



NAMI

Cape Cod

The Nation's Voice on Mental Illness **February 2009**

President's Message:

By LeRoy Spaniol, PhD

THE PAIN AND THE POSSIBILITY: THE FAMILY RECOVERY PROCESS: Part II

The previous issue of the Newsletter described some general characteristics of the family recovery process. In this Newsletter I will describe the recovery process itself based upon research, personal reports of family members, and my own personal experience.

THE FAMILY RECOVERY PROCESS

The following phases describe the general experiences of family members. Remember that each person is unique and may not experience the following recovery process exactly in the way described. The phases are guidelines only and are not meant to prescribe what a family member should experience.

Shock, Discovery, Denial

The occurrence of an acute onset of a mental illness is a shocking experience for family members. The abrupt changes they see occurring are hard to understand. "What is happening?" or "These are not ordinary behaviors of the person I have known" are common reactions. As family members become aware that something is happening they may explain it away. Family members may believe that their loved one's condition is not really so serious. They may not be aware of the nature of the symptoms they are seeing if they have not been exposed to mental illnesses before. Or, they may have negative or exaggerated images of people with mental illnesses from the media and their family member may not conform to those images. They may develop alternative and more "acceptable" explanations for their family member's behavior such as "This must be due to alcohol, drugs, laziness, or bad friends." Even family members who are mental health professionals may have the same puzzled reactions.

As the relationship with the family member begins to change, family tensions and frustrations increase. Family members often attempt to find answers through any possible source, such as friends, clergy, or professionals. An all too frequent lack of clear and specific communication about what is happening supports the confusion family members feel. These attempts to seek out information are often frustrating because of shame, embarrassment, and self-blame, and, the frequent lack of knowledge or resources on the part of the person being asked.

Denial can be persistent and can linger throughout all aspects of the recovery process. It is hard to begin the recovery process when denial persists because some level of acceptance is necessary to move on to solutions. Also, it is hard to take steps to alleviate a problem we don't understand. And because the level of understanding will always vary with each family member, so will their level of active recovery vary. Thus, each member of the family must deal with his/her own recovery. Members of the family can support one another but they cannot recover for one another.

Disbelief is sometimes a more accurate word to describe the experiences of some families than denial. Disbelief is primarily a conscious process and it implies some acceptance, but "it is hard to believe it is happening to us." Belief begins to set in gradually as the reality of the disability makes it difficult to avoid. Family members need to be supported during their disbelief and they need to be gradually helped to see the disability for what it is.

The support of other families who have been through similar crises is very helpful to families who are new to this crisis. Referral to NAMI family support or to NAMI hot lines can help families on their journey through the many painful and confusing emotions they experience, the knowledge they need to acquire, and the decisions they may have to make.

Recognition and Acceptance

Acceptance is a process. It occurs as family members gradually become aware that their family member has a serious mental illness. Acceptance does not mean approval or that you have to like what is happening. It means seeing what is, fully and completely. Initially this awareness may increase their hope in professionals because professionals are expected to know the answers. Unfortunately, some professionals may not be as informed (cont. on page 2)

Cont. from Page 1 President's Message:

as they should be about the possibilities for recovery and how to support it. Some may even be discouraging and suggest accepting a limited future for their family member. This can lead to profound feelings of loss and disappointment for family members. The myths that support hopelessness and family causation are still widely held (Harding & Zanhiser, 1994).

As awareness of the seriousness of the illness increases, so may feelings of guilt, embarrassment, and self-blame. Family members are part of the general culture which has supported these feelings. If family members encounter professionals who maintain that families are responsible for the illness, then family members will have a double burden, because their worst fears will be confirmed by an "expert."

