

## Accommodating Students With Chronic Illness: A Concern For Teacher Training

Patricia A. Fennell, MSW, LCSW-R; Albany Health Management Associates, Inc.  
communications@albanyhealthmanagement.com

Paula Leitz, PhD; Pacific Lutheran University  
leitzph@plu.edu

Ann Fantauzzi, B.S.Ed., M.S. Ed.; Albany Health Management Associates, Inc.  
annfantauzzi@yahoo.com

### Abstract:

This presentation discusses the Fennell Four Phase Model for accommodating in educational settings the growing chronically ill student population and minimizing illness-related under-education, absenteeism and poverty.

### Outcomes and Methods:

- Participants will understand the impact of and unique issues concerning chronic illness and the educational process.
- Participants will recognize the importance of accommodating students with chronic illness in the educational process.
- Participants will demonstrate an understanding of the Fennell Four-Phase Model and differentiated instruction and their application in the educational process.
- Participants will understand ways to use differentiated instruction and FFPM to improve educational outcomes in children with chronic conditions.

### Discussion:

#### A. Statement of the issue:

The prevalence of chronic illness is increasing among all age groups, including the student population.

This increase is coincident with improvements in medicine that have converted once-terminal diseases, such as cancer and HIV/AIDS, into chronic conditions, and with the overall rise in prevalence of chronic conditions such as diabetes, asthma, autoimmune diseases, depression and autism.

Education, poverty and chronic illness are intertwined, as school-age children with chronic conditions (or who are caring for family members with chronic conditions) are at higher risk for school absenteeism and drop-out, and lack of

education is a major cause of lifetime poverty and poor health.

Educational institutions are challenged to accommodate chronically ill students to maintain their participation in the educational process, comply with disability law, avoid disparities among the acutely (statically) ill, chronically (dynamically) ill, and the non-disabled population, and minimize the long-term impact of under-education on income and health outcomes. These institutions are looking to schools, colleges and departments of education (SCDEs) to provide guidance and empirical data on how to best include chronically ill students in education.

#### B. Literature review:

Chronic conditions are defined by the World Health Organization as "health problems that require ongoing management over a period of years or decades."<sup>1</sup> They include illnesses such as diabetes, cardiovascular disease, mental illness, autoimmune diseases, asthma and communicable diseases such as HIV/AIDS.

Managing and accommodating chronic illness is one of the greatest challenges facing our health care, employment and educational systems today. In America alone, there were 129 million people with chronic conditions in 2005; this is expected to grow by 32 percent to 171 million in 2030, according to Partnership for Solutions, a research cooperative led by Johns Hopkins University.<sup>2</sup> The costs of chronic illness to the United States are huge, accounting for at least 75 percent of all health care spending, or about \$1.65 trillion of the \$2.2 trillion spent on health care in America each year.<sup>3</sup>

1 World Health Organization. "Innovative Care for Chronic Conditions: Building Blocks for Action." Accessed 2/20/09 at:

[http://www.improvingchroniccare.org/downloads/who\\_innovative\\_care\\_for\\_chronic\\_conditions.pdf](http://www.improvingchroniccare.org/downloads/who_innovative_care_for_chronic_conditions.pdf)

2 Glabman, M. 2005. "12 trends you should know about". *Managed Care*, Volume 14, No.8.

3 Hartman, M., Martin, A., McDonnell, P., Catlin, A., National Health Expenditure Accounts Team. 2009. "National Health Spending In 2007:

Worldwide, chronic conditions are responsible for 60 percent of the global disease burden; by 2020, 80 percent of the disease burden in developing countries will be tied to chronic conditions. In developing countries as few as 20 percent of individuals with chronic illnesses adhere to treatment protocols, placing added stress on systems of care and individuals and families. The escalating costs of chronic conditions have serious economic, social and health-care resource consequences for governments worldwide.<sup>4</sup>

