

# COMMUNITIES

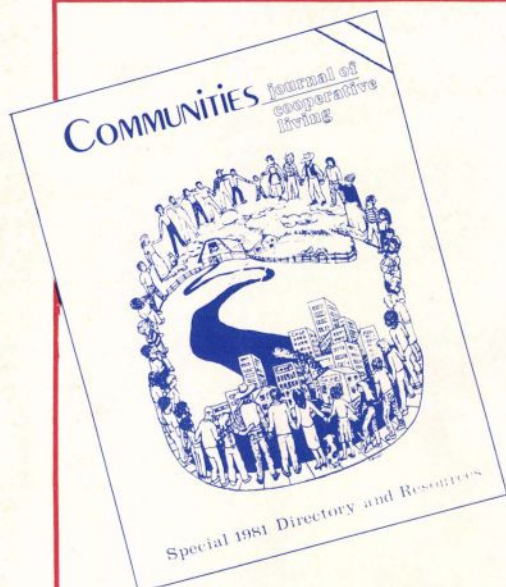
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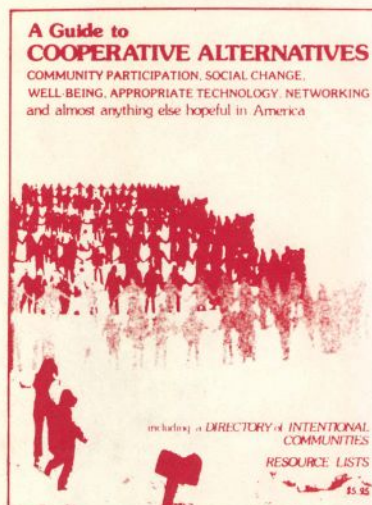
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# COMMUNITIES

journal of  
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## Table of Contents

<b>INTRODUCING THIS ISSUE</b>	2
<b>GETTING THE GOODS ON CANCER</b>	4
<i>How the author, a member of the Philadelphia Life Center, responds to his bout with cancer</i> <i>by George Lakey</i>	
<b>THE CONNECTICUT HOSPICE</b>	10
<i>The Hospice experience as told to Melissa Wenig</i> <i>by Sally Bailey, Art Director</i>	
<b>GOOD GRIEF</b>	15
<i>The importance of grieving and how the Grief Education Center deals with helping people grieve.</i> <i>by Mimi Wegrzyn</i>	
<b>A DEATH IN OUR FAMILY</b>	18
<i>Edited by Melissa Wenig, Introduction by Chip Coffman</i>	
<b>The Story</b>	20
<i>The retelling of the events of the last week of life of Twin Oaks member Seth Arginteanu</i>	
<b>Conversations on a Sunday Afternoon</b>	24
<i>The sharing of the effect of Seth's death on other members' lives</i>	
<b>SETH'S JOURNAL</b>	33
<i>A year and a half quest for the right combination of community and political activity . . . only to be interrupted by cancer</i>	
<b>BRIDGING THE GAP</b>	36
<i>An interview with oncologist Cliff Russell</i> <i>by Larry Lenske</i>	
<b>HOME DEATH</b>	40
<i>Ways to have control over our own deaths</i> <i>by Larry Lenske</i>	
<b>RITUAL</b>	43
<i>Creating our own rituals for death</i> <i>by Gareth Branwyn</i>	

## Departments

<b>RESOURCES</b>	46
<b>REACH</b>	52

October/November 1981

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Louisa, VA 23093. Second Class postage paid at Louisa, VA with additional entry at New Haven, CT 06511. Send contributions of editorial material to: CPC, Box 426, Louisa, VA 23093. Communities is \$10.00 for one year, \$15 for institutions. Single copies \$2.00. Add \$2.00 for foreign subscriptions. Publication number: 006570





Like birth, death is one of the most profound transitions in life. In this century the health professions have increasingly mystified these processes and taken them out of our hands. This has become a major concern for many of us who wish to reclaim power and control over our experiences of birth and death. We are finding that with community based support systems we are more and more empowered to do this.

This issue focuses on ways for all of us to regain control over our experiences of dying. It is written by people who have had community experiences that offer models of death as a growing and fulfilling process. The impetus for this issue is the death of Seth Arginteanu, a member of Twin Oaks Community and co-worker on this magazine. Seth died of cancer last December at the age of 22. For Twin Oaks, going through death with Seth was an empowering experience. It was as healing and renewing as it was hard. And since Twin Oaks is both co-publisher of the magazine and the home of several of its workers, the experience has left its mark on this issue.

Several of the articles are attempts by Twin Oaks members to share what has been learned from living and dying with a person who has a life threatening disease. "The Story" is an account of Seth's last week of life. It is the transcription of the cathartic sharing that occurred the morning after Seth died as the whole community gathered to hear the details of Seth's last hours and days and to begin preparing for the burial and memorial service.

"Home Death" is an article written by Larry Lenske, one of the main

organizers of Seth's Twin Oaks support system. Larry and Seth worked closely together on the organization of Seth's nursing care, community involvement during his illness and dying, and on the business details of death: wills, burial sites, funeral arrangements, etc. This article deals predominantly with the legalities and logistics of community or family controlled dying, funerals, memorial services, etc. It gives a sense of what was done at Twin Oaks, what might be possible for others to do, and where to go for further information. Both of these articles reflect the result of having good planning, organization, and communications, and hopefully provide models and options to learn from and use.

"Seth's Journal" and "Images of Seth" are included to provide a portrait of Seth. By age 17, at the writing of his journal, Seth had already defined his life directions. He spent the remainder of his life dedicating himself to the fulfillment of those goals. He was a strong activist — politically, socially and emotionally. He expected his doctors to treat him as an equal and his friends and family to accept that he knew what was ultimately best for himself. He demanded that he himself actively take charge of his own life. His journal has been inspiring to many of us. It is an abridged but unedited version. Only the names of Seth's acquaintances and friends have been changed.

To give a more updated picture of Seth during the past four years we have included quotes made by people who were present at his memorial service. They are testimony to the effect he had on the lives of others.

From a series of interviews with Seth's family, his doctor and Twin Oaks members came two articles — "Conversations On A Sunday Afternoon" and "Bridging the Gap." "Conversation On A Sunday Afternoon" gives an opportunity for readers to experience some of the grief and growth that Seth's family and friends experienced. These con-

versations have themes that are common to many of us. "Bridging the Gap" shows the kind of doctor-patient relationship that is possible when patients are as direct and assertive as Seth and when doctors are as open and supportive as Cliff Russell, Seth's doctor.

"Getting the Goods On Cancer" is a powerful article by George Lakey. George shares his experience of having a life threatening disease and how having the support of the Philadelphia Life Center, an MNS Community, helped him through that time. This article was published in *New Age Magazine* several years ago. We thank both George, who is alive and well and continuing on with the revolution (see Issue no. 49) and Peggy Taylor at *New Age* for permission to reprint.

"The Connecticut Hospice" describes a community's response to a movement to create a nurturing and supportive environment for people who are facing death. The goal of hospice care is to make people as comfortable as possible in their last days. Hospice has become more prevalent across the United States as more communities want the choice it offers. Hospice can be a group of 8-10 volunteers offering care to the dying or can be an inpatient institution like Connecticut Hospice featured in this issue. Sally Bailey is the Arts Director of Connecticut Hospice and makes a strong statement about the humanity of hospice care.

Mimi Wegrzyn has been involved in community organizing for many years. For the past four years Mimi has used her organizing abilities to establish the Grief Education Center in Denver, Colorado. Good Grief is an article that provides a greater understanding of the function of grieving in a healthy culture.

We have also come to appreciate and value the necessity of ritual as a part of that grieving process. Gareth Branwyn offers a look at the place of ritual and the ways and resources we can use to create meaningful rituals for ourselves in our particular situations.



All the articles in the issue provide information that can help us all give death a better name. We understand the grief process more clearly and can listen to a bereaved person without feeling engulfed by the enormity of that person's loss. We can help organize hospice care in our neighborhoods, towns, intentional communities. We can offer help to one who may be home bound with a life threatening disease. We can look into the options we have for our own deaths and start choosing them now.

This issue has both helped me work through my own feeling about death and has been part of my process of grieving for Seth . . . For the many of us who have shared this experience, death no longer has the same mystique that it had in the past. It's easier to see it as one stage in the cycle of life, as many cultures have told us in their rituals and myths. We need to continue to share our experiences of death and dying with each other and empower ourselves to make death as acceptable a part of life as birth.

It is a challenge and it is happening.

Melissa



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Sketches in Seth's Journal are of  
objects Seth held dear

### Special Thanks

Dennis Pearson of the Advocate  
Press, Survival Graphics, Madison,  
Wisconsin, Jules, Mary and Judy  
Arginteanu for permission and  
encouragement, Aviva for  
proofreading, Larry for  
inspiration, Tom for continuity  
and Twin Oaks Community

### Community Publications

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at Twin Oaks; Paul Freundlich in  
New Haven







# Getting the Goods on Cancer

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by George Lakey

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*Seth once lamented that he should be writing about his experience of going through cancer in community and then said it was okay because George Lakey had already written it.*

*This article was originally printed in New Age Magazine. After meeting Seth at an MNS training session George sent Seth an autographed copy of the article.*

*Dear Seth,*

*Want you especially to see this. There is a profound solidarity between us, yes? Let's stay in touch.*

*For liberation,  
George*

An old acquaintance who had lost touch with me ran into a friend of mine in the fall of 1977 and asked, "How's George Lakey?" My friend replied, "Oh, George is fine. Well . . . he's got cancer, but basically he's doing fine."

That characteristic attitude on the part of my friends helped me through the hardest struggle of my life, which began on a conscious level when I was admitted to Presbyterian Hospital for severe hemorrhaging in late May 1977. I had been bleeding internally for more than half a year, but repeated tests had discovered no cause. After a few days of transfusions to build up my weakened body, the surgeon operated and found a large intestinal tumor which was malignant. Unable to cut out all of the spreading cancer, he took what he could and sewed me back up.

Three things became clear very early. In this fight for my life, there could be no delegating the decisions. I would have to make the hard choices and put the doctors on notice that this was my style. It was also clear that I would need strong and effective support. Having lived in community among people involved in the Movement for a New Society in West Philadelphia, I was used to giving and getting support, but this time my need would be enormous. Finally, it was clear that I would use a variety of approaches as I mobilized all the resources I knew about. I already knew that cancer is a many-level threat; I decided to make a many-level response.

Many people have urged me to describe the process of recovery, which one of my doctors described as a "miracle." I've wanted to write an article for some time,

but found that the writing raised such heavy feelings that I was blocked. I kept trying because I know how much it can mean to others who suffer from cancer or know people who do. This article, therefore, is the product of hours of emotional working through and is, in every sense, a labor of love.

## **Pain and Presence**

I still can't remember the surgeon telling me that the tumor was malignant, and I can't remember telling the news to a friend who came into the room immediately afterward and was struck by how pale and scared I looked. I was a stranger to this size fear, at least in my adult life, and I had never experienced pain like this. Yet I didn't think I would die. The challenge was the heaviest so far in my journey, but not one I expected to overwhelm me.

About four days after surgery I learned from the medical staff that the pain-killer they were giving me was slowing down the healing. I therefore took myself off the drug, and learned more about me. From my journal:

*Of course there must be worse pain than what I experienced, but I knew that Sunday after surgery, when I stopped accepting Demerol and fought from 5:30 A.M. to 7:00 or so in the evening (until relief came) — that was pretty extreme. Time was so frozen in my head — there wasn't a sense that this hurting is only temporary and later I'd feel better. Now seemed the only time in the world that there was or could be.*

In the middle of the day a friend who had experience with pain made a helpful suggestion: "Introduce yourself to the pain, George. Acknowledge that it's here and get to know it; stop trying to resist it." As she coached me, I role-played a formal introduction, talking about myself and then taking the role of the pain and talking about it and why it was visiting. That process of conscious

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*George Lakey is a member of the Philadelphia Life Center and The Movement for a New Society. He is the author of Strategy For a Living Revolution and a wonderful human being.*





recognition was effective. It helped reduce my sense of the pain as being an alien intruder, vicious and mean. I learned to regard the pain as my companion, sharing with me in the process of healing.

*The pits was that Sunday, as far as pain duration goes. For the worst moment, that goes to the time in early morning when the stomach tube had worked its way up to my throat and I called the nurse and asked her to let it out for a couple of hours of respite. She refused, and stuck it back down with an agonized cry from me. Thank God, Alan was there to hold me! I'd like not to do it alone.*

*Then when the tube was taken out! Bursting into tears — Stephanie and I'm not sure who else holding on while I cried my relief and joy. That was a high point.*

I learned I could handle a lot with the help of loving friends. For the first six days after surgery I was in a private room so friends could be next to me around the clock. They wrote notes to each other in the notebook by my side:

*George's body is healing well. He's experiencing quite a lot of pain. I think it's good to gently encourage him to be aware of things happening around him. When he's not sleeping, talk about real things happening in your life, in the room, outdoors — not from your need but just to be real and human with George. When he's resting, gently sit beside him. Touching him is always on target (reading to yourself or resting or thinking about George).*

Whenever I awoke, even in the scary moments of the night, a friend was there to reassure me. One afternoon I awoke to find my hand was being held by a man who himself was taking a nap in the chair beside me. Musicians brought their instruments and played my favorite songs while tears streamed down my face.

One night shortly before midnight a friend was stopped by the head nurse on the floor. "Don't you people realize that visitors are very hard on patients, and you are probably hurting George by being with him all the time?" My friend tried to explain that our community, the Life Center, knows the skills of nurturance and therefore was a healing force. And it's true that there were only two visitors during those days whom I had to tell to change their tack (they were starting to worry out loud about me): all the others parked their anxiety at the door sufficiently so that they could pay attention to me when they were with me. The nursing staff was won over as they watched this love-bath in which I was continually immersed.

Unfortunately, I found it hard to simply relax and enjoy all this caring. My own background is the kind that focuses more on serving others than on accepting warmth for myself, and I get uneasy if I cannot "pay back" someone for the attention I get. I have an emotional block to the experience of grace. Lying in the hospital bed, with a variety of tubes coming in and out of me, there was no way



I could reciprocate, and the result was teary feelings of unworthiness surfacing in the presence of "unearned love." I probably cried as much from the loving as I did from the pain!

### MOBILIZATION FOR LIFE

I asked a friend who knew me intimately to make a poster that would remind me of times when I was unambiguously a lover of life. Another friend hung a giant picture of a wooded stream. Another held my hand after I first dared look at my belly when the surgeon dressed it; he gazed with clear, warm eyes while I trembled and stormed at this violation of my body. Another friend patiently helped me think about the meaning of the intense dreams I began remembering.

All my friends were saying, in different ways, that it was right to take time, to journey into myself, to mobilize all resources — inner and outer — for the struggle against cancer. "It's another campaign," they said, "this time not against the Pentagon or the patriarchy, but just as worth lavishing your energy and talent on. And we'll help."

From my journal dated June 14, two weeks after surgery:

*I feel as though this experience has been so full and positive for me, and the thought that the waging of the struggle against cancer will bring more rewards with it is a thought I cherish. It's all so unexpected. I expected to do my George Lakey endurance number to get through all this, like getting through a summer working in a factory (during my college years) or the worst of the 'Phoenix' voyage sickness (sea-sickness during a sailing trip to South Vietnam with medical supplies) or prison at Leonardo (in N.J. in the course of antiwar protests). But this was too profound, and the support was too great. I couldn't tuck my awareness inside my turtle shell and just wait it out.*

During the rest of my month in the hospital I decided on the main outline of my "campaign." My journal helped me keep track of information from outside and feeling from inside. My friends brought me information, offered suggestions, listened to me think out loud. As it turned out, I used the same approach in this personal struggle that I do in my political work: those of us in Movement for a New Society refuse to put all our strategic eggs in one basket, but instead insist on a multidimensional approach to working for social change.

After consulting with medical people, both orthodox and unorthodox, I decided on chemotherapy. To get in touch with the abundance of positive energy and loving wholeness in the universe, I explored spiritual healing. To release the anxiety of being a cancer victim, and work through the old emotional wounds that were related to my disease, I increased my use of Re-evaluation Counseling. To enhance my immune system and support it against the attack of the chemicals, I turned to the meditation technique developed by the Simontons in Texas. To learn more about the shadowed side of my life experience, I did Jungian dream analysis. All of these methods helped me to learn about the *meaning* of my cancer, why it grew in me

and how I need to change to reduce my vulnerability to it.

I also accepted the discipline of daily physical exercise (psycho-calisthenics) and paid new attention to nutrition, especially vitamins. Although my chemotherapist scorned the vitamin approach, I wanted my body to have additional support as it faced the rigors of the chemicals. I took B, C, and E, and impressed everyone in the cancer center with my energy and resistance to infection during this dangerous period.

My wife, Berit, organized a support committee for me as a kind of ongoing strategy group, to help me sort out the options, to make sure I wasn't overextending myself, to help with my children (for whom I had, and still have, primary parenting responsibility), and to challenge my lifestyle. It is amazing to me now, two years later, to read the minutes from the meetings of my support committee. The group systematically looked at each area of my life to see how I might change to increase my well-being. They looked at my parenting, my cooperative household, my political work, my income-producing work, my co-counseling, my relationships. They made sure that each time I went to the doctor I was accompanied by a friend, that in the hours after each chemotherapy session I had support through the nausea, and that I was giving myself more playtime and musical experience than I ordinarily would. Because there was a variety of perspectives in the group, there were disagreements, which expanded my understanding of alternatives I could take in my journey to health. Members of the group found it helpful not only to me, but also to themselves, because it pushed their own ability to think and care in a scary time.

### THE SPIRITUAL DIMENSION

From my journal, seventeen days after surgery:

*Inside me is a cathedral, grand, like St. Mary Redcliffe Church in Bristol, a gothic gem. Inside me is exquisite color, shining on walls, on floor, and most brilliantly seen when the glass is directly apprehended. Great peals of the organ resound in the cavernous stone recesses (I am vast inside) and also the merriest music available, like that Bach cantata we sang in the choir. Inside, tapers are lit, dramas occur, continuities are maintained, fresh words are uttered for new days, doors swing open, the sunshine comes in. I am clean and healthy and wholesome, and love is everywhere, completely without apology.*

When I was in my late teens I had a rich interior life and trusted my intuition. With little support from my peers and none from my family (this was the 1950s!), I decided to dedicate my life to making a just and peaceful world, however little the world might appreciate my decision. I was fiercely unconventional, but not very lonely, because my friends loved me, and, on the really important things, I had myself.

In my twenties I took steps which broadened me and increased my understanding, but decreased my confidence in my intuition. I got married and lived in another country where the cultural cues were new and different. I adopted a



fairly conventional lifestyle and tried to bury my gay love for other men. I joined the Society of Friends, where some of my values and abilities were supported, but my upward mobility (away from my working-class background) was accelerated; in my effort to grow more sensitive middle-class antennae, I undermined my solid sense of the fundamental me. Graduate school tried to teach me that only those things are true which can be supported by footnotes. The reaction against individualism which came for me in the beginning of my thirties resulted in a clumsy collectivism which sometimes substituted groupthink and leveling for the wisdom of authentic community.

And now here at age thirty-nine, in a Philadelphia hospital, I was rediscovering the power of the interior me! Why? I wondered.

The stakes were big: cancer doesn't just mess around.

- High-intensity love was surrounding me; some of it had to get in and reach the stale corners of self-doubt.
- I had to rely on my intuition on medical questions where only I had enough of the whole picture to decide. I learned not only that advocacy is needed in any bureaucracy, including the medical (I already knew that in theory), but that I could really count on myself to make solitary judgements when I needed to.
- I had to bear the physical pain alone. I couldn't share that with even my dearest friends, and although their support was incredibly important, I had to walk *that* lonesome valley by myself.

While still in the hospital I attended a chapel service organized for me. The singing was beautiful: "Healing River," "Joy Is Like the Rain," "Dear Friend." Friends recalled times, often humorous, when my commitment to life shone through. I listened and cried. We prayed. At the end I stood in the middle of the circle and everyone touched me. Kent Larrabee asked how I was healing. I said, "Beautifully." Kent asked me again. I said, strongly, "Like an oak!" The group said, "So be it!"

In my journal, scattered through the pages, I wrote in capital letters, SO BE IT!

Two months later I attended a retreat for spiritual healing at Powell House, a Quaker conference center in New York State. I learned much in a field where I had been highly sceptical. I loved how matter-of-fact Friends were about healing. My stereotype of healing had been of self-important people talking in hushed tones — a stereotype dashed to pieces by the merriment in Evelyn Dane's eyes. I was prayed for, and I felt warmth where the cancer was. One friend who practiced 'laying on of hands' with me noticed the warmth in *her* hands when they reached the site of my tumor, and asked, "Is that where it is?" I was buoyed by the hope and expentancy, and stayed at Powell House after the conference to continue to dwell at my center without the distractions of home life.

I also visited evangelical healing services in suburban Philadelphia and was boggled by what I heard and saw there. Trained to be a skeptical sociologist, I was not prepared for the healings which occurred. Again, I was reassured by the lack of hocus-pocus among the healers there: they went at it almost with the air of a garage mechanic starting in on a damaged car. And I was deeply

moved by the power in the place: a church jam-packed with people on a rainy Friday night, supremely confident that Jesus was healing and loving them at that very moment.

My own disease had ceased to give me feedback in the form of pain, and it was buried too deep in my groin to show up on X-rays. I had no way, therefore, of knowing if spiritual energy played a role in getting rid of the cancer at all! I *am* aware of ways spiritual healing was good for me, including the knowledge that people around the world were praying for me in that period. If prayer made a difference in ways I cannot put my finger on, so be it. SO BE IT!

## THE PSYCHOLOGICAL DIMENSION

My experience with spiritual healing — at least in the forms it takes among middle-class people — is that it underrates the importance of the emotions. True, the suburban church had boxes of tissues all over the place, and they were needed, but there is such an emphasis on acceptance of Jesus' healing presence as a conviction, as a statement of faith, that I doubt people gain enough permission to keep on feeling their real doubts and terrors.

I found Re-evaluation Counseling invaluable for working with my feelings. I was already experienced in this discipline of peer support, and I knew what a difference it could make to shake when I was scared, cry when I was sad, giggle when embarrassed.

Accordingly, when I was in the hospital getting ready for surgery, I decided I wanted to work through my childhood tonsillectomy — an emotional experience I had never resolved. My co-counselor gently encouraged me as I tried to remember what that experience was like, and as I told the story over and over, details started to return. Each time, however, at the point of anaesthesia, the memory would end. She suggested: "Tell little George what was happening then, and why he doesn't have to be afraid anymore." So I began telling myself as a little boy what was happening step by step and why it was all right, and suddenly I re-experienced the physical sensation of my throat tickling where they cut out the tonsils. The cold sweat of fear turned to tears of relief as that little bubble of anxiety, hidden away inside me all these years, finally burst.

That kind of work paid off in the bargaining I was able to do with the medical staff and the powerful way I continued to make decisions about my own body and its treatment. The less I felt like the victim of past manipulations of me, the more I could take charge of my present and my future.

I also used part of the therapeutic approach to cancer developed by radiation oncologist Carl O. Simonton, M.D., and Stephanie Matthews-Simonton, a psychological counselor, at the Fort Worth Cancer Research and Counseling Center. The part I used was meditation, including relaxation and visual imaging. The Simontons have found that picturing the tumor and one's immune system at work seems to mobilize the white blood cells and even to affect the pain level for those patients whose cancers cause pain. For me it was encouraging to "watch" with my mind's eye the chemicals and white blood cells engulfing the cancer cells and disposing of them. The



meditation was also helpful in working on the emotional stress I experienced in that period.

A friend and I used Jungian theory to work on interpreting my dreams, to see what the subconscious might be saying about my condition. My dreams often shed new light on the dilemmas and opportunities that faced me.

Using these disciplines as tools, I was essentially trying to figure out what the meaning of it all was. To my surprise, I located deep inside me a wish to die. I was hidden from me by my physical bounciness, my enthusiasm for political work, my zest for intellectual challenge, my love for my family and friends. But along with the positives, there was a hope which had turned to despair — a despair which even now I do not know how to name. It has to do with love, and idolatry, and living again what can never be relived. It has to do with holding back, with hiding my power, and also with hiding my need. I've worked very hard on the vectors of this despair, and I don't think it can grow cancers anymore. Someday I'll have it worked out more, and then its name will be apparent!

## CELEBRATION

My fortieth birthday party that fall was a jamboree. Trollheim, my cooperative Life Center house, was stuffed with jubilant people. We made ice cream, cooked crepes, sang and danced. Daniel Ellsberg told a story about me. At one point small groups went off to corners of the house to prepare skits on various aspects of me: Quaker, gay man, teacher, peace activist. The skits were hilarious and sometimes moving. Then there was silence, and people holding hands, and wet eyes as we sang softly together about love and strength and the dear gift of life. At that moment I hoped everyone would know deeply that we all deserve such fierce and tender comrades, and that it *is* worth the struggle □

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*For more information on the Movement for a New Society, write: 4722 Baltimore, Philadelphia, PA 19143.*

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## Healing Resources

- **Spiritual Healing** has been approached in many ways. A book that helped me a lot is *Healing* by Francis MacNutt, O.P. (Ave Maria Press, 1977).

- **Re-evaluation Counseling** is a peer technique in which co-counselors take turns listening to each other and giving support. Information is available from: Rational Island publishers, P.O. Box 2081, Main Office Station, Seattle, WA 9811.

- **Meditation** as a means of fighting cancer and influencing health is described in *Getting Well Again* by O. Carl James Simonton, M.D., Stephanie Matthews-Simonton, and James Creighton (J.P. Thatcher, 1978).

- **Dream Analysis** may be done in various ways. The approach I used is described in *Applied Dream Analysis: A Jungian Approach* by Mary Ann Mattoon (V.H. Winston & Sons, 1978).

- **Psycho-calisthenics** is an approach to exercise which borrows heavily from the yoga tradition, adapted for the American setting. Techniques are described in *Arica Psycho-calisthenics* by Oscar Ichazo (Simon and Schuster, 1976).

—G.L.



# The Connecticut



## HOSPICE

*Hospice is a specialized health care program emphasizing the management of pain and other symptoms associated with terminal illness. Hospice includes the family, thereby making it a unit of care, and centers the caring process in the home whenever appropriate. Inpatient services are available when needed.*

*Knowing that pain and other symptoms are nearly always manageable, the goal is to enable patients to carry on an alert and pain-free existence through the administration of drugs and other forms of therapy. Of primary importance is quality of life for patients/families as they themselves define it. Care for the family continues through the illness and bereavement period. Hospice care for the dying is not a new concept. In*

*ancient times hospice was a way station for pilgrims and travelers, a place for replenishment and refreshment. Later it became a place where the dying would find care and comfort in their journey from this life to the next.*

*Today, Hospice is a response by communities throughout this nation to provide dying people with the right to live fully up to their final moment of life.*

*Hospice is an attempt to turn around the concept of America as a death denying society. As in most attempts to take charge of our own lives, the row to hoe is not an easy one. It is not easy to find funding for hospice and home care insurance is often not available to patients. Much lobbying and letter writing to Washington will be needed to make hospice care a common part of our culture.*



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*This interview between Melissa Wenig (editor, Communities) and Sally Bailey (Connecticut Hospice) took place as an effort to further understanding of the hospice movement. There are now over 300 hospices in the United States. Many of them are grass roots based and home care oriented. The Connecticut Hospice, by its size, building, funding and staff is a model hospice facility. Sally Bailey is Director of the Arts program at the Connecticut Hospice and has been a member of the staff for 5 years.*

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**Melissa** — How did the first hospice come into existence?

**Sally** — The founders of The Connecticut Hospice were people from the New Haven area who, in the late 1960's, were inspired by a talk given at Yale-New Haven Hospital by Dr. Cicely Saunders, founder of St. Christopher's Hospice in England. She touched a responsive chord in her listeners and they recognized the need for hospice care in this country. By 1971 The Connecticut Hospice was officially incorporated. We first thought of an inpatient building for hospice care since that was what Dr. Saunders had done in Britain. But the first potential building site was in a town which focused less on our positive and helping goals and more on fear that a place which cares for the dying might be a somber, and therefore detracting, element in the community. Of course we still wanted our building, but when we were stymied by problems with building sites and funding, one of the founders said: "Why don't we just begin by giving care in the home? That is where people basically want to be rather than dying in isolation in a hospital." It took a long time to get the people and resources needed to do the planning that was necessary to be authorized by the state. Three years later, in 1974, Hospice began its Home Care program.

Home Care has been a going program ever since. But we still wanted that back-up inpatient facility, so we were delighted by the cordial welcome we received in Branford. The town's receptive response was in large part due to our Home Care patients, a Branford resident, who stood up at a public meeting and said: "I can tell you how much we need this building because I am a Hospice patient." People were utterly dumbfounded that someone at that stage of life would speak openly to a large group saying: "I am dying. Here I am."

One of the reasons we have been so happy with this site is that we are so much a part of the Branford Community. We are close to a church across the street from a school. At the entrance to our driveway is a little park where the Hospice and Branford communities together planted 1500 flowering spring bulbs on November 1st. We also have a preschool for three to five year old children within the Hospice building itself. It is not only for children of our staff, but children of Branford and other surrounding communities. Hospice focuses on keeping generations together and keeping people together. There is one main door here and everybody passes through it. Visitors,

patients, staff and even the preschoolers all come in by the front door with its hand-carved Tree of Life design.

