

Sixth Annual Chronic Illness Initiative Symposium

Chronic Illness & The Arts

DePaul University Student Center
Sponsored by DePaul University's Chronic Illness Initiative

Presentations by
Patricia Fennell, MSW, LCSW-R
Albany Health Management Associates, Inc.
www.albanyhealthmanagement.com

9:30–10:30 a.m.

*When Illness Tears Your Soul, Art Gives It Back:
Finding Meaning in Illness Through Artistic Expression*

10:45 a.m.–11:45 a.m.

Working the Third Phase: Meaning, Community and the Arts
Co-presenter: Lynn Royster, Ph.D.,
Director, The Chronic Illness Initiative, DePaul University

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 Characterological 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

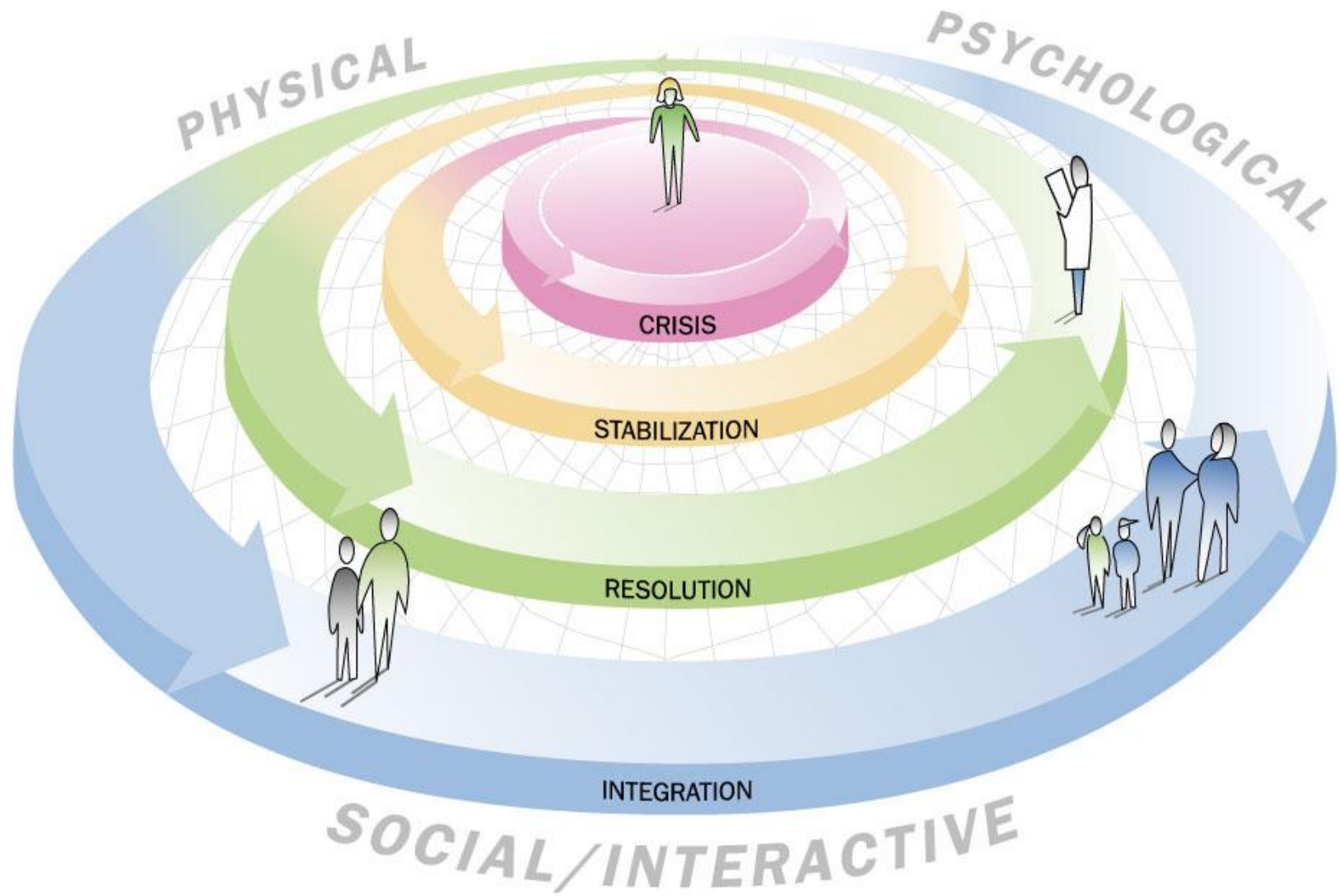
DYNAMICS

- 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



ALBANY HEALTH MANAGEMENT ASSOCIATES, INC.
582 New Loudon Road, Latham, NY 12110
Patricia A. Fennell, MSW, LCSW - R, President
(518) 782-0551 Fax (518) 783-4793
E-Mail: communications@albanyhealthmanagement.com
website: www.albanyhealthmanagement.com

When Illness Tears Your Soul,
Art Gives It Back

*Finding Meaning in Illness
Through Artistic Expression*

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Improvisation, Creation and
Innovation

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Innovation & Creation

- Improvisation → Creation → Innovation
- Change is:
 - Inevitable
 - Good
 - Bad
- Improvisation, creation & innovation help us respond to change.

3

Creation

- A powerful stance against helplessness.
- Requires active reflection and creative action.
- Must be authentic.

4

Authenticity

- In the process of creation, it's absolutely necessary to maintain insight about your limitations and your abilities.
- This is often painful.
- It's necessary to consistently strive for authenticity, and thus freedom, in the creative process.
- "The price of freedom is eternal vigilance."

–Thomas Jefferson

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The 5 Capacities

- Allow people with chronic illnesses to establish acceptance and meaning in their changed circumstances.
- Your discipline, personality or circumstances may mean other capacities are required.
- Discover and define them.

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1. Tolerate Ambiguity

- Ambiguity is unavoidable.
- Learn how to survive the “not knowing.”
- Take the time to be uncomfortable to get to where you need to be.
- Learn how to do the “emotional heavy lifting.” This leads to wisdom.
- Wisdom: Appreciating the value of the unknown. The realization that something good will come of this.

