

Chronic Illness in Children: Global Implications for Academic Success

Supplemental Materials

Association for Childhood Education International

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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 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

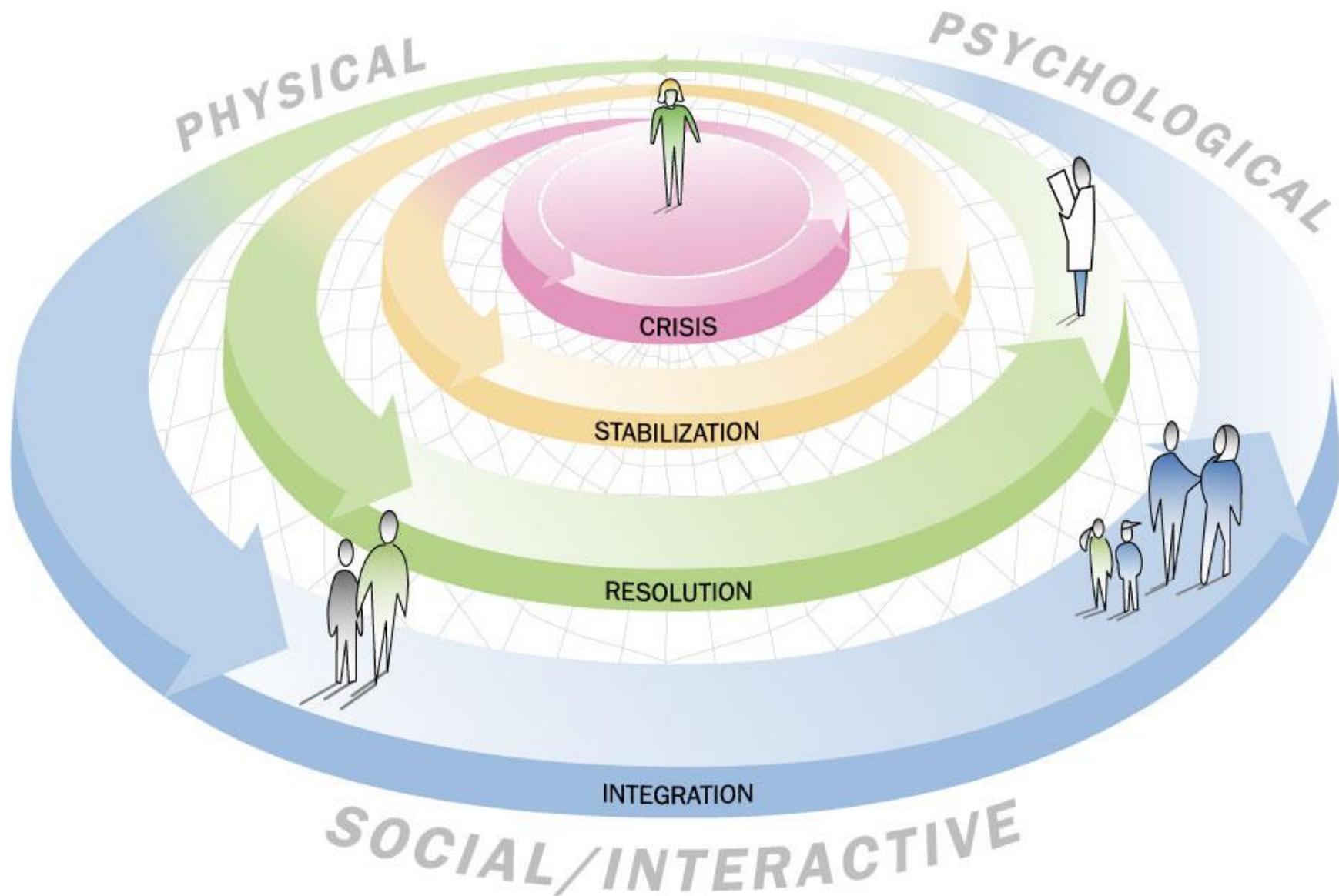
- Inadequate Language/ Models/ Metaphors
- Impact of Discourse
- Disease Maturity - Societal Acceptance

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™



Chronic Illness: A Paradigm Shift in Medicine

Paradigm Shift in Medicine

- 20th century: focus on acute illness
- Expectation was that treatment resolved illness OR patient died
- 21st century: increasing focus on chronic illness
- Increased prevalence of chronic illnesses
- Chronic vs. acute care
- Necessity of chronic care models
- Chronic comprehensive case management
- Comprehensive case management vs. clinical treatment

Chronic vs. Acute Illness

- Traditional chronic illness manifests differently than acute illness
- Chronic illness can be difficult to measure and treat
- Chronic illnesses tend to affect several different body systems at the same time
- Impact of chronic illness on the physical, emotional and social domains persists and affects reporting, compliance and coping
- Medicine has not adapted to the chronic model of care
- Patients with chronic conditions often fare poorly in the acute, episodic care-delivery environment
- Necessary interventions require multiple disciplines and tight coordination of care
- Patient needs vary over the duration and phase of the illness
- Patients suffer from social stigma, economic losses, and lack of knowledge and understanding about their conditions
- Health care providers, patients, family members and friends can become frustrated with the unpredictable symptoms and chronicity
- These factors may exacerbate the patient's condition

Why the Shift to Chronic Illness?