**Q** — Is Home Care still a big part of your Hospice program?

**A** — Yes, it certainly is. We began as a home care agency and this is still our major emphasis. Both Home Care and Inpatient Care are part of Hospice.

**Q** — Why do people choose Hospice?

**A** — There are a variety of reasons which prompt a patient to come here. Patients come in to get their symptoms under control. Our interdisciplinary team is particularly skilled in easing physical, psychological, sociological and spiritual distress. After time spent with continuous monitoring, symptoms may be sufficiently relieved and a care plan developed so the patient can return home. Patients sometimes come in because their families are exhausted and need a respite for a while. Also, there are times when a patient has no family member or close friend who can take the responsibility for being the primary care giver at home. And since Hospice serves the entire state of Connecticut, the inpatient facility is a needed resource for those people who live outside our 18 town Home Care service area.

**Q** — How did you find the funds for this building?

**A** — We received a million dollars from the Federal government and a million and a half came from the state of Connecticut. The rest of it came from corporations, foundations and individuals who wanted to see this Hospice come into being.

**Q** — How can people afford to come here? Is this a way of dying for the rich or middle class only?

**A** — Right now we are one of the 26 hospices in the United States chosen by the Health Care Finance Administration as a demonstration project for Medicaid and some Medicare patients. In addition, we receive third party reimbursement from Blue Cross and private insurance plans. However not all patients are covered by present insurance regulations. For example, patients have been covered, but family and bereavement care are a new concept. Changes are being made on the national level to make it possible for hospice care to be interwoven into our existing health care coverage in this country. Our nurse to patient ratio is like that in an Intensive Care Unit, but we do not have the high overhead necessary in an acute care hospital with its wide variety of sophisticated equipment.

**Q** — Besides finding a site and money, what were some of the major stumbling blocks along the way?

**A** — I would say that it was people's attitudes initially. A tremendous amount of time had to be given to raise peoples's consciousness about the need for hospice care. And there had to be the people with the courage to take the risk: the first patients and families who allowed helping strangers into their homes at a time of dying.

Attitudes of other health care givers were important too. We had to convince doctors, nurses and other health agencies that our goal is to supplement, not duplicate,



existing services. We work together cooperatively to bring the best possible care to patients and their families.

**Q** — How did you get authorization to get started?

**A** — The first three years of Home Care were financed by the National Cancer Institute and our patients were cancer patients only. This gave us a base of experience from which to apply for licensure as a Home Health Agency. A separate application had to be made to the Commission on Hospitals and Health Care for licensing of the inpatient facility. It took some one to stand up in public forums to say why we need hospice care. We had to show that existing agencies, however capable, were not enough: there was a health care gap.

**Q** — How many patients can you accomodate?

**A** — We have 44 patient beds, but not all are filled at once. Some are being held for patients who are making short home visits — especially over the holidays — and some are reserved for Home Care patients the staff feels may need to come to the facility soon. There must be sensitivity to the needs of the caregiving staff so they are able to be supportive of patients, families and each other. Because, of course, when you talk about Hospice care, you are not only talking about patients, but their families as well. Families will often have far greater needs than the patients themselves.

**Q** — How long do or can people stay here as patients?

**A** — We are licensed as a 'Short Term Hospital; Special, Hospice,' so we are limited by definition to short term care. People come here with a diagnosis of only six months or less to live. Although patients have been with us a few months, the average length of stay is 19 days. Some patients are discharged because their symptoms have been brought under control or their disease has gone into remission.

**Q** — Not only is the site you've built on lovely, but the

building itself is unique. It bears little resemblance to a hospital. How did that come about?

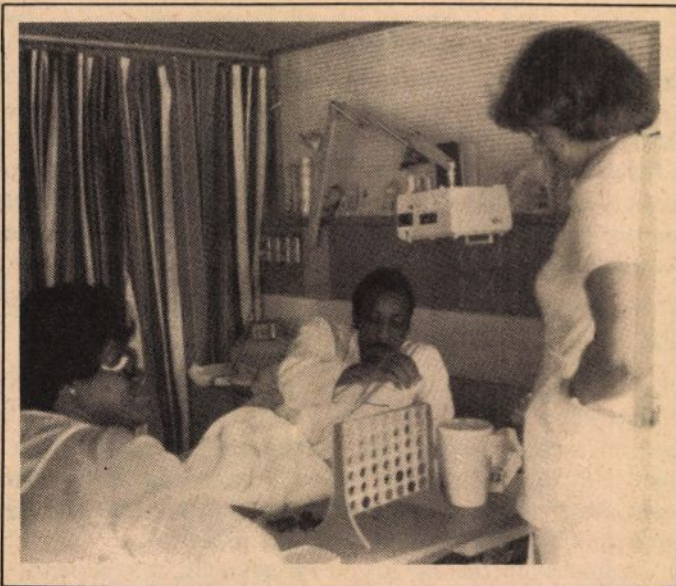
**A** — The architect visited St. Christopher's and gained a great deal of sensitivity about what it would be like in a place whose goal is to care for the dying and their families. He designed the building so that you would approach it along the side, passing the patios so you could see patients and families sitting out underneath the patio umbrellas surrounded by flowers. It was a way of adapting people to what they would be facing and helping them to deal with their fears. Also, there are long walls of glass forming greenhouse corridors along the outsides of the patient wings. Through these glass walls the patients can easily watch family members, visitors and staff coming down the road and have at the same time close contact with the earth and nature. We have wonderful occasions on these patios. We've had brass quintets, dance bands and jug bands, and several dance groups. Last fall we had a marvelous Hawaiian Luau outside. People want this place to look like their homes and we want them to feel at home. Patients have the freedom to wheel out to the patios to pull weeds or tend plants if they want to. Our gardening volunteers are aware of what having familiar plants means to patients. It is quite amazing what being close to the earth does for the lives of us all.

For example, one weekend several people died and there seemed to be a pall over the house that was difficult to dispel. But then the gardening volunteers came and made May baskets with the patients using beautiful local wildflowers. The gardening volunteers had an incredible day. They brought in the life, the touch from the earth, the things that were alive and growing. Hospice patients are able to keep that important contact with the earth since they are all on the first floor with window walls which go from ceiling to floor so they can see the birds and small animals which come around.

Our attitude towards this building is that it is for the patients and families. It was designed with nooks and crannies where people can get away from it all. When you enter, you don't go down long corridors the way you do in so many hospitals. We have family rooms with comfortable furniture, fireplaces and games for children. There are two pantries where families can bring their patient's favorite foods and warm them up. We have a large area, the Commons, where we celebrate big occasions. We even had a wedding reception here when one of the patients got married just a few days before he died. Again, space is so important. Many people who are developing hospice facilities think that they can take any kind of space and have a hospice; that human contact is all that is important, but beauty is a healing thing that helps staff and patients alike. Also the space allows the family members to participate in the care by assisting with bathing, walking and feeding. This is what Hospice intends both at home and in the facility also if family members want to have that involvement.

**Q** — I've noticed that people don't seem to have private sleeping rooms here. Was that for financial reasons?

**A** — Not really, but it is an interesting question. Calvary



*Hospice patient*

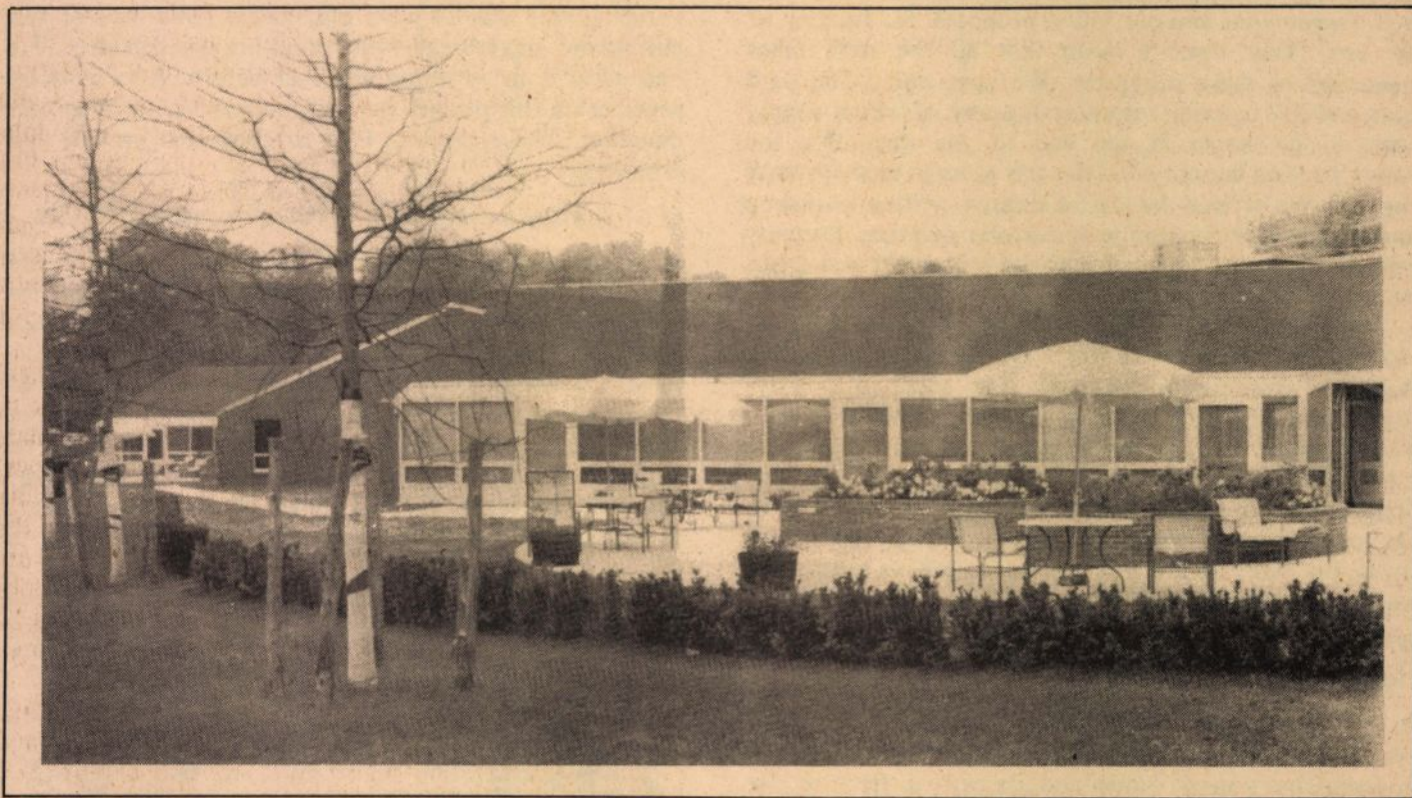


Hospital in the Bronx has cared for the dying for years and all patients have private rooms. But the St. Christopher's model has four-bed units. At the time we were designing our Hospice there was a lot of uneasiness because some cultures are more used to being cozy and close than we are in the United States. But after considerable study we went ahead with four-bed spaces and it's working just beautifully. Patients as well as families support each other and that has helped build community here. I remember one time when, after a patient died, his wife came back from saying her final goodbye to her husband to say goodnight to the patient who had shared her husband's room. She also returned later on because she had become attached to some

*A* — No, but those who could did come. The memorial service also helps the staff, who are involved, as well as the family.

*Q* — Are many people who come here in an accepting stage in their feelings toward death or do you find people still resisting their approaching death?

*A* — I can't answer that with percentages or statistics. People are just too variable. One of the important things about Hospice is that people are not categorized. We receive people from wherever they are in their journey through life. There may be people who would say: He or she is at stage three or four of Elisabeth Kubler-Ross'



*The Connecticut Hospice*

of the other patients. Families like to come back to visit and we are deeply touched by that. We have a very active bereavement program here because hospice care does not end when a family member dies.

*Q* — Would you say more about that?

*A* — The Bereavement Team is headed up by two skilled and sensitive caregivers: a nurse and a social worker. After a death the nurse who has been primarily involved with the family addresses how much and what kind of follow-up is going to be needed. A bereavement volunteer will visit at their homes or check with them by telephone. We have just started a monthly bereavement night when families can come back to Hospice to meet in a support group or participate in a social hour later. We have just had our first memorial service for all the families of patients who died over the past year.

*Q* — Did the staff all come to that?

'stages,' but this is something we do not do. At hospice we give a great deal of attention to each person as an individual. Performers who have shared their artistic gifts with us have, without exception, told me that they want to come back. I have asked them why. It seems that they get a strong feeling that the people here are unique individuals and not just people 'lined up in a faceless group.' At Hospice we try to listen to people's needs and adapt ourselves to meeting them.

*Q* — When you work with the dying every day, as you do at Hospice, how do you stay mutually supportive and not burn out from all that giving?

*A* — We are receiving a tremendous amount just by being here. When people ask, "What is it that is so special here? Why are we so deeply touched and moved by it?" I reply that "One of the reasons you are having that experience is because patients and families leave so much love here." Their love remains, I'm convinced of it. We receive the



richness of all the families and traditions that move through here.

In addition we work in a very nurturing environment. We create ways to reach out to each other. Apart from the usual report session when nursing shifts change, the nursing staff spends part of almost every morning in a 'huddle' with members of the other caregiving disciplines. I try to go to huddle two or three times a week. This is how this sort of community feeling is born.

Also, the various disciplines offer in-service experiences which are supportive to the staff in terms of communication and information. When I began to develop the arts program, I felt strongly that the arts should never be for the patients and families only, but had to be for the staff as well. I wrote that into our initial proposals for funding of the arts. That doesn't mean that all the staff takes advantage of these programs. We have about 160 paid staff and 217 unpaid (volunteers), many of whom simply want to go home at the end of the day. But the administration has provided the arts as an avenue for staff support. We offered the staff a creative writing workshop and a six week workshop in watercolor painting. Recently we had a marvelous woman who did movement and dance with us.

When we were preparing to move into the new building, Hospice received a grant which permitted us to have a thorough orientation program. We spent nine days together before we ever worked together as staff members. The orientation period was intended not only to provide information and knowledge about Hospice philosophy and organization, but also in large part to give us a chance to get to know each other. We consciously try to reduce stress, but since we are a new organization we realize the waters are uncharted.

**Q** — What kind of hierarchical structure do you have at Hospice?

**A** — I have very strong feeling about that question because for Hospice to work there cannot be hierarchical designs. That's an old model and it's more difficult to give Hospice care in that kind of structure when actually we work as a collegium of caregivers. But people come from many different life journeys, so you will see traces of hierarchical dynamics at work in this setting as well. That doesn't mean there isn't going to be structure, but the structure has to have a sense of the whole. The image which best describes what I have in mind is a circular rather than pyramidal one, with the interdisciplinary departments all around the families and patients who are in the middle.

**Q** — You are the head of the arts program. How are the arts part of Hospice?

**A** — This is the first time to our knowledge that a health care program had the inclusion of the arts mandated in its license. I am not speaking of the therapeutic arts which are intended primarily for emotionally or mentally ill people. We received initial funding from the National Endowment for the Arts and the Connecticut Commission on the Arts to plan and implement a program in which artists could share their talents and draw forth the talents of others going through this particular stage of life. This doesn't

deny that the arts can be therapeutic; it's just a different perspective and focus. At Hospice we accept dying as a natural part of life just as being born is; it is just at the other end of the spectrum.

**Q** — What other kinds of activities do artists provide besides entertainment?

**A** — Visual artists work in the patient/family areas on projects with both patients and families or even at patients' bedsides. These projects bring another kind of life into the patient areas. Family members as well as patients often get involved in what is happening. At Christmas time, for instance, we had little workshops in making tree ornaments and small gifts. I brought in gingerbread dough. One of the patients, who was 74 years old, had a good deal of fun cutting out gingerbread men for all his grandchildren. He had never done anything like that before. Also working together on this project were a grandmother, mother and daughter. These projects lead to continued growth and interaction.

**Q** — Is there a religious or spiritual focus to Hospice?

**A** — Hospice is an interfaith institution; all faiths are welcome here. I think our spiritual focus can best be described by saying that we minister to the body, mind, emotions and spirit. But this always reflects the perspective of the patient and family in their life's journey. Many of the people who work here have strong spiritual beliefs, but there is complete agreement that other people must be allowed the freedom to make their own way. Our responsibility is simply to accompany them in their journey in whatever direction they are going. □



*Melissa Wenig and Sally Bailey*

*For more information about the Connecticut Hospice, write:*

*The Connecticut Hospice  
61 Burban Drive  
Branford, CT 05405*



# GOOD GRIEF



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by Mimi Wegrzyn

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Just recently someone asked me what I do in my life. I said, "Well, I build community and the way I've most been involved with building community over the past few years is through the grief work I do."

In 1976, the seeds of the Grief Institute in Denver were planted. I was on the board of the Rappahoe Mental Health Center in Colorado and was doing a lot of work with NOW. I ran the NOW lectures bureau and taught New Directions for Women. I was constantly in contact with many people and in a seven week period just happened to be confronted by seven people dealing with death loss.

One significant experience happened while lecturing at the University of Denver. A young woman asked me to lecture at her class. I knew she had been pregnant and asked about her child. I said, "How do you like being a mother?" She said, "I really don't know." I asked several other questions and finally discovered that her baby had died within 12 hours of birth. This woman was very stoney about her loss. Her knuckles were white and her fists clenched. I really didn't know what to say so I bumbled along and said a few inarticulate things. And, as I got up to leave I put my arms around her and said, "You'll never

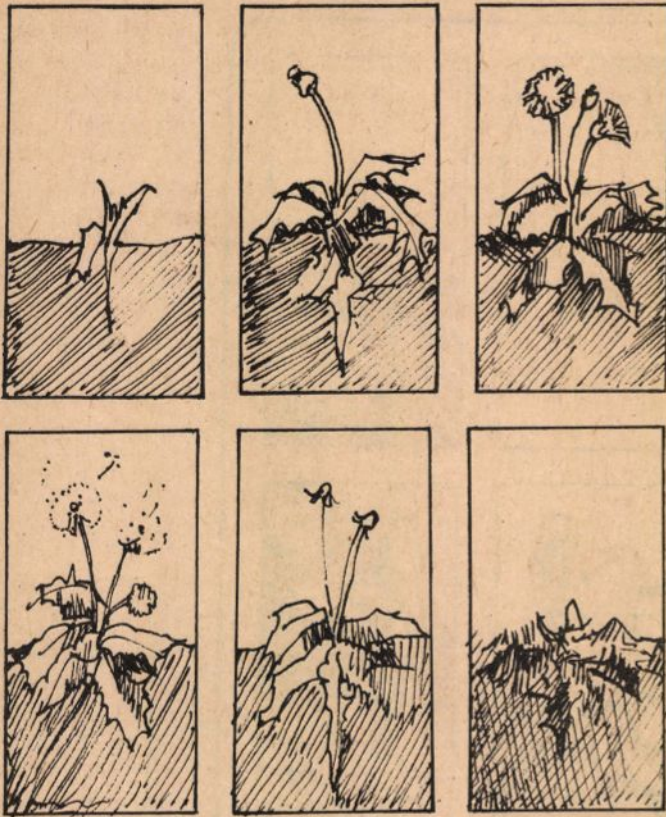
forget this for as long as you live." And at that point she burst into tears and said, "I've been waiting for someone to say that. Everyone says, 'You'll get over it. You'll forget it.' And I don't want to forget it. She was my first baby, my first daughter and I may never have another child."

So you see, the Lord led me to say a very appropriate thing. But it didn't come out of wisdom. It came out of my own pain, knowing I could never forget something like that.

Experiences like that continued happening to me. Finally, I went to the leaders of my Quaker meeting, the people at the Mental Health Center, and some ministers and chaplains and asked, "What's being done for these people? Here are really very together people and I can't get over the fact they're having so much trouble." And everyone I confronted said, "There really needs to be something done. If you will do it, I will help." So I got together a panel discussion with those people and, in June of 1977, we started our first Grief Group.

I've learned a lot about grieving. One reason we have so much trouble with it is that we don't have strong communities anymore. Our society is very mobile and many people no longer live in kinship families. The trauma





of moving, of uprooting often affects how people deal with their bereavement. If you are living in your home town and you have your relatives around, your church community and traditional support systems it is a lot easier to deal with your bereavement than if you are living thousands or even hundreds of miles away.

One of the things that we have found to be very very important is actually being a part of the dying or mourning process. We discovered when a death occurs overseas and the body is cremated and the ashes are sent home, there is a great deal more difficulty in dealing with that death, because it's so unreal. If a person dies and the significant others go into the hospital room, bedroom or hospice room, and touch that person's hands, or brush their hair back from their forehead, or give them a kiss, or say "Thank God it's all over," or say goodbye in some way, then the body can be taken to the crematory and cremated. You don't need embalming, you don't need viewing, and you don't need the real formalized funeral ritual. But where people are denied access to the body, even with the best intentions, it usually really complicates the grieving process due to the lack of reality. Seeing really is believing.

We recently dealt with a very traumatic situation where two children were killed by a train. The mother and father had previously discussed what would happen if any of them died, and had said they would never want body viewing. The man was with his children when they died. His wife was out of town. He was able to hold both children after the accident. One died in the ambulance on the way to the hospital, one died right there on site. After they got to the hospital and the children were officially pronounced dead, he had someone call the funeral home and said there is to be a closed casket because he

remembered the agreement he and his wife had made. His wife was so distraught, she never objected to it. But, afterwards she could not believe her children were dead. She kept hearing them walking and talking. We worked with this family and helped them through some hard times.

Participation in ritual is so important. We had a woman call us who was upset because her son was getting married on Saturday. Her sister had just died on Tuesday; she could not go home for the funeral. What could she do? I put her in touch with a minister, and we were able to arrange a memorial service for her sister in Denver at the same time as the memorial service was being held in Connecticut. Then the family made phone contact with each other immediately after the ceremony. So they were all present in one way or another and that was important.

When my father died a year ago February, several of my children and my husband were not able to get away. We're Quaker but a Catholic priest offered to have a memorial mass said on a Saturday. He invited many of my friends from the Grief Institute, from the parish that I had ministered to, and all the members of my family. The gathering could have been a picnic or watching a sunrise on the beach. But setting some time aside to think on the person who has died, the meaning of their life, and saying goodbye is very important.

Today, we have a lot more variations in how we deal with death. In California they have something called "Body Disposal Corporations." A company just comes and picks up the body, cremates it, and sprinkles the ashes and very often, the families are not even involved. The traditional rites of saying goodbye are dispensed with. This really robs individuals of the opportunity to say goodbye, which is a very important part of healthy grief work. So some of the short cuts that this culture offers are making the grief process more difficult and leading us into dead ends. We are learning that the wisdom of some of the old traditions were well thought out and planned to meet the needs of a bereaved person. People who have turned their backs on these traditions have not substituted different rituals but are avoiding their grieving process. But there is only one way to avoid grief and that is never to love anyone.

Usually a lot of energy goes into suppression of buried grief. That energy is no longer available to be used in creative expression, in relating to other people and living a fulfilling life. It limits life potential. People who suppress their grief are often in a continual state of stress and shock and are unable to move beyond it. Their bodies feel the effect of it, sometimes in high blood pressure, ulcers, cancer for those who have a predisposition to it, and other body ailments. We have also found that about 80 percent of parents whose children have died, divorce. So, if we are interested in preserving nurturing families and healthy individuals, it's very important that we help people deal appropriately with their grief so they're not destroying their bodies, their psyches, their marriages or other relationships.

Two months ago my psychiatrist's father died very suddenly and unexpectedly, having a very traumatic impact on her. And she called me, reached out to me by phone, in tears, and said, "Oh, my God, I don't have anyone who



has more training in the area of bereavement than you. Are you comfortable with me asking you for help?" And I said, "Certainly. I'm comfortable, as long as you're comfortable getting help from a client." We met together, and I shared material with her. I asked her what other deaths she had met that were not resolved. And she burst into tears and said, "When I was in medical school my mother died, and I couldn't deal with it. I just had to put it in a little box, and put it on the shelf." I said, "OK, you're going through a double whammy. That's what happens when you don't deal with grief. You can postpone it, but you can't avoid it. A more recent death will stir up the muddy waters." My psychiatrist just opened her mouth and looked at me agog, "Ahhh, I never connected it."

To help her work it through, I got her started keeping a journal. We don't do it in the formal Ira Progoff style, because bereaved people are too flaky to follow a process. When you're bereaved, you're at sixes and sevens. You're suffering from great inertia, and you cannot follow anything as structured as the Progoff journal. I also insisted that she pace herself. I said, "You need more time in between your appointments. You're going to have to choose some of your clients to relegate to another doctor for the next three months." But she believed she would be able to work at her normal pace, and continued to submerge herself in work too fast, ending up in a worse state. Finally, when she went to her family doctor and found her blood pressure was up, she went to bed for five days and started on a new regime of pacing herself and cutting down on her work load. Now she's back to her regular schedule and working through her grief.

One young mother who contacted me at the Grief Center told me, "After my husband was killed, I finally took your advice and decided that I had to get out and talk with my neighbors. I got my kids in their snow suits. Everyone was out in the street, but, by the time I got to the curb, everybody had gone inside. I just went back into the house and cried."

One of the ways I build community would be to get as many of her neighbors' names as I can. I go and knock on their doors and give them our little bookmark from the Grief Center and say, "This is what happened this morning with your neighbor. You did the only thing you were capable of doing and that's O.K. Lots of people run away from bereaved people, even rabbis and ministers and close family. But this is what your neighbor needs now. If you think you could be part of her support group and listen and

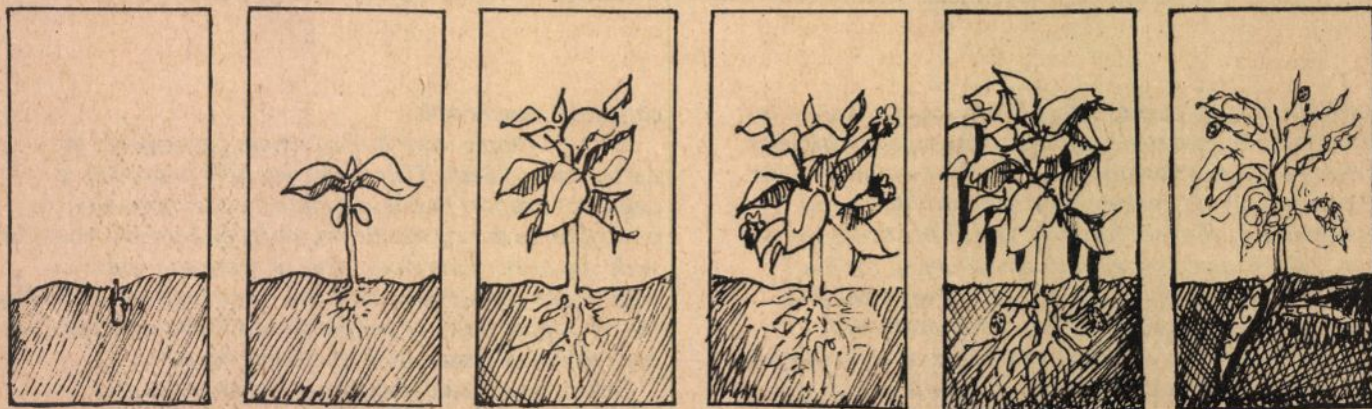
talk with her, go shopping with her, help her with her kids, it might well save her emotional life. Here's my phone number. Call me if you can help." I go to half a dozen neighbors and I might get two or three who offer to help. Then I go to my files and find out who else is a young widow and lives a reasonable distance from the person. I call her up and see if she can help. If my ex-client can help, I tell her that I will give her name to my present client. I never exchange numbers without making sure both people are in the emotional state for that contact to be made. I also find out what church she may have gone to in the past or might go to now. And eventually I build a support system of five to nine individuals who are willing to commit themselves for a period of a few months to ease this person through the very lonely, difficult and frightening time after the death of her young husband.

All of our support group processes — be it this one or rap groups — have a built-in termination time. Our focus at the Grief Institute is not death and dying but life and living. We don't want to develop professional grievers. We want to pick them up, hug them, carry them through the trauma and put them down on the other side of the bridge.

We now offer a ten-session support group for bereaved persons. We have two facilitators for each group and a recorder who might also be a person in training. That way there are always two familiar people there which makes it possible for one to take time with someone who might need individual work. We limit our groups to about 8 persons. When the group ends, many of the participants become volunteers at the center and get trained to help other people. And, in their training to help other people, they continue to be helped.

There are probably three to four thousand bereaved people the Grief Center has had contact with. We've served close to five hundred people in support groups, several thousand with telephone counseling, and many through correspondence. We have about 125 members and, when they don't renew, we say, "Good!" They've moved on to other things, and have found community through other involvements. □

*Mary Clare (Mimi) Wegrzyn is the founder of the Grief Education Institute in Denver, Colorado. She has recently moved to Southern California to continue with bereavement work and to attend graduate school. She can be contacted at 8712 Magnolia Avenue, #234 Santee, CA 02071.*





Part of everyone's vision of community is to have the difficult life experiences and transitions of birthing, old age, illness and death transformed from lonely and demeaning trials into joyous, richly meaningful occasions shared fully and without sacrifice by a loving support group.

At Twin Oaks we realized a lot of this vision with the very special life and death of Seth Arginteanu, who lived with us for four years before succumbing to cancer last December. His unusual openness and courage allowed many of us to participate intimately with him, as he defined his needs and got support. Seth's parents, Jules and Mary, and sister, Judy, gave us full support and permission to care for him, bury him at Twin Oaks, and mourn/celebrate his passing as we chose. Reevaluation co-counseling, which Seth, himself, along with our teacher, Penelope Shea, initiated, provided Seth and all of us with an important therapeutic tool to keep us open and healing each other. Thus, our experience of Seth's life and death included, along with the grief, a solemn joy and celebration of 'death as the final stage of growth.'