The link between chronic illness and poverty is clear, as individuals with chronic conditions face higher levels of unemployment, underemployment and school absenteeism and increased costs for medical care.<sup>5</sup> Education is key to erasing poverty: a year of primary school increases an individual's lifetime wages by 5-15 percent; each additional year of secondary school increases wages 15-25 percent.<sup>6</sup> Education is also crucial in improving health and enabling people to cope better with illness. For example, the Global Campaign for Education estimates that educating all children could prevent 7 million cases of HIV/AIDS in the next decade and reports that children born to illiterate mothers are 50 percent less likely to survive past 5 years of age.<sup>7</sup>

Worldwide, 75 million children are not receiving an education; a third of them have a disability. Millions more leave school to care for a family member who suffers from a chronic condition or to join the workforce to help support their families. Girls in developing countries are at particular risk given cultural norms that place greater value on education of boys.<sup>8</sup>

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Slower Drug Spending Contributes To Lowest Rate Of Overall Growth Since 1998." Health Affairs, Volume 28, Number 1, 246-261.

4 World Health Organization. "Innovative Care for Chronic Conditions: Building Blocks for Action." Accessed 2/20/09 at: [http://www.improvingchroniccare.org/downloads/who\\_innovative\\_care\\_for\\_chronic\\_conditions.pdf](http://www.improvingchroniccare.org/downloads/who_innovative_care_for_chronic_conditions.pdf)

5 World Health Organization. "Innovative Care for Chronic Conditions: Building Blocks for Action." Accessed 2/20/09 at: [http://www.improvingchroniccare.org/downloads/who\\_innovative\\_care\\_for\\_chronic\\_conditions.pdf](http://www.improvingchroniccare.org/downloads/who_innovative_care_for_chronic_conditions.pdf)

6 Global Campaign for Education. 2009. "Millions Miss Out." Accessed 2/20/09 at: <http://campaignforeducation.org/en/why-education-for-all/millionsmissout>

7 Global Campaign for Education. 2009. "Millions Miss Out." Accessed 2/20/09 at: <http://campaignforeducation.org/en/why-education-for-all/millionsmissout>

8 Global Campaign for Education. 2009. "Millions Miss Out." Accessed 2/20/09 at: <http://campaignforeducation.org/en/why-education-for-all/millionsmissout>

### C. Contribution:

Chronic illness presents a series of issues that make school attendance difficult. Many of the challenges of accommodating chronically ill students are due to the nature of chronic illness itself. Chronic illnesses often have a relapsing-remitting pattern, can be static or dynamic<sup>9</sup> and are frequently "invisible" (as contrasted with obvious disabilities like blindness, hearing impairment or mobility disorders). There is also a lack of standardized protocols for accommodating students with chronic illness.

Ensuring that students with chronic conditions have access to the fullest range possible of educational services is essential, not only because it is required by federal disability law, but also because these individuals need to be trained to join the workforce as adults. Education is an essential component of managing chronic conditions; research shows that people with higher levels of education are less likely to engage in lifestyle choices that lead to some of the most common chronic illnesses (i.e., obesity and smoking as etiological factors in cardiovascular disease, cancer, diabetes, etc.), and are more compliant with treatment protocols. As Freudenberg and Ruglis wrote, "Education is one of the strongest predictors of health: the more schooling people have the better their health is likely to be. Although education is highly correlated with income and occupation, evidence suggests that education exerts the strongest influence on health."<sup>10</sup>

### D. Relevance:

Governments and other policy-making organizations have a significant role in establishing policies that promote the inclusion of students with chronic illnesses in the educational process. There are significant risks should chronically ill students be excluded (or dissuaded) from gaining an education.

- A study of dropouts in Israel showed that a large percentage of dropouts come from families in which one or both parents have a serious problem in functioning (e.g., a chronic illness or disability, involvement in crime, unemployment). A significant percentage of these youth are exposed to neglect and violence.<sup>11</sup>

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9 Fennell, P.A. 2003. *Managing Chronic Illness: The Four Phase Approach*. John Wiley and Sons Inc., New York.

