# Association of Oncology Social Work

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# Engaging the 5 Capacities of Improvisation Coping With Trauma and Loss

Presentation by

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# Socio-Cultural Factors, Chronic Syndromes and Traumagenic Effects

## Factor: Intolerance of Suffering

DYNAMICS
- Social/Clinical Controversy
- Pressure for Non-disclosure
- Negative Reinforcement for "Genuine Reporting"
- Attitude Conveyed of Characterlogical Inferiority
- Iatrogenic Health Care Experiences

EFFECTS
- Avoidance of Intimacy
- "Passing"
- Addiction
- Social Abandonment/Rejection
- Social Contract Violation

## Factor: Intolerance of Ambiguity

DYNAMICS
- Contagion / Contamination Powerlessness / Fear Transferred
- Unknown Etiology / Prognosis
- "Just" World or Deserved-Punishment Notion
- Survivor as Burden

EFFECTS
- Generalized Guilt
- Grief
- Depression

## Factor: Intolerance of Chronic vs. Acute Syndromes

DYNAMICS
- Pressure for "Cure"/ Normalization
- Inadequate Treatment Models
- Competence Frustration Conveyed
- Punishment of Healthy Self Care
- Reward of Unhealthy Self Care

EFFECTS
- Normalization Failure
- Identify Confusion
- Increased Salience of Abuse Issues
- Avoidance of Intimacy
- "Passing"
- Social Withdrawal / Suicide

## Factor: Cultural Climate

DYNAMICS
- Pre-sentiment of Suspicion Conveyed
- Negative Personality Characteristics Assigned
- Survivor perceived as Damaged/Social Example

EFFECTS
- Social Shame
- Diminished Self-worth
- Cultural "Pariah"

## Factor: Media

DYNAMICS
- Scapegoating
- Public Ridicule/Support
- Public Judgment
- Public Assignment of Role and Worth

EFFECTS
- Loss of Privacy
- Increased Fear/Anxiety
- Increased Isolation
- Increased Grief
- Decreased Sense of Worth

## Factor: Syndrome Enculturation

**DYNAMICS**
- Inadequate Language/ Models/ Metaphors
- Impact of Discourse
- Disease Maturity - Societal Acceptance

EFFECTS
- Increased/Decreased Powerlessness
- Increased/Decreased Sense of Efficacy
- Increased/Decreased Sense of General Safety, Trust and Stigmatization

From: Fennell, PA. Phase-Based Interventions. Chapter 22 in Jason, L.A.; Fennell, P.A.; Taylor, R. (editors), *Handbook of Chronic Fatigue Syndrome and Fatiguing Illnesses.* John Wiley and Sons Inc., New York, NY: 2003