### *A Sketch of Seth*

Seth came to Twin Oaks to apply for membership in 1976. Many of us were attracted to this gentle, energetic and principled young man of 18. His demeanor and costume varied from the revolutionary's beret accompanied by rhetoric about 'political awareness,' to the skirt, scarf and mellowness of the androgynous feminist man. He was forthright and serious about the ideals represented by these costumes, yet there was also enough gentle self-parody and humor to make him irresistible. We responded to him with affection and respect, tinged with some of an older sibling's indulgence for the expressive antics of a younger brother.

Seth's slight, strong young body already had one long scar from major cancer surgery, and he was bald from the side-effects of on-going chemotherapy. His doctors' prognosis for the rare mesothelioma in his chest was

wise decision, as it turned out . . .

Seth's work schedule throughout his years at Twin Oaks gave little hint that he was struggling with a life-threatening disease. A typical week in his life would include construction work; organic gardening; some child care; and hammock weaving — all interspersed with the varying demands of dealing with unexpected new faces in his capacity as visitor manager. On top of a 50-hour work week, Seth would provide organizing leadership for Twin Oaks' 25 active co-counselors, for the local energy committee he'd helped found, and also for his Latin America solidarity organization.

All of this he undertook joyfully, as a happy synthesis of personal growth, community building and political work that constituted his approach to revolutionary social change. His energy found full celebratory expression at Twin Oaks' holiday dances, where his spontaneous, writhing style and improvised physical contact delighted and inspired his fellow dancers.

In the summer of 1978, the process of full community involvement in Seth's struggle against cancer was initiated at a reevaluation co-counseling workshop, organized to teach us skills in emotional release and personal growth through work in pairs of friends. Plans for the workshop were thrown out by our perceptive and flexible teacher, Penelope, when during the initial go-round Seth shared feelings about his disease and fears of recurrence. What emerged from that day was a profound sense of community unity and a plan for intensive co-counseling by Seth.

Throughout the increasingly serious struggles and bouts with chemotherapy, Seth had difficult work to do in combating despair and fear of death. In his co-counseling work, he would shake and scream, then stick out his tongue and call death names ("You turkey!"). Another life-affirming therapy he undertook is the Simonton's radical approach. Twice daily for a number of months, he would perform the guided meditations and imagery of his body's strength and success in combating the 'weak and

# A Death in Our Family

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indefinite, but not encouraging. Thus, his application for membership caused some soul-searching and controversy for the Twin Oaks decision-makers. How would it be for us, emotionally, to deal with a protracted illness and possible death, the first for Twin Oaks? Medically, would Twin Oaks be a healthy enough environment for him? Could we bear the labor and indirect money costs that might ensue from his illness? But sentiment in the community was overwhelmingly in favor of accepting him, along with whatever problems that might bring. A very

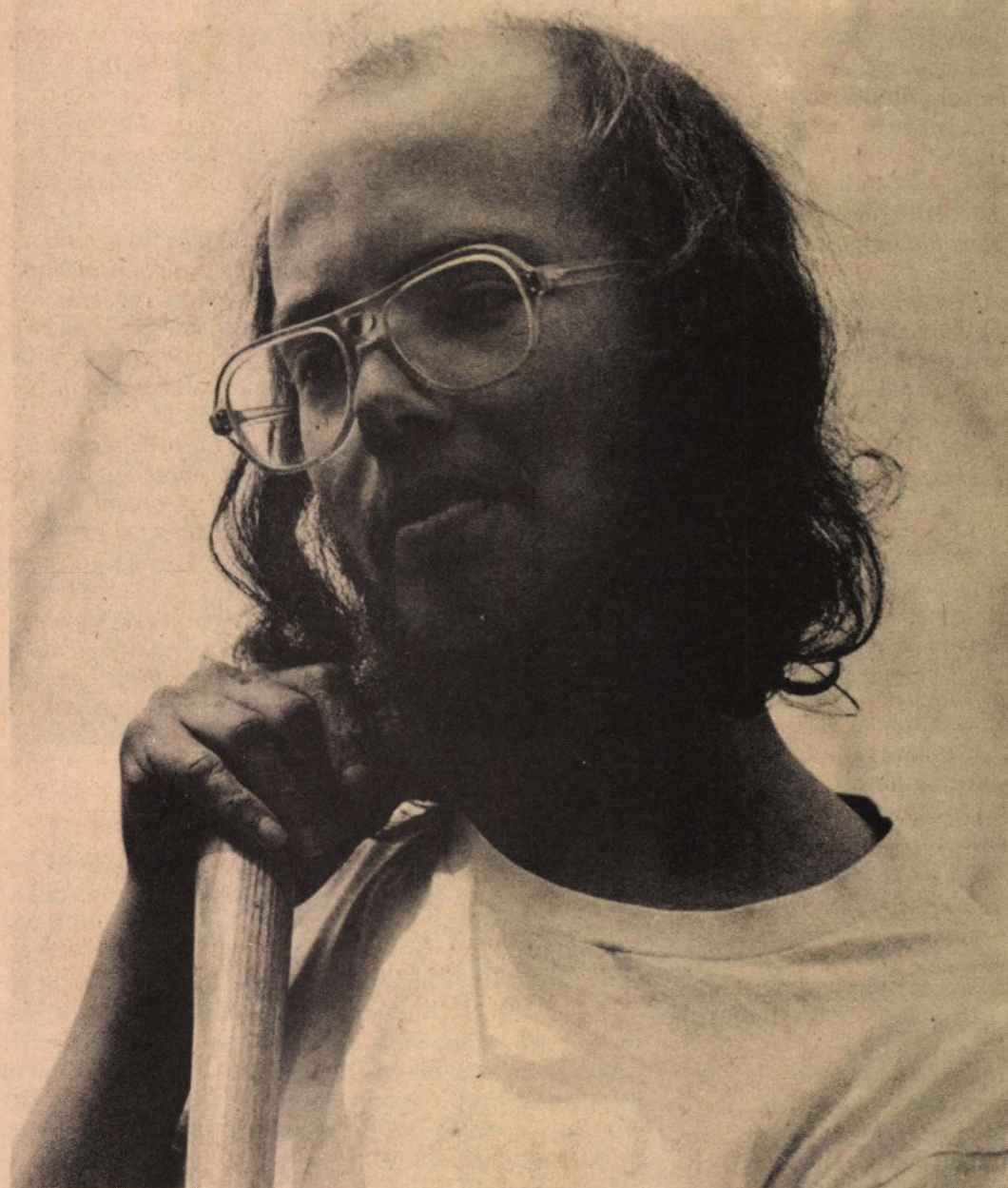
confused' cancer cells.

With 77 people, over half of whom participated in taking care of Seth, Twin Oaks was able to provide a degree of support that is rare outside of community. At critical times during his illness, shifts of 2 people would be with him around the clock. One or more coordinators would take care of communication and logistics, including the emotional needs of people closest to Seth, medical and legal technical issues, and scheduling his care.

Seth bounced back from his early surgeries and



Edited by  
Melissa Wenig



## Seth

chemotherapy amazingly well. In one instance, he was jogging and doing push-ups within 2 weeks of having a lung removed.

For up to 2 years at a time, it would appear that his body and will had defeated the cancer, only to have another recurrence. His several years of active life after the cancer's discovery outdistanced even the most optimistic medical prognosis. But by the middle of 1980, it was clear that the cancer was winning, as he became increasingly short of

breath, and his healthy glow was replaced with the pallor and emaciation of impending death.

... What follows is an account of his death and community response to it, taken from hundreds of pages of transcribed interviews and community gatherings. We hope that these, along with excerpts from his journal, convey a picture of this life and death in community.

Introduction by Chip Coffman



# the story

*Most of us who have experienced a death in our lives know the importance of retelling the details and*

*moments of a loved one's last days. This is a part of the grieving process and many cultures build in a time and way of mourning in which an audience fully colludes in the cathartic experience. This is seen, for example, in Irish wakes or the Jewish custom of 'sitting sheva' (the 7 day mourning period).*

*It has been no different for us in our community. We have found ourselves retelling the story of Seth's death to family, friends and strangers. Here, 9 months later, we retell it once again.*

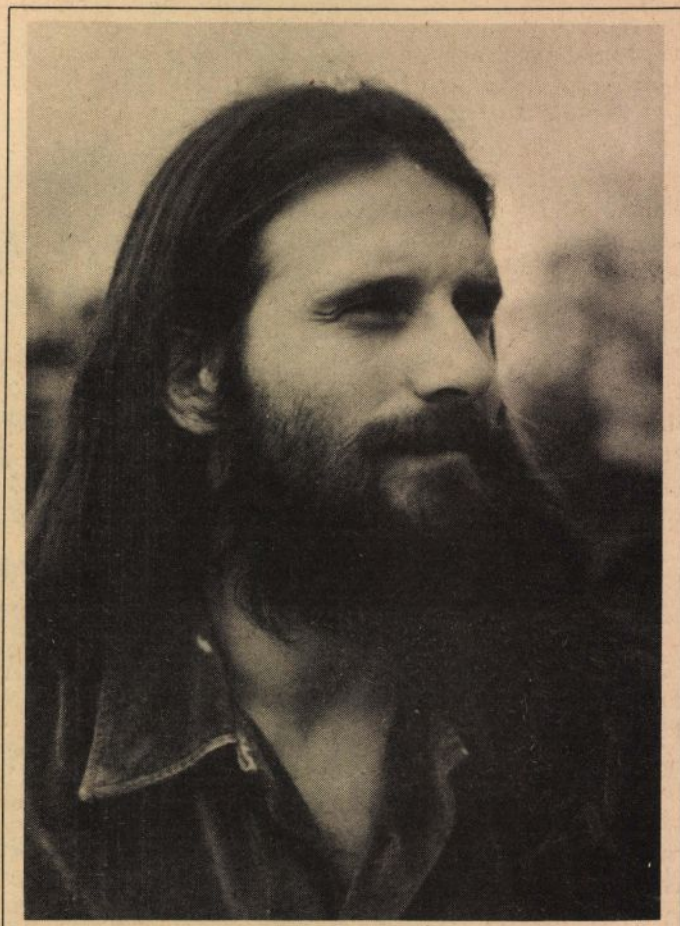
*At 10 o'clock on the morning after Seth died, we gathered together as a community to share the story of Seth's last days. Our moods ranged from open grief, to relief, to curiosity about what had just happened and what was to come, to a solemn joy at the beauty of his life and death and our unity at this time. Larry, who was closely involved with all aspects of Seth's last months, begins the story:*

**Larry** — Last Thursday was the last time that Seth and I went in for a regular appointment at the hospital. We had been going in weekly to have his blood checked and to get x-rays. He had a pretty good day that day. His doctor told us to come back into Richmond on Monday to check out his counts again and, if they were low enough, they would give him a transfusion that might ease his breathing.

Seth was still working close to full time. We put a desk outside his room so he could be close to his oxygen, but he found it easier to work in his room. From Thursday on he started increasing his use of oxygen, at first using it just at night and by the end of the week being on it all the time. Through all this Seth was feeling a little anxious but more often just irritated that he had to be spending so much of his energy dealing with oxygen, breathing and the other medical aspects of his life.

We went into the hospital on Monday, expecting that he would get transfusions that night. We were in pediatrics emergency which is somewhat like a MASH unit. But we found out that it wasn't his blood that was making his breathing difficult, it was his rapidly growing tumor. We didn't deal much with that information at that point and his mother drove us back to Twin Oaks at six in the morning.

On Tuesday I talked to Cliff, Seth's doctor. A couple of weeks ago Seth stopped asking for medical information and I felt I needed more information so I began to talk to Cliff independently of Seth. This was fine with Seth. He just didn't want to be involved in it. His basic take was that whatever anybody else wanted or needed to do was just fine. I had previously spent quite a bit of time with Cliff talking about all the possible aspects of Seth's life and death and had developed a good rapport with him. On Tuesday he told me, "The tumor is growing rapidly. Things could happen at any time now." After my conversation with him I went to talk to Seth for a couple of



*Larry Lenske*

hours. I told him what Cliff said and answered his questions about everything I had learned. We also talked more about the details of his death, wills, etc. which was something we had been working on together for some time.

He cried some, although it was hard to cry because of his breathing, counseled some and our time together was very special. We would work on one aspect of something. He would go through his emotions about it, come back out of it and go "Next." I was able to go through everything with him and he was being his perfect self, crying, counseling, working through and with it all.

When I asked Seth if he had any preferences for what happens after he dies, he would always respond, "No, it doesn't matter to me. When I'm gone, I'm gone. Just take care of yourselves. Whatever you all want to do is fine with me." And I asked him that again because we were going through burial site possibilities but he didn't care. He just didn't want to waste his time dealing with it.

It was on Tuesday that we decided to institute "24 hour Seth care." We had dozens of oxygen tanks sitting outside his room and all of his "care" folks got trained in the use of the equipment and dosage, including Seth. We set up a communications system and got nursing care (mainly bringing food and keeping Seth company) and co-counseling support together. Seth chose who would be with him and Chip, Gareth and I organized the care.

One of the things Seth had wanted to do with the



community was a ritual in which he talked about what it was like for him living here with all of us. I think Seth's desire for a ritual before he died was a desire to share his love with us. One thing he said about the gathering was, "I'd really like to have it about three days before I die, but I guess we can't predict that, so let's go ahead and do it Thursday. He ended up working a good number of hours on Tuesday. He was basically in good spirits and folks were with him most of the time. He started looking at things he hadn't dealt with, sorted through his files and asked me to give them to the appropriate people. That night he met with Henry who was a member of the Energy Commission in Louisa that Seth helped start. He realized that some of his work wouldn't continue and he was sad about that but he also realized that much of it would go on and he wanted to make sure all the information got passed on to the right channels.

Throughout all of this Seth had very little pain. His tolerance was incredible anyway and he did very little in the way of pain killers.

**Chip** — His line on Tuesday was, "I'm fine except I can't breath." And he really meant that. He was just living his life and having this big problem at the same time.

On Wednesday, things were pretty much the same. Seth and I did a co-counseling report. We had some stuff to work out, some irritations, ways we rubbed each other wrong, ways we could improve. It felt like a complete communication, just the way I'd do it with him under any circumstance. Of course, it was particularly meaningful to me to be able to do that. It felt like just another way in which Seth was living things out fully.

**Larry** — Wednesday night Christopher stayed with him and he finally got some good sleep. He was just so tired. My image of Seth has been of a marathon runner who never stops, but quickens the pace as the time goes on. Seth was working real hard to breath and only had one lung to do that with. He'd be in a cold room and be sweating. His pulse was like a baby's, 160, 180 at times. He had to sleep sitting up and it wasn't so easy.

On Thursday morning I found myself wandering about but not wanting to take any of Christopher's time away from Seth. I finally came in about eight. This was one of the harder days Seth had. He was nauseous, vomiting a little and not at all wanting or feeling like doing a community gathering. I was sorry that I didn't have him do it on Wednesday because it seemed possible that it might never happen. Thursday was an uncomfortable day. He ate some broth which finally settled his stomach. By this time he was like someone who had been on speed for four days, exhausted and needing sleep but really wired. At times he would get anxious and we would hold him and stroke him to settle him down and do chest percussion to loosen up the phlegm in his lungs. About five o'clock Chip said, "Maybe you should leave for a while. You may not be here through it all. You may be doing a birth and Seth shouldn't get too dependent on you." But we were getting closer and closer and he was depending more and more on me.

I left for a while and came back to give him a dinner tray

# seth



*If it had not been for Seth there would have been no campaign against the North Anna nuke. There were others who played very important parts but without Seth it wouldn't have happened. In that way he translated thoughts and ideas into very immediate actions. Also, Seth improved our meetings. We had to have business meetings but they are horribly boring things. Seth went to a conference somewhere and came back with a little document which had some marvelous ideas about how to make meetings really involve people, get them doing things and stop boring them to death. He didn't succeed entirely. Seventy-eight year old people like me are kind of hard to change. But before he finished the meeting of the group campaigning against North Anna were very different from what they had been when he started. To me, that is the thing that says the most about Seth. He was always looking for a better way, and he never tired.*

— Haven Perkins

*I share a different side of Seth. After one of his operations, the one where they removed his lung, he wanted to start running again. I remember running with him and he set a pace that was tiring me out. Then I remember doing one arm push ups with him. That was a side of Seth that, for me, had a lot of spirit.*

— Robin



that night. I knew I shouldn't. I was exhausted but the pull to Seth was always strong. I finally left, leaving him with Joyce. At about eight Carroll came over to my room and said Seth would like to see me before I went to sleep. I was totally wasted by then but got it together and walked over in my nightgown to say goodnight. I walked into his room and was amazed. My full energy returned as Seth was beginning to go through incredible spaces . . . sometimes anxious, sometimes exuding love. Joyce and I were with him for the next couple of hours, stroking him and being with him. His breathing had become very fast and we knew he couldn't keep it up forever. We thought that from what Cliff had told us that from that point he could possibly burst an artery or go into a coma.

Being with him those hours was like being with somebody who was tripping or being at a birth during transition, the hard part. He was talking about being scared at times. He'd say, "This is really hard work." Sometime during the day he's said something like, "scary thought that I'm ready to let go, ready to give up." And then he turned to me and said, "I'm not ready to give up, not ready to go — but I may be." Now he was saying, "Help me through this, it's scary. This is really hard. I'm really confused. I don't understand it." It seemed he was speaking as much out of awe as fear for what he was going through, this incredible journey. Then he'd go into, "I love you, I love everybody. You're wonderful. I'm

wonderful. Whatever happens, I'll do great." He said that a number of times. At that point we were just going with him, holding and stroking him, and in some way really trying to help him go to sleep and get some rest.

**Chip** — He'd say, "What's the next step?" That was the term he'd use in political work.

**Larry** — It seemed like he was asking in a really personal way, "What's next?" and really questioning the world, "What next?" Then he'd say, "It doesn't matter what happens, everything's o.k." He'd go through these spaces and it was ecstatic being with him. Slowly over that period of time I was less and less in direct, conscious contact with him and more and more just going through it all with him. There would be times when he'd repeat things over and over again like a broken record and we'd try to draw him back to us again. On one level it was, "Oh this heavy thing is happening" and on another level it was like playing with this energy and directing him some. Sometimes I'd do a relaxation exercise with him. One that was really special to me had to do with choosing a burial site. We'd been thinking of two possible sites. He didn't want to talk about it, he didn't care. But this night, as a starting point for a fantasy to take him from being anxious, I asked him, "What's your favorite place at Twin Oaks?" He popped out with, "the High South." Then I took him on a guided

## seth

*My friend, Judy, was visiting with me and Seth decided to take us on a nature walk. We went to the river field looking for wildflowers. It was early spring and Seth was looking for hepaticas. He found some and was so impressed that he got down on his knees, looked at it and said, "Hi, Sweetheart," and kissed it. It was a special way of doing something. I could feel his love for flowers and for nature.*

— Orion

*I started working with Seth about a year and a half ago, organizing care and going in to the hospital with him. I wasn't particularly good friends with him and that made it real easy. That changed as time went on and we slowly developed a friendship. One thing that strikes me about Seth, one of his teachings, was how he always demanded and exuded quality but in a compassionate sort of way. He was a very demanding person. I couldn't gossip around him much. He always made me behave. I hope when I die I do it the way he did. The sign up on his door dated October twelfth said: "There's nothing to be afraid of anymore. Whatever happens, I'll do great." And he did and that was Seth.*

— Larry





fantasy through the four seasons in the woods and pasture of the High South. I felt better. I felt he'd just chosen his place to rest.

This must have been about nine or ten that night. It was difficult to draw myself away but I felt it was time to call the doctors and his family, so I left. Chip and Corb spent the next hour or so with him.

**Chip** — The pull to Seth's room was just incredible. It felt like something real special was happening. I guess I'd describe him as somewhat delirious but he was talking about real things that were happening with him. Joyce and Corb and I were with him. We were all still thinking that he might relax and go to sleep and be around some more. But that didn't turn out to be the case.

All we were really doing was reminding him that we were there, that he was there and that it was o.k. He'd say, "What's next?" or "I'm confused as shit." And we'd say, "It's o.k. to be confused. You don't have to figure it out. Just relax."

He was very responsive. We'd tell him he was doing great and he'd say, "I'm doing great." At this point he was beyond guided fantasies. I'd heard Larry do the one about "What's your favorite spot?" so at one point I said, "Tell me what your favorite place is." He said, "Everywhere. Let's go there."

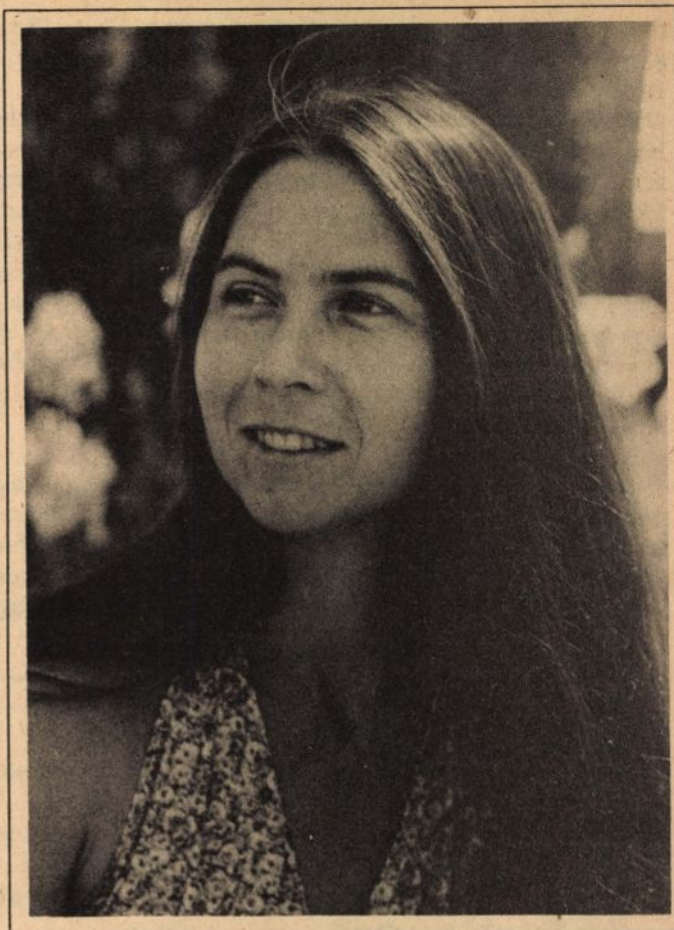
**Larry** — A couple of times, including last night, he said, "Someday we'll talk about all this." Like I'll meet you on some other place . . . or "Hey, after this experience I really want to process it, this is incredible."

**Chip** — One thing that connects with the quickness and ease with which he went was that I think he made a real decision. He would go through periods of being very anxious and would say, "Help, help!" We'd say, "We're right here," and he'd say, "O.k., let's do it! Let's get it over!" And when he would come back from his anxieties or his litanies we would sing him songs, his favorite songs and he'd sing along. He'd follow it and every now and then he'd get a word or note out.

**Larry** — When I was outside the room I could hear Seth singing inside. He'd pick up on the last line of things. Then he was singing "Dear Friends," so some of his last words were "I love you. I love you."

I went back in the room. Seth was breathing hard and it was silent in the room. I didn't know at that point if he was asleep or in a coma. I went through some feeling of disappointment that he might be in a coma. Something like, "Wake up, Seth, I want to say goodbye. I want more contact with you." I went through my feeling of, "Oh I spend so much time running around and organizing that I miss things." But what it really gave me a glimpse of was that this was just the tip of missing Seth. My attitude all along was that this was an incredible journey and yet part of me thought, "Soon it will be over and Seth will just come walking through the door." I hadn't been thinking that Seth was really leaving.

**Chip** — We kept talking to Seth even after he stopped



*Joyce Brown*

responding. His body went from being warm and sweaty to being very cool and clammy. He must have been breathing thirty or forty times a minute, really gasping at the end. His skin started changing color. We knew he was going into a coma rather than sleep.

**Larry** — That's when we were more aware that this was Seth's time and people started going to let everyone in the community know. Folks started gathering in his room and right outside. Chip felt that he might still be able to hear us on some level so we just started singing and kept singing for the next hour or so. Seth's small room was full of people. A number of us were with him on his bed. I was holding Seth in my arms.

I started a chant, singing my heart out to Seth. "From you I receive, to you I give, together we share, and from this we live," over and over. When we stopped, Seth's breathing slowed. I took it as a sign from Seth and felt content. His breathing and pulse were normal for the first time in a while. I put my hand on his heart and it was down to eighty, ninety beats and real strong. Soon his breathing slowed further to a deep breath about every five or six seconds. As I remember, he just shook a little bit, started breathing very shallowly and his heart kept getting fainter.

Gareth quietly spoke into Seth's ear, "Follow the light, don't turn back, follow the light." And Seth was gone. For me, there was no instant of passing, just the continuum.



Others felt the moment of death. We 'om'-ed. We lay Seth down. Silence. We quietly gathered outside the room.

**Carrol** — One thing I'd like to share. I was sitting on the bed with Seth when we all were singing to him. (Carrol cries some.) Seth was in a sitting position, his eyes were half open and it was almost like having direct eye contact, this strong connection. I would get into singing for a while and then I'd lose it and cry, and then sing a while again. Then all of a sudden, the sadness was gone. I imagine this was around the time when his breathing changed. I didn't experience it like him giving up. He had done all of his work and had made the transition. He was just coasting. It was just beautiful.

**Chip** — That was my main feeling. In some ways the last two or three hours were close to a place of ecstasy. There are definitely times to deal with the grief and sadness, but that wasn't the time. If I was a religious person, I would say it was a very religious experience. I just felt profoundly

grateful to be at Twin Oaks. What all of us did with Seth was profound and special.

*Shortly after Seth died, his parents and a friend arrived from Richmond. Although they had been in close touch with us and with Seth, the suddenness of his death made it impossible for them to be there during his last hours. When they arrived, some of us took care of them, holding them and sharing some of the beauty of what had happened, as they faced their shock, remorse and grief.*

*After they left, most of the community remained in the small living room outside Seth's door, in nearly complete silence, well into the early morning. We slowly dispersed, each to address Seth's death in co's own way. One small group chanted Tibetan rites to his departed spirit. Others of us went to the High South pasture where Seth would be buried, to share reminiscences, light conversation, and the beautiful moonlit countryside, in a companionable release from the intensity of the evening.*

## conversations on a sunday afternoon

*On a Sunday afternoon, three months after Seth died, Larry and I gathered together some of the people at Twin Oaks who played an*

*important part in Seth's life and death.*

*At that point our intention was to gather material for this issue on Death and Dying, but, for many of us, these conversations became part of the grieving process. The talking we did allowed us to feel sadness, anger and to share our love and growth.*

*A measure of the powerfulness of Seth's death is the ripple effect it had. It affected us and people who didn't even know Seth but who heard our story. It acted as a catalyst for people re-examining their lives and their relationships to other people.*

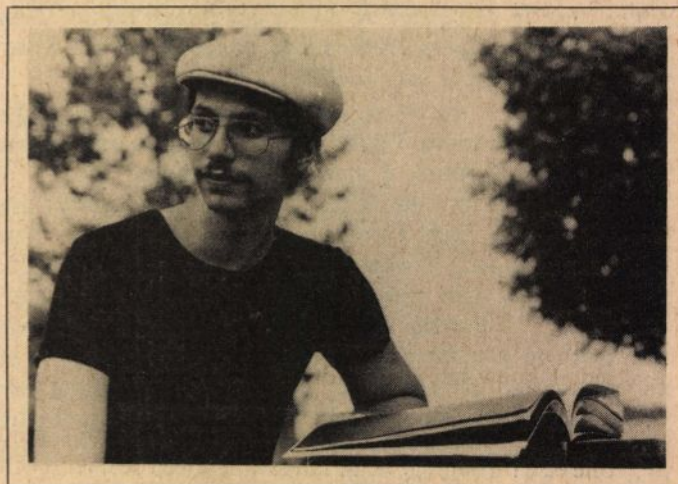
*The more we explore death and dying, the more it becomes clear to us that many experiences are universal and therefore meaningful and comforting to others as well as ourselves. In that light, we would like to share with you some excerpts from that afternoon gathering.*

### DREAMS

**Melissa** — I have had several dreams about Seth. The first one was fairly soon after he died. We were having a dance out at Tupelo and Seth was there. I was excited to see him. I knew he wasn't supposed to be there and I didn't know if anyone else could see him. He and I danced together and it was a very intense and wonderful interaction. Then he was gone. In a way it was a closure for me, having one last

dance with Seth. Recently I had a dream about my mother's death. I dreamed that Tom and I went to be with her while she was going through her dying time. Tom was holding her in his arms and we were both telling her it was o.k. We were lying down with her, cuddling her. It was quite wonderful and very moving, very much the same feelings as the night Seth died. It was powerful to be able to translate my experience with Seth to something that I am going to be involved with sooner or later.

**Orion** — Before Seth died I had a lot of dreams about my own death. It was pretty terrifying for me. In the dream someone would tell me I had cancer and I would freak out. The dreams made me aware that death is a pretty scary idea for me. It is less so now and I feel more relaxed about it. I haven't had any more dreams.