10 Freudenberg N., Ruglis J. Reframing school dropout as a public health issue. *Prev Chronic Dis* 2007;4(4). [http://www.cdc.gov/pcd/issues/2007/oct/07\\_0063.htm](http://www.cdc.gov/pcd/issues/2007/oct/07_0063.htm). Accessed 4/5/09.

11 Cohen-Navot, M., Ellenbogen-Frankovits, S., and Reinfeld, T. *School Dropouts and School Disengagement*. Myers-JDC-Brookdale Institute. RR-

- There is a pronounced impact on families with a child with a special health care need (SHCN); in one study 20.9 percent of these families reported their child's health care caused financial problems, and 29.9 percent reported cutting back or quitting work because of their child's condition. These adverse child- and family-level impacts were concentrated among low-income and uninsured children with SHCNs.<sup>12</sup>
- Chronic health conditions place tremendous strain on children and families. Epidemiologic data show that children with chronic health conditions and their parents have higher rates of mental health problems than children without such conditions. Yet, it appears that the psychological and social needs of these children and families are not adequately addressed through conventional systems of care.<sup>13</sup>

A number of organizations have implemented recommendations or policies that would address the inclusion of chronically ill students.

- The World Health Organization's Global School Health Initiative defines a "health promoting school" as one that constantly strengthens its capacity as a place for students and teachers and all others to work in a healthy setting for living, learning and working. This school creates conditions for best practices and choices in health and education with success, knowledge, attitude and guidance available.<sup>14</sup>
- The National Education Association in the United States has proposed eight principles for improving the No Child Left Behind act, formerly known as the Education for All Children Act, and ensuring that children receive an education that prepares them to live and work in the 21st century.<sup>15</sup>

381-01, <http://brookdale.jdc.org.il/?catid=percent7B4F4E1AC1-FC18-43D3-8995-2FD34D702D2Dpercent7D>. Accessed 4/8/09.

12 van Dyck, P.C., Kogan, M.D., McPherson, M.G., Weissman, G.R., and Newacheck, P.W. Prevalence and Characteristics of Children With Special Health Care Needs. *Arch Pediatr Adolesc Med.* 2004;158:884-890. <http://archpedi.ama-assn.org/cgi/content/abstract/158/9/884>. Accessed 4/10/09.

13 Bauman, L.J., Drotar, D., Leventhal, J.M., Perrin, E.C., and Pless, I.B. A Review of Psychosocial Interventions for Children With Chronic Health Conditions. *PEDIATRICS* Vol. 100 No. 2 August 1997, pp. 244-251. <http://pediatrics.aappublications.org/cgi/content/extract/100/2/244>. Accessed 4/10/09.

14 World Health Organization. "What is a health promoting school?" [http://www.who.int/school\\_youth\\_health/gshi/hps/en/index.html](http://www.who.int/school_youth_health/gshi/hps/en/index.html). Accessed 3/1/09.

15 National Education Association. "NEA's 8 Principles for ESEA/NCLB Reauthorization" <http://www.nea.org/home/1335.htm>. Accessed 3/1/09.

- The fact that students with chronic illnesses are a vital part of the education system in developed nations like the United States and the United Kingdom is a credit to improvements in education and policy that have opened up the classroom to those who may not have had access only a few decades ago.
- Chronic illness models, including the Fennell Four-Phase Model (FFPM) of chronic illness, address the universe of issues and concerns facing students and families with chronic conditions. FFPM 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. 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.
- Differentiated instruction is an important pedagogical practice that is designed to accommodate the varying learning needs of students, whether they are gifted, learning disabled, chronically ill or typical. Differentiation allows teachers to provide high-quality learning opportunities while engaging each class member at his or her own level.<sup>16</sup> Differentiation is also validating for students. It presents curriculum in a way that is relevant to their lives and helps them make connections between concepts, which in turn helps them to retain new ideas.<sup>17</sup>

#### *E. Implication for Action:*

By blending the FFPM approach with differentiated instruction, educators can develop individualized approaches to teaching students with chronic conditions that meet the students "where they are." By using FFPM to take into consideration the medical, social, familial and psychological situation the student is facing, educators can use differentiated instruction to develop curriculum and assignments that are relevant to the student's life, interests and abilities. Combining these approaches offers students a greater opportunity to maintain their education while coping with the relapsing/remitting nature of chronic illness.

