

Spirit of Recovery

– A CONVERSATION WITH –

Ed Knight, Sheila Le Gacy, and Nancy Kehoe

*Speaking from the heart
about mental illness and recovery*

DISCUSSION NOTES



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Origins of Spirit of Recovery

For over ten years, the Mental Illness Education Project (MIEP) has created and produced educational videos through a collaborative process that gives voice to the experiences of people with psychiatric disabilities. Using the first-hand experience of mental health consumers, family members, and clinicians, the tapes are intended to facilitate wide-ranging discussion on a variety of mental health issues. *(Please visit www.miepvideos.org for a complete list of MIEP videos.)*

Nancy Kehoe approached me at a mental health conference about the possibility of filming the training she provides to health care professionals in taking a spiritual history of their patients. Zlatka Russinova, a researcher in the area of spirituality and mental health at Boston University, Center for Psychiatric Rehabilitation, suggested that I broaden the scope to include mental health consumers and family members.

Fortunately, both Ed Knight and Sheila Le Gacy were excited about the idea and agreed to participate. We all communicated by phone and by email over the next several months to iron out logistical details and discuss possible topics.

Sheila and Ed came to Boston for the filming, and met Nancy for the first time. Their conversation was recorded at the Society of the Sacred Heart community in Newton, Massachusetts.

The DVD also includes a section with short concentration exercises led by Ed Knight that he has used in his own recovery.

I wish to extend my deepest gratitude to Ed, Nancy, and Sheila for sharing their hearts, their insights, and their “delusions of grandeur” in the making of this DVD.

Additional thanks to Bill Anthony, Peter Ashenden, Ken Byalin, Patrick Corrigan, Larry Culliford, Zlatka Russinova, Alex Young, and Emily Scott for valuable input in the finishing details.

Lucia Miller
Director

DISCUSSION NOTES

Description

Three mental health professionals, representing three different viewpoints, speak about recovery from serious mental illness. In an engaging conversation, Dr. Ed Knight, Sheila Le Gacy, and Dr. Nancy Kehoe share their personal experiences of living and working with people with psychiatric disabilities. This DVD is an introduction to some of the topics that have been glaringly absent from the dialogue about mental health recovery.

Why This DVD Was Made

Recent research has found that nearly 90% of consumers of mental health services identify themselves as religious or spiritual. However, other studies have shown that less than 50% of mental health professionals endorse religion as a core value. This DVD explores the many facets of recovery from mental illness, including the topics of working with difficult emotions, moving from denial to hope, and sharing insights about faith.

This DVD is not intended to sum up all the issues, for such a summary would necessarily be different for each audience. It is intended to bring into the light of day a subject that is rarely discussed and to provide a springboard for meaningful discussion about these issues.

The length of each of the three sections makes it possible to view them and still have ample time for discussion during a normal forty-five minute class, workshop or training period. We believe that the value of the DVD can be greatly enhanced by the discussion following the viewing.

You may also choose to view the DVD by individual chapter in order to focus more in depth on a particular topic. The quotes and questions that follow are intended to help further discussion on these topics.

Remember that a major purpose of this — and all of the pieces we produce — is to elicit a discussion in which members of your group share their experience, thoughts and emotions with others. There are seldom easy answers to the issues these tapes raise. We want to raise people's sensitivity to many important issues and to combat the stigma of mental illness.

Notes to the Discussion Leader

Before viewing the DVD: You will probably want to preview a section before using it with a group. We strongly recommend that you not talk about your own reactions until the others in your group have discussed theirs.

While viewing the DVD: Groups will react differently depending upon the experience of the participants. The size of the group will affect how audibly its members respond. For example, laughter tends to happen more readily in larger groups.

After presenting the DVD: When the film ends, there may be a silence while people collect their thoughts. This is particularly true if people found it moving. Allow this to happen. There should be no rush to get people talking.

Your discussion will be more productive if you take care to ask open-ended questions. Every audience has different needs. Allow the audience to take the discussion where their interests lead them.

Terms Used in Spirit of Recovery

Mental Health Consumer — In the US and Canada, individuals with severe psychiatric disorders are often referred to as “consumers”, “recipients of services”, “ex-patients”, “psychiatric survivors”, “clients”, etc. In the UK and in several international organizations (e.g. The World Fellowship for Schizophrenia and Allied Disorders) these individuals are referred to as “users” and families as “carers”.

High Expressed Emotion or High E.E. consists of two principal factors: critical comments and emotional over-involvement. The main dimension of e.e. is verbal criticism.

Pro-dromal symptoms are early symptoms and signs of an illness that precede the characteristic manifestations of the acute, fully developed illness.

The Windhorse Project is a therapeutic community that was first established in Boulder, Colorado by Naropa University faculty Jeffrey and Molly Fortuna and Dr. Edward Podvoll, a psychiatrist and author of the book, *The Seduction of Madness*, (reprinted by Shambhalha Press in 2003 as *Recovering Sanity*). Through their work in East/West psychology, the founders integrated the skills of mindfulness-awareness with their approach to assisting persons with mental disturbances.