As family members begin to accept that there is a serious long-term illness, they experience a deep sense of loss. Perhaps the most striking loss is the image of the life that they had envisioned with and for their family member. This feeling of loss is also experienced by the family member with the illness. All family members share and must come to terms with this deep sense of loss. Acceptance of the loss is often made more difficult by the cyclical nature of the illness. Improvement of the family member raises hope that their family member will return to normal previous functioning. This on-again, off-again experience becomes an emotional roller coaster ride for family members. As the persistence of the illness becomes obvious to the family, the grieving process can begin more fully as family members let go of old hopes and expectations and begin to create new ones.

The families' understanding of the possibilities for recovery, even the expectation for recovery, can facilitate the recognition and acceptance process. It is important that families work with professionals and other families who have hope for people with mental illnesses. Given the appropriate medications and recovery-oriented interventions people with serious mental illnesses can have lives that are satisfying, productive, and contributing to others. All family members need this sense of hope and possibilities, including the person with the illness.

It should be noted that this new awareness also creates a crisis in meaning. Questions about oneself, one's relationships to others, to one's work, and to meanings and purpose in life become important. As these meanings change, family members change. As family members begin to develop new answers to these basic questions, which incorporate the reality of their loved one's disability; openness to the possibilities for unanticipated outcomes for their loved ones; and a developing sense of their own changing sense of self; they are often transformed in profound ways.

Coping implies struggling with a problem with inadequate knowledge, skills or support. This is how family members begin to cope. At some point it becomes clear that family members need to continue on with their lives and begin to think of supporting their loved one over the long run. This is when coping begins to take the place of grieving. Family members cope with the disruption in normal family life, recurrent crises, persistence of the illness, loss of faith in some professionals and the mental health system, and aspirations of their family member with the mental illness. Professionals may feel family members are intrusive at this phase because family members may become more angry and assertive. They may question professional competency and demand additional services. Their anger at professionals and outrage at the mental health system derive from their frustrations with poorly trained professionals or inadequate resources when seeking care. However, it is important to be aware that the anger family members feel is augmented by the hopelessness they often feel. They cope with pessimism and despair.

As families persist in their coping, they experience less distress and more empowerment (Lucksted, Stewart, & Forbes). Belief in the expertise of other family members grows. Family members value the support of other families who are struggling with a family member with a mental illness and gradually learn to accept the limits of what they can do about the illness. They begin to focus increasingly on the management of symptoms and improving the functioning of their family member. They become more interested in improved inpatient care, community services, housing, and rehabilitation. They gradually identify professionals on whom they can rely, and work more closely with them. Family members come to see valued professionals as necessary, but not sufficient to their efforts to cope. (Continued on page 8)

SAVE THE DATE: SUNDAY, MAY 31, 2009
NAMI WALKS FOR THE MIND OF AMERICA

Why We Walk

For the past five years, through the Annual Walk, we have accomplished many of our goals, beginning with decreasing stigma. We have added new programs, such as NAMI Connection and In Our Own Voice, which were developed to aid those with a mental illness in their recovery. NAMI Cape Cod has developed a Speaker Series, updated our literature, purchased a new modern printer/copier, upgraded our Web Site, and set aside a percentage of funds raised by consumers for consumers. We are presently helping consumers to provide their own social activities, to replace what has been lost through budget cuts. Both NAMI MASS and NAMI Cape Cod need you to be involved with the walk, so that those on Cape Cod with a mental illness and their family members can receive continued support and participate in new programs and opportunities.



For further information, please call Charlie at (508 540-1808)

Education and Support for Families

NAMI Family Support and Education programs get revitalized each year with spring trainings which are available to any NAMI family member who wishes to participate. All that is necessary is a desire to give back service with a commitment to teach two 12 week sessions of the NAMI Family-to-Family Education Program or a two year commitment to facilitate monthly NAMI support groups.

The first of two trainings was held on the weekend of February 8, 9, and 10 in Falmouth for support group facilitators. The following NAMI members completed the training: Peg and Fenton Burke from Martha's Vineyard, Kara Anderson from Sandwich, and Wendy Rennett from Wellfleet.