16 Tomlinson, C.A. 1999. *The Differentiated Classroom: Responding To The Needs Of All Learners*. Alexandria, VA: Association for Supervision and Curriculum Development.

17 Tomlinson, C.A. 2003. *Fulfilling the Promise of the Differentiated classroom: Strategies and Tools for Responsive Teaching*. Alexandria, Virginia.: Association for Supervision and Curriculum Development.

## 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

# 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.

## Accommodating Students With Chronic Illness: A Concern For Teacher Training

Presented by:

**Patricia Fennell, MSW, LCSW-R;**  
Albany Health Management Associates, Inc.  
**Paula Leitz, PhD;** Pacific Lutheran University  
**Ann Fantauzzi, B.S.Ed., MS Ed;**  
Albany Health Management Associates, Inc.

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## Agenda

- Chronic illness and education
- Importance of accommodating students
- The Fennell Four-Phase Model of chronic illness
- Aligning FFPM and classroom practice

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## Culturally Competent Teachers

Core Values:

- Competence
- Care
- Leadership
- Difference
  - gender, ethnicity, culture, race, health
- Service

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## Chronic Illness is Increasing

- Childhood rates of chronic health problems doubled in just 12 years, to 1 in 4 children in 2006, up from 1 in 8 in 1994.
- Rates of chronic illness are higher among boys and Hispanic and black children.
- Older children are more likely than younger children to have a chronic health conditions.

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## Chronic Illness is Increasing

Chronic illness is rising among the student population due to factors such as:

- Better medical care
- Infant mortality declines
- Increased prevalence of conditions like diabetes, asthma, autoimmune diseases, depression, autism, obesity

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## Chronic Illness & Education

- Students with chronic conditions (or who are caring for family members with chronic conditions) are at higher risk for school absenteeism and drop-out.
- Dropouts are more likely to suffer from illness or disability.

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## Chronic Illness

- Intermittent, waxing and waning symptoms
- “Invisible” illness – students don’t look sick
- Sudden emergencies
- Bed or housebound; general frailty
- Less time available due to illness symptoms and management of illness (doctor’s appointments, social service management, medications, etc.)

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## Accommodating Students With Chronic Illness

- Legal mandates (IDEA, Section 504, ADA)
- Maintain student’s participation in learning
- Avoid disparities among the traditionally disabled, chronically disabled, and non-disabled - equal access
- Reduce dropping out and poverty
- Prepare students for workforce

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## The Fennell Four Phase Treatment (FFPT™) Approach

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## Philosophy of the Phase Method

- A Systemic Approach
- False Dichotomies
- The Phenomenon of Chronicity
- Traumatization and Chronicity
- The Integration Assumption
- Palliation
- Clinician as Active Equal Participant

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## Condition/Syndrome Trauma

- Chronic Condition/Event Trauma
- Iatrogenic Trauma
- Cultural Trauma
- Vicarious Trauma

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- Pre-Morbid / Co-Morbid Trauma

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## Traditional Disability vs. Chronic Conditions

- Chronic conditions on a continuum
- Static vs. dynamic disability/illness
  - Fixed disability
  - Relapse and remission
  - Waxing and waning
- Legal definitions of disability/chronic illness
- Social or colloquial definitions
  - Disability
  - Illness
  - Disease/condition/syndrome

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## Chronic Care in Context and Culture

- Delivery Systems
- Levels of Discourse
- Socio-Cultural Factors
- Domain Assumptions
- Traumagenic Effects