References to teachings and teachers mentioned may be accessed via the Internet. They include: Hazrat Inayat Khan, Søren Kierkegaard, Theresa

of Avila, Patanjali, Satchidananda, Rumi, John Nash, Milarepa, Lama Surya Das, Sufism, Insight Meditation, Theravada, and Centering Prayer.

Articles Available for Download

Several articles related to the topics discussed in *Spirit of Recovery* may be downloaded for free from the Mental Illness Education Project website. Go to www.miepvideos.org and select “Articles and Reviews”. The section includes research and guidelines by Dr. Ed Knight, Sheila Le Gacy, Dr. Larry Culliford, Dr. Patrick Corrigan and Dr. Nancy Kehoe. An audio file of *Meditation for Recovery*, presented by Dr. Knight is available from the MIEP website. You may also download this booklet for free by clicking on “Discussion Notes.”

Questions and Quotes

The following are quotes from each section along with suggested questions that may be used to get discussion started.

1. Key Ideas

Getting Through Pain

- What gives you hope?
- Is the fear of fear an important issue?
- How do you tolerate negative emotions such as anger, anxiety and fear?

“It’s really helping people go in to the pain that allows them come out on the other side.”

“I think it’s important to take out that pain and look at it. In order to have the joy that is due to all of us, it’s very important to look at your pain and honor it.”

“Don’t ever give up your delusions of grandeur; those are your goals.”

Denial is not a rational process

- Can denial be a positive coping mechanism?
- What do you consider to be spiritual gifts in your life?
- Do you feel it is important to distinguish between your own pain and a friend or loved one’s pain?

“In some basic way, the first phase of recovery is denial. It’s a very important defense mechanism.”

“Relating to the person’s anguish is the quickest road through denial. It gives an outlet for the pain and opens up a way of dealing with the pain.”

“I think that stigma is much too weak a word. I think what happens to us, who are diagnosed with serious mental illness, for most of us is a social death sentence.”

Spirituality and Recovery

- What helps you to cope?
- Do you have a spiritual practice?
- What do you do for stress?

“A study by Patrick Corrigan and others found that 90% of consumers believe that religion or spirituality is very important in their recovery. And a much smaller group of professionals, (clinicians) find spirituality or religion important. The article...said there is a lack of cultural competence among the clinicians if they do not acknowledge the importance of religion and spirituality in the people that they’re working with.”

2. Healing Practices

Faith and Authenticity

- Do you feel you have a strong faith?
- Has that faith helped you to cope in times of intense pain?
- Are there other sources that have helped you to cope?

“The great spiritual gift of the tragedy in my life — and I think all great tragedies have a spiritual gift — was that I found that I wasn’t the center of my life and that it was a relief not to be in charge of my life — that I didn’t have to control everything — that in God’s world there are no mistakes. If you can accept and relate to the pain of the situation you’re in, it’s possible to grow because of that.”

Spiritual Experience or Psychosis?

- Do you feel it is possible to gain spiritual insights from suffering?
- What makes a spiritual practice authentic?
- What does a spiritual path look like to you?

“The quickest route to psychosis for me is for me is to engage in extra sensory perception and I think that most of the great spiritual teachers say avoid those things.”

“There’s a great Buddhist saying that says, ‘Just because a voice is disembodied doesn’t mean it’s wise.’”

Internal Silence and Meditation Practices

- What helps to calm you during stressful times?
- Do you feel that techniques to access internal silence might be helpful to recovery?
- What do you think about short (2 minute) meditation exercises?

“I started out meditating a minute with my eyes open on an object and then closing them and drawing that object into my mind for a minute. So I started out with two minutes of meditation.”

“It’s the honoring of our own experience that makes the work we do effective.”

Listening without an Agenda

- What do you think it means to be listened to “without an agenda”?
- How can it empower you to be listened to in that manner?
- What does it feel like to listen to someone without an agenda?
- Can you listen to someone’s pain and suffering without taking any action?

“When you listen without an agenda, on the one hand, there’s a sense of powerlessness, that you’re listening, but you’re not listening to do something. You’re listening with openness, and so there is sense of powerlessness, but it’s also giving power to the other person. It’s a trusting that there’s something profoundly alive in another person when we’re listening without an agenda.”

Quotes About Suffering and Transcendence

One of the primary conditions for suffering is denial. Shutting our mind to pain, whether in ourselves or others, only ensures that it will continue. We must have the strength to face it without turning away. By opening to the pain we see around us with wisdom and compassion, we start to experience the intimate connection of our relationship with all beings.