The second training for education class teachers will be held on the weekend of April 11, 12, and 13 at the Holiday Inn in Marlboro. If you are interested in participating, you must notify Cindy Nelson at the state NAMI office. The number is 781-938-4048 and email is namimassedu@aol.com.

Kara Anderson and Pat Martins are presently exploring interest in holding a spring 12-week session of family education on the Upper Cape. Anyone interested in taking this course should call the local office at 508-778-4277.

All support and education programs and trainings are free and open to NAMI members.

IT'S A WRAP

NAMI Cape Cod held its annual Wrap Party on December 17, 2008. **Thank you** to all who donated gifts. Many of you did so anonymously, and we are very appreciative. We had many volunteers who sorted, wrapped, and delivered Christmas gifts to those who live in residential housing. Over 100 gifts



were donated and disbursed, including sweatshirts, hats, gloves, socks, toiletries, sundries, gift cards, and more. Employees from Fellowship Resources assisted the NAMI volunteers in their efforts. Many thanks to Polly Rice for purchasing all the wrapping paper, tape, and supplies, and thank you also to Bob Samson of the Professional Driving School for donating the space.



It was a festive morning as everyone got into the spirit of the season.

Polly Rice, left, bought supplies and sorted and wrapped with a festive flair. LeRoy Spaniol, right, was a master wrapper.

Valentine's Dance is a Big Success

An idea was formed and a dream came true!!

The three Clubhouses on Cape Cod (Cove Club, Fairwinds, and Bay-bridge) came together with some members of the Board of NAMI Cape Cod (Judy Russo, Charlie Manning, and Justin Horner) and held a successful Valentine's Dance on Saturday, February 14, 2009.

In cooperation with each other, and with donations from over 40 restaurants, grocery stores, and individuals, the Club House members decorated the hall and set up the refreshments; DJ Joe played the music, and everyone enjoyed an evening of dancing and friendship.

Over 150 people attended and danced the night away. Donations of food were made from restaurants all over Cape Cod. Pink, red, and white balloons with ribbons festooned the hall. Fresh flowers and a large Valentine cake were donated, as well.

Three goals were accomplished in holding this dance. In requesting donations, people were able to educate the public about mental illness. Those with mental illness, in spite of all the State budget cuts, were in charge of creating their own event. And finally, **EVERYONE HAD A GREAT TIME!!!** New friendships were forged, and people are looking forward to the next get together.



*The Edward Bangs Kelley and Elza Kelley Foundation
makes a grant to NAMI Cape Cod*

Thanks to many efforts, our NAMI Cape Cod office now has a new capacity for increased outreach to our members and all of Cape Cod, by purchasing a new office printer/copier/scanner/finisher. First, we applied for a grant in order to extend our abilities to reach out, and **thanks** to a generous Grant from **the Edward Bangs Kelley and Elza Kelley Foundation**, we were on our way. We then launched a special fund raising campaign, and **thanks** once again to the generosity of **our members**, NAMI Cape Cod was able to purchase a new office printer/copier/folder. It has been a goal for us to print our own newsletters, flyers, and announcements. Our hope was that this would have a two-fold benefit. One benefit is the cost savings of doing our own printing, and secondly, we are providing work to consumers in the printing, assembling, and mailing of the newsletter and other mailings.



John Looney, an Office Volunteer, is trying out our new printer.

Our objective has been reached to have the newsletter you are now reading being printed at the NAMI office. We are grateful for everyone's efforts, and have already taken steps to increase our outreach program for improved mental health services and support on Cape Cod. Our goal is to reach all mental health professionals, schools, hospitals, human services agencies, family members, and people with mental illnesses on the Cape, to make them aware of the many resources available for, and unmet needs of, people with mental illnesses. NAMI Cape Cod has developed outreach information packets that can now be printed more efficiently and at less cost, allowing broader circulation of materials for support, referrals, and advocacy Cape-wide.