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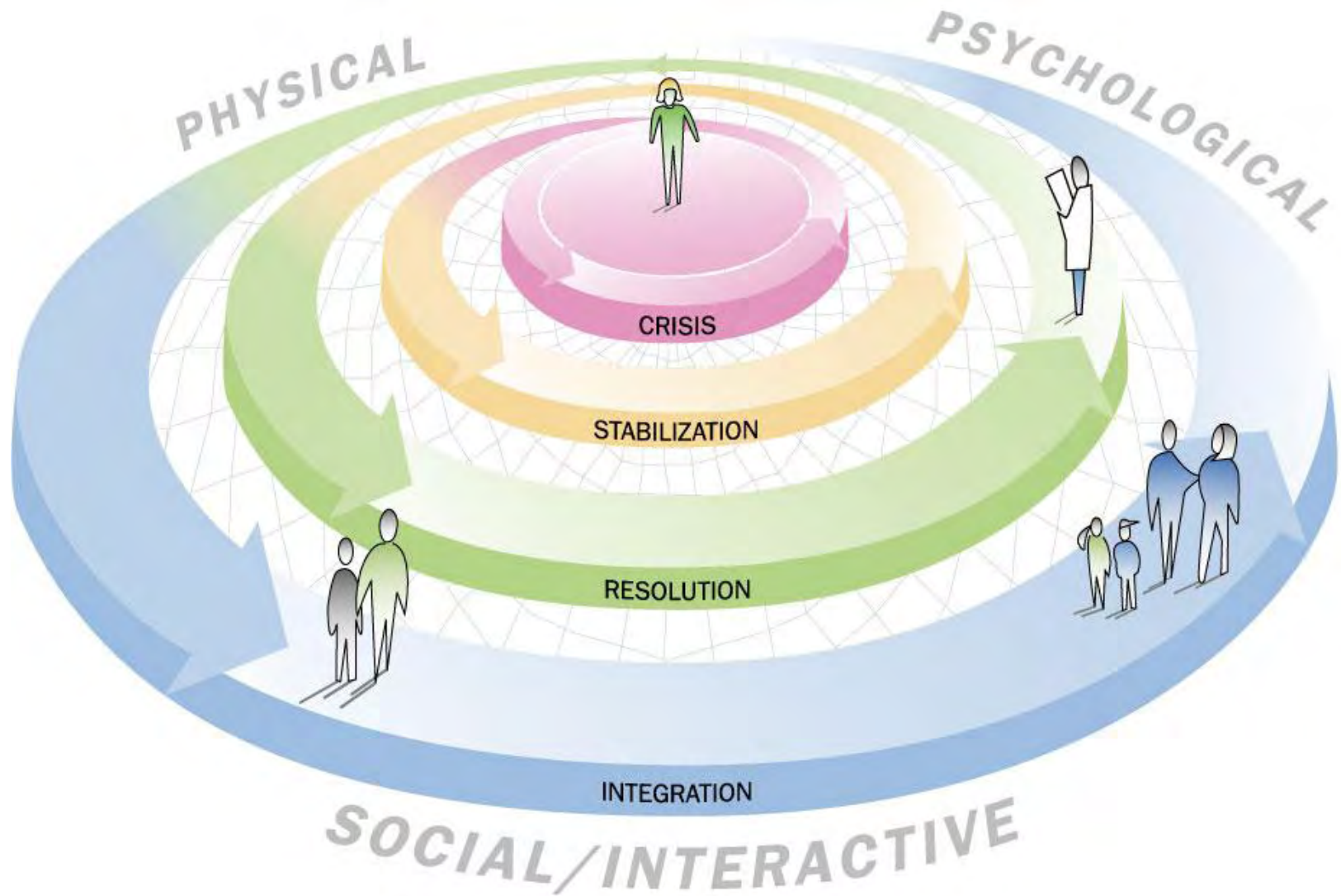
# The Fennell Four-Phase Model

The **Fennell Four-Phase Model (FFPM)** is a framework for explaining how people who are experiencing chronic illness or trauma can adapt to the changes in their lives. It outlines four phases that people commonly pass through as they learn to incorporate their altered physical abilities or psychological outlook into their personality and lifestyle.

It was developed by Patricia Fennell, MSW, LCSW-R, in 1992; first published in 1993 in *The CFIDS Chronicle*; subjected to validation research several times in the 1990s and 2000s; and fully presented in Fennell's 2003 book, *Managing Chronic Illness: The Four Phase Approach*.

The Fennell Four Phases are: **Crisis**, **Stabilization**, **Resolution**, and **Integration**. Within each phase, FFPM addresses three domains: the physical/behavioral, the psychological, and the social/interactive.

- In **Phase 1 Crisis**, the individual moves from onset of the condition to an emergency period when he or she knows that something is seriously wrong. Onset may be specifically detectable, such as a serious and disabling automobile accident, or may happen gradually, as in the case of multiple sclerosis, where a period of symptoms precedes diagnosis. The task of the individual, caregivers, and clinicians during this phase is to cope with and contain urgency and trauma.

- In **Phase 2 Stabilization**, the individual discovers that he or she fails, sometimes repeatedly, to return to normal, regardless of interventions or behavior. The task in this phase is to initiate stabilization and life restructuring.

- In **Phase 3 Resolution**, the individual recognizes deeply that his or her old life will never return. Early in this phase, many experience significant grief and loss. The task of this phase is to begin establishing an authentic new self and start developing a supportive, meaningful philosophy.

- In **Phase 4 Integration**, the individual defines a new self in which illness may be an important factor, but it is not the only or even the primary one in his or her life. Integration of the illness into a meaningful life is the goal the individual seeks.

