperable lung cancer advanced heart failure and chronic lung disease. Because of the program's success it will be expanded and its care model extended institution-wide. CIA played an important role in this project by providing trained volunteers to be a part of the hospice team. More than half of the patients in the study were able to have a better transition because CIA volunteers were there.

Chairman Dannion Brinkley, an internationally recognized expert in the integration of complementary and alternative medicine with conventional medicine, and advocate for improved end-of-life care for veterans testified before the White House Commission on Complementary and Alternative Medicine Policy on several occasions and played a significant role in securing recommendations relative to end-of-life care and veterans. The report and its recommendations can be reviewed at [www.whccamp.dhhs.gov](http://www.whccamp.dhhs.gov).

CIA's Chairman and volunteers played a crucial role in encouraging increased research funding from the Federal government for improving end-of-life care treatment for veterans with the inclusion of complementary and alternative medicine. The project called Vet-Heal was included in the FY 2004 Defense Appropriations. More information about this project will be forthcoming in the spring.

In 1999, when CIA's Chairman testified before Congress about the improving end-of-life care with complementary medicine, the Director of the National Institute of Nursing Research (NINR) at the National Institutes of Health (NIH) also testified. Late in 2003, NINR published its research agenda for the future. **Enhancing the End-of-Life Experience for Patients and their Families** is one of five foci of activities for NINR. The NINR made the following statement about this issue:

*“Recent findings from a study commissioned by Last Acts reported that the United States does not adequately address the job of caring for seriously ill and dying patients. A significant number of Americans continue to be dissatisfied with the way the healthcare system provides care to the dying, with 93% of Americans believing improving end-of-life care to be important. These findings were similar to those of a 1997 study by the Institute of Medicine, As the lead Institute at NIH for coordinating research on end-of-life/palliative care, NINR has a compelling obligation to support research that analyzes current end-of-life care and develops methods to improve it. Research includes:*

♥ Studies of the end-of-life that encompass the spectrum of care

settings, including hospital, nursing home, residence, and hospice, for all demographic groups e.g., ethnic and cultural, all ages, genders, and socioeconomic levels.

♥ Development and testing of models for palliative care that clarifies when it should begin and how it should be structured.

♥ Studies addressing management of physical and psychological aspects of symptoms at the end-of-life, including identifying, assessing and managing symptom clusters to improve symptom control and patient comfort; and understanding the importance and use of spirituality and other psychological influences to enhance the quality of life at the end-of-life.

♥ Optimizing the interactions between the patient, the family, and the healthcare provider regarding decisions about advance directives and other concerns.

♥ Investigation of family support and the bereavement process.

♥ Assessing the effectiveness of complementary and alternative therapies at the end-of-life.”

*CIA's Chairman addressed the National Cancer Advisory Board at the National Academy of Sciences. The National Academy of Sciences (NAS) has published several reports since 1997 on improving end-of-life care. They include:*

♥ Describing Death in America: What We Need to Know

♥ Improving Palliative Care: We Can Take Better Care of People With Cancer

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*Why have you stayed?*

I stayed because no one need die alone.

*What have you taught?*

I taught that time spent with a patient was their gift to ME.

Linnaea Newman



*What made you join The Twilight Brigade?*

It was a year and a half since my mother passed away. I mentioned to my friends that I missed the intimacy of being with mom, taking care of her, talking with her. I wasn't sure if I was good at it because it was mom and I love her, or if I was truly good at being with the dying. I wasn't afraid to listen to her talk about dying. Medically Hospice was taking care of her pain. I felt it was my job to make sure she was as emotionally pain free as possible.

*Why have you stayed?*

I just love to be at the training sessions. They are so profoundly moving. I learn something about my self each time I volunteer at one. It is also awesome to see how some trainees come in defensively or in pain and leave with new insight, comfort and wisdom.

*What have you taught?*

Listening is a magnificent gift that anyone can learn to give.

