

A LIGHT IN THE MIST

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HOSPICE
A STUDY IN COMPASSION

“**M**aitri is a concept and has been from the beginning: compassionate friendship. What we provide is first and foremost a home in which loving care is administered gently and with respect for life. We are a composite of all the personalities—past and present—who have lived, died and worked here. We have 209 beautiful spirits protecting and guiding us as we continue this work (209 people have died here since 1987). We have a huge extended family in this community, whose energy and love power us in what we do. I consider myself so very lucky to be working in a place, on this island of Maitri, that isn’t concerned with ‘productivity’ in the traditional sense. What we produce (instead of widgets) is an expansive space in which healing, love and compassion naturally occur.”

“A zen ‘home’ for people with AIDS. It’s a small house very ‘family’ oriented—not institutional at all. You get a sense of a community here.”

“A place of compassion and care for those in need and a healing environment with all the warmth of home.”

“A brilliant bright entity that draws and brings together so many classes of people, each one like the divine androgyne full of goodness, hope and ready to give and give.”

Hopes and Fears

“I fear that in the process of becoming licensed we will lose our sense of home, because most of the institutions in charge just DON’T GET IT. . . Hopes? I hope that never happens.”

“. . . I’m just going to remember to take a deep breath as new challenges unfold.”

“I hope that it will retain its renegade flavor and resist institutionalism while remembering its roots.”

“I hope and believe that Maitri will continue to serve from the heart, as it always has.”

Meaningful Moments

“There are so many! There’s Mario, whose room was infused with orange light for two days after he passed. . . And David—‘can you spare a minute to help me?’ ‘Sure.’ ‘Actually, I need about four hours.’ . . . I remember the



Photographs by: Thayer Allison-Gowdy



Mary Ellen



David



Yirko



Spirit Dove



Catherine



Fran



Carl

hand-holding, the hugs, driving people to the doctor’s office where they got the news that there were no other medical options and then driving them home to Maitri in silence as they took it all in. I remember Mario calling me ‘Angel’ and buying me a coffee on Market Street after I stopped him from shoplifting a pair of shoes. I remember that David never remembered my name and called me ‘sweet-ums.’ . . .”

“So David Darveux was everybody’s favorite. He sat on that porch everyday and greeted everyone. I used to sit on that porch with him almost daily. To me David was an example of the love that comes out of Maitri. He had a pretty rough background and I think the reason he lived at Maitri for a year and a half (before protease) was because he finally got the love and care he’d been deprived of for too long. Just before David died he had lots of talks with me about how things were gonna be ‘o.k.’ He had this little mini-buddha that he told me he wanted me to take after he was gone. He told me it would protect me from earthquakes—it still sits in the plant next to where he used to sit everyday. I think it’s better left with the house. Oddly enough the next resident to stay in his room (Howard) made a mold out of that buddha and gold-leafed it for me when I was sick. He had no idea the significance of it—strange.”

“All moments are meaningful with all the residents here at Maitri.”

“I had an unforgettable moment with a young resident several months ago. He asked me to come to his room when I had finished my work. We had a brief, but beautiful moment of deep connection. It was the last time I ever saw him, but I will never forget it. I look upon it as one of life’s blessings.”

Looking Ahead

“People aren’t going to stop dying, with or without AIDS. It is the one thing we know for sure. Hospice care is an essential and grossly undervalued function and obligation of the medical-care profession.”

“Yes [treatment] has become more effective, but there are other illnesses which need the same care and compassion with understanding.”

“People are still dying—drugs are nice and all and give us a few more years but they’re no cure. Plus there’s always cancer, etc.”

“I hope it will remain what it always has been—a place of love and refuge for those who suffer.”

“I am sorry to have to hurt you,” the doctor said. My eyes welled up with tears. Not because of the pain. Because of the compassion. In ten years of intrusive tests for my condition, no one had ever acknowledged my pain.

All of the world's great spiritual traditions stress the importance of compassion. From the Latin *cum passio*—meaning “with suffering”—compassion is the gift of “being with one who is suffering.” For nothing increases another's suffering more than a sense of isolation; a sense of being alone with one's pain.

What is the path to compassion?