Gareth Branwyn



**Joanie** — I don't usually remember my dreams, but I did this particular one. In the dream I was dying, but it was not clear why. I saw myself lying on a stairway, dead but not yet dead. People were coming to mourn for me. But it was not clear whether they were waiting for me to die or I was already dead. I was running around doing things to make them feel comfortable, setting up tea, etc. It was quite weird because the people were all talking to each other and here I was laid out on the stairs as well as taking care of them. The sense I had was of not giving up. The part that was most moving to me was that at one point I went over to me, picked me up and started carrying me around and comforting me. It was a very bizarre image but nice also. It seemed like I was saying goodbye to myself. I don't remember what happened after that but it was clear to me that in some ways I was saying that I'm not ready to die. And that's true. I'm not.

**Larry** — About one month ago I dreamed I was dying from the same thing Seth was dying from. I was feeling very frantic and was looking for people to co-counsel with. I think I found Chip and Gareth. I knew I didn't want to be with Melissa yet because I needed to deal with myself before I could deal with helping her. I needed to be able to go through my fear and panic. I did that and then found Melissa.

A week or so ago I had a dream specifically about Seth. I was in a house and Seth showed up. I've had quite a few dreams where Seth is just there. My reaction is always a combination of surprise and taking it for granted. We were being together in this house and it was nice to see him. A few other Twin Oakers were around including the kids. Seth started getting a little bit weird and he was not supposed to be there anyway because I knew he was dead. He started getting aggressive, touching, hugging, and grabbing on to people in a way that just wasn't quite right. We were upset because one of the kids was present and we didn't want to see this strange thing going on. Finally, Seth came up to me. I was trying to push him away and we started fighting and it got violent. He was trying to hang on to me and I was pushing him away, trying to crush him to death. I was yelling, "Go away, you don't belong here." After I woke up I stumbled around the house still caught up in the dream, still saying to myself, "Fuck you, Seth. Go away. You can't do that. You can't hang around here." It was a very powerful dream.

**Judy [Seth's sister]** — I had about five or six dreams which seemed to be a kind of series. The first one couldn't have been more than a few days after he died. I was here at Twin Oaks and was in the Tupelo living room. Seth was there and I was talking to him and it was very normal. Then I walked out the door to leave and thought, "Wait a minute, he can't be dead; I just talked to him." I felt very confused. I knew he was dead and yet I didn't. It really hadn't sunk in.

In another dream I had, he was leading me and someone else through a bleak landscape. Seth seemed both transparent as well as alive in a flesh and blood sense. There was a sense of knowing that he was on loan from the



*Chip Coffman*

dead for just a little while longer. The last dream I had was a very mundane one. I was just about to start a job the next day and needed to have some nice looking clothes for the job. In the dream, Seth and I were in a house that reminded me of the old apartment complex we lived in when we were both very little . . . only he and I were the ages we are now. I was simply trying on clothes and Seth was helping and just talking to me. There was a real sense of comradeship between us. I woke up with a sense of him being dead, but at the same time being with me on some other level.

## CHANGES

**Chip** — I came away with a much greater appreciation for the roles of certain rituals in conventional culture . . . the funeral, the memorial services and the whole grieving process. And yet, the emotional healing that can happen within those rituals didn't happen for me with the deaths and funerals of my grandmother and a close high school friend. I felt frozen out and alienated from those rituals. Even before I adopted countercultural values I saw them as alien and unfathomable.

We created our own rituals around Seth's death that were closely tied in with Twin Oaks and with Seth. It was not until then that I began to really understand what rituals



# seth

*Seth and I came here within a month of each other. About six months later I broke my leg. I had my cast on and he wrote something like, "Greetings from your revolutionary comrade." That was Seth with the earring and the beret. Hammocks were so bourgeois, everything was bourgeois. But, boy, did he mellow out. In the past year Seth had taken off his earring to go into town for meetings. I've found him going up to 'community clothes' to find nice clothes. He would ask me, "How should I wear my hair?" It was an incredible transformation from someone who was into totally changing the world by storm to someone getting used to smaller steps. I saw that more and more in the time I was with him. Some of it was from some of the training he did and some of it was Seth just growing up.*

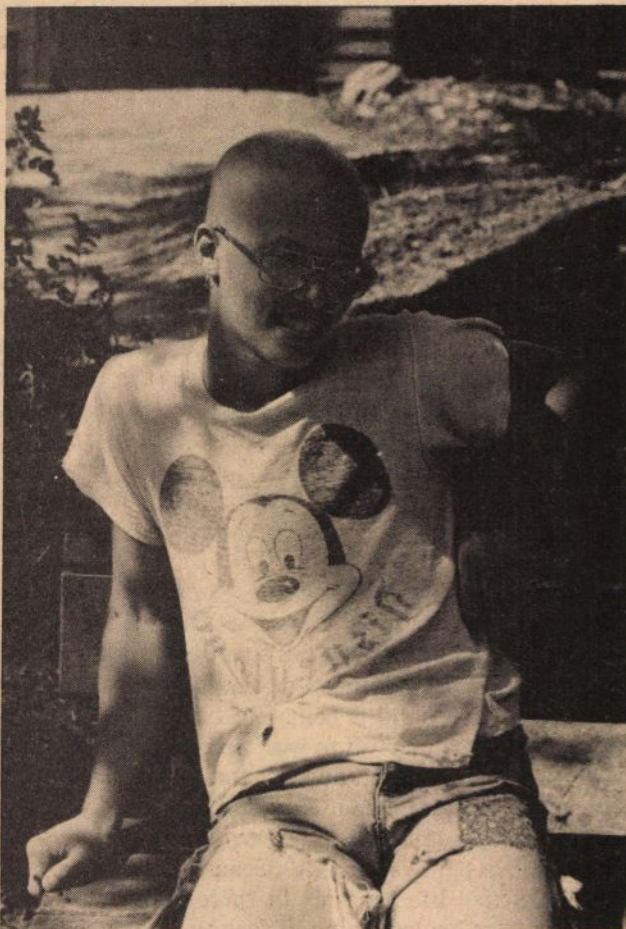
— Joanie

*The last time I went in with Seth to the hospital we went by and visited Jules (Seth's dad). After we were leaving his office, standing by the elevator, I said, "You know, Seth, I think your father is real neat." And he said, "Yeah, I think I've been a big influence on him."*

— Gareth

*It's true. Some of that caused gray hairs on my head.*

— Jules



are for. And, I began to appreciate the aspects of other rituals we incorporated into our own funeral and mourning service.

My images of death have been profoundly reshaped by Seth's death. Before this experience my images involved people with scared looks on their faces hooked up to lots of tubes, and myself trying to related to dying folks in a hospital setting but not having the language or the cultural permission to say, "Hey, I understand that you're dying. I'm here."

**Carrol** — I feel less angry at death because we didn't have to deal with the bullshit that I had to deal with when my ma passed on; funeral directors, limousines, expensive coffins, the money ripoff, etc. I know now that our culture here has a much healthier way to help people make life and death transitions. Also there's a change in my attitude towards life. I'm aware of trying to live my life more fully because death can really happen at any time . . .

**Corb** — My attitude towards death was only reinforced by Seth's experience. I see it as something we are all going towards and I choose to look forward to it. I feel that it's going to be an enlightening experience where all the mysteries of life will be dealt with. I cried at Seth's death but it didn't upset me. I was with Seth in his last minutes of consciousness. The energy was very high and very validating. I felt like I was being honored to be able to be there.

**Orion** — I always had a real hard time believing that Seth would die. I know all of his operations were very serious but I took it for granted that he would do well. When I heard that his cancer had recurred I started thinking, "Oh, if only there could be some kind of cure for him. If only I could find some answer." I kept thinking we can't let him die. He's just too precious. Finally, when he started getting thinner and more frail it was obvious that he was very near death. At this point I started thinking of it differently, and by the time of his death I thought, "Wow, that was a great experience for Seth." I changed from wanting to keep him from the experience, to accepting that he was going with it, to letting him go with it. I tried to think of it in terms of a growing experience for him and something that was wondrous.

**Judy** — In some ways I still feel I don't have any idea of what death is. I tell myself that Seth's gone and I won't see him anymore. But that in itself is not a big thing because I didn't see him very much in the past two years. I guess I've started to think about my own death a little. I have thoughts about life after death but maybe that's just to make myself feel better. The last dream I had tells me, "Yes, he's dead — but at the same time he exists on other levels." I feel that part of him has been dispersed into the general atmosphere and part of him still exists, on some level, as an incorporeal being.

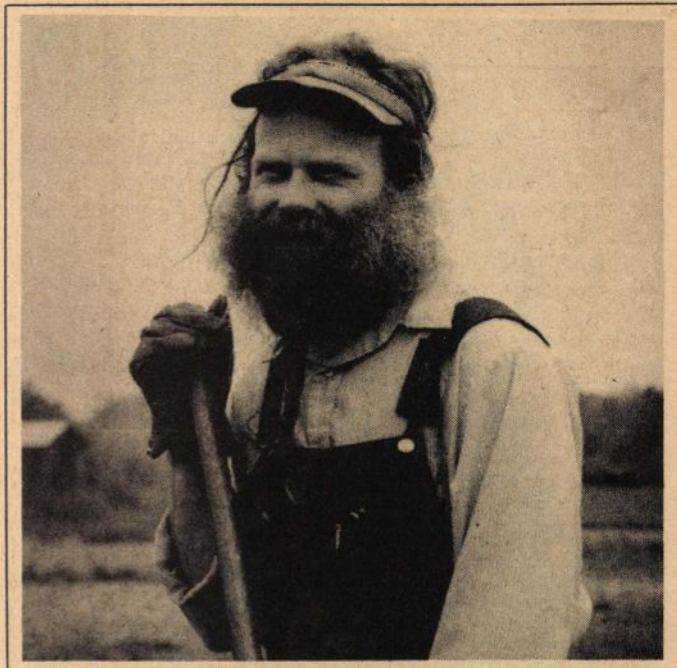
**Melissa** — I went through a lot of changes around Seth's death. My father died when I was 17. It was a very



different experience. I was very removed from it all and didn't cry until years later, as I spent most of my time protecting myself from being swallowed up by my family. I wasn't with my dad when he died and I insisted the casket be kept closed because I didn't want to see him dead.

I have always had a terrible fear of death, other people's and my own. When Larry came and knocked on the door around 11 I didn't want to answer. I knew it probably meant Seth was dying. Nevertheless, I woke Tom and we went out in the living room. I made myself go in and be with Seth in his last hours, crying and singing while he was in a coma. I made myself go dig some of the grave. I made myself go to the funeral, help lower the box, and attend the memorial service. And at the same time I was battling with myself to do all that, I was in a very high place with it all. It was very intense and moving and I knew something important was happening to me. But every step of the way I had to really push myself not to cop out because of my fear. And I was afraid. I remember asking Larry to tell me what I would see when I went into Seth's room. He did and then I was able to go in. I also remember being in the woodshop when Seth's body was being carried out to be put in the casket. I was peering around the corner because I both wanted to see a day old body and I didn't want to. I'm glad I did all that for myself. It demystified death for me in a really healthy way and I feel that I could go through it again and not be afraid.

**Gareth** — I think a big part of the fear around death is the aspect of 'not knowing.' What does somebody look like when they die or the day after? What is it like to touch a dead person? I experienced a lot of that curiosity around



*Carrol Jones*

Seth's death and was able to understand more of what happens when someone dies. The day after Seth died a group of us went in to his room and we all sat around his bed with him. We were mainly there to keep him company and to be with each other in his company. At one point we all had a hand on him. Patch (a doctor friend of ours) had Seth's head on his lap and began telling what was happening biologically with his body. If someone had told me ahead of time that we would do that, I'd have thought it was very weird. But it didn't feel eerie or strange; it just cleared up a lot of things for me.

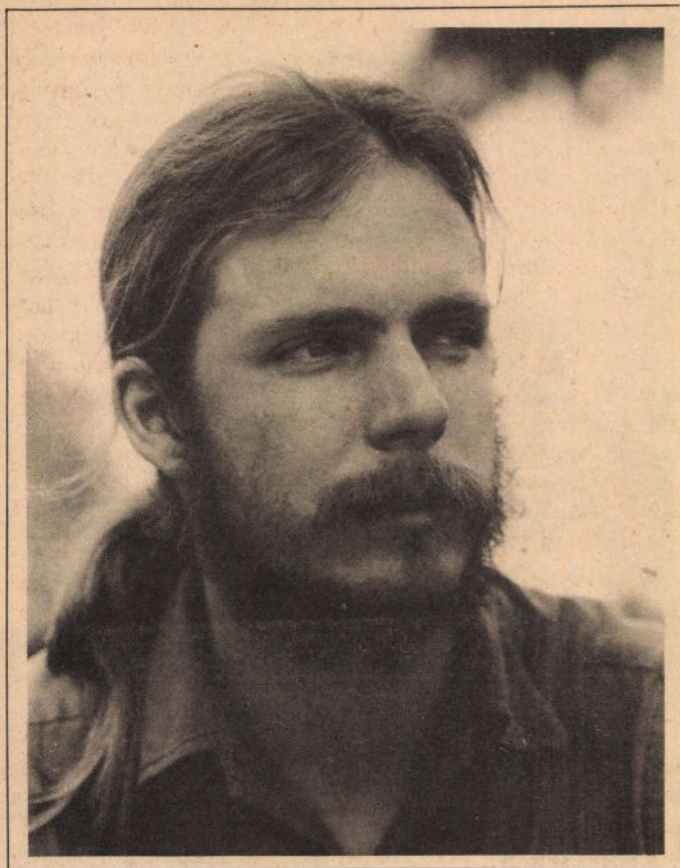
**Joanie** — For me there's no question that his death was a very moving experience but his dying or illness was nothing to glorify. I don't want us to forget that his cancer was a political thing. It was cancer that caused him to die and he shouldn't have died. Seth and I did an MNS training together. I wasn't with him during our street speaking workshop but apparently Seth got up and talked about his cancer and how that form of it is often caused by too much exposure to asbestos. People didn't just pass by when Seth spoke; they stopped and listened. Apparently his speaking was very powerful. Remembering the politics behind why Seth died is important to me, as important as telling the world how he died.

The main thing that Seth's death did for me was to give me a kick in the pants to get back to the work Seth and I were doing . . . some political work, some local relations work. On the one hand it feels like I have this big whip cracking down on me to get to work and at the same time I have this feeling of stumbling around with bricks on my shoulder. I feel abandoned by Seth. "How could you leave me with all these things to do? I'm finally into this and you're not here." I feel badly because for the past few months of Seth's life I wasn't in there giving him much support in what he was doing. I feel badly that he might



*Orion*





*Christopher Pax*

have died wondering if this work was going to go on. The work is continuing, I think he knew it would, but I'm not sure. I miss him a lot as someone to talk to about the political work. We really shared a similar perspective on things although he had a lot more energy than I did. I don't know how he did all the things he did and still dealt with his cancer.

#### **FAMILY/PARENTS**

**Gareth** — My grandfather, whom I was close to, died a couple of days ago from a heart attack. My mother and father called me up and were quite upset and my mother was treading very lightly with me because she thought I'd really be upset. She said, "Your grandfather died this morning of a heart attack." I said, "Oh, tell me all about it." She explained all the particulars. I asked how everyone was doing and then my Dad got on the phone and I found myself giving him a lot of support. I remember saying, "It's o.k. to cry, just get it out, take care of yourself." And I told my Dad I loved him, which I hardly ever do. That kind of exchange is rare for us. But my reaction to the death was very positive. I didn't feel like I had lost my grandfather. Yet, it would have been different without my recent experience with Seth.

**Taylor** — My mother's always been terrified of dying. I've been aware of that since I was about 8. This past fall she came to visit and I talked to her about what was

happening with Seth. I ended up committing myself to take care of her and/or being her patient advocate should she ever need me. I have a lot of ambivalence about that commitment. I didn't feel forced to make it but it feels like I've given up a piece of control in my life. In fact I feel like it's the first piece of control I've ever given up as an indefinite commitment. She could need me for a long time, and that could really change my life.

**Melissa** — I called my mother the day after Seth died. I was a little hesitant, being unsure how to express it meaningfully and in a way she could hear. When I told her about his dying and our response to it the first thing she said was, "That's what happens when you have a good support system." I also couldn't imagine her thinking it anything but bizarre that we had a dance right after the memorial service and that Seth's parents were out there rocking and rolling. But she really picked up on the joy and release and the fact that dancing was such an expression of Seth's life. This past month I've been working with her on what she wants to have happen when she dies. It's an exciting process.

**Larry** — I just had been with my parents the month before and had told them a lot about Seth. My father has had cancer for the past several years and he started sharing a lot about himself with me. So I wanted to call them but I was feeling very open and vulnerable, and I wasn't sure what kind of space I'd catch them in. It was the morning of to wish me a happy birthday. My mother as always asked what's new. I told her we were burying Seth this morning. She said, "Oh I'm really sorry," and I said, "No, it's o.k."

I started telling them the whole story of the last week. I shared it with them from a real place of strength, a place I'm usually afraid to be in with my parents. My mother went from "Oh really" to "Oh that's very interesting" to "That sounds very good." Towards the end of the conversation my father said, "Well, I haven't been saying anything because I've been crying through the whole conversation. You all are way ahead of the rest of us." I was blown away by his response. Somehow I was being pure enough or the experience was pure enough that I was able to relay the events in a way they could really relate to. They are at an age where a lot of people around them are dying all the time.

On New Years they called me to wish me a happy new year and told me that they had been telling the story of Seth's death and how we handled it to everyone. Again they told me how it was totally different from anything any of them had ever experienced and how wonderful it was. I'm looking forward to talking to them more about it. I'm also now ready to talk to them about what they want to happen when they die.

**Chip** — Going through this with Seth has pushed me to reenact a death experience I had with my closest high school friend. From ages 12-18 my friend Brit slowly died of Hodgkin's disease. My father was his doctor and one day when I was 13 years old, he told me Brit was going to



die. That was it. We never talked about it after that, and I couldn't talk about it with Brit. It just wasn't right to do that in our culture, and my forms of participating with Brit were very limited. I could go hunting and fishing with him, but we never talked about what he was going through. I felt like I never gave him full support, and hadn't been able to really work through what I was going through myself.

But through a co-counseling reenactment I was able to tell my friend Brit that I really loved him, that I really felt his death, that I supported him. I acted out holding him in intensive care and other things I never did and really needed to do. I'd carried Brit's death around with me, unresolved, for 11 years with an enormous amount of energy tied up with it. Through this co-counseling work, and through the experience of full support and participation in Seth's death, I now feel much more reconciled to Brit's death. And it's prompted my family to talk about both deaths at a more intimate level.

**Larry** — I guess a number of us have had a strong impulse to share Seth's death with their families, even those of us who aren't close to our families. I think that we've all had an experience that almost transcends the cultural differences between us and our parents. Even though we might be alienated in many other ways we want our parents to understand this very basic and profound thing that has happened to us. I think we also want to be sharing how it can be. I know for me there is a little bit of proselytizing energy in it as well.

## GRIEF

**Joanie** — I feel like I went through particular phases after Seth died. I understand traditional ritual a lot better now. I remember the first week as a very vulnerable time. We spent a lot of time with each other, doing things together that were comforting, like digging the grave.

After about a week I began to get twinges of missing Seth and would cry easily. Then after six weeks I stopped doing that, and also noticed that I was missing those feelings. I felt a little nostalgic and sad. The music was very important for me especially the Pachobel canon. We sang that a lot and I found myself singing it for weeks after Seth died. I don't do that anymore.

**Taylor** — Music has been an important part of the grieving process for me, too. The Holly Near song, *It Could Have Been Me* goes round and round in my head. The singing is the most vivid image I have of Seth's dying. It's a very cleansing thing. Another important part of the grieving process has been the grave. I've had other opportunities to be around graves but it's never affected me this way. When I go near Seth's grave, I can feel my grief and hurt and deal with the fact that he's gone. I stay there and grieve and walk away. It's very powerful.

**Judy** — I felt a lot of grief when Seth first left home after high school. We were having a good time for the first time in our years together and I knew it was going to be a great relationship. Then he left. Seeing the whole relationship

nipped in the bud, not knowing him the last few years of his life, realizing I won't know him as I grow older is really hard. I was very afraid his death was going to become a casual event in my life. Something where I could say, "Oh yes, I was 21 when my brother died," on the same level as I would say anything else.

I wanted to be here when Seth died. I was in close contact with my parents. They called me the Wednesday night before he died and said, "Well, you better come home." So I did. I would have been really upset if I had not been able to see Seth. I needed that final connection because I had been feeling so disconnected from him and because I needed to realize he was dead. I'd rather have the pain than have his death be unreal for me.

I was with my Dad when I first saw Seth's body. It was shocking because he looked like a little Egyptian mummy. I just burst into tears, which was good. At first I wanted to touch him but I felt funny about it. Then I saw my Mom do it so I touched him too. I stroked his face and talked to him a little bit and said, "I love you so much. Why do you have to go?" I wanted to kiss him so I did. I talked to him some and it was closure for me.

**Carrol** — I saw myself as a behind the scenes person the night he passed on and the next few days. It gave me a real sense of involvement and self worth to be there the last night and to be able to give Joyce a massage and help her relax after she spent several hours with Seth. It was a really uplifting experience to be in Seth's room with the singing



Taylor Fromm



going on and not having any fear, just some sadness at the transition and a whole lot of happiness and renewal of faith.

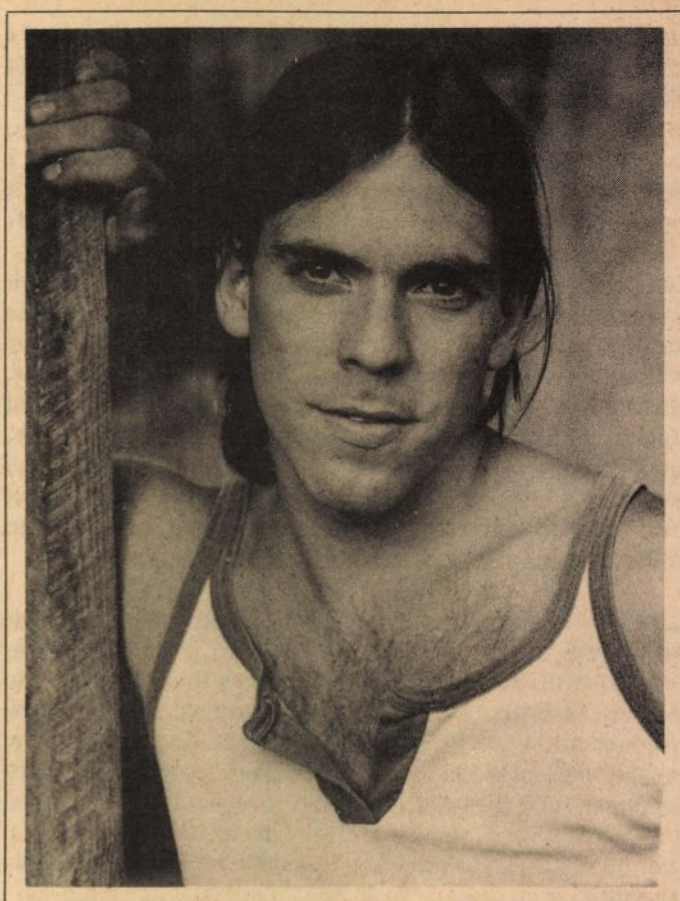
I worked at the grave site quite a bit of the time. It was a good meditative space for me as well as a good release, especially when we'd run into the rocky areas. It was an outlet for dealing with a hopeless situation and doing everything that we could to get through. Bit by bit the rock disappeared and we got through it. It was a good way to deal with the frustration of what happens when it's time for someone to pass on. It was really energizing the way we drew together as a community and all opened ourselves up to Seth's family and friends.

### CONFLICTING FEELINGS

**Judy** — I realized how confused I felt when he died. Up until a few months before his death I was feeling that this was the most terrible thing I had to deal with in my whole life. But towards the end I started getting angry at him. I was really really tired of waiting. The last time I saw him we weren't getting along. He didn't want to see me at all. He felt like I was breathing down his neck; that the only reason I wanted to see him was because he was dying. Of course that colored everything but more than anything I just wanted to see him and be with him.

Also, he was on my case because I wasn't acting in ways he thought I should. I hear other people saying, "Seth always made me act my best. I had so much to learn from him." But for me Seth was acting like a sanctimonious old man trying to tell me how to act. In our relationship he always seemed to have a streak of holier-than-thou, which I always had a terrible time with. This wasn't always a source of conflict because in previous times I'd just laugh at him. But with him dying it was different. I could say, "Boo" and he would say, "I don't think that's a very loving way to be." I'm sure I probably did let some of my anxiety get the best of me at times, but he really was being a jerk during our last encounters.

**Christopher** — I was one of Seth's co-counseling partners and it caused me to have some distance from him. I had a real defined role, I was his 'yes' person. "Yes, you're doing great — Yes, you're going to get through this." At the same time I could see Seth was dying but I couldn't talk to him about it. He wouldn't talk about it. It was a split reality for me. In the last six months I found myself growing away from Seth. I think some of that was my own fear of death and some was that I couldn't be real open with him. I couldn't talk about death with him and I didn't quite share his political perspective as much. I tried talking to him about death but he would tell me he didn't want to talk about it. I think the thing I might do differently is to challenge him more on that or at least let him know how it made me feel. As a result of not doing that I feel like I never cleaned house with Seth. It's funny because at dinner



*Corb Ardrey*

time of the evening he died I thought I really wanted to go and connect with Seth. It didn't happen then and by the time I was woken up he was already in a coma. That's probably one of my regrets around the whole thing, that I didn't get things cleared with him before he died.

**Larry** — I'm real glad you mentioned that split reality. I feel that there is a tendency for us to idealize and canonize Seth as a saint in this whole experience. We lose sight of the fact that in some ways Seth was a young punk. Seth chose a set of attitudes towards life and death that were very strong and positive but like any set of attitudes they had tradeoffs. Part of the tradeoffs was the schiziness of knowing that Seth was dying but having to deal with his not accepting it and really drawing on us for affirmations and support of living.

**Chip** — There were times in our co-counseling relationship when Seth would ask, "Do you believe that I will heal myself?" I just couldn't say, "Yes, I believe that" and that was a tremendous conflict for me. I felt like I was letting him down and not giving him support when he really needed it, but at the same time I didn't feel that I could be dishonest. He and I talked some about that the day before he died. I realized that I was holding on to too literal an interpretation; that I could say, "Yes, I'm sure you're going to live," without meaning it literally. I think that conflict was also tied to my wanting Seth to have more



acceptance of his death. I was afraid he was going to die fighting and be stuck in denial, in the Elizabeth Kubler-Ross sense of the word.

If I was going to prescribe the perfect death for Seth, I would have had the community gathering he wanted to have where he told us what he appreciated about living with us and I would have had him spend his last few days in a more accepting place. It's paradoxical to me that this was a very high and beautiful experience, and at the same time quite imperfect. We were just bumbling our way through Seth's dying, making many mistakes. I made mistakes as a co-counseling partner, Larry and I made mistakes facilitating the death and dying community workshop the month before his death, we didn't have Seth's farewell gathering, and then there were those damn dogs running over his grave during the funeral. And yet I feel totally content with it. Those things ultimately just didn't matter; the experience was perfect even with its flaws.

**Larry** — I found myself in a schizy position in my work with Seth. On the one hand I was doing a great deal of death research, not just for Seth but for all of Twin Oaks, and on the other hand I was supporting Seth in healing himself and living. Actually I needed to do it for reasons other than Seth because I had no desire myself to be focusing on 'when Seth dies.'

One day we were dealing with legal stuff. Up to that point I hadn't shared with Seth any of my concerns or difficulties in dealing with him. They had all been easy enough to take care of through my own counseling sessions and I didn't want to burden Seth. But I needed to share my dilemma with Seth and so I did, breaking through the fear. Seth responded by sitting up, looking me in the eyes and saying clearly, "Larry, I have a life-threatening disease. I may die soon. I am living fully and I am working completely to heal myself. Does that help you?" I said 'thanks' and we moved on to wills and burials.

**Gareth** — Up until Seth's last recurrence Seth would jokingly refer to me as his guru and I would refer to him as mine. He would get into spaces where he really wanted to deal with death. One day, several recurrences back, I asked him if he had thought about death. He totally shut me off saying, "Don't talk to me about that." Somehow it ended up that we did get into a discussion and I told him my philosophy which is, pretty much, that you don't die. We went back and forth over the months with this discussion. He'd come back to me and say, "Wow, I think I want to hear more about this," or, "I think I can really get into this idea," or "I think I've finally overcome my fear of death." But towards the end of his life he didn't want to hear about it anymore.

**Chip** — Seth was generally pretty irritable in the last few weeks. Calm, neutral support was what was working for Seth rather than intense emotional energy. I think Larry was so effective with him because he came from that neutral place. It's interesting for me to hear people's different relationships to Seth and what they were getting or giving to him the last six months. I think my needs were

fully met by simply participating in his life, his illness and his death. For me, that was the healing element. I did everything from coordinating his care, to bringing him food and sleeping with him, to getting the oxygen, to singing with him as he slipped into a coma, turning off his oxygen after he died, digging his grave, helping to plan his burial and memorial service, being with his body after he died, chatting with people in both light and serious veins about Seth, singing about him afterwards. It was a very rich and cathartic experience. It was a total involvement, and the real gift that Seth gave us was opening his life and death up to this full participation.