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2. Become Curious

- Change is an opportunity.
- Curiosity leads to innovation and change.
- Our culture squelches children’s curiosity, wonder and risk-taking.
- Culture’s toleration of curiosity is influenced by gender, race and social class.
- It has positive (childlike wonder), negative (nosy, “killed the cat”) and ambiguous (questioning authority) connotations.

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3. Take Risks

- Take the risk of getting started (every day).
- Conscious v. unconscious (impulsive) risk taking.
- Calculated risk taking:
 - Informed by knowledge of limits and abilities.
 - Isn’t impulsive.
 - Minimizes shame, embarrassment, fear of failure.
 - Has an “exit strategy” if things don’t go as planned.

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4. Improvise

- Improvisation requires that you make a choice.
 - Statement/choice → reaction → react to the reaction.
- Choosing in the moment: do you pick up the paintbrush? What color will you use?
- Did you get the light bulb? Do you need to?

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5. Innovate

- You've taken risks, been curious, made choices, innovated.
- The result – an idea, a paragraph, a picture, a song – whether small or large, is a victory.
- Ask for outside help. Get training, instruction or assistance.
- Accommodate your limits and abilities.

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Application

Using the 5 Capacities to Respond to Change

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“You never want a serious crisis to go to waste. And what I mean by that is an opportunity to do things you think you could not do before.”

-- Rahm Emmanuel

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Respond To Your Crisis

- Define your crisis.
- How can the 5 capacities of improvisation be applied to the crisis/trauma of chronic illness?
- Which of the capacities are your strengths?
- Which are your weaknesses?

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Apply The 5 Capacities

- What is your creative medium?
 - Music, visual art, writing, drama, etc.
- What kind of help do you need?

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Persistence & Fortitude

- Willingness to fail, developing self-reliance.
- Importance of community:
 - When you don't feel you can persevere, you can borrow from strength of others.
 - Faith
- Allow yourself extra time or help to do the more difficult things.
- “Fall down 7 times, get up 8.”