Maria Arsenijevich



*What made you join The Twilight Brigade?*

I joined TB/CIA because I enjoyed

being with the volunteers; it was like coming home. Also, I wasn't going to do bedside at that point in my life and it gave me a way to contribute to the hospice movement.

*Why have you stayed?*

I have stayed with TB/CIA because I know I am needed and appreciated by the group and it is fun to meet and share with the trainees.

*What have you taught?*

I have taught that unconditionally listening and being compassionate is something we all need.

Linda Piegore



*What made you join The Twilight Brigade?*

I got involved because I have always been interested in comforting the dying. No one should die alone unless he/she chooses to. At the opportune moment TB/CIA came across my path.

*Why have you stayed?*

I am still involved because it is very satisfying work (although even here we have bureaucratic BS).

Charles Donaghy



*What made you join The Twilight Brigade?*

I resonated with the heart and the energy of the people involved with TB/CIA and believe that the volunteers live a deep and spiritual approach to service.

*Why have you stayed?*

Although my administrative situation had changed, I have always represented TB/CIA at the bedside, because, as Sister Sledge says, "We are Family!!"

*What have you taught?*

Peace, I hope...

Kimberly Hasselmark



*What made you join The Twilight Brigade?*

My reason for doing hospice is that I have learned more from someone who is experiencing the last stages of their life than I have anyone in my life time. I find the experience peaceful and a certain satisfaction knowing that I have made a difference.

Donna Morse-Johnson



*What made you join The Twilight Brigade?*

I joined The Twilight Brigade because it seemed an answer to my question of how can I best serve. When I visit a patient, I am not there to be with someone who is dying, but a living person who just happens to be dying. To be invited to share in their very personal and private experience of dying, I consider an honor. I plan to stay involved with TB/CIA because I am continuing to be more and more of service by being able to train others to do this very important work. Most gratifying!

Sandy Hatfield



*What made you join The Twilight Brigade?*

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# Volunteer Awards

**Diane Forsythe**

*San Diego, CA Affiliate*

In 2003, Diane was awarded the Southern California Cancer Pain Initiative Award for excellence in pain management.



**Linda Merrick**

*Portland, OR Affiliate*

In 2003, Linda was awarded the John H. Harland, Company 80 at Eight Award for Volunteer Service with The Twilight Brigade.

**Gene Mask**

*Portland, OR Affiliate*

In August 2003, Gene was recognized for outstanding performance and lasting contribution to The NW hepatitis C Resource Center.

**Tom Bodner**

*Long Beach, CA Affiliate*

In 2003, The Long Beach VA Medical Center recognized Tom for volunteer hours spent at the bedside.

**James Lewis**

*Los Angeles, CA Affiliate*

In 2003, The West Los Angeles VA Medical Center recognized James for volunteer hours spent at the bedside.

**Keith Jachim**

*Chicago, IL Chapter*

In 2002, Keith was awarded the Motorola CEO Award for Volunteerism.

**Dannion Brinkley**

*National Office*

In 2003, Dannion was awarded the National Foundation for Women Legislators, Courage and Valor Award for Dedicated Service to our Veterans. ♥

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♥ Approaching Death: Improving Care at the End-of-life

♥ When Children Die: Improving Palliative and End-of-life Care For Children and Their Families

♥ Working Together We Can Help People Get Good Care When They Are Dying.

These reports are available for purchase from the NAS Bookstore or can be read online. The NAS website is <http://www.nas.edu>. ♥

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Well, this work chose me... I began doing hospice work before I was doing it formally.

I do this because I love--and at the end of life for one of God's children, I wanted to be the facilitator of this knowing. What it does for me is help me deeply feel the "all of it". The sadness, the sorrow, the inexplicable joy, the crazy, irreverent gut-slitting humor. It reminds me how to live, daily--side by side with huge loss and huge glory.

That's why!