## RELIEF

**Christopher** — There is also a great relief for me in Seth dying. I watched him decline over the months, watched him getting weaker and thinner. I remember during the last couple days urging him to die, within myself of course. I slept with him and cared for him the night before he died. He was having such a hard time the whole night trying to get some sleep, having a hard time breathing, being nauseous. At times I'd just focus on him really intensely and silently say, "You can go now. You can go to your rest." The night he did die, when we were all in there singing to him, I was again urging him on. It was the end of a long trip with Seth and it was time for it to happen. □



Joanie Kanter



# seth

*I've been coming to Twin Oaks now for four and a half years. Invariably it's been at a time of celebration. I come for my own selfish reasons, to dance. I look for other people on the dance floor who are going to keep me alive and up late dancing. That's been my relationship with Seth almost all this time. I've been naked and sweaty with him, had him climb all over me, and been in piles on the floor with him. I felt a very strong kinship with him because we share a lot of similar feelings about dance.*

— Patch

*I suppose you all know how little he wanted to come here. He was well acquainted with some of you but you were not on his agenda. His plan was to go to East Wind. And then when he applied here, I couldn't understand why you didn't want this absolutely adorable child with six months to live. "What do you mean you're taking a risk? You're getting my son." I've long since come to appreciate what a sticky issue it was and what a difficult one. Had I been in your shoes I might have been on the wrong side and have said, "No."*

— Mary [Seth's mother]

*One of the things that's made me realize how ripe a life Seth led in 22 years was having a conversation with him about how we got started in political activism. We were both saying that we got started about ten years ago with antiwar stuff and progressed from that. Then I realized that ten years ago put me at age twenty and Seth at age twelve. Pretty amazing.*

— Chip





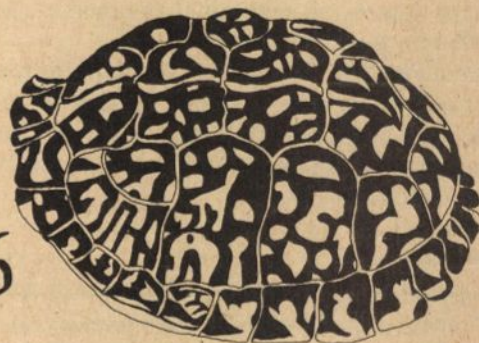
*Seth Arginteanu joined Twin Oaks when he was 18 years old. Much of how he would deal with his life and death over the next 4 years was already a part of his self definition. His Quaker background, his family, his alternative education experience, his attraction and involvement with intellectual thought and meaningful action and his desire to make a place for himself in this world as an activist and humanist were already an integral part of him.*

*During Seth's last year of high school, Seth made a decision that he wanted to live in an environment that*

*could both support his desire for community and his desire to better the world through political and social activism. He planned a year long cross country trip in pursuit of that quest. During this trip he kept a detailed journal from which this article is excerpted. Parts have been cut out due to length but the language remains untouched. This journal is not only a record of that quest but a study of Seth's character at age 17. There is nothing we could write about Seth that could more accurately describe him today at age 22.*

# Seth's Journal

## april 1975—december 1976



### *April, 1975*

Post Graduation Plans. For a while I was definitely going to live on a rural farm commune somewhere. Then I decided that I wanted to stay politically active, and that a political collective was the thing for me. Today, after looking thru 'Someplace Else,' a sourcebook for alternative living and learning situations, I'm changing my mind again. Perhaps a stay (6 months to 1 year) at a rural commune might be good for a while. Actually I never thought it wouldn't, but the inner calling to political action seemed to override it. I have to check out a lot of things in both areas. Write letters, visit, etc. Probably change my plans again tomorrow.

I have been feeling a little insecure lately about my plans for splitting to the West Coast through July-August. This is the same way I felt about visiting communes before plunging in. However with the West Coast, my plans are much more vague and general.

### *May 29th*

... Body News — I am getting stronger, working out in the VCU weight room occasionally, and doing push-ups every day. I am gaining strength in other categories as well. I'm now up to nearly 25 push-ups daily.

About this whole body trip. It might be construed by some that I am into a macho trip but that isn't the case. I am a radical femi-humanist but am also into my own body which happens to be male. Everyone in my Group is also into their body and everyone works out, men and women both.

I am reading "Revolutionary Non-Violence" by Dave Dellinger, which is recommended reading for the Peace Makers Conference. As yet, he has said very little that I haven't already considered or wasn't aware of, but I find much of it inciting me to revolutionary anger.

I find much that I read these days (particularly in publications of the establishment news media) incites that sort of feeling within me. This anger is difficult to direct at this point and is for that reason often unproductive for the material that incites this anger is usually stuff I'm already aware of. Therefore I've stopped reading most editorials and articles on the Indochina situation (for instance) in the mass media if the information is not new to me. I can justify reading material like "Revolutionary Non-Violence" because I expect to learn something from it as well.

### *June 2nd*

I am seriously having trouble relating to a lot of institutions in the dominant culture.

I have been getting angrier a lot more at the absurdities and oppression of capitalism, imperialism and centralized government. I am feeling a slight bit oppressed mainly because of my age. I can't go to bars with Jeremy and Rob et al, even if I don't drink anything. My sexuality — Rob can't express physical affection for me in public in the same manner as Samantha. I can't fully undress in the park if I feel like it. These are trivial in comparison to the bulk of the oppression now occurring, but they relate directly to me. More and more of all aspects of this culture make no sense to me in human or rational terms. It's not like I can't



survive, but I think I will be happier and more productive as part of the alternatives movement or counter-culture. . . . The Dellinger book had several essays on his visits to Revolutionary Cuba. He paints a pretty picture of a society that is moving towards true egalitarianism and socialism without repressive centralized government. This has started the germ of a fantasy for me to go to Cuba. At this point, it is totally at the fantasy stage, and is not something I would want to do for a while anyway. I have a feeling that this is a fantasy I may realize.

#### *June 4th*

We cannot counsel against violence unless we can offer a viable non-violent alternative. Ghandi said that it is better to resist oppression violently than not at all. I have to develop my pacifism a lot more.

Began reading "Revolution and Equilibrium" by Barbara Deming which is along the same lines as Dellinger's book. Several passages have caused me to get strange body rushes and I feel tears starting during some of these. Getting heavy.

#### *June 6th*

Movement for a New Society: Orientation Weekend. I am in Philly at one of the Life Center homes. I thumbed up here with smooth sailing all the way. Talked with several of my drivers about social change. One was supporting, one was a former idealist, now hardened against possibilities for change, and one attacked radicalism although he claimed to support change. So much for that.

I found out some more about MNS/LC all of which reinforced my positive feelings towards it and my feelings that I would like to live in such a situation when I move back to the city. But mainly it provided the kind of affirmation reinforcement that I have been experiencing throughout my travels that there are other people into what I'm into, and that what I want to do is possible. This is a feeling that was expressed by many of the other participants. There is a refreshing lack of ageism in MNS/LC. I am also noticing my own attitudes towards myself in that respect are changing. I don't feel as limited by my age as I have in the past. This obviously doesn't apply to legal things, but rather self-imposed limitations. I realize that there's no reason to wait until I'm older to do most things I want to do. I have been planning to do most of them anyway but with some reservations because of my age.

There is an MNS group in Durango, Colorado, that I want to investigate further and hopefully visit on my way west. They are not based in a big city and have 40 acres of land they're working with somehow as well as doing social action work with Indians, Chicanos, organizing men's and women's groups and other things or so I'm led to believe. Sounds nice.

#### *June 10th*

We heard a little about Re-evaluation Co-counseling this weekend. It looks quite interesting and I'd like to check it out further although I don't particularly feel I need it right

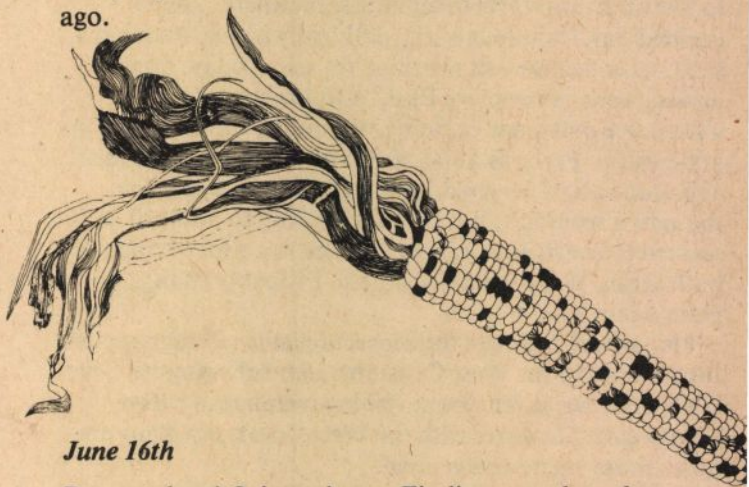
now because my life is going so well and I am feeling very good about myself.

We did an interesting exercise today at the closing of the OW. It involved writing and sharing a letter supposedly written 2 years from now telling another participant in the weekend what you'd been doing for the past two years. Mine went something like this: I traveled for six months checking out communes, alternatives and such, and then settled down on a rural, egalitarian, non-sexist etc. commune. Have been there for the past year and a half and learned much about relating to people and also picked up such skills as farming and carpentry but now, two years later, I was thinking of getting more involved in social action and plan to start searching for a political community that would meet my needs. This may involve moving back to a city but I might be able to get into that.

We had a party tonite. I really got into dancing. I was told I was a good dancer which is reinforcing since I'm often inhibited about my dancing cause I wonder how good I am. (Silly I know, but . . .)

#### *June 12th*

I went to Open High School's graduation on Thurs. It was an interesting experience which I don't feel like going into depth about except that I went really stoned, was dressed a little wildly and folded my diploma into a paper airplane. I got my picture in the paper and also a lot of shit from other people, including students about the diploma bit. Going to graduation party that night was a weird scene partly because I was incredibly stoned, but also the whole trip that people were into was something I'd left a long time ago.



#### *June 16th*

Peacemakers' Orientation — Finding some broader definitions of non-violence then my non-definition all these years. I have lately been thinking mainly in terms of strategy and tactics (as well as simple living) but these people are actually talking in terms of loving the enemy. Seriously, this is a concept I think is really far out but it's not something that fits in well with me right now. I want to hear and think about this more. I also still want to learn practical applications of strategy and tactics.

I am horny off and on although not in the strictly sexual sense but broadly, wanting to have people I was close to whom I can relate to in a physical way which of course includes sex.



### June 25th

I'm becoming aware of an inability in me to do intellectual analysis and come up with new conclusions or ideas on my own. I'm doing a lot of listening and feel like sort of a receptacle for ideas and facts but I'm having some problem organizing and synthesizing the information. This is all stuff that I am observing rather than worrying about.

### July 6th

Just got back into town from the Twin Oaks Conference and I'm feeling really high because of it. Although it wasn't this way throughout the whole weekend, I left feeling very reinforced and so happy to have met and interacted with so many fine people, people who really seem like they're advancing and progressing. I also made several important contacts.

I've never seen so many just plain physically attractive people at one time in my life. I don't know if it is just their style of dressing and carrying themselves or if people into communities are beautiful because of their lifestyle.

People seemed so open. I think a lot of people really gained much from the conference and I think several people found communities they wanted to join.

### July 9th

Springtree Community — I have spent a lot of time here with another visitor, Rachel. We met slightly at T.O.

I am somewhat sexually attracted to her but don't imagine anything will come of it. I've had very vivid dreams the two nights I spent here, but, I don't remember many details. The first nite they were mainly centered around community, this one specifically. Last nite I remember hearing that my mother had been told by a fortune teller the exact date of my death which would be in the near future. I think the date passed and I didn't die.

I'm reading "Strategy for a Living Revolution" by George Lakey which I think is "Manifesto for a Non-Violent Revolution" expanded upon which I found stimulating.

### July 19th

I stayed up all night at Jeremy's and he drove me to the Interstate at about 7 am (Saturday). Saying goodbye to him was rather an emotional moment for me, we have become such good friends in recent months.

I got into Albuquerque, 2 pm, Monday, having slept beside the road for about seven hours Saturday nite. At that time, Monday, I had spent approximately \$1.50, all for food. I've had strange eating habits, consuming very little food, particularly right now because I have a goddamn cold which I'm finding draining. Traveling and illness definitely don't mix.

### July 29th

Well, incredibly enough, I made it. I hitchhiked across the country and without getting raped, pillaged, or murdered. I'm not sure how long I will be here in the L.A. area or exactly what I'm doing after I leave here. Right now I have

letters from three communities okaying visits. While in L.A. I do want to check out what's happening in the alternative activist scene.



### August 2nd

L.A. — When I was coming out here I wasn't very sure at all what I would be doing the first month or so. The main idea was that I would be spending time with Samantha and friends. Now that she is going to be gone for the first couple of weeks of my time out here, things are more complicated. I'm having some trouble dealing independently with a rather unstructured situation, mainly because of inexperience, I think, but trouble nonetheless. Although my life generally has a pretty defined clear direction, it doesn't now and for the next few weeks. All this leads to fear, anxiety, doubts and worrying, boredom, general downness.

Will I be able to find lots of places to visit? Will I be able to actually investigate them? Back to doubts about my future. Will I find a community living situation in which there is compatability between me and it? Intellectually I know things will work out, although not necessarily, and most probably not as planned or expected, and not without hassles and struggles.

### August 7th

After a week and a half of sitting around bored, depressed, and rather inactive in Santa Monica, Carlsbad, and Hollywood, I finally got my ass in gear and phoned up the Catholic Worker house in L.A. They were the only involvement group here that I had really had previous contact with. At this point, I was starting to suffocate and stagnate from lack of contact with likeminded, similar lifestyle people. I phoned up yesterday and they said to come on down. This was an optimum time to get in touch with them because they and other area pacifist/activist groups are doing action for Hiroshima-Nagasaki Day.

Today I participated in the downtown vigil and I'm staying at the CW house tonight. I will be working in their free kitchen (their main project usually) and vigilling tomorrow. And I will be participating in the walk. Reasons for my participating in the walk. Politically, socially, morally I feel it's a good thing to do. I find such experiences personally fulfilling, energizing and

*continued on pg. 56*



*This interview between Larry Lenske of Twin Oaks and Cliff Russell, Seth's doctor, took place several months after Seth's death. Larry's desire was to understand more fully Seth's and Cliff's relationship and the effect, if any, that Seth had on Cliff's life and his relationships with his patients.*

*Cliff Russell is a pediatric oncologist at the Medical College of Virginia in Richmond. Cliff was Seth's doctor throughout most of Seth's illness. Although we may not share Cliff's philosophical or biological interpretation of Seth's extended life, there is no question in our minds that Cliff's energy and attitude was a major factor in Seth's positive approach in dealing with a life threatening disease.*

# BRIDGING THE GAP

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Interview by  
Larry Lenske

**Larry** — I'd like to know more about your work and how Seth fit into your life.

**Cliff** — Seth and I met when I first came here in August of 1976. He had just had surgery in California and I had started my two years of training as a fellow. I had been doing a fair amount of general pediatrics but I was beginning to get my feet wet in this business of doing full time hematology oncology.

Dr. McWilliams was the one who was principally involved with Seth at the start but we are a team of four and try to treat all of our patients as a group. In many cases one of us gravitates toward one person over another. Sometimes it's easier to communicate with one person than another. More than any other factor, that's how Seth and I got together. It certainly wasn't by virtue of my particular expertise with his disease. Seth's problem was very unique for his age group and I could practice in this business for twenty more years and never see another case of it.

I think that oncologists in general and pediatric oncologists in particular have a different relationship with their patients than most physicians. We are seeing someone very early in their life with a potentially lethal disease. We go into therapy of that disease very optimistically. Our assumption is that this is a basically healthy individual with a problem that could shorten his or her life. Our job is to keep that from happening and to try and make whatever life they have left as tolerable as possible.

In addition, our relationship with the patient is a longitudinal one. We don't see them once and treat the disease. We see them frequently and on days when they don't feel good or days we don't feel good. We learn from

every patient and develop a real relationship with each of them. Trying to be a friend is the best way I can handle my relationships with my patients. Other people handle it differently. There are those who come across as being authoritarian or those who seem to be dealing strictly with the science involved. But all of those are protective devices to cope with the stresses that are involved.

**Larry** — How is coming across as a friend a protective device?

**Cliff** — It's self protective in that they know I care for them as a person and they then are able to forgive me for getting them medicines, operations or radiations — the unpleasant things. I really like to have the three year olds come up and sit on my lap even though I know they're going to go on down the hall and get a shot. I think if I were seeing them just briefly I wouldn't be concerned about that. On the other hand I wouldn't feel comfortable in a strictly formal doctor patient relationship and I wouldn't enjoy going to the clinic every day.

**Larry** — Could you say more about why Seth seemed to have so fully accepted you as he did?

**Cliff** — I think it was because I didn't try to push him into my concept of what should be done. It just wasn't important to me that he do what I thought he should. It was more a question of my being comfortable with him doing things that didn't fit the mold. The best example of that was his going to West Virginia to fast and do a complete cleansing of his body including coffee enemas. This was something that he did when we decided not to continue chemotherapy after his second surgery. I can't





say that it was something I have real warm feelings about. I hate very much to see people be deluded by things that have no basis in fact or have little chance of success. But I don't think it's my job to take away that hope. It's a thin line. There's no way in the world that I think taking baths and coffee enemas are going to do any good but I never mentioned that to Seth then or later on. It's stupid to say, "I told you so," when a person in a desperate situation needs to do something that makes them feel that they've contributed to their care. I'll go along with anything as long as I don't think it's harmful. I didn't want Seth taking excessively high doses of Vitamin A because it can cause problems. It's a toxin and in high doses you can get poisoned. I let him know I wasn't in favor of that.

**Larry** — How was Seth unusual?

**Cliff** — He was medically unusual due to the rarity of the tumor he had. There was no recipe for its management. We were dealing with a disease that didn't fit any mold. We had to take our experience, our knowledge of drugs, other therapies and whatever was written in the literature and devise something. There's just very little known about this disease in children.

Most people who get mesothelioma are dead within a year. But, I don't think there is anything mystical about why Seth lived longer. When we removed the original tumor some cells were left behind. These cells took a reasonable amount of time to regrow until there was enough seeding that it was no longer feasible to remove those lesions. I don't think we ever successfully controlled them with drugs and I don't know what prolonged his life. I could not even say definitely that chemotherapy had anything to do with it. We would love to think that it did. But if that were the case it should have worked again after his later recurrence and it didn't. After his second surgery we decided not to treat him with chemotherapy. Despite his concerns about chemo I think he was disappointed and felt we were throwing in the towel. That wasn't the case. After a lot of discussion we just felt that the relative benefits were so small that the risk involved was not worth taking.

By that time we didn't think that the chemotherapy was what had caused the tumor to stay away the two years after his first surgery. That was coupled with the fact that only a very few of the drugs used with this kind of tumor have shown any responsiveness at all.

**Larry** — How was Seth different than any of your other patients, if indeed he was?

**Cliff** — Well, there are some people who really stand out in whatever group they are in. Seth was one of those people. He stood out because of his age, and the fact he looked so much younger than he was. I also believe that Seth's intellect was vastly superior to patients we come in contact with on a daily basis. At first I found him to be a little intimidating. That didn't last long and it wasn't real. It was more me projecting it on our relationship, not him.

He was one of the people I really looked forward to seeing in clinic. He was someone I could talk or listen to on a little different plane than the usual kids I saw. He was a unique individual and everyone recognized it. I found him incredibly easy to work with. He was very concerned and knowledgeable about his disease and he wanted information. There were times when I think I probably gave him more information than he wanted, and there were times when I couldn't give him the information he wanted because I just didn't know. It was important to him to be treated as an equal, a person, rather than a patient. He would never allow anyone to talk down to him. I believe in that kind of honesty with all my patients and I think it's the way you have to approach people in general, be it the newspaper person, the patient in the clinic or one of your colleagues.

I felt very straight around Seth. I felt that he thought I was a real nurd. It was important to me to have his approval. I think he always saw me as a very possession oriented, republican doctor. If I'd come in in coveralls and sneakers I think he would have been more relaxed with me. But on the other hand, we used to talk about anti-nuke rallies and other political issues. I think it must have been very frustrating for him, because either I didn't take a stand at all or I took a stand that would be somewhat different than he expected.

**Larry** — Has your experience with Seth affected your attitudes toward the way you treat other patients?

**Cliff** — My experience with him just reaffirmed the importance of the individual, especially adolescents. Adolescence is a particularly difficult time to have the disease we're talking about. It's a time when one goes through very dramatic body changes and disfigurement. At the same time one is just escaping parental authority only to be faced with physician authority. I think a lot of adolescents have a great deal of difficulty with that. Dealing with Seth in an open honest way is something I hope to carry over to lots of relationships with other patients. When you do something that works you want to keep on doing it. I don't feel as badly that Seth died as I do about those kids who are probably going to do beautifully and live to 102 but who are making every treatment session, every day at school, and everyone around them miserable including themselves. There are ways to live, and



how you live each day is important. Seth knew how to do that.

**Larry** — You said before that you didn't attribute Seth's longevity in his disease to either your drugs or his will.

**Cliff** — Right. And I know you want me to say it was his will that caused him to live longer than expected. But if I were ever dishonest with Seth it was in that regard. I let him say those things and I agreed with him either openly or tacitly. I don't think there's anything spiritual, mystical, or religious about it. If you've got a tumor, I don't believe an act of will can do anything about it. It's going to do what it's going to do. I was trained as a biologist first and I still believe in biological principles. This gets me in a lot of trouble with other people around here, so I try to stay away from discussion of it as much as possible. I basically see my role as a supportive one, however people decide to approach their disease. If they want to believe it's God or two grams of vitamin C that will keep them in remission I will support them . . . But more and more kids with leukemia are alive now than there were before 1960. Did God love those children less? For me, when I find someone with an unusual response, such as Seth, I look at it as a biological variation.

**Larry** — How much did Seth's actual decisions around treatment vary from your recommendations?

**Cliff** — I daresay that throughout the initial course of two year chemotherapy, he didn't miss a dose of his own volition. There was a period of time after the second surgery when we decided not to put him back on chemo and he decided to try a different kind of treatment in West Virginia. I had no serious objections to it but I was upset when he came back and had lost 17 pounds after fasting 14 days. When you weigh as little as he did it's hard to lose that much, but he did and came back quite ill. He also had hyper vitaminosis A at that time as well. I couldn't say "That hurt you and therefore you shouldn't have done it," because we certainly did things that hurt him too. Throughout the rest of the course of his disease he never refused therapy and I think if we had said the day before he died, "Seth, we've got a new drug here that might help," he would have taken it.

**Larry** — At one point you were enormously impressed with Seth's support system. Could you expound on that?

**Cliff** — Well, one of the things we see over and over again with people with malignancies, and particularly adolescents, is a feeling of being alienated from family and friends, a feeling of really being alone. Some of that is because the family tends to be overprotective at a time when, as a teenager, you want to get away from family ties and you tend to rebel at that. Also you go back to school without hair, you've lost 20 pounds, you've got a scar, you can't do things you used to do and your friends are scared of you. They don't know what is happening and they react out of fear. Everyday you are confronted with teachers, friends, and parents who are scared of you. At Twin Oaks Seth had people around him who were not scared of him, who accepted him the way he was at any point and time along the course of his illness. People loved him for the

individual he was and didn't make demands on him other than to be himself. I don't know what else you can really expect out of life. That's why I say I don't feel sad at the way he lived or the way he died. He got the kind of support he needed and wanted and he couldn't have choreographed it better. You all expected him to pull his share of the load and when he wasn't up to pulling his share of the load other people helped him.

**Larry** — What I'm hearing is if there is a formula for dealing with sick folks, it's to treat them normally and deal with their real needs. If they have extra needs, just deal with those too.

**Cliff** — That's right. They just want to be treated normally.

**Larry** — Seth really demanded that for himself in his life. His statement was, 'I am a person with a life threatening disease, but I am above all a person.'

**Cliff** — Yes, but that I think shows that you have come to grips with yourself and most people have not done that in their lives. It's a rare person who can demand to be treated in a certain way and have it happen. Either they haven't formulated how they want to be treated or they are afraid that if they do, they will alienate people they were formally close to.

**Larry** — What's the biggest challenge in your work?

**Cliff** — At the point that I know someone is probably going to die with their disease, it's trying to figure out how to help that person and family get the most out of what life is left. That's as much a challenge as which drug combination to use.



**Larry** — So what's frustrating to you is the situations when you see people not living their lives fully.

**Cliff** — Yes, I can think of any number of kids who display a strength, courage, and personality that other people could learn from and copy. If they die, they have



died leaving a lot. Seth was one of those people and I see others like Seth come through here periodically. And yet there are other kids whose families are as much a part of the problem as the disease is; taking the child to this, that and the other medical center, doting on the child, making themselves and their child miserable. And yet I cannot say to a father, "Your whole approach to your son and his illness is wrong." That would be intolerable of me. All I can do is hope that the parents' support group, or some interaction I or others of us have, will affect these folks in some positive way.

**Larry** — Who takes care of you? What is your support system?

**Cliff** — First, I recognize the fact that I need to get away and I do. And the rotational aspect of this job, splitting my time between teaching, research, and patient care, is important. The variety here is good and it's a healthy one for me. Another thing that helps me to cope is being part of a team. Every Friday morning the four of us get together and talk about each patient, particularly problem cases, and how to manage them. Plus we see each other many times a day. As a team we get to share the good things that happen and the blame for the bad things that happen.

**Larry** — Do you have many instances of people choosing to die at home?

**Cliff** — Actually we do. I suspect that a third to a half of our patients die at home. The people who don't want their child to die at home are either people who have not coped well from the beginning or who don't feel capable of coping with it. There is a certain strength involved in learning to be with a dying person and to be able to take care of them up until the end. That doesn't mean you have more or less love for them. People are just very different and have different coping mechanisms.

**Larry** — What kind of support systems, if any, do you have for families of children who die?

**Cliff** — There are quite a few ways that people still get support from us after their child dies. One is through the parents' support group. Another is joining the fundraising group for cancer research. And a lot of the volunteers here are people whose kids have been treated here and died.

**Larry** — Perhaps a part of the grieving process for people is to do something positive after your own child has died, a way to counteract the feelings of hopelessness.

**Cliff** — I think that's true. On Wednesday I saw a volunteer in the clinic whose daughter died three months ago after a five year bout with leukemia. This was her first time back to the hospital and that first trip is very difficult and traumatic. But it is the way that woman is choosing to work out some of her grief. I'm glad we have those opportunities for people to stay involved with us.

**Larry** — Are there other support systems you think would be beneficial?

**Cliff** — Yes, I'd like to see a peer group for the older kids

who come here for treatment and also some kind of support for siblings of the kids with these diseases. I think siblings get left out in the cold a lot. They see their brother or sister getting a lot of attention and parental time. They know they are supposed to love this person who has a very serious disease but they are mad as hell at them because they are taking time away from them. The only thing left is guilt. It would be good to see something good happen with these kids.



**Larry** — Are you familiar with the hospice movement?

**Cliff** — Somewhat. I think there comes a time in many people's lives when we and they have to make the decisions as to whether we are going to control the disease, to prolong life through drugs or whether we will stop because there is no reason to continue administering those drugs. Once a decision has been made that we are not going to continue, then the goal must be to give the best quality life possible for the duration of someone's life. I think that's the role of the hospice program. Most people don't want to throw in the towel. They are always anxious to try something new. Yet there sometimes comes a time when there really is no point in doing anything else and it's obvious that there is little lifetime left for a patient. It's often at this point that people choose hospice.

**Larry** — Do you ever have a problem getting over involved with patients?

**Cliff** — I don't know if over involved is the right description. There are some kids that I'm very close to. The more contact I have with them the closer I get to them. This was certainly true in Seth's case. I learned a lot from Seth and from so many of the other kids I see. I am continually learning from the patients I see. It's one of the benefits of this business. □



# A Practical Guide to Home Death

by Larry Lenske

*Home deaths are like home births. They don't take planning and preparation to allow for the fullest participation and the least worry.*

*There should be a book written called 'How To Do Your Own Death, Burial, Etc.' We couldn't find one. This article describes what we learned when we chose to experience full control over the circumstances of our first death and burial. We did the advanced planning and gathering of information necessary to have a 'home death' for Seth. Each situation is unique, each state has its own laws and many details here are specific to Louisa County, Virginia. Nonetheless we hope that this information and approach will be helpful to others who wish to take control over their own death or help their friends and family take control of theirs.*

## WHO'S IN CHARGE

*"We have an amazing custom of displaying dead bodies in a costly elaborate routine. When death occurs in a family in which there is not planning, the survivors find themselves virtually helpless in the face of entrenched custom, and dealing with a funeral director who expects them to follow this custom."*

*Manual of Death Education and Simple Burial*

Who is in charge when somebody dies? Generally one's family assumes the responsibility and the authority. Most people and institutions are used to a family working through a funeral director. If a friend or other party is to assume responsibility, out of convenience or preference that person needs to be authorized in a will or separate



*Seth's funeral procession*



document which explains the role that person is to assume. I'd recommend a notarized paper stating that person X is responsible for disposal of the body, arrangements for the funeral, etc.

## WHERE TO START

The place to start one's research is with a little book called *Manual of Death Education and Simple Burial*. This book deals with all the pertinent issues of death. One needn't agree with all the premises or even general philosophy to gain a great deal of valuable "how to" information.