The experience of chronic illness or trauma does not remain the same over time. The physical, emotional, and social needs of an individual in the early stages of the chronic experience can be considerably different from the needs of an individual who has been ill for several years.

Additionally, unlike other phase- or stage-based models, such as the Kübler-Ross theory of death and dying, FFPM does not assume that individuals move through the FFPM phases in a linear fashion. Rather, physical or emotional setbacks can precipitate a temporary move back to a previous phase.

# Creativity, Resolution, Art, Illness & Community Webinars

Creativity is vital in developing a healthy response to chronic illness and trauma. By using our powers of innovation, we're able to devise better ways of overcoming obstacles and dealing with the cards we've been dealt. And the arts — writing, music, painting, sculpture, dancing or other creative expression — offer an outlet for expressing our emotional and physical feelings. Art is both informed by and informs our suffering.

There are five capacities of improvisation that are explored through the arts and that people with chronic illnesses need to acquire to establish acceptance and meaning in their changed circumstances. These capacities are 1) tolerate ambiguity, 2) take risks, 3) become curious, 4) improvise, and 5) innovate.

The **Creativity, Resolution, Art, Illness & Community**, or CRAIC, Web-based group offers a community for people with chronic illnesses to get feedback on our art and our experiences. We meet periodically using a Web- and phone-based system to learn about creativity and artistic expression, set individual goals and share our creative work.

Craic is a Gaelic term that, loosely translated, means having a good time and laughter with friends, and that is an aim of this group. The CRAIC group is not a support group or therapy; rather it's a safe environment to learn, develop community and get feedback from others on our progress.

**For More Information:**

For information about upcoming CRAIC webinars, please visit the Events section of our website, www.AlbanyHealthManagement.com. To watch past webinars, please visit the Webinars section of our website. And, to be added to our email list to receive notice when we schedule webinars, please send an email to communications@AlbanyHealthManagement.com and ask to be added to our webinar email list.

# The Fennell Four-Phase Treatment for Chronic Illness

By Patricia A. Fennell, MSW, LCSW-R

## The Challenge of Chronic Illness

Managing chronic illness is one of the greatest challenges facing our health care system today. There were 129 million people with chronic conditions in 2005; this number is expected to grow 32 percent to 171 million in 2030, according to Partnership for Solutions, a research cooperative led by Johns Hopkins University.[1] The costs of chronic illness to the U.S. are huge, accounting for at least 78 percent of all health care spending, or well over a trillion dollars per year.[2]

Patients with chronic conditions often fare poorly in the current primary care delivery environment, which is structured for acute, episodic care. Care is often delivered with little coordination across multiple settings, providers and treatments.[3] Several variations of managed care have emerged in the past decade in an effort to improve care, reduce unnecessary service utilization and control spiraling costs. But the fragmented nature of services in the managed care market has not achieved the initial promise of truly coordinated care. Furthermore, managed care programs seldom address the complexity inherent in chronic conditions that may result in more frequent, rather than fewer, doctors' visits and hospitalizations. Chronic illnesses tend to affect several different body systems at the same time. In addition, the impact of the illness on the patient's physical, emotional and social condition persists over time and significantly affects patient reporting, compliance and coping with the illness. The physical, psychological and social needs of a patient in the early phases of the chronic illness experience can be considerably different from the needs of the patient who has been ill for several years.

## The Fennell Four-Phase Treatment (FFPT)™ Model

The Fennell Four-Phase Treatment (FFPT) is a flexible clinical approach, empirical paradigm, and assessment tool designed to enhance current managed care approaches by helping the health care team determine what may be expected over time and the best ways to intervene to improve the patient's quality of life at any given point. Research supports the concept that individuals coping with chronic illness progress through four distinct phases as they learn to deal with their illness.[4, 5, 6, 7, 8, 9] The FFPT provides a framework for understanding this critical process. Patients may respond differently to various treatment modalities depending upon which Phase of Illness they are in. Research has suggested that matching best medical practice to phase of illness can help both physicians and allied health professionals treat patients more effectively, increase compliancy and save time and resources.[10, 11, 12, 13]

Within each Phase, the FFPT addresses three domains: the physical/behavioral, the psychological, and the social/interactive. In **Phase 1, Crisis**, the individual moves from onset of illness, which may be specifically detectable or may happen gradually, to an emergency period when the patient knows that something is seriously wrong. The task of the individual, caregivers, and clinicians during this Phase is to cope with and contain urgency and trauma.