First and foremost, in order to feel compassion for others, we must feel compassion for ourselves. To connect with the pain of others, we must have connected with our own pain. In order to do so, one must let go of fear and also of judgement. For compassion and judgement cannot go hand in hand.

Secondly, and this is extremely difficult in Western society, we must let go of the need to “fix” things. One of the greatest barriers to a sense of compassion is Western arrogance. A hard lesson of the AIDS epidemic has been that for the first time in recent history, Western medicine has been faced with human suffering on an overwhelming scale. Suffering for which there is no cure. Suffering which we cannot “fix.” Americans have been forced to confront their fear of death, their denial of death, their tendency to see death as defeat.

We have been forced to discover a new reality—the reality of transcendence. The reality that one can be “healed” without being “cured.” The reality that quality of life may be more important than quantity. The mystery that tragedy may beget epiphany, and that a spiritual awakening may be born from an epic epidemic.

But how can one rest in the face of death, day after day, without being numbed by the pain? We secular Americans have tended to stress self-reliance and stoicism. These will not serve us for the long haul. Those of us who do not have spiritual traditions will have to learn to look deep within. We will need to draw on our higher selves, on the universe if not on a deity, to renew ourselves in our commitment to compassion. We will need to explore tools of renewal, such as meditation, to be refreshed and re-born daily. For as a Japanese sage once said: “A clear wind can blow ten thousand miles.”

So then, let us create a circle of compassion. For ourselves. For our loved ones. For all those struggling with life-threatening illness. For their caregivers. For their medical personnel. Let us, like Maitri, form a community of compassion. Let no one suffer alone. KS



Percy



Sheila



Top



Snookie



Danny



Tove



Top



Donna



Ella

Words of Inspiration

“Believe in what you do and stick to it, even when the institutionalized voice of modern medicine tells you to downsize and conform. Know that they are mistaken. Hospice is a philosophy, not merely a profession. It is a path, not a job.”

“Hospice work has changed my life completely. . . . No matter how much you try to give you always get twice as much back.”

“You are special, very special.”

“. . . Recognize your own divine power and unleash it! . . .”

“We need more people to care and take an active part in helping our fellow man.”

“Know that in any way that you serve others, you serve yourself, because we are all One.”

“One of my favorite prayers:

*O love, O pure deep love, be here, be now
Be all; worlds dissolve into your stainless endless radiance,
Frail living leaves burn with you brighter than cold stars:
Make me your servant, your breath, your core.*

Rumi

*Just as with her own life
a mother shields from hurt
her own, her only, child,
let all-embracing thoughts
for all that lives be thine,
— an all-embracing love
for all the universe
in all its heights and depths
and breadth, unstinted love,
unmarred by hate within,
not rousing enmity.
So, as you stand or walk,
or sit or lie, reflect
with all your might on this;
—'tis deemed “a state divine.”*

Buddha



My work with Maitri is almost purely passion. I have long dreamed of assisting in the

acquisition of furnishings and the installation process of a healthcare setting—with the purpose of creating a healing environment. The readers who are familiar with us know our mission loud and clear—to comfort the suffering. In creating a healthcare setting with the institution, the architects and the other people who help make it happen—I am now able to walk my talk in the design world. There is no shortage of inspiration.



My first encounter with Maitri was on a work-related assignment, our core group at Healing Environments was to meet the then-executive director, George Hurd, at Maitri. I was immediately swept off my feet with a love and respect for this home-hospice that felt like a part of my own home. The warm sunlight bathed a frail man lying on a sofa in the living room. Who, as I stood staring at the beauty of this room, asked, “How are you today?” Gulp. I saw an enormous dining room table that serves hearty meals for all that can attend (staff, visitors and residents eat together); a core group of people that create a calm sense of security and strength. I was overcome with a desire to know these people better and in some way to help them.

About eight months later, I was asked to help Maitri in designing and facilitating their new expanded home. For months, we climbed up ladders leading to the second floor of 401 Duboce, which in seven months would be their new address. Amidst the rubble, wire and various materials, a soul was being nurtured with every day of work.