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## Socio-Cultural Factors

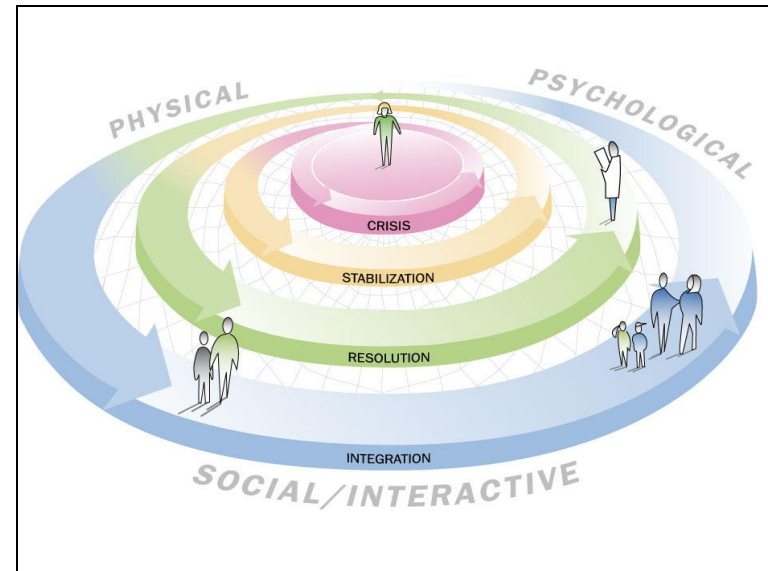
1. Cultural Intolerance of Suffering
2. Cultural Intolerance of Ambiguity
3. Cultural Intolerance of Chronic vs. Acute Syndromes
4. Pre-Existing Cultural Climate Toward Chronic Syndromes
5. Media
6. Initial Syndrome Illegitimacy and Subsequent Enculturation

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## The Four Phases of Chronic Change:

### The Smith Family's Story

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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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***Socio-Cultural Factors  
Chronic Syndromes  
and  
Traumagenic Effects***

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**Factor: Intolerance of Suffering**  
DYNAMICS                      EFFECTS

- |   |  |
|---|--|
| <ul style="list-style-type: none"> <li>• Social/Clinical Controversy</li> <li>• Pressure for Non- disclosure</li> <li>• Negative Reinforcement for “Genuine Reporting”</li> <li>• Attitude Conveyed of Characterological Inferiority</li> <li>• Iatrogenic Health Care Experiences</li> </ul> | <ul style="list-style-type: none"> <li>• Avoidance of Intimacy</li> <li>• “Passing”</li> <li>• Addiction</li> <li>• Social Abandonment/Rejection</li> <li>• Social Contract Violation</li> </ul> |
|---|--|

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**Factor: Intolerance of Ambiguity**  
DYNAMICS                      EFFECTS

- |   |  |
|---|--|
| <ul style="list-style-type: none"> <li>• Contagion/ Contamination<br/>Powerless Fear Transferred</li> <li>• Unknown Etiology/Prognosis</li> <li>• “Just” World or Deserved Punishment Notion</li> <li>• Survivor as Burden</li> </ul> | <ul style="list-style-type: none"> <li>• Generalized Guilt</li> <li>• Grief</li> <li>• Depression</li> </ul> |
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**Factor: Intolerance of Chronic vs. Acute Syndromes**  
DYNAMICS                      EFFECTS

- |  |  |
|--|--|
| <ul style="list-style-type: none"> <li>• Pressure for “Cure”/ Normalization</li> <li>• Inadequate Treatment Models</li> <li>• Competence Frustration Conveyed</li> <li>• Punishment of Healthy Self Care</li> <li>• Reward of Unhealthy Self Care</li> </ul> | <ul style="list-style-type: none"> <li>• Normalization Failure</li> <li>• Identify Confusion</li> <li>• Increased Salience of Abuse Issues</li> <li>• Avoidance of Intimacy</li> <li>• “Passing”</li> <li>• Social Withdrawal / Suicide</li> </ul> |
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**Factor: Cultural Climate**

DYNAMICS

EFFECTS

- Pre-sentiment of Suspicion Conveyed
- Negative Personality Characteristics Assigned
- Survivor perceived as Damaged/Social Example
- Social Shame
- Diminished Self-worth
- Cultural "Pariah"