Other help with advance planning can come from memorial societies. These nonprofit organizations formed in some 130 cities in North America and thousands of families are now being helped to secure dignity, simplicity and economy in their funerals.

After reading *Manual for a Simple Burial* and having Seth fill out the Putting My House In Order document we got from the Memorial Society, we knew what we wanted but not how to go about getting it. We started by calling the local and state health departments and the local and chief medical examiners. We were somewhat unique in that we weren't planning on using a funeral director but everyone was very helpful and supportive and a number of officials reminisced about how everybody used to do it this way when they were young.

We ran into very few snags due to several factors. Seth's instructions were that he didn't care what happened to him after he died as long as it was simple, cheap and ecological. Seth's family lives nearby, are good friends of the community, have a Quaker background and shared the same basic values we did in terms of death and burial arrangements. And we live rurally in a state that has few restrictive laws about burials. Virginia's conservatism, in this case, means you can still do it by yourself if you so choose.

## DETAILS

*The Law of Death and Disposal of the Dead* is a book that gives good background to the laws and practices concerning death and disposal and summarizes pertinent laws state by state. The information that follows is specific to Louisa County, Virginia. Check your own state's laws. Memorial societies usually have all this information and are glad to give it to you.

### Death Certificate

A death certificate must be filled out and signed by a doctor within 24 hours of a death. The doctor must be familiar with the patient and able to certify cause of death. The certificate must then be filed with the county health department where death occurs within 3 days. If cause of death is unknown, suspicious, violent, unexpected, or that of an out of state person, the local medical examiner must be called in and he fills out the death certificate.

### Funeral Homes

Some do a sensitive and fine job of giving the family the services they want at a reasonable price. Others use the vulnerability of the family at the time of

death to make a lot of money. Some states, like Virginia, have few restrictive laws. Other states, through lobbying efforts of funeral homes, crematories and others involved in the business of death, have laws that essentially require expensive disposition of the dead, such as requiring that a cremated body come to the crematory in a casket, which serves no purpose other than making money for the industry.

For the funeral home to take charge of the body, they need a signed death certificate and signed authorization of an authorized party, preferably next of kin.

### Embalming

It is a strong custom, and usually policy, to require embalming "although no state requires that a body be embalmed in advance of burial, if burial or other disposition is to take place in the community where death occurred and within a short time after death." Embalming is a convention and, in most cases, is done for cosmetic rather than sanitary reasons.

### Cremation

Cremation involved approval by the local medical examiner which means he must view the body and fill out forms costing \$50. It is illegal to destroy human tissue without approval from the medical examiner. A buried body can be exhumed if necessary at a later date and inspected; a cremated body is gone.

To cremate, one needs the signed form from the



Lowering the cedar coffin



medical examiner and authorization from the next of kin or authorized person. The crematory is used to dealing with the funeral director, so this is an instance where it is useful to have a document clearly giving a third party (not a relative) authority to request cremation. In Virginia the cremations takes 4 hours and costs \$120, which includes an ashinary can.

### Transporting

A funeral home usually provides the service of transporting a dead body within the state. However, a private party may do this. A stretcher with a sheet covering the body in a station wagon, for instance, works quite adequately. To transport a body out of state, one must obtain a transit permit from the health department where the death certificate has been filed.

### Burial Site

In picking a site for a cemetery/burial ground, some considerations include health (nearness to drinking water supply), seclusion, aesthetics, non-interference with other land use, accessibility by backhoe for digging in case the grave can't be dug by hand, soil percolation and the realization that the site is permanent. An ideal area is flat, has a lot of soil coverage and a few rocks, and a low water table. There are no local laws in Louisa County regarding the placement of a burial ground on private property. The Sanitarian at the local Health Department was helpful in discussing considerations and possible sites.

For us, digging the grave was hard work and took all day. We didn't know how deep to go so we went 6 feet because of custom. We suspect it doesn't need to be so deep. A simple pine box suffices well for a coffin. The day the grave was dug folks here made a fine cedar coffin out of home grown wood at our woodshop.

### The Body

Dealing with Seth's body was a privilege for us. Many people shrink away from the thought of dealing with a dead body. I imagine most of us felt that way before this experience.

*A Manual for a Simple Burial* recommends a memorial service without the body rather than a funeral with an open casket so as to focus on the person's life rather than on the dead body. We did a lot of both. We found it extremely important for people to have contact with Seth's body. When he died we laid him on his bed and folks visited him for the next day saying goodbye and emotionally accepting that he was really dead. Within the day his body began to smell even in a cool room of 50 degrees. So we put him in his coffin and took him to the garden where folks could visit with him until the funeral. We made sure the coffin cover was on securely in case any animals were attracted. It seemed

from our experience, that a body needs to be refrigerated, maybe even frozen, if it's going to be around in an unsealed coffin for more than 25 hours.

### Property

What happens to one's property upon death? It's more complicated than we would have thought. Seth had no property other than a loan to Twin Oaks which he wanted to donate to the community upon his death. Sounds simple. Why couldn't he just have written a simple will to this effect, have it filed in the courthouse and have Twin Oaks do a simple accounting procedure? Even with all the work we did ourselves plus some help from a friend who is a lawyer, we ended up paying hundreds of dollars and going through a variety of processes just to settle a simple estate.

One probably needs a lawyer to do a will correctly. You can to a lot of the legwork but the laws and procedures seem so complex that an attorney you can trust and who is familiar with wills is needed in most cases. To avoid a will altogether you may be able to set up a Living Trust. You can find out more about this from a book called, *How To Avoid Probate* which has forms and a great deal of "do it yourself" information. Your banker can also tell you about setting up Living Trusts.

### SUPPORT SYSTEMS

A fair amount of work goes into preparing for a home death. Ideally that work is carried out by a support system that extends beyond the dying person, immediate family and closest friends. The more the burden is shared by a group, the more support people feel and the easier it is to cope with it all and experience it as a joyous act of service. Support systems can be made up of members from religious organizations, people at work, neighbors, and friends. It is good to pull a support system together early on if there is time.

With Seth, there were two support systems. At Twin Oaks many of us were involved to a greater or lesser degree in taking care of Seth through several operations recuperations, chemotherapy, and as he weakened, in his last months, helping him in whatever he needed. One of us would go in to the clinic with Seth for his regular checkup and sometimes his chemotherapy treatments. When he was in the hospital there were usually two of us with him holding him, counseling with him, reading to him and running interference with the staff. There was a strong co-counseling community for him both at home and in the hospital.

There were also people to take care of the folks dealing directly with Seth, offering them whatever support they needed. As the time of Seth's death drew near, there was an amazing consciousness in the community of full cooperating with the folks coordinating Seth care. This included 24 hour a day care, dealing with a dozen large oxygen tanks, an emergency communication system and taking care of ourselves through it all.

The other support system was a support committee that



Seth's mother, Mary, set up for herself and the rest of her family to help with emotional support and the arrangements for Seth's death. This committee, made up of ten members of their Friends Meeting and a couple of folks from Twin Oaks, researched the information contained in this article, helped the family with emotional and other support especially around the time of Seth's death, and planned the memorial service at Friend's Meeting.

#### YOU'RE IN CHARGE

Many folks do not have the communities to draw upon that we did. A lot of what we were able to accomplish was a result of the basic existence of these communities, both Twin Oaks and the Friends Meeting. It serves as a good

argument for community. But what about the rest of us?

You can contact your closest memorial society, locate a funeral director who meets your needs now, look into hospices, look at the potential support groups around you or consider where you might pull one together, write your will, find in advance what your family wants and needs in terms of your or their death.

Through advance preparation and re-educating ourselves about death in a way that reduces our stress and revulsion toward dealing with it and through our friends, collectives, and existing support groups many of us can experience death and dying in a positive way and as the final stage of growth. □

# Ritual

*Creating meaningful and effective ritual doesn't need to be complicated or difficult. The trick is to create a ritual that is meaningful and appropriate for the people who will be attending. In our instance we got together a small group of people to do the planning. We attempted to synthesize the tastes and desires of this planning group, the community, relatives and friends, and of course, Seth. We provided time for each aspect of the funeral/memorial process. What follows is a brief rundown of the services and rites we found useful. Hopefully, it will give you a basic*

*groundwork from which to create you own dying rituals transposed into your own cultural context. The beauty of our largely ecumenical cooperative movements is that we can freely pick and choose rituals from a geographically and philosophically diverse range of traditions. We are not tied down to any fixed religious institutions, long atrophied with dogma and leached of any real meaning. Even those groups with a firmly established spiritual doctrine are usually reconstructionist, combining elements of both East and West.*

by Gareth Branwyn



*Grave rubbing made by Seth and his family in England.*



## *Pre-Dying Preparation Rituals*

This of course is only possible in the event of a terminal illness or other dying situation that is not sudden. We had planned a gathering (on Seth's request) where he could share with us what it had been like living with us and we could share with him our love and appreciation.

## *Transition Rites*

A ritual can be performed during the time of passing, a farewell blessing or communion with the dying person and those in attendance. In our instance we sang songs, chanted, gave Seth massages, and encouraged him to relax. Guided fantasies were used to reduce anxieties and physical discomfort. As more and more people began assembling a circle was formed, first just in the room and then spilling out into the adjoining living room. At the moment of death we 'om'-ed. Most people then filed out into the living room for silence, crying, and holding each other, while individuals paid their last respects.

## *Post Death Preparation*

This is an area that involves any ritual preparation of the body. Many cultures wash and/or anoint the body, dress it in fineries, paint or alter it in some other way. This can serve as one of the first ritual acts that attempts to impress the mind with the death and can serve as the beginning of the mourning process. We obviously had no established traditions that were particularly meaningful. Seth was wrapped in a decorative blanket and 'dressed' in his favorite jewelry. Many people did pass in and out of the room during that night and the next day, meditating, mourning, accepting.

## *The Funeral Service*

Greeting/Orientation: The morning of the service, as relatives and friends outside the community arrived, we shared with them the night's events, answered questions, lent shoulders to cry on and filled them in on the day's activities. Especially where we have developed our own customs and practices, it is important to take some time with newcomers, discussing what will be happening and what the rituals and traditions mean to us. These people, already in a sensitive state, can be quite shocked or confused by — in our case — an open coffin in the vegetable garden, strange hindu chants, laughter, colorful costumes, and other things not often associated with funerals.

The Funeral: Our service was brief and to the point — a characteristic of our 'ritual style.' We had a chanting funeral procession from the garden to the burial grounds, offered personal farewells, whether out loud or silently, sang a few songs, and then moved on to the memorial service.

## *The Memorial Service*

We did some readings and song sharings that were

particularly relevant to Seth. In many cultures the service immediately following the funeral is a festive occasion. In my Lebanese family it is customary for the deceased to have left plenty of money in the will to pay for an extravagant party complete with fine foods, decorations, barrels of alcohol, traditional music, and dancing. These raucous memorials, often associated with the Irish, can be seen in many cultures throughout the ages. Unfortunately, like many of our other modern day rituals, they have in many cases been reduced to status symbols and a last demonstration of monetary strengths.

## *Costumes*

A trademark of many of our celebrations — solstices, equinoxes, and Community Anniversary — is costuming. Many people can be seen on these occasions altered in a host of different ways. This alteration of the physical by wearing special clothes, little or no clothes, painting the body, cutting hair, beards, etc., seems to be a common practice among tribal cultures. Especially during rites of major life transitions, separating this time from all others, and linking up with 'the ritual space' is more easily accomplished by these costume gestures. Other forms of ritual preparation can include fasting of some sort (from food, sex or speech), isolation, drug ingestion, or some other special acts.

Whatever you or your group decide, keep in mind these rituals are not to be used as a crutch or permanent escape from the reality of someone's death. They are simply to be employed as tools in creating an experience that will be meaningful to you and provide you with a creative framework from which to overcome the emotional trauma of a death.

Dying rituals are a means by which the living perform a ritual 'dance' to recognize and cope with the transitions that will occur in their lives as a result of the death. These rituals mark the beginning of the gradual process of rebuilding that, if successful, will release the living from the psychological weight often associated with the memory of those who have gone before us.





## ritual

**Book of the Hopi.** Frank Waters. An incredible book covering many important aspects of Hopi life and spirituality. Lots of information on Hopi rites and ceremonies. Illustrations. Random House.

**Seven Arrows.** Hyemeyohsts Storm. Filled with moving photographs and text, this classic of American Indian studies (written by an Indian) contains much information about the meaning of Indian names, shields, and the medicines of the Four Great Directions. Full color mandalas. Random house.

**Earth Festivals.** Dolores LeChapelle. A book we've relied on for years in planning our seasonal celebrations. Many exercises and activities for both adults and children. Also includes chants, poems, recipes for ritual foods, etc. Full color mandalas.

**The Masks of God.** (4 volumes) Joseph Cambell. A more contemporary exploration of mythology than Golden Bough with a higher sensitivity to the cultures and practices being studied. An excellent source of material for ritual designing. Viking Press.

**Myths, Rites, Symbols:** A Mircea Eliade Reader. Reane and Doty (2 volumes). A good introduction to Eliades work which tends to be cumberson and heavily academic. Well done editing job on a difficult author to render readable. Harper & Row.

**The American Book of the Dead.** E.J. Gold. A 'translation' of the Tibetan Book of the Dead using contemporary language and symbols. The humorous style and illustrations (drawings by George Metzger in the earlier editions are the best) coupled with the relevancy to today's experience make this book easier to read and more accessible than the ancient dying manuals. I.D.H.H.B. Press.

**Celebrations of Death: The Anthropology of the Mortuary Ritual.** Huntington & Metcalf. The significance of death in various cultures is explored and a variety of death rituals are presented. This book uses death rites as a focus for a general anthropological survey of the ritual phenomenon. Cambridge University Press.

**The New Golden Bough.** Theodor Gastor. A modern translation of James Frazier's original 13 volume study of the ancients and their 'primitive' beliefs and practices. Although Frazier's 'civilized white man observing the howling savages' style is rather nauseating, there is plenty of good material about ancient myths and rituals. Also many songs and poems are included which can be incorporated into contemporary celebrations. New Am. Library.

**Dictionary of Pagan Religions.** Wedeck & Baskin. A compendium of cults, rituals, and other practices associated with polytheistic religions both past and present. Citadel Press.

## legal

### **Memorial Societies**

For information about memorial societies and a list of their locations in the U.S. and Canada contact: Continental Association of Funeral and Memorial Societies, Inc., Suite 1828, L Street N.W., Washington, D.C. 20036. Also try the yellow pages for memorial societies in your area.

**Uniform Donar Card.** In some states a card is part of a driver's license. It can be obtained free from: American Medical Association, 535 N. Dearborn, Chicago, Ill. 60605.

**Putting My House In Order.** A document that provides survivors with a guide for attending to the legal, tax, funeral, obituary and other death related matters. This is not a will or legal document but helps focus a living person on what s/he wants done when s/he has died. 40c/set. 3 sets/\$1.00. Order from Continental Association of Funeral and Memorial Societies, Inc. Address above.

**Manual of Death Education and Simple Burial.** What everyone should have who is trying to take charge of their dying process. \$3.00 order from: Continental Association of Funeral and Memorial Societies, Inc. (address above) or from: Celo Press, Burnsville, North Carolina 28714.

**The Law of Death and Disposal of the Dead and How To Make A Will/How to Use Trusts.** \$5.85 each from: Oceana Publications, Inc., Dobbs Ferry, NY 10522.

**The Living Will.** A request that 'heroic measures' not be used to prolong your life when there is no reasonable expectation of recovery from physical or mental disability. Available from: The Euthanasia Education Fund, 250 W. 57th St., N.Y., NY 10019.  
corrections rest of Seth's Journal





# RESOURCES

The following list of resources should give you some access to the large volume of material [finally] available on *Death and Dying*. Although there is this increasing amount of discussion on the subject, much of it is academic and/or poorly written. There still needs to be

of death and dying — what it feels like to those doing it, those around it, and what we can do to experience it in a healthy way. *To Live Until We Say Goodbye* is an attempt at this and some of the hospice books include 'personal testimonies.' Hopefully this issue of Commu-

nities and its resultant waves of thought and dialog will also help to serve in the liberation of this hitherto deep and dark subject. Towards the light.

Gareth

All reviews by Gareth unless specifically noted.

## Special Interest

### Dying

Miriam Dyak  
New Victoria Publishers, Inc.  
7 Bank St.  
Lebanon, NH 03766  
1978, \$3.00

Miriam Dyak writes in the introduction of *Dying*:

"In 1973 we were a community of four people, two women and two men — potter, woodworker, poet, musician. We had a strong commitment to each other and to a practical, simple way of living. Then one of us, at age 27, became sick with cancer of the colon and after seven months he was dead.

"This book grew out of a journal of notes and images kept during the months he was dying. As a writer, they were my instinctive outlet . . . they were also a conscious expression of creation, a protest against destruction.

"At one point I told (Michael) I was writing about what was happening to him and to us and asked him how he felt about it. He said, 'But you always write poems, that's what you do.' "

This book of free verse touched me deeply with what must be an almost universal experience of dying among a group of people (whether community or family) sensitive beyond the level of "humaneness" offered by the current

death institutions of our culture. Those living a gentle rural lifestyle immersed in the elements can't help but gasp at the sterility and regimentation of a hospital chemotherapy treatment, laced with hollow apologies and calculated smiles:



the gaping chasm between this land of much knowledge, little wisdom and even less healing, and the warmth of HOME — community, friends, lovers, and simple familiarity. The stress and fear of loss, the slow deterioration of the body, and the emotional roller coaster rides

can threaten to destroy even the last vestiges of living. So much to do, so much to think about, to resolve — and in how much time? The love and compassion one can feel for a loved one passing and the guilt of resentment, the disgust at the ugliness of it all. The confusion . . . and, sometimes, the clarity unveiling the beauty, the cyclical nature of it all. The hand of death — Cold? Warm? Both.

Such is the storm in which Miriam Dyak erects a shelter. In flowing word images, trains of thought, and emotional outbursts, Dyak charts the diverse thoughts of a dying "midwife." These poems hold a mirror to the process of dying itself and to the dying person, sometimes profound, then sad, angry, beautiful and intense, always confrontative. Raw to the truth, the reality of impermanence. I was taken back to my own experience of a dying friend and the immense weight of both clarity and confusion that characterized the process. The great wheel of life and death turned in a complete cycle for me in those months. Life and death were equally real, equally present. Miriam Dyak rode this same wheel and chronicled its movement. What she brought back is a passionate, textured statement that is not overwhelming, not life denying, not death defying, but simply, profoundly, human.



### **A Hospice Handbook:**

#### **A New Way to Care for the Dying**

Edited by Michael Hamilton and Helen Reid

Wm. B. Eerdmans Pub.

255 Jefferson Ave. S.E.

Grand Rapids, MI 49503

196 pages, \$5.95

This collection of essays by some of the leading doctors, nurses, and volunteers involved in the hospice movement presents the full range of needs of the dying and how hospice can creatively and effectively meet those needs. (See interview on the New Haven Hospice in this issue for more information on hospice.)

Part One contains several moving articles describing what death is often like without hospice. A reprint from an article by B.D. Colen which originally appeared in the *Washington Post* chronicles "Ten Bad Days Among the Dying," when Robert Buckingham, Evaluation Coordinator for the New Haven Hospice, admitted himself into the Royal Victoria Hospital in Canada as a dying patient. From this cover, Buckingham was able to gain firsthand experience of what it might be like to die in a regular medical facility. Needless to say, it was not pleasant.

Part Two of the Handbook, entitled "The Response of the Hospice," includes a background piece on St. Christopher's Hospice in Sydenham, England (the original hospice), various articles by hospice personnel, and the reprint of a complete case history of someone dying of cancer at a regular hospital. The purpose of including this 36 pages of hospital forms and reports was rather puzzling to me. No notes are given to explain its function. And why isn't it in Part One with similar material? Oh well.

Part Three outlines some of the basic information necessary in setting up hospices in local communities. An excellent Bibliography and Filmography lists additional material available on hospice, death and dying, bereavement, and related subjects.

**A Hospice Handbook** forms a comprehensive introduction and useful guide to this creative and humane method of caring for the dying.

### **The Law of Death and Disposal of the Dying**

Hugh Y. Bernard

Oceana Pub.

Dobbs Ferry, NY 10522

114 pages, \$5.95 hardbound

One of a series of legal almanacs for lawyers and lay people, this little book



contains a lot of useful information on the legalities of death and disposal. It covers in a forthright and readable style the rights and duties of disposal, the nature of legal problems affecting funerals, funeral directors, cemeteries, crematories, etc. Other topics include legal documents, grave markers and monuments, pre-planning and arrangement of funerals. Some state-by-state laws are also listed.

Although not written as a consumer advocacy manual, **Law of Death** presents enough information on laws and funeral industry practices that it serves as an outline of the various legal and business pitfalls to avoid when dealing with death and disposal.

Many libraries carry the entire legal Almanac series and I would recommend that for questions on death and disposal or any other legal matters you consult them. A brochure describing the entire series may be obtained from the publisher.

### **A Practical Guide to Death and Dying**

John White

Quest Books

306 W. Geneva Rd.

Wheaton, IL 60187

171 pages, \$5.25 paperback

**A Practical Guide to Death and Dying** is a simple, sometimes bumpy journey through the varied corridors of death and dying thought and research. Its author, John White, a long time educator in human development, outlines the wide range of abstract and practical approaches to overcoming the fear of, and preparing for, our own physical demise.

The book seems to kangaroo-hop back and forth from the practical (coping with

and admitting fear of dying, writing an obituary, checklist of things to be done) to a discussion of life after death, eastern ways of dying, and other not so practical (but equally important) topics of consideration. A chapter entitled "Scientific Evidence for Life After Death" makes a rather weak argument for immortality with very little if any scientific credibility present. White does bail himself out by mentioning the one excellent study of reincarnational memory that could be called truly scientific (which even many scientists still consider pseudo-science): **Twenty Cases Suggestive of Reincarnation**, by parapsychologist Dr. Ian Stevenson. Someone who is skeptical of such ideas as survival of consciousness after death is going to need more than the few paragraphs on mediums communicating with the dead, stories of ghosts, and spirit voices presented here.

Valuable exercises are included in several chapters offering simple methods through which to gain a greater sense of peace and acceptance of death. A concise chapter on meditation explains how this technique can be effectively employed in reducing fears and anxieties.

The most valuable chapters of this work discuss several service organizations such as The Phenix Society (a friendship association for older men and women), the hospice movement, Shanti Nilaya, and others. The addresses and phone numbers of these organizations are included, a feature often missing in many books.

I came away from **A Practical Guide to Death and Dying** feeling as though two books, covering the same topic, but different aspects of it, had been mistakenly mixed together. One "Book" outlines the spiritual frontiers of dying while the other sticks to nuts and bolts. Perhaps my only difficulty with them being combined is that only one 'Book' is described in the title and both subjects are mixed together in what appears a haphazard manner. This guide will probably best serve as an introduction and stepping stone for further study of the diverse approaches from which death and dying can be viewed.

## **Elizabeth Kubler-Ross**

### **Death: The Final Stage of Growth**

Elisabeth Kubler-Ross

Prentice-Hall

1975; 181 pages



This work, edited by Dr. Kubler-Ross, is a collection of essays covering various topics related to death and dying. Sections include "Why Is It So Hard To Die?", two articles on the fears of death and fitting death into the context of life, "Death Through Some Other Windows," dying and bereavement as experienced by various cultures, and "Death and Growth: Unlikely Partners," which outlines the concept of dying as a growing experience. A beautiful end piece entitled "Omega" is a personal statement by Kubler-Ross and her collaborators on the book, that reads almost like a manifesto on 'humanistic dying.'

#### On Death and Dying

Elisabeth Kubler-Ross, M.D.  
Macmillan, 866 Third Ave.  
New York, NY 10022  
1970; 289 pages

This book has become a classic in the field of terminal illness. Dr. Kubler-Ross applies her years of experience with the dying in creating a useful "map" of the dying process. The book outlines many of the important things the dying have to teach their loved ones, health professionals, and clergy, about their experiences and how they can be treated in a more loving and "healing" manner. The five stages of dying (denial, anger, bargaining, depression, and acceptance)



#### QUESTIONS AND ANSWERS ON DEATH AND DYING

Elisabeth Kubler-Ross

form the main body of the text and each stage is fully explored.

**On Death and Dying** is a very useful tool for anyone involved in a dying experience. It can put many of the tumultuous emotional swings often asso-

ciated with dying into a more clear and manageable perspective.

#### Questions and Answers on Death and Dying

Elisabeth Kubler-Ross  
Macmillan Pub. Co.  
866 Third Ave.  
New York, NY 10022  
1974; 181 pages  
\$4.95 postpaid

This book contains questions frequently asked Dr. Kubler-Ross about the various issues around death and dying, including suicide, funerals, terminal illness, etc. Dr. Kubler-Ross' answers give an accessible introduction to her sometimes cumbersome writing on the dying experience.

#### To Live Until We Say Good-Bye

Elisabeth Kubler-Ross  
Prentice-Hall  
1975; 181 pages  
\$12.95 (Hardbound)

This well done and sensitive work chronicles the lives of four individuals approaching death. In text by Dr. Kubler-Ross and excellent photographs by Mal Marshall, the strengths, fears, power, and insights of these dying patients are made real to us, revealing a gentler, softer side of dying.

## Children and Grief

#### Should The Children Know?

Marguerita Rudolph  
Schocken Books  
1978; \$5.95

#### Learning To Say Good-By

Eda LeShan  
Avon Books  
1978; \$2.95

#### If You Listen

Charlotte Zolotow  
Harper & Row  
1980; \$8.95

This is a difficult topic for me and I've been doing some avoidance, obviously, since I've had these books around for a while. But I realize that my avoidance is the reason these books were written. It stems from my own inability to deal with grief; an inability, according to these authors, that cripples many.

So I'll digress for a short moment. When my father died, death was still a taboo word (and for many even a taboo

event). We knew my father would die and we three girls well on our way to adulthood, learned to live from day to day, helping both our parents in any way we could. We took care of our father whose body was wasting while his mind remained ever clear. Never, never once did we say die, death, or any closely related word — not to him, not to my mother, who in her daughters' somewhat distorted perception couldn't possibly be strong enough to bear the loss of this man to whom she was devoted, and only occasionally to ourselves. Mother felt the need to keep up a strong front for her girls and for Daddy. And as for Daddy, himself, I think he just couldn't talk about those things.

My greatest regret and the reason that I still mourn after these many years is that we did not confront his death. In my mind, I carry about dialogues with him and Mother and my sister, about things we needed to say to each other. Although the shock of his death may not

have been softened, the events of his last days could have been more strengthening.

Please take heed. Helping children deal with grief is a tremendous and difficult responsibility.

Marguerita Rudolph's **Should The Children Know?** is based on her own experiences, those with children whom she taught in nursery school, her grandchildren, and children of people she's known. It deals with children's encounters with deaths of animals, classmates, remote relatives and parents. Her approach to death with children is honest and predictably she gets honest and astute answers from them.

Her book begins with the sudden death of Rachel, a member of Ms. Rudolph's nursery school class. Saddened by Rachel's death and wanting to share her sadness with Rachel's classmates, she first consulted the parents of the children to determine their attitudes



and approach to helping their children deal with death. Most felt that to "tell them Rachel moved" would be an easy answer to the children's questions. But Ms. Rudolph pointed out that the answer would be dishonest and that children have a keen sense for detecting dishonesty. She wanted to tell them that Rachel died. The parents, some reluctantly, agreed that she should do so.

The children's responses to Rachel's death ranged from curiosity (Will Rachel come back? Did Rachel's mother cry when she died?) to realism (When my grandfather died . . . my nanny got herself another man) to resistance (My mother doesn't want me to die). The importance is that an event, too often concealed for children was brought into the open and allowed them to examine and question their feelings about what happened. It allowed the children to express some of their most secret thoughts about death and was probably a first step in enabling them to understand both life and death. Ms. Rudolph goes on to narrate and discuss further dialogues of children who have encountered or are worrying about death.

One of her most important points is that not allowing children to take part in the rituals of death makes the event unfinished for them, makes them feel isolated and even unwanted:

*. . . when parents keep knowledge of death from children and deny them participation in funeral procedures, the children will feel isolated and burdened by confusion and by unexpressed grief. Communicating the truth to children, fact and feeling, when death in the family occurs, encouraging their expression of grief, and bringing children in on whatever religious, spiritual, or ethnic form of funeral are important in developing family feeling and respect for tradition. The personal experience with death can add to the strength and spirit in one's own life.*

Lists and references to books appropriate for children lend an important value to the book.

Eda LeShan directed her, *Learning to Say Good-By*, to the bereaved child. She discussed the range of emotions the child may have and the awkwardness the other children may feel toward a person whose parent has died. It could be comforting for a child of twelve or over to read, but may be more appropriate for an adult reader who can then share with a child certain passages from the book. It focuses strongly on relating stories of other children who have lost a parent in

its frank discussion of the mourning process. For example:

*An idea which may come into your mind is that if you had not loved your father or mother so much, you would not be so miserable now that he or she has died. Maybe it is better just not to love anybody too much! . . . You have had to learn, at a very early age, what some people don't understand until they become much older — that pain is a part of life . . . we need to love in order to live. Sometimes that need will lead to suffering — but it will also lead to the greatest happiness that is possible.*

Other emotions include the fear of losing the parent who is still alive, feeling angry at the living parent, worrying that you, too, may get sick and die, feelings of relief at the death of the parent, and dealing with memories:

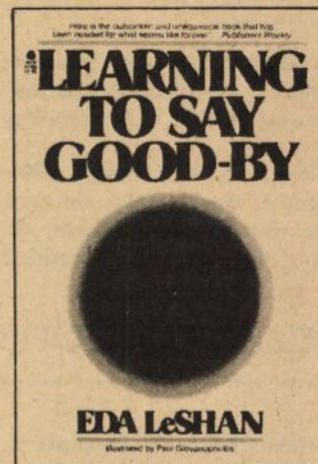
*Difficult as it is, most people begin to recover from a death more easily if they don't try to push away their memories. This is called the "Work of mourning." When something terribly sad has happened to us we need to feel that sadness for a long, long time.*

A most important feature of the book is that it allows the child whose parent has committed suicide to confront that event, too.