In **Phase 2, Stabilization**, the individual discovers that he or she fails, sometimes repeatedly, to return to normal regardless of interventions or behavior. The task in this Phase is to initiate stabilization and life restructuring.

In **Phase 3, Resolution**, the individual recognizes deeply that his or her old life will never return. Early in this Phase, many experience significant grief and loss. The task of this Phase is to begin establishing an authentic new self and start developing a supportive, meaningful philosophy.

In **Phase 4, Integration**, the individual defines a new self in which illness may be an important factor, but it is not the only or even the primary one in his or her life. Integration of the illness into a meaningful life is the goal the individual seeks. For a graphic example of matching medical intervention to phase of illness for a specific chronic illness, see the chart on the following page. [14]

Another promising approach is the Chronic Care Model (CCM), which provides a holistic framework and methodology for transforming a health care system so that patients receives coordinated care from a trained interdisciplinary health care team and planned follow up.[15] What the CCM does not appear to consider in its approach to team-based treatment is the need to match medical interventions with the patient's Phase of Illness. This is important given the ebbs and flows of symptoms, and the cycles of relapse and remission that characterize many chronic conditions.

## Case Management

As described previously, case management can be extremely complex in chronic illnesses because of the large number of medical professionals and treatments that can be involved. The FFPT can be used successfully as a chronic illness case management tool. The goals in case management run parallel to the clinical goals.

In **Phase 1**, the case management goal is to establish a case management focus. This includes restructuring the activities of daily living, engaging in family case management, assisting patients in navigating the health care system, intervening in the workplace if necessary, and acting as the patients' advocate.

In **Phase 2,** the case management goals are patient data collection and activity restructuring. With the help of the case manager, patients assess and restructure their activity levels and develop new parameters and norms. The case management continues to help with family case

management, negotiation of the health care system, intervention with the employer, and patient advocacy.

In **Phase 3**, the case management goal is helping patients develop self-management skills. Patients learn to monitor their activities, coordinate their medical care, become their own health care advocates, and in general assume advocacy for themselves in the world at large. In **Phase 4**, the case management goal is to deepen patients' self-management skills.

A holistic approach such as this captures essential elements of experience that can determine whether interventions will be successful. It particularly points to the necessity of solving problems -- familial, social, economic, and philosophical, among others -- that are rarely part of the conventional medical treatment model. Because teamwork is essential, among a broad assortment of professionals, all committed to involving the patient whenever possible in the process, a case management approach seems best suited accomplish this in a successful, ethical manner.

## Summary

The Fennell Four-Phase Treatment (FFPT)™ channels the efforts of the health care team to match best medical practices to the patient's phase of illness. By identifying different functional capacities and symptoms at different phases, the FFPT™ helps the physician, nurse case manager, and other members of the health care team select the most appropriate and effective interventions and avoid choosing treatments that, although useful at another time, may be counterproductive at the patient's current Phase of Illness. By intervening with treatments suited to the patient's particular Phase -- a time when they are more likely to be compliant -- health care providers can help patients break out of a pattern of repeated crises that usually require more extensive resources in response. The goal of this approach is not pursuing the ever-elusive cure, but integration of the