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**Factor: Media**

DYNAMICS

EFFECTS

- Scapegoating
- Public Ridicule/Support
- Public Judgment
- Public Assignment of Role and Worth
- Loss of Privacy
- Increased Fear/Anxiety
- Increased Isolation
- Increased Grief
- Decreased Sense of Worth

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**Factor: Syndrome Enculturation**

DYNAMICS

EFFECTS

- Inadequate Language/ Models/ Metaphors
- Impact of Discourse
- Disease Maturity - Societal Acceptance
- Increased/Decreased Powerlessness
- Increased/Decreased Sense of Efficacy
- Increased/Decreased Sense of General Safety, Trust and Stigmatization

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**Aligning FFPT and Classroom Instruction**

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### Alignment of Practice with FFPT Through Differentiation/Accommodation

- By using FFPM to take into consideration the medical, social, familial and psychological situation the student is facing, educators can use differentiated instruction and accommodations to develop curriculum and assignments that are relevant to the student's life, interests and abilities.

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### Alignment of Practice with FFPT Through Differentiation/Accommodation

- Combining these approaches offers students a greater opportunity to continue their education while coping with the relapsing/remitting nature of chronic illness.

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### Classroom Practices Aligned to Phase 1

Classroom Strategies

- Provide assignment sheets
- Provide weekly overviews
- Allow for connections between concepts, identify similarities/differences

Phase 1:

- Contain the crisis; manage urgency
- Assessment – psych/med evaluation
- Analyze ADLs and restructure
- Relationship building
- Personal narratives

### Classroom Practices Aligned to Phase 2

Classroom Strategies

- Use a modified group memory strategy (S)
- Monitor study time (S)
- Offer steps in process (T)
- Provide color coded handouts (T)
- Vary use of color (T)
- Provide thinking maps (T)

Phase 2

- Stabilize symptoms – med/psych
- Review/modify all activity groups–value clarification
- Counseling – grief, coping
- Illness etiquette – family/case management
- Use logs for symptoms and activities
- Classroom modification

S=Student; T=Teacher

## Classroom Practices Aligned to Phase 3

### Classroom Strategies

- Generate/test own hypotheses (S)
- Review /monitor for consistency (T)
- Use time for written reflection & learning (S)
- Write study/test questions (S)
- Provide thinking maps (S)
- Use modified group memory (S)

### Phase 3

- Personalize/find meaning
- Establish self-regulation and priorities

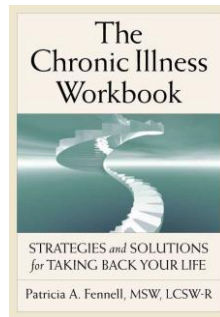
S=Student; T=Teacher

## For Information:

For further information on the following, please contact AHMA  
**communications@albanyhealthmanagement.com**  
**www.albanyhealthmanagement.com**

- certification in the FFPT™ approach
- the Fennell Phase Inventory™
- research projects
- books and related articles
- clinical services
- consulting
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## The Chronic Illness Workbook

Using her extensive experience with chronic illness patients, Patricia Fennell has created an original, comprehensive, research-validated approach that brings clarity and order to what feels like an unmanageable and isolating experience.

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## 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.<sup>1</sup> 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.<sup>2</sup>

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.<sup>3</sup> 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.<sup>4, 5, 6, 7, 8, 9</sup> 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.<sup>10, 11, 12, 13</sup>

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.<sup>14</sup>

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.<sup>15</sup> 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)<sup>™</sup> 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<sup>™</sup> 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
<b>Definition</b>	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
<b>Task</b>	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
<b>Medical Assessment &amp; Intervention</b>	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”
<b>Phase Assessment &amp; Intervention</b>	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.