Success is the sum of small efforts, repeated day
in and day out. Robert Collier, Author

Forum held on Mental Health Issues on Cape Cod.

The **Falmouth Democratic Town Committee** sponsored a **MENTAL HEALTH FORUM** at their monthly meeting on January 21, 2009. The first panelist, **Dr. Timothy Lineaweaver**, a psychologist at the Community Health Center of Cape Cod, described the results of a project that screened 16,161 patients. The project found that nearly 7,000 of them had some level of depression, about 4,000 patients had either alcohol or drug addiction, another 4,000 experienced both depression and anxiety, and just over 800 patients had severe depression. **Dr. Lineaweaver** said that Cape Cod has higher than average alcoholism, drug addiction, and teenage suicides. The good news is that there are tremendous resources available, but getting to a resource can be difficult because of distance needed to travel to get help, plus doctors may not have office hours when patients are free. The Community Health Center of Cape Cod is one of the few places on the Cape that has, in addition to primary care physicians, both a psychologist and a psychiatrist on the staff. Many primary care physicians, when they discover a patient with mental health issues, cannot easily find the help these patients need.

Dr. Kenneth Terkelsen, the second panelist, is on the staff at the Community Health Center of Cape Cod, at Gosnold and at Cape Cod Human Services. He described the lack of psychiatrists on the Cape. Cognitive Therapy is a newer psychotherapy for depression, which is backed by solid research. This therapy helps people to challenge lifelong habits of gloomy thinking which are common in people suffering from depression. It turns out that many people who do not respond to medication do respond to Cognitive Therapy. Electroshock therapy is usually considered a last resort for people with severe depression even though it is still the most effective treatment for depression yet developed. **Dr. Terkelsen** said that other treatments, also backed by solid research, are being developed but are not yet available for use locally.

Dr. John Dmochowski is the staff psychiatrist at the Hyannis VA Clinic and one of the staff psychiatrists at the New Bedford VA outpatient clinic. He described the services available to veterans with Post Traumatic Stress Disorder (PTSD). There is a large veteran population from all wars living on the Cape. VA services attempt to respond immediately to need and as soon as possible for every veteran requesting services. There is a 24-hour HELPLINE phone number that is given for use by veterans, family, and friends of veterans in distress. A trained person is there to answer the emergency call and to deal with the person in the most appropriate manner. Primary care physicians, psychologists, and psychiatrists are all available, and they work as a team on individual patients. The psychiatrist is not the first person to see any patient. Support groups are available for veterans with substance abuse problems and for combat related issues. Not every traumatized individual develops PTSD, and not every sufferer goes on to have chronic trouble. The full-blown clinical illness is rare. The National Institute of Mental Health reports that 7.7 million American adults are affected, and it can affect children as well. Individual and group therapies are helpful, and various medications help with various symptoms.

Charles Manning, the fourth panelist, had a career working in Boston at Mass Mental Health Center for 35 years and then working at a Group Home for those with a mental illness before retiring and moving to Cape Cod. His presentation described the work done by the **National Alliance on Mental Illness (NAMI)**. It is an organization of families and people with mental illnesses. NAMI provides emotional support and practical coping skills through support groups for families and for people with severe mental illnesses. In education, NAMI offers a series of 12 weekly classes to help caregivers understand and support individuals with serious mental illnesses while maintaining their own well-being.

NAMI is a strong advocate for the mentally ill. It promotes recovery-oriented legislation, policy and practices. A recent legislative success has put insurance coverage for mental health on parity with other medical coverage. NAMI has been a strong advocate in several other areas: Urging decent housing for people with severe mental illnesses; asking drug companies for more effective medicines; asking Cape Cod Hospital to set aside more beds for psychiatric patients; helping to bring three clubhouses to the Cape to provide opportunities for self-help activities, work, and social activities for consumers; organizing annual NAMIWALKS to raise money; introducing jail diversion to provide a better way to handle people with severe mental illnesses who interface with the courts; working for less fragmented treatment for children and adolescents.

