

Biography & Contributions to Hospice Volunteerism & End-Of-Life (EOL) Caregiving

INSPIRATION

Greg Schneider began serving the public in End-of-Life (EOL) care in 1996 as a hospice volunteer in a residential facility located in the heart of San Francisco. He has personally served hundreds of dying adults and children as well as their families as a patient care volunteer caregiver, bereavement counselor and harpist. After a few years in hospice he began to see quite clearly that the general public were grossly under-educated about care at the end of life. This inspired him to found a 501(c)(3) non-profit organization called the *Hospice Educators Affirming Life (HEAL) Project* in 1999 whose primary mission is EOL care education utilizing collaborative models to achieve the highest quality education programs possible.



PRIMARY OBJECTIVES OF THE HEAL PROJECT

The HEAL Project is focusing on three education-related objectives in fulfilling its mission:

- *Increasing public dialogue* about EOL issues through unique education initiatives
- *Advancing caregiving volunteerism* in EOL care through better education programs
- *Better preparing institutional and family caregivers* to provide EOL care

MAJOR CHALLENGES TO ACHIEVING OUR OBJECTIVES

Society exhibits these characteristic challenges to overcome in achieving those objectives:

- *Ignorance* of death issues such as EOL care options and associated planning
- *Avoidance & waiting* until death is staring them in the face to think about EOL
- *Fears* of death such as when it will occur, its physical process and existential anxiety
- *Isolation* from family and friends due to the first two challenges such as not knowing what to say to someone who is dying and fears of contracting their illness.
- *Losses* from death such as control over life, individual identity and loved ones

LEADERSHIP ROLES IN HOSPICE VOLUNTEERISM & EOL CARE

October 1996 – Began serving as a hospice volunteer with the Zen Hospice Project during the AIDS epidemic. Greg soon began getting involved with activities at the hospice and training and mentoring new volunteers. He personally served hundreds of patients at the bedside there as well as learning to play the harp, which he still does today for his hospice patients. He served there until 2004 and then chose to embark on a new volunteer experience at the first stand-alone EOL care facility in the U.S. to serve dying children and their families called the *George Mark Children's House* in San Leandro, CA.

December 1999 – After a few years of serving as a hospice volunteer at the Zen Hospice Project, Greg came to the realization that education was urgently needed to increase awareness of the uniqueness of hospice care as an EOL option. There were so many residents and family members that came to him at Zen Hospice telling him they could not believe there was a place like hospice. They would ask “*How come I have never heard of hospice?*” This was the original motivation Greg had for creating the *Hospice Educators Affirming Life (HEAL) Project*. HEAL's mission was initially to help the general public understand hospice better. When a prominent author, physician and surgeon like Dr. Atul Gawande declares publicly in his latest book that he thought hospice care was “a morphine drip” and that people in hospice were left to just let nature take its course, then there certainly was and is still much work to do.



GREG SCHNEIDER

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January 2003 – After about 6 months of web development and writing by Mr. Schneider, the HEAL Project began its public service program, the *Community Outreach Program in Education (COPE)*. This public service program utilized the Internet to publish and distribute two free educational series:

- *Series I – Caring for a Terminally Ill Loved One – Making Compassionate Choices* – this series focused on the various facets of caregiving starting with the diagnosis of a terminal illness through to death of the loved one and the bereavement period that follows. Each monthly issue was one page that was short and to-the-point and easy to understand. It even included an example of an EOL situation that applied to the topic being discussed. Twelve topics were published in the series.
- *Series II – Caring for a Child Approaching the End of Life & Keeping the Family Together* – this series describes the formidable emotional, psychological and spiritual challenges that families face that are caring for a child that is approaching the end of life. Parents become the primary caregivers, most often at home. This series provides useful information to families that will help guide and support them on their journey. Greg created the Hannah's Friends volunteer program because while the families rely on traditional medical institutions for their ongoing medical care, the need is extremely high for highly skilled “community volunteers” who can fill the gap by providing more practical support to families, helping to reduce the family stresses associated with caring for a dying child. Hannah’s Friends used the strategy that it is important to establish a relationship with families before they need to make the decision to move to hospice care, which is an extremely difficult decision to make. The pilot program was initiated in Sonoma County in Northern California and served two families for several years.



October 2004 – The *Hospice Volunteer Association (HVA)* was created by the HEAL Project because no such organization existed anywhere in the world to serve hospice volunteers and their managers. HVA has created a variety of services and resources for hospice volunteer programs since its inception. Most notably its online magazine, *Hospice Volunteer News (HV News)*, was very well accepted as a very educational publication (see next item – June 2005 for more information about HV News.). Since its founding HVA has registered over 7000 members who are hospice volunteers, hospice volunteer managers, academics and members of the general public. The HVA *Caregiver’s Store* is an online store that offers unique products related to EOL care and hospice volunteerism such as books, music, training videos on death & grief and special lap harps.