The question I am most often asked is how do I create a healing environment. Not an easy question to answer with clear-cut design specifica-



tions. I have often sat in Maitri’s living room basking in the sunlight. Allowing myself to be nurtured just as I saw the resident being awhile ago. Simple inspiration. I have spent countless hours talking to staff and residents about how they spend their days, what they need vs. what they want, and what residents of the past have done to their rooms (and to the staff) with their strong sense of character. I try to be aware of people’s stories of what kept them going and what they needed but never had access to—much of my design starts in understanding the possibilities of the space (and limitations). But more importantly, I try to honor the personalities, the mixed—often raw—emotion that the space will need to contain.

In design I feel there first has to be a sense of the individuals who will inhabit the space. How do people want the space to feel overall? These basic questions come to mind—of course, depending on your project, more questions can easily be generated.

What will be people’s first impressions as they enter the space?

Do patients have flexibility to bring their own things? To what extent?

In regard to color palettes—again, what is the philosophy or desire of the overall theme(s)?

What is made available for the people to interact with (books, music, games, computers, etc.)?

What emphasis is placed on art in the space?

Is it disorienting to move through the space?

How will the rooms be used on a day-to-day basis?

Are the living room/lounges used regularly? By whom?

Are TVs turned on in public spaces?

How many?

Can visitors stay overnight?

Furniture

In accepting donations, I have tried to consider how each piece of furniture will be used. For instance, a place to relax into after a filling meal might need comfortable furniture with neck support and relative ease in which to lift oneself. A place for group discussion, whether for pleasure or business, could use armchairs and maybe a loveseat that can easily be moved. Despite the need to accumulate enough pieces to fill the new space, I have chosen to be more conscious of both form and comfort over quantity. There will be a fair amount of table and floor lamps throughout the public seating areas to bring the warmth of low lighting to the user. We are also very fortunate to have inherited, through a design volunteer, a wood Victorian fireplace mantel for the formal living room. There will be a strong mixture of old and new, wood and fabric, Eastern and Western, beautifully combined to form a whole just as Maitri does.

Fabrics

I have chosen fabrics, thanks to trade professionals who have supported this project, with a mood and again with comfort as the basic recipe. In the case of Maitri, the group tends to prefer rich colors that lend themselves to a feeling of history and, in some cases, Asian influence. There is a consistent attention to softening the space and to personalizing it.



the new Maitri under construction

Resident Identity

There are many phases to this project, not only in terms of furniture, but also with regard to the layers of details that will make the space feel less institutional and more experiential. I have been fortunate in my relationship with Maitri because I can assist with the creative design for even the smallest details that will hopefully better unite the resident and staff with their space. The staff would like to develop a bulletin board/mail slot outside of each resident's door, a place for a name, and maybe a place for the resident to "mark" his or her territory with photos or mementos. The goal again is to create something unique, inexpensive, and functional for the long term.

Art

We are interested in creating a collection of healing art that will be used throughout the building—paintings as well as sculpture chosen with good intent and care. I like the idea of placing key pieces in areas where direction changes. For example, a wonderful screen painting of irises could be placed at a juncture between corridors—to be both a directional cue, "make a left at the iris painting," or to calm fragile nerves that may feel anxious at any confusing crossing.

A Memorial Book

Another important way to create a healing environment in the case of Maitri is to recognize and always remember those who have passed away under their roof or left Maitri, moving on to the next phase of their lives. The group would like to create a handmade book with a page dedicated to each person who has lived at Maitri. They

do not want to forget who and what made them what they are today. I strongly support this in the transition from moving from an older space to a brand-new space. They need to commemorate their past with ritual. We will also place pieces of artwork from the former address into the new site, marking the installation with a small ceremony.

Donor Recognition

We are investigating different artists' conceptions of a donor recognition area—a place to honor and acknowledge those who have contributed financially, provided materials and given of their time to help finish the job. There are many examples of interesting and creative solutions to link the community to the building and to the people who will use it. Examples are becoming more easily found, but let me just cite two. One is a beautiful mosaic containing the names of donors and found objects from the job site imbedded into the surface (found at Bailey-Boushay House in Seattle, WA). Another favorite example is the donor tile installment at Monterey Hospice in Monterey, CA. The handrail that leads through the space was created with a wood backing that has slots for rectangular tiles. Each tile is handpainted with the donor's name and placed in a row along the handrail. The result is a feeling of profound community support.