Mr. Manning mentioned to the attendees that NAMI Cape Cod needs volunteers to help with many activities, financial support to continue these activities, and input on needs in the community.

A question and answer period followed the speakers' presentations.

Two Family-to-Family Courses Being Offered on Cape Cod

NAMI of Cape Cod is sponsoring two NAMI Family-to-Family Education Programs specifically for families of persons diagnosed with a serious mental illness

This 12-week series of once-per-week classes provides information about schizophrenia, the mood disorders (bipolar disorder and major depression), panic disorder and obsessive compulsive disorder; coping skills such as handling crises and relapse; basic information about medications; listening and communication techniques; problem-solving skills; recovery and rehabilitation; and self-care around worry and stress. The curriculum was written by an experienced family member mental health professional.

The course is taught by NAMI Cape Cod family member volunteers who have undergone intensive training as course instructors.

This course is designed specifically for parents, siblings, spouses, teen-aged and adult children and significant others of persons with severe and persistent mental illness. It is not appropriate for individuals who themselves suffer from one of the major mental illnesses .

The NAMI Family-to-Family Education Course is free and is co-sponsored by the Mass. Department of Mental Health through a special grant to NAMI-Massachusetts. Pre-registration is required.

One course begins on Thursday, February 19, 2009 on Martha's Vineyard. It meets from 6:30 PM to 9:00 PM. Registration is needed. Please contact Fenton or Peggy at 508-693-5872 or email at pegsb4.1@comcast.net for location and more information.

The second course begins on Tuesday, March 10, 2009 at St. Joan of Arc Catholic Church Parish Center, 61 Canal St., Orleans. Class meets from 6:30-9:00pm. For more information or to register, call LeRoy Spaniol at 508-349-2475 or Jim Roberts at 508-255-6281 or email at jar.jrr@comcast.net.

Announcement:

Our Newsletter is now available in 3 formats: 1. By regular mail, 2. By email; and 3. On-line. The NAMI Cape Cod website is: www.nami.org/sites/capecod. Click on the left hand column at Newsletter, all of our newsletters dating from November, 2007 are now available to read for the first time, or for future reference.

Please inform the office by email (namicapecod @verizon.net) or by telephone (508 778 4277), if you would like to change the way you receive your newsletter .

Cont. from Page 2 (PRESIDENT'S MESSAGE: THE PAIN AND RECOVERY PROCESS)

Personal and Political Advocacy —Family members gradually come to a new awareness of themselves in the recovery process. This awareness can include a greater level of personal advocacy and increased assertiveness and confidence. Family members say they feel differently about themselves. Even though the illness of their family member continues, they have changed. They blame themselves less. They let go of what they can't change or don't want to change and become more focused on efforts to bring about the changes they see as necessary. They work out new roles and relationships with professionals which are more collaborative and based on equality. Their interest in the training of professionals may increase. They become more persistent over the long run. For many, political advocacy becomes important. United action to change the system becomes valued. Family members experience their power, often for the first time in their lives. They experience their ability to influence the systems that are supposed to support their family member. At this point, they have integrated and/or deepened new meanings and values about themselves, others, their work, and larger concerns in life.

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A WORD FROM A NEW NAMI Cape Cod BOARD MEMBER

I would like to take this opportunity to introduce myself. My name is Justin Horner and I most recently have joined the NAMI Cape Cod Board of Directors. Part of my duties as a board member is to help chair and oversee The Clubhouse Committee which is already starting to form, believe it or not. I feel at this time of change we as clubhouses need to come together and discuss some of the issues that we are facing. I also have a strong belief to have some fun along the way. With help I hope we can plan some fun and exciting social events for clubhouses, the mental health system and the community to thoroughly enjoy. I have much experience in the clubhouse world and feel that this is the time to take action. We cannot just hide in the corners. We as adults must have our voices heard. If you would like to join us, we are always looking for new people to join The Clubhouse Committee .