— Sharon Saltzberg (2006) [Author of “Faith: Trusting Your Own Deepest Experience”] from her website www.loving-kindness.org

*The Lord is my Shepherd; I shall not want.
He maketh me to lie down in green pastures:
He leadeth me beside the still waters.
He restoreth my soul:
He leadeth me in the paths of righteousness for His name' sake.*

*Yea, though I walk through the valley of the shadow of death,
I will fear no evil:
For thou art with me;
Thy rod and thy staff, they comfort me.
Thou preparest a table before me in the presence of mine enemies;
Thou anointest my head with oil;
My cup runneth over.*

*Surely goodness and mercy shall follow me all the days of my life,
And I will dwell in the House of the Lord forever.*

— The 23rd Psalm

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*Fidelity, patience and fortitude are evident when the helpful person is present during the most difficult of times and does not simply come around when recovery seems promising. People who are experienced as helpful are able to hold the relationship during times when the other does not reciprocate affection and care. This holding of love and relationship, even during the most barren and anguished winter of recovery, requires compassion. The word compassion comes from the Latin *passio*, to suffer and *com*, to be with. To be compassionate is to suffer with the person in distress. To be compassionate is a way of being with the other without an agenda to change them, to relieve their suffering or to suffer for them. Through compassion we can reach out to the other even when they refuse to reach back. With compassion we see the person, not the diagnosis or disorder.*

— Dr. Patricia Deegan "Relationships Can Heal"

Pat Deegan Ph.D. & Associates offer a wide range of services to help transform mental health systems into recovery oriented service systems that promote self determination for people with psychiatric disabilities.

Source: www.patdeegan.com/blog/archives/000015.php

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Sometimes called bare, or naked, attention, it is defined as the "clear and single-minded awareness of what actually happens to us and in us, at the successive moments of perception." (2) It is different from our usual modes of perception in that it is detached and receptive, allowing for an exact registering of whatever is happening in the mind and body, carefully separating our mental or emotional reactions from

the core events, themselves. Sometimes called mindfulness, or moment-to-moment awareness, bare attention is the sine qua non of meditation, the distinctive contribution of the Buddha's approach. It might be described as a kind of radical acceptance of, or tolerance for, all of our experience.

— Mark Epstein, M.D., "Sip My Ocean: Emptiness as Inspiration".

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Vulnerability is your greatest spiritual resource on the path through life's difficulties. The noblest heart is one that sheds its armor, opening it self fearlessly to both heartaches and delight.

... The strength that can come only through embracing the pain of your own experience.

— Pema Chodron

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We can only be with people in their pain to the extent we are willing to be with our own pain within our own life experience.

— Dale Walsh, "A Journey Toward Recovery: From the Inside Out". Psychiatric Rehabilitation Journal, Fall 1996, Vol. 20, no. 89:89

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We need to get over questions that focus on the past and on the pain as "Why did this happen to me?" and ask instead, the question which opens doors to the future. "Now that this has happened, what shall I do about it?"

— H. Kushner (1981) "When Bad Things Happen to Good People". New York: Schocken

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Researchers have found higher levels of acute and ongoing grief in families with a chronically mentally ill child than in families whose child has died. The families studied included children with chronic depression, bi-polar disorder, schizophrenia, or personality disorder.

— S. Atkinson, (1994) "Chronic Grief may Affect Parents of Children with Schizophrenia" The Menninger Letter, 2, 1-8.

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Suffering is a function both of the pain and the degree to which the pain is resisted.

Pain is one thing, and resistance to the pain is something else, and when the two come together you have an experience of suffering ... whenever there is resistance there is suffering. As soon as you can see that, you gain that insight, you'll begin to have some freedom.

Grief is a normal, healthy, spontaneous and necessary response to loss. Moving through the process of grief and mourning toward some kind of resolution is hard, painful, and sometimes frightening. This process, called “grief work,” involves acknowledging the full measure of pain you feel, in whatever way it manifests. Grieving is not only a process of coming to accept loss, but grieving, in itself, is a kind of healing. Once grief is no longer the central issue, other growth is possible.

— Shinzen Young (1994) “The Humanist Psychologist”



Don't get me wrong: grief sucks; it really does. Unfortunately, though, avoiding it robs us of life, of the now, of a sense of living spirit. Mostly I have tried to avoid it by staying very busy, working too hard, trying to achieve as much as possible. You can often avoid the pain by trying to fix other people; shopping helps in a pinch, as does romantic obsession. Martyrdom can't be beat. While too much exercise works for many people, it doesn't for me, but I have found that a stack of magazines can be numbing and even mood altering. But the bad news is that whatever you use to keep the pain at bay robs you of the flecks and nuggets of gold that feeling grief will give you. A fixation can keep you nicely defined and give you the illusion that your life has not fallen apart. But since your life may indeed have fallen apart, the illusion won't hold up forever, and if you are lucky and brave, you will be willing to bear disillusion. You begin to cry and writhe and yell and then to keep on crying, and then, finally, grief ends up giving you the two best things, softness and illumination.

— Anne Lamott, “Traveling Mercies”



Through suffering one learns to share the suffering of others, and through the gift of compassion, the experience of chronic illness offers protection against apathy, an indifference toward life that means, literally, “not suffering.” Above all, chronic illness leads to the recognition that “somehow, things work out” in an examined life that is judged to be worth living.

Transcendence is probably the most powerful way in which one is restored to wholeness after an injury to personhood. When it is experienced, transcendence locates the person in a far larger landscape. The sufferer is not isolated by pain but is brought closer to a transpersonal source of meaning and to the human community that shares these meanings. Such an experience need not involve religion in any formal sense; however in its transpersonal dimension, it is deeply spiritual.

— Cheri Register (1987) “Living With Chronic Illness: Days of Patience and Passion”. New York: Free Press.



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