- Increased prevalence of chronic illnesses
- Advances in public health
- Advances in medical care
- Aging population

Chronic Illness is the Leading Cause of Disability in the U.S.

- One third of U.S. doctor visits are for chronic conditions
- 75% of total U.S. medical care expenditures are related to chronic conditions – about \$2.2 trillion a year
- 2005: 129 million people with chronic conditions 2030: 171 million predicted (32% increase)
- Chronic disease is not restricted to developed nations or older populations: it is growing fastest in low-income countries; almost half of those who die from chronic diseases are younger than 70.

Important Resources

Modifications:

Auxiliary Aids and Services for Postsecondary Students with Disabilities

U.S. Department of Education

<http://www.ed.gov/ocr/docs/auxaids.html>

Supports, Modifications, and Accommodations for Students

National Dissemination Center for Children with Disabilities

<http://www.nichcy.org/educatechildren/supports/pages/default.aspx>

Usually a *modification* means a *change in what is being taught to or expected from the student*. Making an assignment easier so the student is not doing the same level of work as other students is an example of a modification.

An *accommodation* is a *change that helps a student overcome or work around the disability*. Allowing a student who has trouble writing to give his answers orally is an example of an accommodation. This student is still expected to know the same material and answer the same questions as fully as the other students, but he doesn't have to write his answers to show that he knows the information.

Legislation:

A Guide to Disability Rights Law

U.S. Department of Justice

<http://www.ada.gov/cguide.htm>

The Civil Rights of Students with Hidden Disabilities Under Section 504 of the Rehabilitation Act of 1973

U.S. Department of Education

<http://www.ed.gov/about/offices/list/ocr/docs/hq5269.html>

The Rehabilitation Act

<http://www.ed.gov/policy/speced/leg/rehabact.doc>

Americans With Disabilities Act

<http://www.ada.gov/>

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, 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)TM

The Fennell Four-Phase Treatment (FFPT)TM 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 FFPTTM 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 FFPTTM 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 receive 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.

Service Delivery

The FFPT™ is provided directly to patients at their physicians' office, hospital or rehabilitation center through the Mobile Chronic Care™ program. Health care providers are trained in the FFPT™ in a variety of settings as intact health care teams and as individual clinicians.

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 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.

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

References

- ¹ Glabman, M. 2005. "12 trends you should know about". *Managed Care*, Volume 14, No.8.
- ² Anderson, G. 2004. "Medicare and Medicaid are programs for people with chronic illness...but do not know it." Presentation. General Accounting Office, February 5, 2004.
- ³ Chen, A., Brown, R., Archibald, N., Aliotta S., Fox, P. 2000. "Best practices in coordinated care." Mathematica Policy Research, Inc., Princeton, NJ. As cited in Mollica, R., Gillespie, J. 2003. "Care coordination for people with chronic conditions." Partnership for Solutions, Johns Hopkins University., Baltimore, MD.
- ⁴ Fennell, P.A., Bateman, L. 2004. "Matching best medical practices to phases of illness." Presentation. AACFS Conference October 2004.
- ⁵ Fennell, P.A., Jason, L.A. and Klein, S.M. 1999. "Measuring phases of recovery in patients with CFS". *Journal of Chronic Fatigue*, Volume 5, No. 3-4.
- ⁶ Fennell, P.A., 1998. "Capturing the different phases of the CFS illness." *CFIDS Chronicle*, Volume 11, No. 13.
- ⁷ Jason, L.A., Fricano, G., Taylor, R.R., Halpert, J. and Fennell, P.A. 2000. "Chronic fatigue syndrome: An examination of the phases." *Journal of Clinical Psychology*. Volume 56, No. 12.
- ⁸ Jason, L.A., Fennell, P.A., Taylor, R.R., Fricano, G., and Halpert, J. 2000. "An empirical verification of the Fennell Phases of the CFS illness." *Journal of Chronic Fatigue Syndrome*, Volume 6, No. 1.
- ⁹ Jason, L.A., Fennell, P.A., Klein, S., Fricano, G., and Halpert, J. 1999. "An investigation of the different phases of the CFS illness." *Journal of Chronic Fatigue Syndrome*, Volume 5, No. 3-4.
- ¹⁰ DiClemente, C.C. 1991. "Motivational interviewing and the stages of change." In W. R. Miller & S. Rollnick (Eds.). *Motivational interviewing: Preparing people for change* (pp. 191-202). New York: Guilford Press.