I would also like to take this opportunity to inform you of an event that took place. Thanks to a couple of other energetic people NAMI/The Clubhouse Committee hosted a Valentine's Day Dance on February 14th 2009 at The Federated Church in Hyannis. There was music, plenty of food, dancing and of course, a great time with friends.

At a time of budget cuts and uncertainty the government must realize that mental illness is not going away. We no longer need to hide in corners and we have the power and the ability to speak our thoughts. Again, this is why at this time of uncertainty that The Clubhouse Committee is of most importance. It is my hope you will come along for this incredible journey of empowerment and positive change for clubhouses across the commonwealth.

For more information on The Clubhouse Committee please do not hesitate to notify me by email at justinma007@yahoo.com and come and be a part of the excitement.

Respectfully,
Justin Horner
NAMI Clubhouse Committee Chair
NAMI Consumer Support Committee

NAMI MISSION

NAMI Cape Cod serves to advocate for improved services and laws governing the care of people with mental illness, to support and educate families and individuals on their path to recovery, to educate all people on the nature of mental illness.

**NAMI Cape Cod
Board of Directors**

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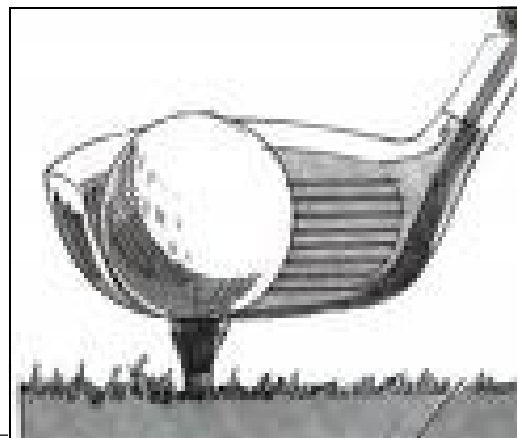
Justin Horner

Nancy Bacher, Advisor to the
Board

Joan Wilds, Counselor to the
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SAVE THE DATE:

**OCTOBER 2, 2009
OUR FIRST ANNUAL
NAMI CAPE COD
Golf Tournament**



Website: nami.org/sites/capecod

508-778-4277

Hyannis, MA 02601

5 Mark Lane

NAMI Cape Cod

The Nation's Voice on Mental Illness



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Support Group Schedule

For Friends and Family of People with mental illness:

First Wednesday of each month—Christ the King Church Parish Center, off Rte 151, Mashpee 7-9 PM. Contact Charlie Bacher at 508-778-0650

First Thursday of each month—First Congregational Church, Main St., Chatham 7-9 PM. Contact Chris Ebel at 508 778 4277

NEW GROUP Third Tuesday of Each Month—St. Joan of Arc Church Parish Center, Classroom #2, Orleans, MA 6 – 8 PM. Contact LeRoy Spaniol (508) 349-2475;

Fourth Tuesday of each Month— The Senior Center, 415 Old Kings Hwy, Wellfleet.. 6:00-8:00 PM. Contact LeRoy Spaniol at 508 349 2475.

For People with Psychiatric Disabilities

First and Third Wednesdays of the month—Louis Gordon Office Facility Meeting Room, 1100 Rte 134, Dennis 6:00-7:30 PM. Contact Karen at 508-385-5078

Last Saturdays of the month—Federated Church, Main St., Orleans 10:00-11:30 AM. Contact Carolyn at 508-255-8521 or Linda at 774-722-3323.

NAMI CONNECTION

Recovery Support Group for people with psychiatric illness. Facilitated by consumers for consumers. Every Thursday evening from 5:30—7:00 pm at NAMI Cape Cod office, 5 Mark Lane, Hyannis, MA 02601. Call 508 778 4277 for more information.