| MATCHING BEST PRACTICES WITH PHASES OF ILLNESS | | | | |
|---|---|---|---|---|
| | Phase 1<br><br>Crisis | Phase 2<br><br>Stabilization | Phase 3<br><br>Resolution | Phase 4<br><br>Integration |
| **Definition** | Individual moves from illness onset (sudden or gradual) to emergency period when the patient knows something is seriously wrong | Patient begins to understand symptom complex and develops new norms and behaviors | Patient recognizes that old life will not return and wrestles with existential questions | Patient defines a new self in which illness may be an important factor, but is not primary in his/her life |
| **Task** | Contain the crisis; manage urgency and possible trauma | Facilitate stabilization of symptoms through medical treatment and life restructuring | Continue ongoing management of medical plan and help patient develop meaning in suffering | Assist patient in integrating the illness into a meaningful life |
| **Medical Assessment & Intervention** | Complete a comprehensive medical history; conduct physical exam; do lab tests as indicated; confirm diagnosis; develop a working list of problems and treatment plan | Schedule frequent patient visits to systematically address major symptoms (sleep, mood/cognitive, pain, fatigue, etc.); review lab tests and do routine ongoing screening; manage all comorbid and secondary conditions; monitor medications and simplify when possible; coordinate rehabilitation efforts (physical therapy, occupational therapy) | Monitor and manage symptoms, modifying treatment plan as needed; simplify and/or reduce medications as appropriate; continue routine health screenings; continue regimen to improve physical fitness within the confines of chronic illness limitations | Continue monitoring of patient functioning; continue focus on guarding against deconditioning utilizing physical conditioning regimen; emphasize lowest effective doses or nondrug interventions; help patient balance trying new treatments with "just living" |
| **Phase Assessment & Intervention** | Conduct psychosocial interview and other relevant evaluations (may include neurological/ psychological tests, sleep studies, etc.); establish multidisciplinary team; build relationship with patients; analyze activity threshold and restructure activity levels as needed | Initiate values clarification and development of new norms; review and modify activity levels; assist patient in coping with challenges like grief and "illness etiquette"; patient/ family case management; workplace intervention and/or modification, or exploration of disability options | Facilitate patient's exploration of existential questions and developing meaning; encourage patient to become own care coordinator and advocate; consider job modifications or workplace separation | Continue meaning development and integration of pre- and post-crisis self; review workplace modifications and/or alternative vocations and activities; maintain dialogue among members of multidisciplinary treatment team |

illness into the patient's life. For patients and their families, the FFPT™ helps them to organize a narrative of their experience, essential for patient education and self-management.

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**Patricia Fennell, MSW, LCSW-R**, is the CEO of Albany Health Management Associates, Inc., an organization that provides counseling and case management in the areas of chronic syndromes, trauma, forensics and hospice care, as well as consulting and education for employers, professional training for clinicians, and collaborative research for the international scientific community. Ms. Fennell is an innovator in the chronic illness and mental health fields, and she created the internationally recognized Fennell Four-Phase Treatment (FFPT)™ approach for understanding and treating chronic medical and mental health conditions. The model has been translated into several languages and is used by clinicians, researchers, and patients worldwide.

Patricia A. Fennell
Expert in Chronic Illness, Trauma and Recovery

# Biography

**Patricia Fennell, MSW, LCSW-R**, is the founder and President of Albany Health Management Associates Inc., a multidisciplinary organization focusing on the global health care effects of chronic Illness and trauma. Through health management, counseling, health-related research, professional training, community education, and chronic illness retreats, Ms. Fennell and her staff have been working since 1989 to alleviate the suffering created by chronic illness, trauma, death and violence and to enhance the psychological, social, and physical wellbeing of patients and their families.

Ms. Fennell is an innovator in the chronic illness and mental health fields. She created the internationally recognized Fennell Four-Phase Model (FFPT)™ for understanding and treating chronic conditions. The model is used by medical and counseling clinicians, medical researchers, and patients in the U.S., Canada, Australia, Africa and Europe.

A popular speaker, Ms. Fennell presents worldwide to the medical, education, and criminal justice communities at conferences and meetings for both professionals and patients. She is frequently requested to offer her expertise to the media, corporations, government agencies, healthcare organizations and academic institutions.

She has authored two additional books on chronic illness: *Managing Chronic Illness Using the Four-Phase Treatment Approach* and *The Handbook of Chronic Fatigue Syndrome* with Wiley. She has also written numerous scholarly and lay press articles on the topic, including the chapter on Chronic Illness for the Oxford *Encyclopedia of Social Work*.

Patricia continues to see patients, train and supervise clinicians, and, utilizing original content and curriculum, she administers a two year training program in the FFPT™.