June 2005 – HVA published its first issue of its online quarterly magazine *Hospice Volunteer News (HV News)*. It was the first such highly educational publication of its kind for the hospice volunteer community. Greg was its creator and managing editor. The magazine was produced as an educational initiative that would show the many facets of hospice care and the importance of hospice caregiver volunteering. After publishing 4 issues, the magazine then began to feature a selected hospice in each issue, which would provide the core content on the 3 primary facets of the hospice experience: *The Volunteer – The Hospice – The Patient & Family Served*.

HVA published 14 issues up until the economic distress that occurred in late 2008, which caused HVA to stop publication for economic reasons. The first issue published had 10 pages, no feature articles and no columnists. The last published issue had 46 pages, 4 feature articles submitted by external authors and 6 regular columnists (one MD, 1 PhD/Psychologist, 1 professor/hospice volunteer/author, 1 PhD/author, 1 Hospice Volunteer Coordinator, HVA President). The magazine was well accepted and praised by its readers for its unique educational focus.

October 2006 – *Interdisciplinary Palliative Care Delegation Member to China and Tibet* – Greg was selected by *Johns Hopkins University* to be a member of this national delegation as the representative for the volunteer discipline of hospice and palliative care in the U.S. The *Beijing Songtang Hospice*, the first hospice in China, initially extended the invitation to have this delegation visit China. The goal of the delegation was to understand how traditional and western approaches to medical care are practiced in China and Tibet, and to see how these countries have developed their palliative and EOL care services. The delegation explored models for hospice care, management of pain and common symptoms, and the integration of palliative care principles and spiritual practices into EOL care.



September 2007 – the *National Council on Hospice Volunteer Education (NCHVE)*, was initially created to advise HVA on the creation of a collaborative educational program with the *International Association of Hospice & Palliative Care (IAHPC)* to train community volunteers in 3rd world and developing countries. This program was put on hold due to the economic distress that occurred in late 2008. The *NCHVE* will also play a significant role in guiding the creation of the HEAL Project's planned *Hospice Volunteer Training Institute (HVTI)*. The writing of the strategic plan for this institute was initiated in conjunction with the establishment of the *NCHVE*.



October 2007 – In early 2003 Greg began development of the HEAL Project's *Hannah's Friends* program, a very unique community volunteer program which provided experienced hospice volunteers to support families who have a child with a life-threatening illness. The primary reason Greg created the program was that the challenges presented to a family that is caring for a child with a life-limiting or life-threatening illness are formidable. Having someone with previous experience on such a journey to provide guidance and support can ease the uncertainty of what lies ahead,

changing the experience from one of trepidation of the unknown to one that transforms all involved in a most healing way.

The program's volunteers are available to support families in numerous ways: in their homes, hospitals and in residential hospice facilities. Their primary purpose was to support and guide families through this most difficult time when their child is dying and then to support them beyond their loss.

In October 2007 a successful pilot program for Hannah's Friends began in Sonoma County of Northern California. The *Hannah's Friends* program operated for approximately two years supporting one family whose child died in 2007 and another family whose child was diagnosed with non-Hodgkin's lymphoma and had undergone 5 rounds of chemotherapy before the cancer was controlled and later she went into remission. Greg was the primary volunteer for both families during the pilot program. The stories of the families served, the program's Advisory Board and the Family Volunteers who supported the program were available online when the program was active. The *Hannah's Friends* program will be the model that will be used for the HEAL Project's pediatric volunteer training and certification program.

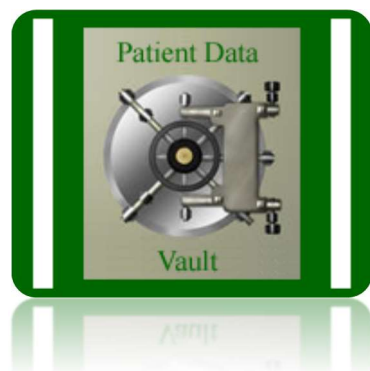
The website also includes a community support network comprised of local businesses and other support organizations such as the *Children's Cancer Community*. The website also has the capability to collect financial donations, of which 90% of the funds would go to the families.

April 2008 – As social media became widely accepted Greg created the *Hospice Community Forum (HCF)*, a free social network for the hospice community as well as the public-at-large. His purpose was to bring together hospice workers and the public into one forum to promote more dialogue around EOL care as well as to provide a place where hospice workers could informally support individuals that were either facing death or being a caregiver for a loved one.



The community has 1,400 registered users as of November 2014. The site also has an educational focus in line with the HEAL Project's mission that offers some of the following features:

- *Forum* – provides a venue for dialogue on a variety of topics of interest or items in the news.
- *Discussion Groups* – along with specified groups related to the community focus, groups are permitted to form organically on a variety of topics. There are currently 36 different groups from “Beginning the Conversation” to “Ethics”.
- *Videos & Photos* – videos on a variety of topics relating to hospice and end-of-life care are available for the entire community. Members are encouraged to share their photographs relating to their personal lives or hospice work.
- *Blogs* – bloggers are invited to contribute.
- *Events* – community members can post upcoming events.