¹¹ Prochaska, J.O., DiClemente, C.C., Norcross, J.C. 1992. "In search of how people change: Applications to addictive behavior." *American Psychologist*, Volume 47, No. 9.

¹² Prochaska, J.O., Velicer, W. F. 1997. "Misinterpretations and misapplications of the Transtheoretical model." *American*

Journal of Health Promotion, Volume 12, No. 1.

¹³ Prochaska, J.O., Norcross, J.C., and DiClemente, C.C. 1994. "The Transtheoretical model of change and HIV prevention." *Health Education Quarterly*, Volume 21, No. 4

¹⁴ Fennell, P.A., Bateman, Lucinda. Summer 2005. "A team approach to

treating CFS: Matching best medical practices to phases of illness." *CFS Research Review*.

¹⁵ Bodenheimer, T., Wagner, E., Grumbach, K. 2002. "Improving primary care for patients with chronic illness." *Journal of the American Medical Association*, Volume 288, No. 14.

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 \(FFPT\)TM](#) 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.

Ms. Fennell is frequently sought as an expert on trauma, forensics, restorative justice, hospice, chronicity, and disability. She regularly lectures on restorative justice and related issues with [David Kaczynski](#), brother of the Unabomber, and Gary Wright, a surviving victim of the Unabomber. Prior work includes developing and supervising the patient suspicious death reporting system and providing data and assistance to the medical

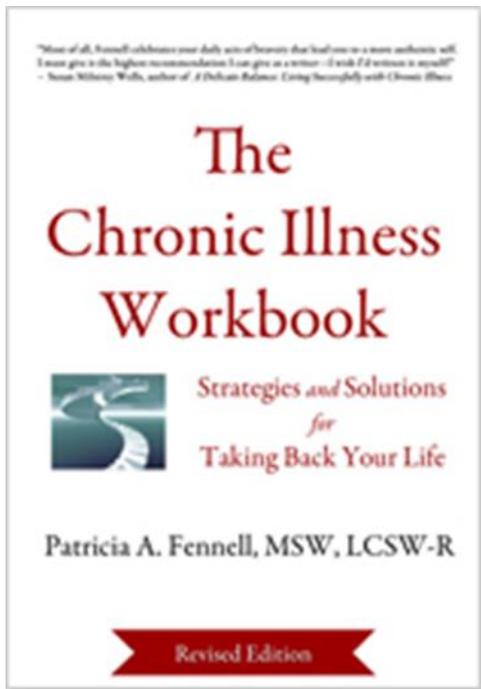
examiner for the New York State Governor's Commission on Quality of Care for the Mentally Disabled. She has provided assessment, treatment and consultation for sex offenders, victims and families in situations involving incest, assault and school-based sex crimes in the Capitol Region of New York. In this work, she has collaborated closely with the social services, law enforcement, and probation and parole. She has also served on rape crisis boards and with school districts as a sex abuse liaison.

Ms. Fennell was invited to serve as a scientific advisor to the U.S. Secretary of Health and was asked to participate as a peer reviewer for the American Pain Society. She was also appointed to serve on an allied health care advisory committee for the U.S. Centers for Disease Control and Prevention (CDC). In addition, the instrument she developed for assessment of patients with chronic syndromes, the Fennell Phase Inventory (FPI)TM, is used in a variety of medical research projects.

She is a dynamic and engaging presenter and is invited to lecture and teach internationally, utilizing her original content and curricula. Pat

Fennell is a theorist, researcher, and author of several scholarly and popular books and articles, including [The Chronic Illness Workbook](#), [Managing Chronic Illness Using the Four-Phase Treatment Approach](#), and [Handbook of Chronic Fatigue Syndrome](#).

Ms. Fennell has received numerous professional and community honors and serves on the boards of several international medical and professional organizations, including the Editorial Board of the *Journal of Chronic Fatigue Syndrome*, the Board of Directors of the International Association for Chronic Fatigue Syndrome and ME, the Medical Advisory Board of the National Fibromyalgia Association, and the Medical Advisory Panel for the Fibromyalgia Support Group for Surrey and Sussex, U.K.. She utilizes her experience in forensics, trauma, death/dying, bereavement, hospice care innovation, and restorative justice to provide consultation for a variety of organizations including government agencies, management consulting groups, patient organizations, Fortune 150 companies, university faculty, and victim and offender services organizations. Ms. Fennell continues to see patients and supervise other clinicians.



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

"*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,

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