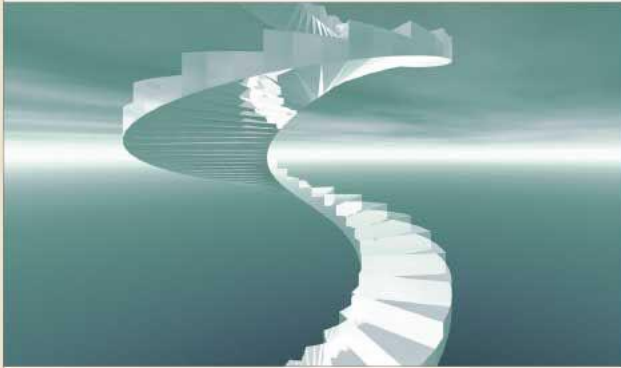
# Accommodation Strategies

(T = Teacher provides; S = Student uses)

Chronic Illness Strategies	Pedagogical Strategies
<p>Review and assess activities of daily living with the goal of stabilizing activity and health.</p> <p style="text-align: center;">PHASE 1</p>	<p>Daily, weekly task scheduling to establish self regulation</p> <hr/> <p>Provide assignment sheets that include the following information (T):</p> <ul style="list-style-type: none"> <li>• Book-Workbook-Worksheet</li> <li>• Page Number</li> <li>• Important information (i.e., Part A, number 1-10)</li> <li>• Due Date</li> </ul> <p>A. Provide weekly overview that includes the following information. (T)</p> <ul style="list-style-type: none"> <li>• Daily topics</li> <li>• Daily Activities</li> <li>• Daily Assignments (Differentiate by highlighting essential tasks)</li> <li>• Due Dates</li> </ul>
<p>Restructure activities of daily living: work, socialization and personal development.</p> <p style="text-align: center;">PHASE 1-2</p>	<p>Scale assignments and establish priorities</p> <hr/> <p>A. Select objectives for each task (T)</p> <p>B. Determine most important to least important tasks and put onto a checklist (T)</p> <p>C. Keep weekly calendar for time management (S)</p> <p>D. Teach note taking and summarizing skills (T)</p>
<p>Use symptom logs and activity logs to predict patterns of activity and health. Establish self-regulation and structure.</p> <p style="text-align: center;">PHASE 1-2</p>	<p>Curriculum compacting -- eliminate redundancy in curriculum to establish core competencies.</p> <hr/> <p>A. Basic Skills compacting (i.e., math, spelling) (T)</p> <p>B. Content compacting (social studies, science) (T)</p> <p>C. Provide rest time between tasks that require cognitive attention (T)</p> <p>D. Shorten assignments by focusing on core concepts and reduce peripheral learning (i.e., reduce number of math problems, reduce sections of reading) (T)</p>

<p>Construct a personal narrative, develop meaning.</p> <p style="text-align: center;">PHASE 3</p>	<p>Relevancy – Personalize Student Learning</p> <hr style="border: 2px solid black;"/> <p>A. Allow for connections between concepts, identify similarities and differences (T)</p> <p>B. Generate and test own hypotheses (S)</p> <p>C. Write own study and test questions (S)</p> <p>D. Provide content vocabulary and teach specific methods for learning vocabulary (T)</p> <p>E. Provide time for written reflections of own learning (T &amp; S)</p>
<p>Use timers to establish priorities.</p> <p style="text-align: center;">PHASE 1-2-3</p>	<p>Utilize study techniques, learning strategies and graphic organizers.</p> <hr style="border: 2px solid black;"/> <p>A. Use modified group memory strategy (S):</p> <ul style="list-style-type: none"> <li>• Write everything you know about the topic</li> <li>• List individual questions you have about topic</li> <li>• Use chat rooms/telephone to share information with identified school partners and write down what is shared</li> <li>• Determine group questions</li> <li>• Use internet to gain additional information on topic and place into a graphic organizer</li> <li>• Check questions</li> </ul> <p>B. Guide own study time by learning conclusion words (i.e., therefore, as a result of) (T &amp; S)</p> <p>C. Provide steps used in a process (i.e., math, science) (T)</p> <p>D. Provide color coded handouts (T)</p> <p>E. Color code white board/chalkboard (T)</p> <p>F. Provide thinking maps (T)</p>

# 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.

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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*

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