Patricia is a jazz vocalist. In 2009 she released the CD, *Frim Fram Sauce*.

For more information, please visit www.albanyhealthmanagement.com

John Esposito
Pianist Composer

# **Biography**

**John Esposito** is a New York State native and grew up in a family steeped in musical tradition. His grandfather was a noted teacher and violin maker who played violin with the St. Louis Symphony Orchestra and also worked with various theatre and jazz bands (including the Paul Whiteman Orchestra) on violin and reeds starting in the early 1920s. John's first performance experiences were playing harmonica in a blues band as a teenager. He attended SUNY Albany as a composition major.

He spent several years after college in Albany as the house pianist at the Gemini Jazz café working with J.R. Monterose and Nick Brignola and led his own group before coming to New York City in 1980. It was then that he began working with talented, young saxophonist/pianist/guitarist Arthur Rhames. For the next five years he would be an integral part of the Arthur Rhames Quartet with Jeff Siegel (drums) and Otto Gardner (bass), documented on only one recording, *Arthur Rhames Live At Soundscape*.

In 1985, John formed Second Sight – a jazz quintet with Dave Douglas, Jeff Marx, Allen Murphy, Jeff Siegel and Fred Berryhill. They recorded *Flying With The Comet* in 1986, an album of original compositions released on John's independent label: SunJump Records. Their second recording, *Tiger Tracks*, recorded in 1987 is an upcoming SunJump release. Of Second Sight, Gene Santoro in *Pulse! Magazine* wrote: "This sextet swings like mad and bubbles over with lively effervescent chops to spare." Throughout the eighties John also put in time as a sideman for Carter Jefferson, John Stubblefield, Roswell Rudd, Hugh Brodie and many others.

In the nineties John began working with the groups of Franklin Kiermyer and Eric Person as a pianist and arranger. He recorded four albums with Kiermyer including *Solomon's Daughter*, with tenor saxophone giant Pharoah Sanders, and *Kairos* with the legendary Sam Rivers. John also played on four albums with Eric Person's MetaFour beginning with *Eric's More Tales to Tell* with Dave Holland and Gene Jackson.

John is on the faculty of Bard College and teaches piano, drums, ensembles, jazz theory, repertoire and advanced composition techniques classes there.

In 2006 he returned to being a bandleader with three CD releases. One is *Down Blue Marlin Road* – a trio album of deconstructed/reconstructed jazz standards with Ira Coleman and Pete O'Brien – another is *The Blue People* – a quintet date of original material featuring Eric Person, Greg Glassman, Kenny Davis and Peter O'Brien - and *A Book Of Five Rings*, an octet recorded live at the Knitting Factory, NYC. His new trio CD of original compositions is *Orisha*.

For more information, visit http://www.sunjumprecords.com.

Ann Fantauzzi
Educational Consultant, Retired Educator

# **Biography**

**Ann Fantauzzi, MS Ed.,** has worked in the field of education for 34 years. She has taught upper elementary grades, as well as administered and taught the gifted and talented program in her district. She is a published children's author, an innovator in classroom teaching methods and a teacher mentor.

She lives with her own chronic illness and is interested in helping others, especially schoolchildren, deal with theirs.

She has been very interested in the outdoors and sports her whole life. She's traveled across the United States and Canada, and has spent some winters in Arizona (where she does a lot of hiking). During college she was a certified Canadian ski instructor and a nationally certified ski patrolman. While teaching, she led groups of young students to Russia and Karelia to visit art schools. Working with Habitat for Humanity taught her many skills in building, cooperation and community.

Retirement has allowed her to open up a new world of travel and service. Shortly after leaving teaching she traveled to assist in hurricane disaster areas with the Red Cross Disaster Relief Services. For the past three years, she has assisted a colleague from a West Coast university in guiding students doing their student teaching in Namibia. This summer she will be teaching in a school for AIDS orphans in Uganda.

Her extensive travel has influenced her teaching and offered her the opportunity to pursue one of her favorite interests and endeavors: photography. She has had a number of gallery shows of her photos of African wildlife.

Ann is involved with the Mature Learning Program at Skidmore College and is studying the History of African Art at Skidmore.