August 2008 – Greg utilized his professional engineering skills to invent the *Patient Data Vault (PDV)*, a HIPAA-compliant hospice & home care volunteer caregiver management software tool that is being used by over 4000 volunteers and their managers across the country. The *PDV* software, which is the foundation for HVA's PDV subscription service, was developed because Greg saw that volunteer programs could be better managed if the Internet could be used to provide volunteers with 24/7 access to their patient information for assignments as well as reporting their visits to the hospice team.

By using the appropriate software technology, HVA could guarantee that the HIPAA (*Health Insurance Portability and Accountability Act*) security guidelines could be achieved thereby protecting the *Protected Health Information (PHI)* and privacy of hospice patients. HVA also saw this software innovation as an immediate response to President Obama's *American Recovery and Reinvestment Act of 2009*, which established the *Health Information Technology for Economic and Clinical Health (HITECH) Act*, to promote the adoption and meaningful use of health information technology. The *PDV* software continues to grow in functionality and is the only volunteer management program available today that is specifically designed to meet the unique needs relating to the management of hospice volunteer caregiver programs.

June 2014 – Formed the *Primary Task Force (PTF) & Secondary Task Force (STF) for Volunteer Training Standards* to develop national training standards for hospice volunteer caregivers. Currently there are no standards; each hospice volunteer program develops their own programs. Experts agree with HVA that a standard is sorely needed. The PTF, which consists of Greg and four national experts on hospice volunteer management, will define the requirements and write a draft of the standard. The STF consists of experts in various hospice disciplines, individuals from academia who are knowledgeable about EOL issues, and clinical educators in EOL care. They will provide guidance and input into various areas of the standard as well as being advisors to the PTF. The writing of these standards is the first step in implementing the strategic plan for the *Hospice Volunteer Training Institute (HVTI)*.

March 2019 – Created *Compassion Gateways LLC*, a technology company founded to facilitate the development of all aspects of *Compassionate Communities*, specifically communities of *Compassionate Neighbors*, whose primary objective will be to spread compassion by teaching communities how to provide non-medical EOL support for others in their own communities. In 2021 he began writing a new book on the topic of *Compassion In Community*. The company was originally founded in 2014.

BOOKS

Title: *The Changing Face of Volunteering in Hospice & Palliative Care: An International Perspective*

Contributing Author: Wrote the chapter: *Volunteering in the USA*

Editors: Dr Ros Scott; Dr Steven Howlett

Publisher: Oxford University Press 2018

PUBLISHED ACADEMIC PAPERS ON HOSPICE VOLUNTEER RESEARCH

Title: *Results from the National Hospice Volunteer Training Survey*

Journal: *Journal of Palliative Medicine* Volume 13, Number 3, 2010

Authors: Elaine Wittenberg-Lyles, PhD, Greg Schneider, MS and Debra Parker Oliver

Title: *Assessing the Readiness of Hospice Volunteers to Utilize Technology*

Journal: *American Journal of Hospice & Palliative Medicine* December 4, 2011 1049909111429559

Authors: Elaine Wittenberg-Lyles, PhD, Sara Shaunfield, MS, Debra Parker Oliver, MSW, PhD, George Demiris, PhD, Greg Schneider, MS

EXPERIENCE AS A HOSPICE VOLUNTEER CAREGIVER

Since 1996 Greg has served nearly a thousand dying patients and their families as a patient care volunteer, harpist, and group bereavement counselor (adults/children) as well training new volunteers for:

2015 - 2019 – Caregiver for spouse, who died from ovarian cancer

2013 - 2015 – Mission Hospice, San Mateo CA

2005 - 2012 – Heartland Hospice, Santa Rosa CA

Hospice of Petaluma, Petaluma CA

Memorial Hospice, Santa Rosa CA

VNA Sutter Hospice, Santa Rosa CA

2004 - 2005 – George Mark Children's House, San Leandro CA

1996 - 2004 – Zen Hospice Project Guest House, San Francisco CA

MEDIA EXPERIENCE

Greg has been a guest on *Grace Cathedral's LightWorks* TV program (KRON-TV Ch4 San Francisco) to discuss the role of the hospice volunteer and the importance of hospice to the community. He also was the featured guest on San Francisco's *KGO* radio talk show to discuss hospice and the differences between curative and palliative care as well as answering questions from the show host and *KGO* listeners.

He also has lectured and conducted workshops for local high schools in the San Francisco Bay Area, teaching students about grief, loss and other issues related to death and dying.

EDUCATION

Master's degree in Electrical Engineering (EE) from the University of Santa Clara

Bachelor's degree in EE from San Jose State University

EOL Counselor Training – Metta Institute

Spiritual Counselor Training – Ananda