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ALBANY HEALTH MANAGEMENT ASSOCIATES, INC.
 582 New Loudon Road, Latham, NY 12110
 Patricia A. Fennell, MSW, LCSW - R, President
 (518) 782-0551 Fax (518) 783-4792
 E-Mail: communications@albanyhealthmanagement.com
 website: www.albanyhealthmanagement.com

Working the Third Phase:

*Meaning, Community
and the Arts*

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Trauma Types

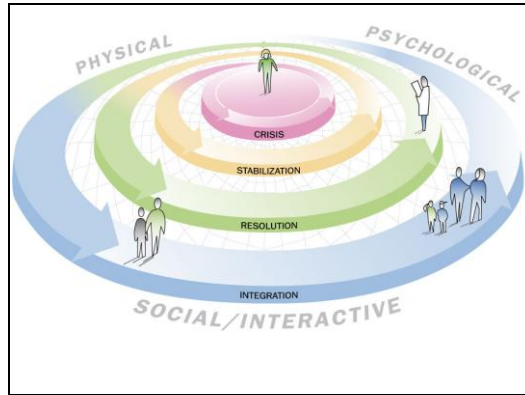
- Disease/Syndrome Trauma
- Iatrogenic Trauma
- Cultural Trauma
- Vicarious Trauma

- Pre-Morbid / Co-Morbid Trauma

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- ### Socio-Cultural Factors
- Cultural Intolerance of Suffering
 - Cultural Intolerance of Ambiguity
 - Cultural Intolerance of Chronic vs. Acute Syndromes
 - Pre-existing Cultural Climate Toward Chronic Syndromes
 - Media
 - Initial Syndrome Illegitimacy and Subsequent Enculturation

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- ### Phase I – Trauma / Crisis
- **Physical /Behavioral**
 - Coping Stage
 - Onset Stage
 - Acute / Emergency Stage
 - **Psychological**
 - Loss of Psychological Control/ Ego Loss
 - Intrusive Shame, Self Hatred, Despair
 - Shock, Disorientation, Dissociation
 - Fear of Others, Isolation, Mood Swings
 - **Social/Interactive**
 - Others Experience Shock, Disbelief, Revulsion
 - Vicarious Traumatization
 - Family/Organizational Maturation
 - Suspicion/Support Continuum

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- ### Phase II –Stabilization / Normalization Failure
- **Physical / Behavioral**
 - Plateau
 - Stabilization
 - **Psychological**
 - Increased Caution / Secondary Wounding
 - Social Withdrawals, Social Searching
 - Service Confusion/Searching
 - Boundary Confusion
 - **Social/Interactive**
 - Interactive Conflict/Cooperation
 - Vicarious Secondary Wounding
 - Vicarious Traumatic Manifestation
 - Normalization Failure

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Phase III – Resolution

- **Physical/Behavioral**
 - Emergency Stage/Diminishment/Improvement
 - Continued Plateau/Stabilization
 - Relapse
- **Psychological**
 - Grief Reaction/Compassion Response
 - Identification of Pre-crisis – “Self”
 - Role/Identity Experimentation
 - Returning Locus of Control
 - Awareness of Societal Effects
 - Spiritual Development
- **Social/Interactive**
 - Breaking Silence/Engulfment in Stigma
 - Confrontation
 - Role Experimentation – Social, Vocational
 - Integration / Separation / Loss of Supporters

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Phase IV – Integration

- **Physical/Behavioral**
 - Recovery Stage
 - Continued Plateau/Improvement/Relapse
- **Psychological**
 - Role/Identity Integration
 - New Personal Best
 - Continued Spiritual/Emotional Development
- **Social/Interactive**
 - New/Reintegrated Supporters
 - Alternative Vocation/Activities

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Phase 3

Resolution:

The Dilemma of Creating
Meaning From Suffering

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Phase 3: Resolution

- Goal: to develop meaning about suffering.
- Recognize deeply that your old life will not return.
- Begin to find meaning in your experience, establish an authentic new self and develop a supportive, meaningful philosophy.
- Artistic expression and community offer pathways toward establishing meaning in the chronic illness experience.