*When a parent commits suicide it is very hard for a child to believe that this death, like most others, was caused by an illness. And yet that is exactly the case. Some people get sick mostly in their bodies, some sick mostly in their feelings.*

The reader is reminded that it takes

about a year to say a real goodbye and the book closes with a goodbye ceremony held by the author at the grave of a very dear friend.



*If You Listen* expresses the grief of a young girl for her absent father. We only know that he's been away for a long time. Her mother comforts her by saying, "You have to stop when you're lonely and listen." You have to listen for things far away that you can't see — like the bell in a church steeple, foghorns on the river, or thunder, after lightening. "But I wish he'd come home." The book doesn't offer a way out, but it quietly recognizes the feeling. The beautiful illustrations in this brief book are made poignant by the wistful expression on the girl's face and the kindness and love found in the face of the mother.

*Reviewed by Kay Kaiser Cook [originally appearing in Mothering Magazine.]*

## Briefly Noted

### **The Hospice Way of Death**

Paul M. DuBois  
Human Science Press  
72 Fifth Ave.  
New York, NY 10011  
1980; 223 pages

### **Hospice: Creating New Models for Care for the Terminally Ill**

Parker Rossman  
Fawcett Books  
1979; 238 pages

### **The Facts of Death**

Michael Simpson  
Prentice-Hall  
P.O. Box 500  
Englewood Cliffs, NJ 07632  
1979; 276 pages  
\$6.20 postpaid

A complete guide to being prepared for your own death or the death of someone close to you. Also contains an access guide to dying centers, pain clinics, death and dying education groups and more.

### **Living With an Empty Chair: A Guide Through Grief**

Dr. Roberta Temes  
Mandala Books  
P.O. Box 796, Amherst, MA 01002

Covers the three main stages of grief, giving helpful guidance on how to cope with each, and how others can participate in working towards overcoming grief. Listing of resources materials.



### Gramp

Mark and Dan Jury  
Grossman Publishers  
625 Madison Ave., NY, NY 10022  
1976; 152 pages  
\$6.95 postpaid

One family's horrible, beautiful, and transforming experience caring for a dying grandfather. A photo essay.

A Comprehensive (over 250 titles) annotated catalog of books and audio visual materials on "Death, Bereavement, Loss and Grief" entitled "The

Thanatology Library" is available from:  
**Highly Specialized Promotions**  
228 Clinton Street  
Brooklyn, NY 11201

### The American Way of Death

Jessica Mitford  
Fawcett Books  
P.O. Box C730, 524 Myrtle Ave.  
Pratt Station, Brooklyn, NY 11205  
1978; 319 pages

First released in 1963, this explosive book was one of the first works to expose the greedy, corrupt, and exploitative

multi-million dollar funeral industry. The 1978 edition contains an update on the current state of America's "Dying for Dollars" industry.

### A Manual of Death Education and Simple Burial

Ernest Morgan  
Celo Press, Rt. 5, Burnsville, NC  
1977; 64 pages  
\$2.00 postpaid

By now a classic on simple, humanistic death and burial. Covers donation of organs, burial and cremation, the living will, and more.

## Organizations

**The Grief Education Institute** in Colorado (see "Good Grief" article in this issue) publishes a periodic newsletter containing articles and resources on grief and related issues as well as reporting on the activities of the Institute.

The Institute provides several services including phone counseling, support groups for the bereaved, educational programs for the public and professionals and a lending library on grief and bereavement.

Membership in the Institute, which entitles you to the newsletter, starts at \$15.00. To join or to receive a sample copy of the newsletter, contact:

**The Grief Education Institute**  
2422 South Downing Street  
Denver, CO 80210  
(303) 777-9234

**The Hanuman Foundation Dying Project**, started by Ram Dass and Stephen Levine in 1978, is an organization of people who see dying, within a reincarnational framework, as a process for spiritual awakening. Working with the terminally ill and/or their loved ones, the *Dying Project* staff members share their insights and experiences with the conscious dying process and offer advice on how the dying person can prepare for death in a conscious way. This work includes meditation, spiritual reflection, and acceptance of death as a positive life process and "great teacher."

Stephen Levine, director of the project, gives 3-5 day retreats on 'conscious living/dying' in various parts of the country. These retreats explore, mainly through meditation, attitudes, reactions, and possibilities relating to the process of dying. The process of the moment-to-moment birth and death of thoughts is also explored as a metaphor



for understanding the mind, meditation, and how they relate to the dying experience.

The Foundation also offers a free phone counseling service for those involved in a dying experience as well as publishing a free (donations) periodical newsletter on their work.

For more information on the *Hanuman Dying Project* and its activities, write:

**The Dying Project**  
P.O. Box 2228  
Taos, NM 87571

**The Clear Light Society** is a service and education organization that helps the dying before and at the time of death itself and provides training programs for people wishing to assist the dying.

The basic "technique" employed by *Clear Light* involves meditation and relaxation to reduce anxieties around death and to provide a smooth transition at the time of death. An attempt is made to tailor the dying practice to fit into and complement the particular spiritual be-

liefs and practices of the dying person (including atheism). Write:

**The Clear Light Society**  
P.O. Box 219  
Boston, MA 02123

**The Shanti Project** provides free counseling services to those facing a life-threatening illness, their family and friends, and those who are grieving. They can offer either phone counseling or personal visits by a trained Shanti volunteer. Shanti has no religious or political affiliation and is committed to recognizing and responding to the uniqueness of each individual and each situation as it occurs. For more information on their services, contact:

**Shanti Project**  
1314 Addison St.  
Berkeley, CA 94702  
(415) 849-4980

Elisabeth Kubler-Ross has established a healing center in the hills of Escondido, California, dedicated to the investigation of the process of living as well as dying. Named *Shanti Nilaya* (Sanskrit for "Home of Peace") the center offers retreats and workshops on a variety of topics associated with death and dying and the release from the negative emotions of fear, guilt, and pain that prevent us from living or dying in peace. The Barham method of psychodrama is employed as the main technique of confronting and freeing up negative personality aspects.

Dr. Kubler-Ross also travels, giving lectures for those involved in dying personally, health professionals, and others interested in her work. Write for a brochure describing more about *Shanti Nilaya* and to find out more about Dr. Kubler-Ross' lecture itinerary.



**Shanti Nilaya**  
P.O. Box 2396  
Escondido, CA 92025  
(714) 749-2008

*The Concern For Dying Education Council* is an organization dedicated to exploring and disseminating information on the bioethics of prolonging life through mechanical measures. As medical technology becomes more sophisticated, devices will be able to pump hearts, and raise and lower lungs while the brain has ceased to function. There is a growing demand for the right of individuals to participate in decisions affecting their lives in such "life prolonging" situations. *Concern For Dying* has been involved in these complex questions since 1967.

They offer a student education program, distribute Living Wills, conduct lectures and conferences. CFD offers assistance to writers and researchers interested in probing the issues of prolonging life, euthanasia, individual choice, and related topics. Resources available from CFD include books, films,

and tapes of their annual conferences. A quarterly newsletter reports on recent developments in the field of death and dying.

**Concern for Dying** offers these suggestions on how you can act:

- Clarify your own views on clinical prolongation and euthanasia before death is imminent.
- Let your wishes be known to those people who may be participating in such decisions.
- Discuss the topic with your physician. If s/he is not sympathetic to your views, change doctors.
- Send for a Living Will for yourself, family and friends. Fill them out.
- Contribute to groups like CFD who are involved in such work.

Contributors of \$5 or more receive a subscription to the newsletter, a copy of the Living Will and other material and benefits. To join or to obtain a free Living Will, write:

**Concern For Dying**  
250 West 57th Street  
New York, NY 10107

**National Hospice Organization**  
1311 A Dolly Madison Boulevard  
McLean, VA 22101  
(703) 356-6770

There are now more than 300 hospice groups in the U.S. If hospice is something you want to create or support in your community the place to start is by contacting the National Hospice organization. I found these folks very helpful and they offer a wide variety of books and pamphlets on hospice care, accreditation process, delivery and payment of care, volunteer help and a locator directory. Write for their resource brochure for complete listings and prices.



## ***A Personal Message from the Staff of Communities***



*For almost ten years, Communities Magazine has survived through the commitment of the staff, Twin Oaks and our loyal readers — and without the angels whose golden wings keep most progressive publications airborne.*

*Now, however, we are faced with a mini-crisis: our aging typesetter is owned by the Advocate Press, which for its own survival needs to sell it. Handprinting the magazine seems an unappealing option.*

*\$3,000 would buy a trusty old clunker and related hardware. A few thousand more to embellish our minimalist compensation and support occasional travel and phone calls wouldn't hurt.*

*So, if there are any angels out there, spread your wings and send your tax deductible contributions to: Communities, Box 753, New Haven, CT 06503 [Communities is a division of the Unschool Educational Services Corporation, a non-profit, educational development corporation, approved for tax exempt contributions by the IRS].*

***SPECIAL NOTE:** If you or an organization you're associated with have an old typesetter you'd like to pass on for the good karma and tax write-off, call Paul Freundlich at [203] 878-6982.*





# REACH

*Reach is a free reader service of Communities magazine. Listings should be 50-158 words in length, typewriting preferred. We reserve the right to edit. Dated material requires a minimum of six weeks lead time. Feedback on responses to listings, as well as donations, are welcome.*

*Thanks,  
Gene Lyons*

## Conferences

☆Nasco Institute '81 will be held October 30 through November 1 in Ann Arbor, Michigan. Institute '81 is for anyone interested in coops: members, directors, managers, leaders and newcomers. Workshops will cover many areas: food, housing students, energy, workers, warehouse, federation and other kinds of co-ops. Some workshops will focus on skill-building, while others will provide the chance to plan for the years ahead. For more information on Institute '81, write to:

**NASCO**  
Ann Arbor, MI 48107  
(313) 663-0889

☆Planetary Peace Feast — On Saturday, October 24th, 1981, (United Nations Day) you are invited to the Planetary Peace Feast. Whenever you sit down to your evening meal on that day, wherever you may be, please join together in spirit with all people on earth as we celebrate our membership in the one family of humanity.

Please don't allow this invitation to stop with you. Circle the date on your calendar and pass the idea on to as many others as you can. Our hope is to reach as many people as possible, in all

nations, with the invitation by October 42th.

Possible ways to extend the invitation:

- Copy this invitation and give to friends, enclose with personal letters, post on bulletin boards where possible.
- Submit the information to any newsletter, bulletin, paper or group announcement you can think of.
- Make a special effort to reach friends or contacts in other countries and ask them to help widen the circle.

This idea belongs to all of us and is sponsored by no particular group or organization, only by the good will of all who become part of it.

Ideas, suggestions, input:

**PPF**  
Box 3911  
Pittsburgh, PA 15219

☆Ozark Area Community Congress — OACC will convene the Second Ozark Congress (OACC II) October 9, 10, 11, and 12, 1981 at Alley Spring Park, near Eminence, MO (Ozark National Scenic Riverways).

All representatives from the First Ozark Congress (OACC I) are called to convene the Second Ozark Congress. All other people concerned about the environmental, political, technological, agricultural, and spiritual aspects of life in the Ozarks and surrounding Bioregions are invited to come to OACC II as Representatives of your watersheds, localities, agencies, groups, philosophies, organizations. As Representatives, we ask you to join with OACC to continue the process of evolving the Bioregional order according to the body of ecological law — the OACC Resolutions — ratified by OACC in October, 1980 at OACC I, and developed by OACC through the ensuing year.

As with OACC I, OACC II will be a working Congress needing your active

participation for the full session. Please come prepared to share with the Congress, and Standing Committees with which you participate, your or your group's work as it relates to the ecology and politics of the Ozarks. There will also be a number of exceptional workshops and presentations.

Pre-registration is necessary for our planning.

Attendance fee: \$5.00 — Barter and trade agreements acceptable (preferably by prearrangement through pre-registration).

Make checks payable to: Ozark Area Community Congress.

Mail registrations, fees, and information requests to:

**OACC**  
Box 67-2  
Caulfield, MO 65626

☆"Learning for the Community" is the theme of an upcoming national conference on non-credit programs. The conference, which will take place Thursday, Friday and Saturday, October 22, 23, and 24, 1981 at the Broadview Hotel in Wichita, Kansas. The event is sponsored by Lifelong Learning Resources, a lifelong learning technical assistance center, and the Free University Network, the national association of free universities and learning networks.

Nationally recognized experts in the field of lifelong learning are slated on the conference agenda. Among the major workshop presenters is Helen Farlow, the author of **Publicizing and Promoting Programs**. Others on the conference agenda include Joan Flanagan and Gerald Graham.

The registration fee for the conference is \$75 (\$55 to members of the Free University Network.) Fee includes all conference materials, all conference sessions and a banquet luncheon. Any one desiring additional information



should call Julie Govert Walker, conference coordinator, at (913) 532-5866, or write:

#### **Learning for the Community**

1221 Thurston  
Manhattan, Kansas 66506

☆ The National Historic Communal Societies Association will sponsor the eighth annual Historic Communal Societies Conference at the Ephrata Cloister in Ephrata, PA on October 15-17, 1981. The conference theme is "The Musical Heritage of America's Communal Societies." Performances of the original musical compositions of the Ephratans, Shakers, Harmonists, and Moravians are planned. Those wishing to give papers or to present updates from their communal research or current communal experiences should contact Dr. Donald E. Pitzer, Center for Communal Studies, Indiana State University Evansville, Evansville, Indiana 47712. To register for the conference write:

**Mr. John Kraft, Curator**  
Ephrata Cloister  
Ephrata, PA 17522

☆ The Ministry of Patrimony and Industrial Development of the Federal Government of Mexico, takes great pleasure in inviting you to participate in the Second Annual World Technology Fair, **Technology for the People [Tecnologia Al Servicio Del Hombre]** which is to be held in Mexico City, November 6-13, 1981.

Technology for the People is a multi-staged exhibition promoted by the United Nations Organization through the United Nations Development Program and other U.N. institutions. This fair is a forum to analyze improved technical innovations serving to open new ways in industrial development. In conjunction with the Fair a Technical Congress is going to be held due to the availability of many experts in applied technology.

We are looking forward to welcoming you in Mexico City both as a participant or visitor in Technology for the People.

#### **Ramon Gonzalez Jameson**

General Director for Joint Ventures and International Affairs

☆ The 17th Annual World Festival of the Unity-in-Diversity Council will be presented in cooperation with the Festival for Mind-Body-Spirit January 15-17 1982 at the Shrine Exposition Hall in Los Angeles.

The Unity-in-Diversity Council will bring together a particularly unique and

prestigious program of lecturers and workshop leaders, beginning with a Unity-in-Diversity Celebration in the 6500-seat Shrine Auditorium on Friday evening, January 15th. It will also provide an interaction process designed to maximize ongoing cooperation among organizations and individuals throughout the year. The Festival for Mind-Body-Spirit will showcase the organizations and presenters in each of the following areas: wholistic health; environment, ecology and energy; arts and crafts, media; spirituality and esotericism; fitness and nutrition; human and social potential, and much more. For information on the Festival and exhibition space write to:

**Unity-in-Diversity**  
c/o World Trade Center  
350 S. Figueroa St.  
Suite 370  
Los Angeles, CA 90071

## **Groups Looking**

☆ Intentional Community looking for people who are interested in being a part of a loving, sharing group, and/or using creative technology in the service of people.

We are involved in: wholistic health and lifestyle counseling; microcomputer sales and service; renovating apartments and houses; foster care for teenagers; running a hardware store; making music; producing solar energy; and growing food.

Our community includes more than twenty people, with diverse spiritualities and insights into a life of service. Our vision is a self-sufficient neighborhood-based community; we're interested in folks who can share and expand that vision.

A non-smoking, drug-free community, we live in an older neighborhood in Arlington in several houses on the same block. Economically independent, we work where we live, intimately sharing play, chores, celebrations, ourselves.

If you want to learn more about us, please call Michael or Melanie at 528-3200.

#### **The Community**

2800 N. Pershing Drive  
Arlington, VA 22201

☆ Wanted Co-op Warehouse Collective Members: to share in the responsibility of the national cooperative herb, tea and spice warehouse. Requires people that

are interested in all aspects of order-processing, including shipping, repackaging, order pulling and computer terminal operation. We are looking for adaptable persons, willing to assume responsibility, with basic herb and spice knowledge. People with coop trucking experience interested in over-the-road tractor-trailer driving are also urged to apply.

Call or write:

#### **Frontier Cooperative Herbs**

410 Vanderbilt St.  
Fairfax, IA 52228  
(319) 846-2591

☆ We are a beginning semi-suburban community concentrating on alternative energy and preserving natural environment. Our two households are in two adjacent houses with our pasture, fruit trees and organic garden close by. In our adjacent travel trailer, and in a new solar house we are building — we have room for more residents — all ages. Residents work in the community part-time or full-time. No cash investment is required.

Our direction is toward simplicity, equality, practicing the Golden Rule, love and growth. We plan to become more self-sufficient through continuing solar house building, and/or future wood-working or other enterprises, and an alternative school. All our real property is cooperatively owned.

Inquiries are welcome, visitors likewise. Visitors should make contact ahead to learn what space we have left.

#### **Teramanto**

10218 147th S.E.  
Renton, WA 98056  
(206) 255-3563

☆ We've established a small rural community here in NE Wisconsin that for the past 3 years has given us many psychological rewards.

Two of our most important standards, open honest communication (no secrets) and polyfidelity (non-monogamy), seem to be at the heart of what leads, for us, to a feeling of lucid serenity, warm companionship, and unlimited possibilities. The honesty assures us that we're in touch with all the information we require to take care of our own needs; and our goals for expanded families allow us to move towards greater intimacy wherever it develops in community without a sense of conflicting loyalties. The result has been accelerated personal growth.

Some of the other ideas emphasized in our social contract are personal respon-



sibility, equality, verballity, economic sharing, and ecological self-sufficiency.

If you're intrigued, send comments and questions and we'll try to fill in the details of this general outline. Right now there are three of us: two women and a man. We're looking for others of any sex or sexual preference who might share our ideals and goals.

#### **Shiloh Community**

Rt. 5  
Sturgeon Bay, WI 54235  
(414) 743-9679

## Groups Forming

☆We are a young family; we laugh, we cry, we fight, we make mistakes, we keep on keepin' on. We want to survive the holocaust — the worldwide chaos we see approaching on the horizon. We are active environmentalists with a deep respect and love of Mother Nature. We are seeking a young mother, 25-35 approximately, race not relevant, attitude and determination are very. We feel that extending our family will be a benefit and enrichment for all concerned. If you want to be in the mountains within 1-2 years, love nature and can give and receive, all else will work out. Please let's communicate now. Reply to:

#### **R.F. Beacon**

Box 210  
Streetsville, Mississauga  
Ontario, Canada

☆We would like to share our house in suburban Philadelphia with a person or couple w/wo child. We are forming an expanded family to practice Jewish communal living.

As an experiment in Guided Evolution, we seek to develop a low resource use life style, with high ego satisfaction. House rules are: a Kosher kitchen, no drugs, no smoking and marital sex only. For more information on the philosophy of Guided Evolution, or if interested in becoming part of the Jewish Family-Community movement, contact:

#### **Ernest and Elaine Cohen**

525 Midvale Ave.  
Upper Darby, PA 19082  
(215) 352-2689

☆House/lot available in 240 acre Land Trust in northern Maine 90 miles north of Bangor. We have been in existence 8 years. Looking for independent, grown-

up people with experience in country living, preferably in a remote area. The philosophy is live and let live/intelligent use of the land. Two houses built and also large garage and small barn. Pond. No electricity. Presently one couple in year round residence. For more information contact:

#### **Battlebrook Farm Trust**

c/o Mark Tuveson  
16 E.J. Lopez Ave.  
Cambridge, MA 02141  
(617) 492-3130

☆We are two no-egg/no-dairy vegetarians. We live at a place called "Godsland" in Kettle, Kentucky. It's open land and there is room for many more people. We'd like to see some sort of community come together here but we're not especially attached to "running the show" or to a lot of structure. Children are welcome. Interested? Write to us. We'd like to hear from you.

#### **Willow and Lexly**

c/o Windspirit  
Box 160  
Kettle, Kentucky 42752

☆Wanted: A partner, person, couple or family with some means and ideas for a new venture — a Nature Park and Health-oriented retreat on 250 acres of beautiful farmland and woods, with survival, self-sufficiency and income for a potential commune in mind. Write:

#### **Eden II**

Lee Brook Land RD2  
Salem, NY 12865  
(518) 854-7806

☆We are a couple with two children; Morgan, 5, and Rebecca, 3. We want to join or start a community that will, hopefully, evolve into an extended family. We are to the left politically and socially, non-religious, free-thinkers, flexible on most things except honesty and work. We own 50 beautiful acres and multiple living quarters suitable for a sane ecological community or as a staging area for future relocation. We prefer families with young children, single women or men with children, or couples, but, if you are single and truly committed, please contact us.

#### **David and Margaret Randell**

Rt. 2, Box 526  
Hiddenite, NC 28636  
(704) 585-2798

☆Couple with top-producing dairy goat herd interested in relocating to supply natural dairy products for well-estab-

lished, multi-dimensional community with emphasis upon environmental welfare. 10 years experience in rural lifestyles.

#### **B. Thiel**

Star Route  
Benton, Wisconsin 53803

☆We are a mature couple, man 63, woman 37, in excellent health and into simple living. We seek a communal situation, rural or urban, anywhere in the country, or outside the country, where we can get away from the plasticity of modern living and get back to basics. We, at the same time, want to remain in the real world in terms of keeping in touch with the progressive struggle around the world and at home, and making whatever contribution we can towards bringing about a more humane and just world. Climate is also important; we desire a non-enervating climate, avoiding extremes of heat, cold and humidity. In a nurturing environment that has a lot to give us, we also have a lot to give back.

#### **Allan Black**

1697 23rd Ave.  
San Francisco, CA 94122

☆Politically aware Black couple, Mother Earth lifestyle, non-materialistic, friendly, non-racist; with cooperative ideas.

We are owners of 20 beautiful bottom land acres in long-growing-season south Georgia. We are located in a secluded but not remote farm area 35 miles from 2nd city, near schools, university, hospital, etc., and only one hour and forty minutes from Atlanta. We are in the process of establishing an organic self-sufficient farm and community. We are also establishing a natural foods (Veg-Meats-Grains) outlet. We have various tools, bus, and truck but are short on help.

We seek open, natural female(s) and/or couples with creative abilities, ideas, and some resources (whatever) to work with us as full partners in development of this project. We are also trying to establish an alternative learning center and craft workshop retreat for adults, but lack the funding (\$19,000) to purchase the 30 acres adjacent to us. This acreage has a 4 acre underground spring fed lake, beaver pond, hard and soft wood, 2 acre, cleared fertile soil, drilled well and hilltop site for possible wind/solar applications. Any foundation contributions welcome, but would join with others that might like to purchase if



you interests are similar. Correspondence welcome from all.

#### **Alton DeVille**

Karol Martin  
c/o 701- AMoye Road  
Columbus, GA 31907

☆ Women only — rental space available to meet your needs. Unique, very private home, pool, courtyard, trees, nature, outside shower. 5 bedrooms/4 baths. Share main house or private space.

Seeking: mature, neat, preferably non-smoker, no children — no heavy drugs.

Current occupants are 25-40, non-smoking, vegetarians.

Rates: \$40 to \$56 a week. For more information contact:

#### **Marty Hicks**

350 Arlington Road  
Jacksonville, FL 32211  
(904) 724-4124 or 744-9071

A Solar Village with 50 membership and a Centre for Appropriate Technology with 20 memberships. Seeking individuals and families strongly attracted to Australia, of one-earth consciousness, committed to win/win communication processes and on spiritual paths.

Both projects will be located on ocean lands on the island state of Tasmania and will feature: Permaculture land-use design; Seminar/Training Centre to serve others and provide economic base for members; Private homes; Meditation sanctuary; Biodynamic food production; Fruit and nut orchards; Wind, water and solar energy production. We will work toward food and energy sufficiency and cooperate with other communities in a regional self-reliance network.

Wonderful weather, schools and economy.

Centre for Appropriate Technology to begin early '82 and needs specific small-homesteading skills.

#### **Dr. F. Gordon**

101 Baintree Pl.  
Los Gatos, CA 95030  
(408) 378-6771

☆ Dividing a beautiful old church into four extra-large "apartments." Each is planned for living and for bulky art, crafts, film-making, collecting, performing arts, etc. Lots of space for co-operative living/work. Financing available to co-owners. Units have 2500 to 4000 square feet, two baths. Church building is 90 years old, in excellent condition, less than three miles from downtown

Portland, good public transportation. Project is intended for mature people. Write:

#### **Arthur Lind**

M.P.C. Restoration Project  
2456 S.E. Tamarack Avenue  
Portland, OR 97214  
(503) 233-1917

☆ Cooperative Village forming in the Ozarks. Ecological balance, simple living. Aim: 32 households on 160 acres. 2-acre homesites, rest common land. Household membership \$2,500 includes investment in village industry. Send SASE to

#### **Living Lightly Village**

c/o EcoCenter  
730 W. Maple  
Fayetteville, AR 72701

☆ Ideal homestead for community groups. This forty acres in the Missouri Ozarks provides the peace and quiet, clean natural environment and homesteading facilities that many community groups are looking for, including:

- Large turn-of-the-century Victorian farmhouse, completely renovated and insulated.

- Energy efficient and ecologically conscious systems:

- Solar greenhouse

- passive central wood furnace with

- wood water heater and sauna

- solar and water heater

hydraulic ram water system  
modern composting toilets and  
greywater filtration system

- The homesteader's farming needs:
  - two story barn, 3000 feet
  - extensive terraced garden, organically fertilized and cultivated for ten years
  - young orchard, several mature fruit trees
  - live spring runs all year
  - fifteen acres pasture/twenty-five acres woodland

For more information or a tour appointment, contact:

#### **New Life Farm**

Drury Missouri 65638  
(417) 261-2553 price \$80,000

☆ The Cherry Hill Cooperative Cannery in Barre, Vermont is in its sixth year of operation and appears solid and expanding. The cannery is a place for members to do their canning with supervision, large equipment and at 'cheaper than you can do at home' prices. The folks at Cherry Hill are also going into commercial production, offering 500 pounds or more orders of maple syrup and apple products at real cheap prices to communities and cooperatives.

For more information, contact:

#### **Don Padgett**

Cherry Hill Cooperative Cannery  
M-R 1  
Barre, VT 05641

**Twin Oaks Community** is selling the 87-acre property on which its Merion Branch was located. Situated in the mild climate of central Virginia's Piedmont area, the property is unmistakably rural, yet lies within 100 road miles of Washington, D.C., and less than 40 miles from Richmond. Most of the property is gently sloped woodland, bearing timber professionally estimated in excess of \$10,000. Of the approximately 10 acres which are presently cleared and tillable, the garden portion has been strictly organically managed for at least the past 8 years. The land adjoins a year-round creek, and abounds with deer and other wildlife.

Buildings on the property include a 6-bedroom house, large barn, and several small cabins (all with electricity) in addition to various sheds and outbuildings. The main house has an oil-fired hot air furnace, 2 chimneys for woodstoves, gas kitchen range, kitchen sink, bathroom tub/shower and sink, a well, septic system, telephone, etc. The property fronts on paved, all-weather State Route 646.

We are asking only \$80,000 for this property — complete — because of two principle factors that hold down its otherwise greater value among potential middle-class purchasers: the highway frontage is short (less than 100') and the house, though structurally sound (built ca 1930, extensively enlarged 1972) does need remodeling, including major plumbing work.

A communal group or other purchaser willing to accept those two principle liabilities can obtain an excellent value in this property by contacting:

#### **Isaac**

**Twin Oaks Community**  
Louisa, VA 23093  
(703) 894-5126



*continued from pg. 35*

reinforcing particularly the feelings and relationship with other walkers. It's a good way to meet people and groups who are into what I'm into.

I'm also helping the CW folks prepare for the march, making banners, etc. Ironically we were using aerosol spray paint to make ban-the-bomb banners, trying to prevent destruction of the world in one way but furthering it in another (through depleting the ozone layer etc. with aerosol cans). This bothered me somewhat. Generally though, I'm feeling quite positive right now and meeting some folks and doing some good activities. Hooray.

#### *August 14th*

Right now I'm in Yosemite Park with some good folks. There was an interesting incident on the way up to Mariposa from LA. I spent the night in Madera and the next morning who should come marching thru but Cesar Chavez, and other UFW people on their 1000 mile march on Gallo. They were marching to Fresno (about 30 miles away) where there was a UFW convention on the weekend. I talked to Cesar a short while and then joined the march for about 15 miles.

#### *August 19th*

I left Richmond exactly a month ago and have spent about \$40. Fun facts to know and tell.