Gratefully,  
Patty Burgess



*What made you join The Twilight*

*Brigade?*

For a long time I knew that I needed to give something back to the universe. Once I had this realization, it became my mission to find the volunteer work that would interest me and keep me coming back for more. Hospice kept calling to me. My grandmother and my ex-fiance were cared for by hospice and I know that they were blessed by the experience, as were their families. I knew that God had graced me with whatever it takes - strength, compassion, an acceptance of death. I have gained so much more than I have given.

Monica Marlowe



*What made you join The Twilight Brigade?*

I joined because...I had a NDE when I was young and I've had many opportunities to explain what hospice offers. Hospice is a blessing. I do believe that no one should die alone... unless that is their wish.

Pam Wedding



*What made you join The Twilight Brigade?*

I got involved with TB/CIA in Feb 2002 because I was "guided" to get involved in hospice work. After my retirement from the Air Force I missed being involved in Community Service work and needed that in my life. I have continued with TB/CIA because I love working with the people in our chapter.



# Resources on End of Life Care

♥ **Overview of the End of Life and Palliative Care Research Portfolio**

National Institutes of Nursing Research

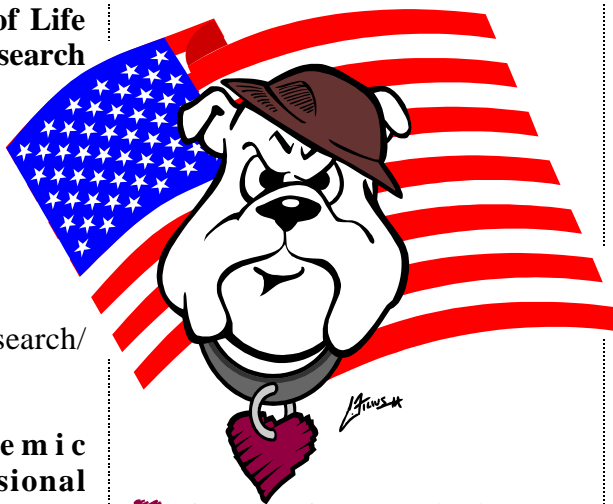
National Institutes of Health

<http://www.nih.gov/ninr/research/dea/science/endoflife.htm>

♥ **Office of Academic Affiliations (Professional education)**

VA Hospice and Palliative Care Initiative

<http://www.va.gov/OAA/flp/default.asp>



♥ **Center for Medicaid and Medicare Services (personal services) Medicare Hospice Benefit**

<http://www.medicare.gov/Publications/Pubs/pdf/02154.pdf>

♥ **Hospice Fact Sheet**

[http://www.cms.hhs.gov/medlearn/hosp\\_article.pdf](http://www.cms.hhs.gov/medlearn/hosp_article.pdf)

♥ **Administration on Aging (Valuable resource for seniors)**

<http://www.aoa.gov/>

♥ **Last Acts**

Last Acts envisions a world in which dying people and their loved ones receive excellent care and are honored and supported by their community.

<http://www.lastacts.org/>

**VOLUNTEERING INSPIRES SELF APPRECIATION!**

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## Our Volunteers in Action



James Lewis (Los Angeles, CA Affiliate) has been a dedicated volunteer since 2001 and has logged over 5000 hours at the bedside. Every Christmas, he dresses up as Santa Claus and visits the Veterans at the West Los Angeles VA.



Dannion Brinkley and Samuel Billison received the "Courage and Valor Award" for their dedicated service to the United States.

### Letter from a VA Patient

From the bottom of my heart, I have a deep love for the wonderful folks that visit with me from The Twilight Brigade, *Compassion In Action*.

I awake everyday glad to be alive; and knowing that I will have a visit from a TBCIA volunteer. Their Love and Compassion has been my support during my time here at the WLAVA.

I know how important and loving this giving of one's self can be to a patient. We all die alone, but, it is great and comforting to know that a TBCIA volunteer will be holding my hand.

Malcolm Megaw,  
Veteran



THE  
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*Compassion in Action*

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*Because no one need die alone.*