The Meditation Room

Spiritual practice has always been made available to the people of Maitri and their community. The staff does not limit what is available for spiritual support but instead bases their foundation on meditation. Maitri is creating a

One of the many consultants working with Maitri said to me when I first met him, "It took me over five years and the loss of many of my closest friends to accept the fact that I too could die from my HIV. When I started to develop symptoms, I finally had to face my reality. Then, suddenly, there was a new drug treatment available; now I have to accept the fact that I might live."

New-found hope has become more widely available with the distribution of the protease inhibitors. In many cases, a person's health can change drastically for the better—although of course, there are still many that die from the ravages of the virus. Maitri has not only had to face tremendous changes in the process of becoming a licensed facility, but also because of how the new treatment has redefined care for a patient.

Maitri originated with a simple act of compassion by Issan Dorsey, a Zen priest, when he opened his door to accept a homeless student dying of AIDS. Their services have changed with the needs of the AIDS community to provide respite care, twenty-four hour skilled nursing care as well as the services of a hospice. The original intent of offering a healing sanctuary remains the same and the desire to do so in a loving environment has been repeated to me as long as I have been involved with Maitri. As I have heard so many times, "AIDS hospice will continue as long as there is need. When there is no longer the need—our work will be done." ■

spiritual network in the San Francisco community—one that extends beyond the practices of any one belief—to acknowledge the needs of those who enter their doors. One of their founders has created an endowment to ensure that the need for spirituality is not lost in moving to their new site.

Many of the philanthropists and staff have shown interest in making the meditation room a very special room. I wish I could express the warmth and thoughtfulness that I have seen in preserving this part of Maitri to everyone that has shown concern. It is much smaller than their current space (a room that can seat 30 people compared to a space that can seat 4). It reminds me of the time when a priest came to bless Healing Environments. Kate and I took him through the space, and at the end of the tour, we asked him if he would bless the space and his response was, "it has already been blessed many times." I feel that the care that has been extended to the heart of this room has blessed it many times as well.

As I write this I am under tremendous time deadlines and managing the constant acquisition of more furnishings. My desire to write as much as I would like on this topic is impossible—my attention needs to go constantly back to the present and future Maitri and to overseeing the process. If I can assist anyone with more information regarding what Maitri will become—what the "final" (it will always be a work-in-progress) product looks like—please let me know at Healing Environments. ■

As my daughter and I travel to San Diego, we recall a family vacation we shared many years ago that is full of happy memories.

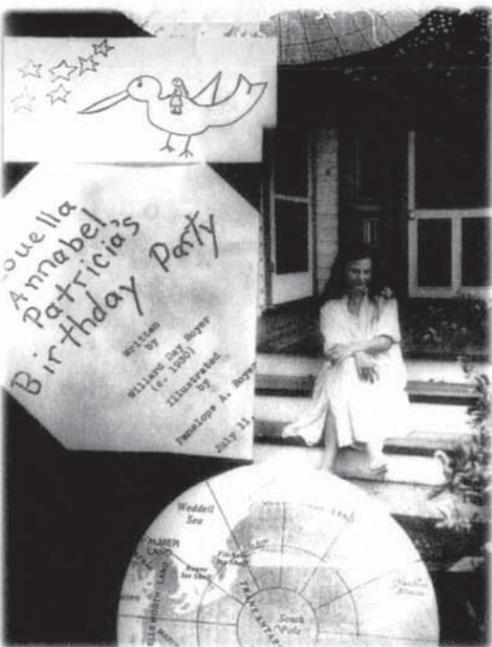
Becca was only seven years old then, and we remember making the rounds to the zoo, Sea World and Mission Bay. It was a lot of fun.

Our journey today has quite another purpose. We are to see a unique exhibition on the subject of hospice by five distinguished photographers at the San Diego Museum of Art.

As we view the images and read the words, it becomes apparent that these photographs reveal the process of death and the compassion of the hospice worker. The pictures are explicit and emotionally disturbing. A photograph, after all, is not fiction.

The goal of *Hospice, a Photographic Inquiry* is to increase awareness of the hospice movement, which provides the choice to be cared for and to die in one's home, thereby offering a humane alternative to aggressive medical treatment.

The photographer and the hospice worker share an intimate exchange with fellow human beings who are affected by serious illness. The photographer, however, bears the mission of communication.