I got back into LA yesterday after about 5 days in Yosemite out of contact with the outside world, hiking, meeting good folks, partying every night, not bathing for a week.

#### *September 10th*

I have completed my move into the CW house and now am a member of the community for all practical purposes which means I will be working at the Kitchen Mon-Fri (about 10 hours a week) and attending all of the obligatory meetings, twice a week discussions, study groups, weekly business meeting, monthly personal meeting. I'll have an opportunity to get into the activist side too. Current projects are WRC Intercontinental Peace Walk (organizing for) and organizing around nuclear power-disarmament. The people here are all warm and open to me living here. The only aspect of this lifestyle I might not get into much is some of their spiritual beliefs and practices. I am going to attend liturgies for a while and see how I feel about continuing. There is no obligation or compulsion for me to attend masses, etc. They only expect me to be open and tolerant, which I feel I am.

#### *October 3rd*

One of the reasons I have been writing so infrequently is because I can't find the time for it. Between the kitchen, community meetings, politically oriented meetings, other various happenings, and spending relaxed, unstructured, non-business time with fellow community members plus showers, meals, etc., there is very little time left for reading, writing, meditation. This is something that I miss.

I have made a couple of resolutions about my personal behavior. 1. To try not to eat as much. I feel it is wrong for

me to be eating beyond my needs when there are others who are starving and malnourished partially because of the overconsumptive wasteful lifestyle of Americans. This does not mean I will not enjoy what I do eat. If I find I am losing a lot of weight I will reconsider this 'resolution' for that might be a sign I wasn't taking care of my own needs. 2. I'm going to try to stop asking people's ages or using their chronological age as a major decisive factor of how I act and react with them.

#### *October 9th*

The bulk of our time and energy goes into our soup kitchen on Skid Row, where we serve 600 plus lunches a day. Other services on the Row include a once a week free medical clinic, and twice a week clothing room. We also can provide lodging for up to four people. Generally people are limited to a stay of three days. We also put some energy into our peace work and our own community.

#### *October 14th*

Impressions and thoughts etc. after 5 weeks in the community. This is by far the longest I have remained at any community I visited this far in my journey. As expected, much of the romance and glamour wears off after one has made a commitment other than that of 'visitor' and starts getting into day to day routine and more responsibilities. Now that I've gotten down the basics of living here, I'm starting to become aware of parts of the dynamic and structure that aren't obvious at the beginning. Consequently I have been up and down the past few days thinking about various aspects of the community and my place in it. This is the first time since joining the CW that there has been any down times.

#### *October 17th*

This evening is perhaps the best time I have experienced since joining the Worker. Ironically little of the wonderfulness was directly connected with the community. Tonight several of the community and friends went to see a modern adaptation of "Electra." I think it's the first time since hitting the West Coast that I saw any live theatre. Leisure activities involving other than the community are rare.

Another non-CW person who came with us was Spring, Bob's lover from back home. He had told me a lot about





Feeling good about being with open loving folks of similar persuasion and being out away from person-made cities with the redwoods and birds which do what they do without profit motive, manipulation or conspiracy. It is good for me to be with people my own age who are into similar things and basically pretty together.

One of the things we did in formal groups was play the 'Name Game,' which is partly to help learn names and also perhaps tell other folks something about yourself. I took the name 'Highway Searcher.' I really like the way it sounds. Seth-Highway Searcher — it seems appropriate right now. Something to live up to.

Had a really fine meeting for worship today in the midst of the redwoods. I spoke, the first time I ever have in a meeting.



#### *April 18th*

Easter Sunday — The whole tone of my travelling is different as compared to last spring and summer. It is a lot less planned out and more flexible. In the past, most of the hitchhiking I've done has been with the intention of getting wherever as quickly as possible. This time round, I'm taking things a lot slower, more easy-going; it's good.

I have lately (within the last few months) really been able to get into watching the ocean. The continuous motion and rhythms remaining constant but always changing. Waves seem almost like orgasms — swelling slowly, reaching a high point then crashing and foaming back down to calm and being drawn back again, the whole process repeating itself.

#### *April 19th*

"It's good to know the ocean,  
know it as a friend.

It's good to know the ocean  
will be there til the end."

from a song by Seth Arginteanu

It's just within the past few days that I consciously realized that one of the reasons I dig hitchhiking and will sometimes even thumb instead of taking a ride with someone I know, is that it gives me a feeling of independence. It's good to have that feeling after the past seven months when my self-image often wasn't that high. Feeling that I wasn't responsible enough, didn't take initiative in too many situations. Overcoming my fears in those and other areas are real things I must deal with eventually but it's also important to feel that I am a good person despite my failings.

#### *April 20th*

"They got some awful awesome waves  
Down at Point Reyes

Yes, if you ever saw some

You would say they're awesome."

from another song by Seth Arginteanu

It is plain to see that the ocean brings out my creativity.

#### *April 24th*

Berkeley — I should learn how to better structure my free time. Meditation, learning a craft or musical instrument, physical activity other than walking, yoga, take classes in any number of things. Much of this would have to wait til I settle down again. My leisure time activities presently consist of reading, spending time with friends, writing in journal, getting high, occasional partying, walking by myself, probably have left out a few.

I compare myself to others a lot and get down on myself for not having learned a certain skill or developed a certain direction. I forget too much that I am still very young and that I, what I am doing, the experiences that I have had are very worthy things many other people never get the chance to do. It's good to be reminded of that.

#### *May 10th*

The Whole Earth Festival — I was a dancer the whole weekend. Dancing is such a joy, worship, release as individual and in group. It was fantastic when there were a lot of people up dancing. Everyone's face was so shining. I think I have had the dance spirit within me always but only recently is it coming out. This weekend was the most and happiest I have ever danced. My favorite music to move to was the conga drums. So basic, animal.

There are gatherings and celebrations like Whole Earth Week happening all summer and I might try to hit a lot of them. After the Missouri Communities Conference I'm probably heading back out West, see and feel more redwoods, waves, birds. On Memorial Day Weekend there is a gathering up in Albion, Mendocino. I would like to travel up then anyway so I may attend Albion Fair as well.



On June 5 and 6 The Rainbow Family is having a gathering at Mt. Tamalpais. I want to go to that one, and then I can go to Berkeley on June 8 to vote on the Nuclear Initiative.

Another gathering that I hope to attend this summer is Pacific Yearly Mtg. to spend time with all my Jr. Friends friends. This is amazing. When I set out a month ago, I had no plans past the Jr. Friends Retreat, except for the Communities Conference. Now I've nearly filled my whole summer up.

### *May 13th*

Am now in Missouri about 80 miles north of U&I Ranch where the Communities Conference will be.

Yesterday I was feeling some burnout both physically and emotionally from being on the road for four days straight. The emotional burnout manifested itself through general anxiety about the direction of my life. "What the fuck am I doing?" I quickly realized what was going on and didn't allow it to develop very far.

### *May 18th*

Homesteading and Communities Conference — The conference changed the direction of my life in how large a way I don't know yet. I met several people from East Wind Community, one of whom remembered me from the T.O. conference. I decided since I was in the area I might as well visit East Wind which is where I am now.

East Wind is a community based on the Walden II — Twin Oaks model, planner-manager government, labor credit system, non-sexism, non-violence, perhaps behaviorism. They are also into rapid growth. I feel from what I know now, all words written and spoken, I could enjoy living here and grow as well, particularly in the area of building and gardening skills.

At this point, my feeling is that I won't commit myself to

any place for a long time but I've been known to change in the past and it will be interesting to see how I feel at the end of two weeks here.

### *May 31st*

I'm starting to get attached to this place. God, am I going to pull another one of my unplanned joinings? Whatever happens. Although I still doubt it at this point.

Starting to get to know some people. Tonight someone told me I blended right into the woodwork, which I took to be quite a compliment.

### *June 13th or 14th*

If I was to settle here, would want to get into construction, small carpentry projects, leather, food processing, garden.

Relationships: Feel the need for a lover. I wish I didn't feel it so much because I find it sometimes effects my actions and attitudes in undesirable ways, mainly trying to spend most of time, being most interested in establishing relationships with people I am sexually attracted to, which means less energy devoted to relationships which are non-sexual, but just as important.

### *June 26th*

Travelling again towards Montana and the Rainbow Gathering and whatever else. I think I may be back here to live.

### *August 1st*

Los Angeles — My health at the present time is shitty mainly from being on the road I imagine. Experiencing a lack of energy, my stomach and digestive system have been giving me some problems ever since overeating for a week. I'm also continuing to have periodic chest discomfort which started before I left L.A. Being back isn't helping at all, I'm sure. I will try to get an X-ray while I'm here.

### *August 3rd*

Surprise. I am in LA county USC Medical Center about my chest. I went to the clinic Monday nite to get a TB test. The doctor listened to my breathing and decided I needed more than a TB test and an x-ray and referred me to the hospital.

Apparently I have a lot of fluid in the right lung. It has always been the right side that was giving me trouble, but I think the fluid is a real recent development. Starting Sunday nite my chest was hurting more than it ever had, a rather sharp pain which has not let up too much since.

Surprisingly, I have not felt very worried or anxious except in a couple of instances, neither preceding my entry to the hospital, nor since. Glen came with me and followed me through till I was admitted to a ward. It made things easier, and certainly was a wonderful, loving gesture.

Entering the hospital is something like hitchhiking, a lot of waiting with bits of action interspersed.

I received my 'official' welcome to LA on Sunday. I was stopped and questioned by a policeman, because I look young, out of place in Pershing Square at night. Looking





back it hardly qualified as harrassment, certainly minor compared to my previous encounters. But it sure pissed the hell out of me.

The police harrass poor people so much. The same policeman and his partner had been walking the square making sleeping folk wake up. (They were being lenient. I've seen people busted for the same 'crime.') The police emptied out an open beer that a man was drinking then reached in his bag, opened an unopened beer and poured that out. Going beyond the call of duty, I'd say. People are always getting harrassed and busted cause they have no where to go during the day or nowhere to sleep at night, or because they just look suspicious. The police prey on the powerless.

The Skid Row garden materialized and it's doing just beautifully. I was extremely impressed when I saw it.

### *August 6th*

Still in the hospital, as expected. Some of the time I feel like I'm going stir-crazy in this room. It's hard for me to concentrate, or read, or right now, to write, cause the TV is almost constantly blaring. Luckily, I've been getting visited a lot by community folks and it sure makes a difference. From that perspective, LA was the best place for me to go into the hospital. In Richmond I imagine my family would've visited every day, and friends that still lived there would've come by occasionally but here I've been getting three or four sets of visitors a day, people I feel really close to.

I called up my parents a couple of nights ago to let them know I was in the hospital. They reacted well with expected parental concern and anxiety but not hysterically. They are more worried than I am, I think. Over the phone it was mentioned that they might fly out here even if the diagnosis was just TB which can be cured relatively simply through medication. I only hope that it is something that can be so easily remedied.

### *August 14th*

Well, they finally decided what they're going to do with me. Yes, folks, they're going to put me under the knife and remove the fibrotic tissue in the pleura which is preventing my right lung from working properly. Surgery is scheduled for Monday. Saturday evening — some changes in strategy. Although I related above, I feel psychically prepared for surgery. Most everyone in the community is having doubts about going ahead with it on Monday. They met together and decided that if possible we should postpone the surgery until we can get a second option.

I just want to get everything over with, get out of here, and get back to doing what I've planned. Even that might be a little difficult. When my parents talked to my prospective surgeon on the phone, he told them something about post-op followup that he hadn't yet told me. That is: I would have to come in to be checked out once a week for the first two weeks after being released, then once a month for a couple months. My father is talking about me either staying in LA or Virginia during that period. I would really like to have settled down at East Wind by then. I don't know if they could handle follow-ups out there very well or

not. We'll cross that bridge later on, if I ever get out of this fucking hospital.

### *September 8th*

We last left our hero as he was about to enter surgery which was to remove thickened pleural tissue, reexpand the right lung and try and determine what caused the disorder in the first place. Well, I have been making swift recovery and have been out of the hospital since Friday. As they say the operations was a success, but . . . When they opened me up they found a big tumor attached to the chest wall. They removed all the tumor and sent it to the lab to be checked out.

As we all know, where there's tumors there could be cancer and with this fear in mind, my father and sister came out to LA to join my mother. We waited several days for the pathology report to come back. I was not particularly anxious especially because I was under the erroneous impression that since all of the tumour had been removed my worries were basically over, whether the tumour was malignant or not.

The pathology lab reported that it was indeed malignant. The tumour turned out to be a rather rare form of malignancy, a sarcoma as opposed to a carcinogen, and a rare form of sarcoma at that. I can't do anything just like everyone else even in the cancer I get.

I still wasn't too worried even after an intern corrected my impression that there was no longer anything to be concerned about. I was still thinking that I could proceed with plans after a slight delay. It was only after they started talking about a chemotherapy treatment plan that would extend over a period of a year or more since it would require frequent trips to the oncologist and East Wind is very far from an oncologist, my plans were starting to get blown to hell.

After a lot of waiting (of course) I got to meet with the chief oncologist, with whom, as with most of the other hospital staff, I am quite impressed. He was straightforward with me and said he would recommend a year and a half treatment program, and if I didn't go into remission, chances of recurrence were high. They can make no promises as to the possibilities of success of the treatment. My form of cancer is rare enough that they do not yet have enough data on which to base statistics.

Anyway, what this all boiled down to, basically, was that I was going to have to decide whether I was going to spend the next year and a half of life in LA or Richmond, Virginia. Both places which I had chosen to leave. This, for me, was the most difficult part of my ordeal. This was the one I had most trouble dealing with. I could not conceive of living for a year and a half in either LA or Richmond and remaining very happy or sane. After much internal turmoil, I decided on Virginia. The major factor in my opting for Virginia is that Twin Oaks is only about 60 miles away from Richmond, and after the treatment is underway I could feasibly live there and continue with chemotherapy. As to whether Twin Oaks will accept me under somewhat special circumstances or whether we will be compatible with each other, I am hoping for the best but at this point I don't really know.



I had had my heart set on returning to East Wind and was very upset that I could not. I know T.O. is structurally similar to EW and there is also a lot of communication and other interchange between the two and so I am hoping to feel in some way still connected with EW and perhaps even see certain individuals occasionally.

Coping with all this heavy stuff. In general I feel that I am coping very well since the whole ordeal started. Of course, I have at various times been depressed, angry, upset, bitter but I realize these are expectable and acceptable and have not felt much anxiety about my anxieties. Generally my first reaction to the 'bombshell' such as having to go into the hospital, hearing about the need for surgery, etc., is fearful and anxious. Then I get down to the business of accepting these things, that are beyond my control. Usually this hasn't taken too long. So far, it has taken me the longest to accept the smashing of my plans. At this point, I have had little trouble accepting cancer itself. None of the traditional 'horrors' associated with cancer seem very real of imminent right now. I realize I might die in a year or two but that is far away. I wish to live until I die whether it's two years or fifty years from now . . . I have found humor a good tool of accepting a lot of the 'heavies' that I've encountered in the past month or so.

One thing I am anticipating (not looking forward to) and already experiencing to a certain degree is dealing with other people's reactions to my having cancer. Most people associate a lot of things with the word, that aren't always true, but contribute to a lot of fears, i.e. incurable, mysterious, slow horrible death. I am at the point where I do not want to make a big deal about it. Just accept it and live my life around it. I do not want to have it as a major part of my identity or image and do not want lots of attention and pity showered on me. I just want to live as much as possible, what for me is a normal life. I realize my feelings and attitudes may change if cancer starts to affect my life more or differently but these are feelings at the present time.

In connection with this, I am considering not using the word cancer around people who do not know I have it. I'll tell them I had a tumor removed and leave it to them to pursue it further if they wish. I lead such a bizarre life.

### *September 18th*

Arrived back in Richmond last nite. Awkward, strange, and sad. I probably was going to be coming through here about this time anyway but under such different circumstances.

Regarding myself and cancer, a few things I want to do are some reading on cancer treatment, getting some counseling, and checking out alternative treatment programs. One group in particular that has been mentioned to me be a couple people is the Cancer Counseling and Research Center in Ft. Worth, Texas. Apparently they use some chemotherapy but to a much smaller degree and are very aware of the importance of and work with the patient's attitude and emotional side in general. They have developed, among other things, a meditation which involves imaging the body, specifically

the white blood cells, fighting, attacking and/or assimilating the cancer and according to the person who told me about it, it has been a successful tool in actually battling the cancer itself. I have already started doing something with the meditation.

I am starting to realize more and more, from talking to various folks, the importance of my attitude regarding the success of any treatment and I am concerned that I achieve the 'right attitude.' Intellectually I give the appearance of dealing with everything and coping well but I think at the moment I'm taking things too lightly and have not dealt with a lot of things on an emotional level. Dealing on the emotional level is difficult because I realize it will probably make me depressed, anxious, and other unpleasant feelings.

My original strategy for dealing with this whole shebang was to ignore it as much as possible while still getting treated but I'm realizing now that I'm going to have to take a more active role. I still do not want to make cancer my major focus and as much as possible wish to live as I had planned to before this came up.

I sure wish I'd had a lover to come home to. Been quite randy the past one and a half months or so.

### *September 20th*

This evening I went with Mom and Judy to visit Joe Cooper. I was very glad to see him but sitting there I felt like I was a 40 year old thinking "Oh, but what promise our generation had," and here's me with cancer and Joe in a mental hospital.

### *September 21st*

I am reading "The Eden Express" by Kurt Vonnegut's son Mark. It is a personal account of schizophrenia. There is a part in it where he talks about being back in the city away from his communal farm and how he started flipping out. That comes close to describing how I was for part of the day. I was alone in the house and realizing how much there was nothing for me to do and getting increasingly upset. It seemed like there was no point in trying to get cured, if the rest of my life would be like this. (There really wouldn't be if I felt like I did earlier, forever.) I started considering just up and going to Missouri very soon. My head started getting very cloudy and I was wondering how long I would feel like this. It felt like it would last forever but it only lasted a short while. I don't expect it will be the last time I get upset and depressed like that.

One of the things I'm having trouble with is that for the past year and a half I usually felt that I could do what I wanted and if things got real shitty in one place I could always move on somewhere else. Now I have little choice. I can stay in this shitty situation and get treated for cancer, or I can go somewhere more pleasant and almost certainly have a recurrence.

I wish that I was living in another situation than with my family. I'm not finding it close to intolerable and I wouldn't want to cut off ties or anything, but I'm aware of certain tensions and a dynamic that I don't like. Even less so because I am falling back into it, mainly just from being back in this house with these people. We all have



tendencies to be over critical and overly thin-skinned around and about each other.

### ***September 22nd***

Back in the hospital again. They're going to run several tests on me to determine if the cancer has spread anywhere else and then decide what drugs to treat me with.

I am on the adolescent's ward which from all reports is one of the best wards in the hospital. It's very loose, there is a lounge with pooltable, TV, stereo, books and comfortable furniture and it is the main hang-out. It is almost like a community club. There is a lot of interaction between patients and many of them are warm and friendly.

Later: this evening I was talking to one of the other patients on the ward and asked him what he was in here for. He told me leukemia and I was a lot more shaken than I usually am about myself. Am I really dealing with my own situation?

### ***September 25th***

There is not a positive diagnosis of my tumor. The oncologists here are calling around to other cancer centers to get an idea how to treat me.

Today I got out on a day pass and went with my mother out to Twin Oaks for a Saturday tour. I went mainly to establish contact and find out some specifics about visiting and joining.

### ***October 3rd***

I underwent my first dose of chemotherapy, three days worth. The doctors have me on three different drugs.

### ***October 7th***

I want to get out of Richmond real bad. I need to be around people more, be in a more structured situation. At this point in my life unfortunately I think I have not



developed many ways of occupying myself (commonly known as hobbies) when I'm alone. Reading, writing, being in a natural setting are exceptions. When given the choice, I spend my 'free time,' leisure time, in the company of others. All this has not prepared me for the present situation very well.

Finally got in touch with Shelly Habeck, at this point perhaps my only close friend in Richmond. Our acquaintance has a rather bizarre twist to it. Since I left here last July Shelly has gotten a job with the MCV Cancer Counseling and Rehabilitation team.

We saw each other tonite at the meeting of 'Make Today Count,' a group for cancer patients and families. Shelly was a speaker, and I went mainly so I could see her. Before she got into her 'official' talk, she spoke tearfully about the impact on her of finding out about me. I also wept. She and I are hoping to spend some time with each other this weekend. She is the first person I have really grieved together with.

Sometimes I am too hard on myself about some things. I worry too much about how my condition/situation is affecting others. I'm tired of blowing people away. Also I get down on myself cause I'm not handling the Richmond situation with great ease and finesse.

### ***October 11th***

My hair has started falling out. Everyone is grossed out by it. I would be too, if I thought about it.

Went to the prison visitation yesterday. Every other Sunday, a group from friends meeting goes down to the State Pen and meets with whatever prisoners show up. Some of the inmates took a liking to me which was good for the ego. I think my experience on Skid Row is helpful in relating to the prisoners with less preconceptions and more as people. It would be easier to relate to the prisoners as equals, than to people in the Kitchen situation because there is not the server/recipient trip which can fall into the pitfalls of patronizing.

### ***October 19th***

My emotional state these days is often poor. Sometimes it really feels like I'm losing it. There's little that makes my life worthwhile these days. Not all the time. But anyway that gets me into a down mood which spirals into 'nothing seems to be worth it, losing motivation, crawl into a shell, lack of identity.' My appearance is changing (hair, weight loss) at the moment I am not capable of a lot of things I used to be capable of because my physical state is not tops and often I feel physically shitty due to chemo side effects among other things.

Today I finally heard from Twin Oaks, thank god. I had been going through the mail anxiously every day for the last two weeks and had just about decided that I wasn't going to get a visit arranged.

Have been getting mail from lots of other folks. A lot of times thoughts are focused on memories of happier times. Often these memories just make me sadder. Everything was going so well until a couple months ago, and all of a sudden those times seem very far away.



### *October 30th*

I'm realizing more and more how important personal and human service to other people is. Even though if I move to T.O. I won't be very actively involved in service work. I think that aspect of the Worker had much impact on the gut level that I'm feeling now. Keeps on popping up. Reading about China (Mao says 'serve the people'). Maybe prison work sometime. Right now I'm hoping that if I do join T.O. there will be some opportunity to get into working with people locally in Louisa.

### *November 6th*

Twin Oaks — This is the first time in my travels that I am visiting a group that, from the beginning, I'm hoping to join and it seems more important that it work out well as my other options are much more limited than in past times (since first leaving home). Seems almost to be a full circle. Twin Oaks was going to be the first place I was going to visit but the arrangements got screwed up and I never made it. Now here I am back at home again, finally getting up here to visit.

### *November 22nd*

Monday nite. I had my meeting with the membership team a couple days ago. Everyone felt good about me as a person, but they all had reservations about me joining because I might be a liability in terms of money and labor. I had expected the financial aspect to be an issue but was surprised that the labor issue — I probably won't be able to work a week out of each month — was brought up. It had not been mentioned to me before although prior to coming here one of my fears was that my lowered work output would affect membership. The issue of my membership is going to be considered by the Community Planners at a meeting tomorrow which I shall attend.

At the moment I feel relatively at ease about the whole situation, but for a good bit of the past three days I have definitely been upset and anxious. And as is often the case with me, my anxiety has mushroomed beyond the immediate issue at hand. Will I be happy here, find satisfying work if I am accepted? What would make me happy anyway? What is the meaning of life? Also fears of recurrence and a lot of wishing that things had developed differently since the beginning of August. While acknowledging that there is no cosmic justice, godammit it just doesn't seem fair that something which is a big enough problem in itself (i.e. cancer) should be causing me all these other problems.

### *December 1st*

My meeting with the planners last week went well. I came out feeling the highest I had since the operation. I finally was getting some positive signs that I might be out of limbo soon.

Feelings about T.O. in general. It doesn't feel like home yet and I'm just starting to feel close to a few people there besides other visitors, but it still looks like my best possible option and I think I can settle into a happy life here.

Blood Family: I'm really not feeling like relating to them very much these days. My operation, etc. arose at a time

when I'm still feeling an adolescent ego need to make a more complete break, feel fully independent before I can get close to them in some ways. But the medical situation meant I required family-type care for a while and I imagine they felt a need to give it. I imagine it would've been much easier for me to accept had I already completed that psychological break.

Also I have the feeling that whenever they are around me or think of me, my cancer and physical state in general is one of the foremost things in their minds (particularly my mother). This is understandable. Such thoughts are generally not too far from the surface of my own conscious mind. But I feel a need to think of myself as separate from an identity as a person with cancer, and being around people whom I sense are not doing that (and I may be off the wall in my perceptions) doesn't help me with need. Unfortunately I think my family's image of me (if it is as I imagine) will be reinforced when the main time they will see me will be when I come into town for my medical treatments.

### *December 10th*

Last nite my membership in the community was one of the two items on the agenda for the public input planners meeting. First the planners each expressed their feelings and then everyone else was given a short time to say how they felt. The issues that were mostly brought up were emotional drain and labor drain, both hours lost when I'm sick and hours spent caring for me. Going around the room more people were for acceptance than against, with some unable to come up with a position.

It was very emotional for me, both positive and negative statements. It felt like being before a jury. Afterwards I went off by myself and worked off some of my anxiety and anger fantasizing about what I might do if I was rejected. I came up with hitchhiking to East Wind or killing myself among other ideas. I didn't realize until talking to other people later that the meeting went largely in my favor.

This morning the planners met to make their decision. They discussed last night's meeting briefly and also input they received from folks not at the meeting. They decided that the community would be responsible for covering labor and other things relating to my situation, that when I came up for full membership my case would be reviewed by the planners and that someone should discuss with my family and me what would happen in the event of my death. Their decision was unanimous but Henry had a lot of reservations. My feeling was one of relief more than anything else.

So another chapter in my life and weird times. Generally I'm feeling pretty optimistic as regards the whole cancer scene. My fears last month about recurrences were dispelled by good test results. I know it's going to be a couple more years yet before I'm out of the woods and I'm also aware that it's possible to become overly optimistic but it sure is a lot nicer than feeling anxious all the time. I'm ready to just settle down and be your every day communitard, working hard, playing hard, eating, sleeping, fucking, walking in the woods. I don't want to be the focus of any more meetings for a while. □

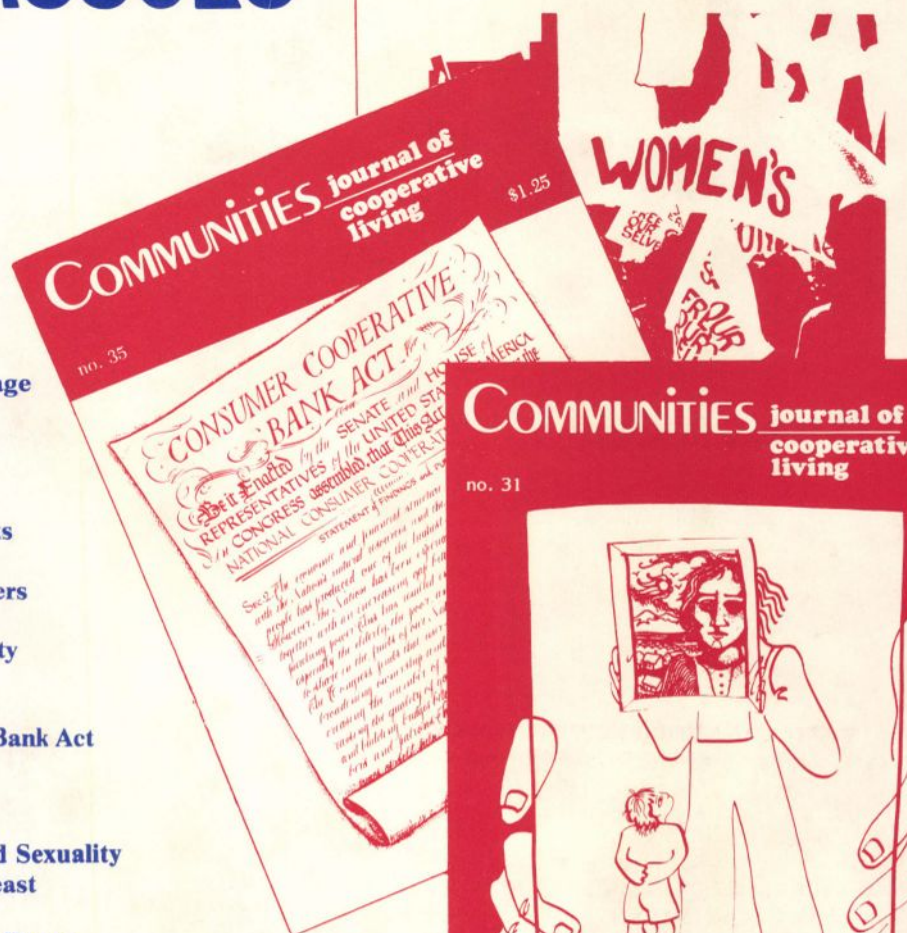


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- 3. Ananda Cooperative Village
- 9. Children in Community
- 10. Work in Community
- 13. Spirituality
- 15. Education
- 22. Networking in the Ozarks
- 25. Don't Start a Commune
- 28. Seabrook; Ex-Twin Oakers
- 31. Learning in Community
- 32. The Future of Community
- 33. A Woman's Issue
- 34. The West and the Land
- 35. Consumer Cooperative Bank Act
- 36. Circle of Gold
- 39. Diverse Issue
- 40. Cooperative Economics
- 41. Friendships, Family and Sexuality
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