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Transformation Steps

- By coming to terms with your own feelings, you can develop meaningful responses to your illness experience.
 - Allowance of suffering
 - Meet suffering with compassion
 - Meet suffering with respect
 - Integrate suffering

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Phase 3 Transformation Step: Meeting The Suffering With Respect

- Regarded with appreciation
- Heroic captivity
- Antithetical interpretation
- Engaging the creative process
- Standing with self

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Working the Third Phase Tasks: Time In The Tunnel

- Maintain insight and reframe issue
- Deep grief for lost self
- Existential dilemma
- Dark night of the soul
- Defining the pre-crisis self
- Analysis of actual losses - external
- Internal changes
- Faith
- Committing to time in the tunnel

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Working the Third Phase Tasks: Phoenix From The Ashes

- Importance of countertransference
- Baseline authenticity
- Antithetical experimentation
- Creative process
- Supportive materials
- Clinician as storyteller
- The noble-disabled danger

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Working the Third Phase Tasks: Meaning Development

- New vision of societal attitudes
- Exploring different traditions
- Meaning development
- Faith and humor

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Persistence & Fortitude

- Willingness to fail, developing self-reliance.
- Importance of community:
 - When you don't feel you can persevere, you can borrow from strength of others.
 - Faith
- Allow yourself extra time or help to do the more difficult things.
- "Fall down 7 times, get up 8."

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Identifying Your Project

- What is your discipline of choice?
- Technology to support the ongoing group
- Resources
- Workgroup structure

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Working the Third Phase Creativity Group

Vote on date for our first meeting:

- June 2
- June 10
- June 16

10 a.m. Central

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Working the Third Phase Creativity Group

- Registration will open in about 2 weeks – we'll send you an invitation by e-mail.
- Information will be posted on AlbanyHealthManagement.com – click on "Events."
- Fill out your name, e-mail address, phone number to receive further information.

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For More Information:

www.albanyhealthmanagement.com
communications@albanyhealthmanagement.com

- Certification in the FFPT™ approach
- The Fennell Phase Inventory™
- Research projects
- Books and related articles
- Clinical services
- Consulting
- Education and training

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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.

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 Crisis	Phase 2 Stabilization	Phase 3 Resolution	Phase 4 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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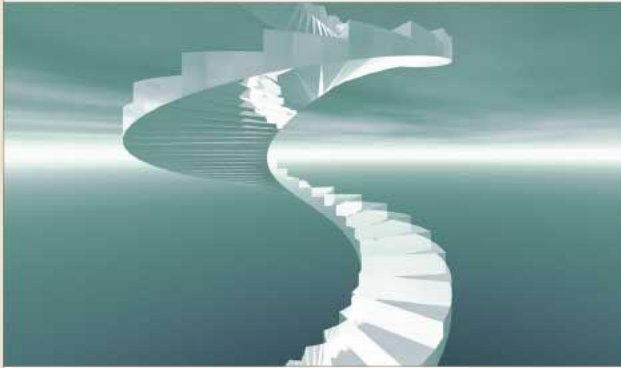
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Patricia Fennell, MSW, LCSW-R, is the CEO of [Albany Health Management Associates, Inc.](#), an organization that provides counseling and case management in the areas of chronic syndromes, trauma, forensics and hospice care, as well as consulting and 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.

The Chronic Illness Workbook



STRATEGIES *and* SOLUTIONS
for TAKING BACK YOUR LIFE

Patricia A. Fennell, MSW, LCSW-R

The Chronic Illness Workbook brings clarity and order to what feels like an unmanageable and isolating experience. It shows both those who are ill and those who care for them how to live a full and meaningful life despite undeniable difficulties. Using her extensive experience with chronic illness patients, Patricia Fennell has created an original, comprehensive, research-validated approach that considers not only the physical aspects of chronic illness, but the psychological, social, and economic aspects as well.

Albany Health Management Publishing
\$20.00
256 pages
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"The Chronic Illness Workbook is a valuable contribution that will be welcomed by the many sufferers of chronic diseases. It is of the greatest importance that patients learn to cope with the problems that cannot be remedied. Patricia Fennell's book provides an original and incisive approach to coping with chronic illness."

Noel R. Rose, M.D., Ph.D., Director of the Autoimmune Disease Research Center at the Johns Hopkins University School of Hygiene and Public Health

For ordering information, or for more information about Patricia Fennell and Albany Health Management, visit:

<http://www.albanyhealthmanagement.com>
(click on Books to purchase *The Chronic Illness Workbook*)

or contact us at communications@albanyhealthmanagement.com