Kathy Vargas

Since the subject of death has been considered taboo by our culture, the question becomes: Can an exhibition containing unpopular subject matter have high artistic value? The answer is a resounding yes.

Each of the photographers drew from personal experiences that had equipped them with the resources to portray this unconventional transition from life to death and to explain the compassionate role of the hospice worker.

Nan Goldin—Faces emerge from deep dark backgrounds of the large ilfochrome prints to reveal both the spirit and the complexity of patients in a New York city hospice. "I realized that the only thing that separates me from dying is time."*

RAYSO



One hospice worker reports driving 250 miles to take a patient to see the ocean one last time.

Sally Mann—Images that patients see from their windows combined with writing. A nostalgic photograph of the horizon with text that explains how a hospice worker drove 250 miles to take a patient to see the ocean one last time.

Jack Radcliffe—Large black and white, candid, penetrating portraits that record real moments with riveting reality. "This project allowed me to experience a new level of intimacy."

Jim Goldberg—In a most personal statement, Jim documents the actual death of his father at home in Florida. The pictures and words detail the event which Jim experienced with his family. "Hospice became an integral part of our lives; it was the antithesis of how the medical profession works. The bottom line is that it's important to be there for our families whether it's with a camera or without one."

Kathy Vargas—Perhaps the most poetic approach to this unique project. Hand-colored photomontage that combines portraiture with personal memorabilia and symbols of the patients' mortality (their x-rays and medical charts). "I wanted to show the persistence of love and memory, along with the role hospice plays in encouraging it."

The exhibition also includes the

HBO commissioned full-length film, *Letting Go: A Hospice Journey* by Susan Froemke, Deborah Dickson and Albert Maysles. This is a moving portrayal of three families and their hospice experience.

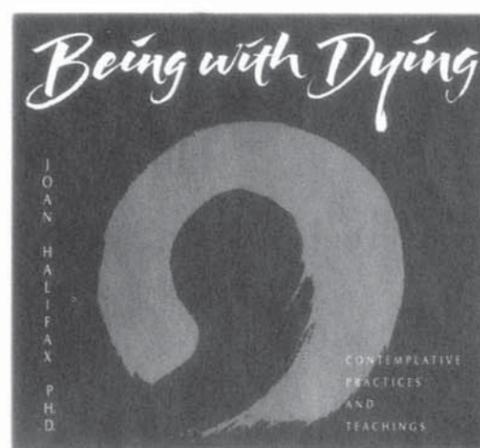


Nan Goldin

This controversial exhibition was organized by the Corcoran Gallery of Art in collaboration with the National Hospice Foundation. It will travel from museum to museum throughout the

F H O P E

thoroughly neglected the social, cultural, and spiritual life of the individual—of both the patient and the doctor. As she witnessed the marginalization of those who were perceived as medical “failures,” she came to understand the profound distinction between *curing* and *healing* that is elemental to her philosophy and practice of contemplative care. “Healing,” for Halifax, “is looking at a person as a whole system, curing is going after a symptom.” In these early teachings, the necessity of seeing people “not just in terms of their suffering, but in terms of their culture, in terms of their communities, and in terms of their deepest nature” was vividly impressed upon her. In asking what she could do as a young woman and as an anthropologist to bridge this world between curing and healing, between spirit and bodily ills, Halifax began a way of life that would ultimately challenge our Western approach to death.



The series of tapes, a distillation of the *Project on Being With Dying* which Joan Halifax created in 1994, share both her personal journey and its lessons. Originally intended as a training for healthcare professionals in contemplative care of the dying, *Being With Dying* sensitively speaks to anyone who is interested in keeping an open heart in the face of pain, confusion, and fear. Halifax's inquiries into subjects such as *Dying in Community* (tape 1), *Perspectives on Impermanence / Meditations on the Nine Contemplations of Atisha* (tape 2), *Mindfulness Meditation / Lovingkindness Meditation* (tape 3), *the Myth of Chiron, the Wounded Healer* (tape 5), and *Compassionate Action* (tape 5) combine the wisdom of many spiritual traditions and help us to understand that “in gently caring for the dying, we also learn to care more wisely for the living—and for life itself.”* DA

*Excerpted from the introductory notes to *Being With Dying*

METTA—THE SENSE OF LOVE THAT IS NOT BOUND TO DESIRE, THAT DOES NOT HAVE TO PRETEND THAT THINGS ARE OTHER THAN THE WAY THEY ARE—OVERCOMES THE ILLUSION OF SEPARATENESS, OF NOT BEING PART OF A WHOLE.

SHARON SALZBERG

photograph by Sally Mann

year 2000. The San Diego Museum is the only one to exhibit it in California, since many museums find this subject disturbing. It ends on July 20th and goes on to the Telfair Academy in Savannah, Georgia.

In conjunction with the exhibition, the museum is also offering a number of related educational programs. The exhibition is staffed by hospice workers who are there to explain their function and provide emotional assistance if needed. They add substantially to the experience.

On the way home, Becca and I agreed that this experience would always be with us. It made us realize and appreciate our lives which we take for granted. Life is good. Hospice helps it pass gently into the night. SS

*All quotations are excerpted from the exhibition catalogue.

LOVE IS NOT MERELY AN EMOTION, IT IS A METTA THAT REESTABLISHES A MORE UNIFIED SPACE OF BRILLIANCE, GOODNESS, AND SADNESS —THIS IS THE FUNCTION OF LOVE IN THE SPIRITUAL TRADITION.

JOAN HALIFAX

THE GENTLE REVOLUTION: PRESENCE, COMPASSION AND EQUANIMITY

Love and death are the great gifts that are given to us; mostly they are passed on unopened.

Rainer Maria Rilke as quoted by Joan Halifax

It is a *gentle revolution* and Joan Halifax—anthropologist, Buddhist teacher and writer—is in the vanguard. “We are so much a culture of knowing,” observes Halifax, “but death is a mystery.” “What would be a vision of restoration in Western culture,” she asks, “in terms of bringing spirit back, in terms of bringing human values back—that would help us realize that all life was precious and that death was an intimate part of life?”

In the early seventies, as a young anthropologist working within a traditional healthcare system at the University of Miami School of Medicine, Halifax was disheartened by the prevailing medical perspective she encountered. As she explains in *Being With Dying*, an audio learning course published by *Sounds True*, she saw in this early exposure to Western medicine a system influenced by an alienated view of human beings which

HEALING ENVIRONMENTS MEETS MAITRI

For more than a year now, Traci Teraoka, Healing Environments' co-director, has been working with Maitri* in San Francisco. For Traci it was a dream come true—to realize the vision of our small nonprofit in physical form—to create a model of all that an institution can be, utilizing the healing elements of design to manifest the warmth and nurturing of home in an institution.

It proved to be a challenge: budgetary constraints, committee meetings, and health regulations. But throughout it all, Traci kept her eye upon the mission—not to be overwhelmed by limits, to see everything, rather, in terms of possibility. Maitri had something very special, and Traci wanted very much to safeguard and enhance that in the new building.

One morning Traci suddenly realized that the spirit of Healing Environments had been transferred to and fused with Maitri's spirit. By focusing on the high goal they have in common—to nurture residents with the warmth of home

—more mundane concerns were falling into place. Traci's and Maitri's impassioned commitment inspired donors with the vision of all that Maitri could be.

We wish to share this with our readers. To encourage you to break out of the mold, to explore the upper limits of what can be. And so we urge you to keep the vision—to seek to make manifest in your institutions a truly healing environment; one which addresses the whole person: body, mind, spirit. One which relieves suffering by surrounding people with life's beauty and meaning. One which enables people to transcend their circumstances by connecting them to the universal through beauty and art. One which gives comfort through this connection.

It is our experience that the more one connects with one's highest self and one's clearest intent, the more the universe will come to one's aid to make good manifest. Through the efforts of many, we will comfort the suffering. **KS**

**Residential Care for People Living with AIDS—formerly Maitri AIDS Hospice.*

TOGETHER
WE
WILL
COMFORT
THE
SUFFERING.

OUR MISSION

Our mission is to aid the current movement toward holistic medicine—toward treating the whole patient (mind, body, spirit) and encouraging hospitals, hospices, and individuals to nourish patients, families and caregivers with healing environments. What is a healing environment? We believe a healing environment is one that offers sustenance to the soul and gives meaning to experience. It is one that enables those who are suffering to transcend their pain by connecting to the universal through the transformative power of beauty and art, and that gives comfort through this connection.

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