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Riding the Chronic Illness Rollercoaster

*What Does it Mean
in Your Life???*

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It Means...

Learning to Hang On as the
Research Debate Rolls On...

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“Amid War on a Mystery Disease, Patients Clash With Scientists”

Wall Street Journal--March 12th 2011

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Agenda

- The Twin Rollercoasters
- Quality Of Life Factors
- CI and the Medical Paradigm Shift
- CI and the Four Phase Treatment Approach
- Nicole's Story: The Phases from All Perspectives
- Research, CI and Q of L Factors Research
- Understanding the Twin Rollercoasters

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The TWIN Rollercoasters

**The Chronic
Illness
Rollercoaster**

**The Research &
Media
Rollercoaster**

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Quality of Life 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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Increased Prevalence of Chronic Illness Worldwide

- Advances in public health
- Advances in medical care
- Aging population

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Paradigm Shift in Medicine

- 20th century: focus on acute illness;
- 21st century: focus on chronic illness
- Chronic vs. acute care
- Necessity of chronic care models
- Chronic comprehensive case management vs. clinical treatment

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Chronic vs. Acute Illness

- Chronic illness can be difficult to define, measure and treat
- Medicine has not adapted to a CI model of care- Pts. often fare poorly in acute 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
- Everyone becomes frustrated with the unpredictability and chronicity of symptoms

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4 Groups of Chronically Ill

- Traditional chronic (CFS, FM, MS, asthma, lupus)
- Acute illness survivors with lingering symptoms (cancer, cardiovascular disease)
- “Persistent acute” (HIV/AIDS, stroke)
- Natural consequences of aging in an aging population

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We gave Terri Dome a future. That is what we do.



Terri Dome

Terri Dome, a successful international marketing executive in a major travel agency in California, had to call, and to learn she was diagnosed by the effects of treatment she had received years before for a childhood cancer. She came to the Texas Heart Institute for help.

We used the latest advancement in treatment and technology—many of which were developed here—and our doctors' vast knowledge and experience. In February 2009, Terri had a heart transplant.

"When I first came, I was very nervous, very scared and very angry. I was afraid I was dying," says Terri. "The moment I got my doctor's name, I would be alright. I was safe. I was in good hands."

Terri is now making the most of her new life, teaching and to counsel other women with heart disease.

She has confidence when you have helped, in living the future she did not have. No wonder! (L. Steve of World Report has ranked us among the top 10 heart centers for 20 consecutive years.)

For information about keeping your heart healthy, call 1-800-292-2221 or submit a question online to Ask a Texas Heart Institute Doctor. texasheart.org



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Chronic Illness and 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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Trauma Types

- Disease/Syndrome Trauma
 - Iatrogenic Trauma
 - Cultural Trauma
 - Vicarious Trauma
-
- 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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The Four Phases of Chronic Change

Nicole's Story: A Survivor of CFS/ME and Disability

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“Everyone’s Story” The Phases From All Perspectives

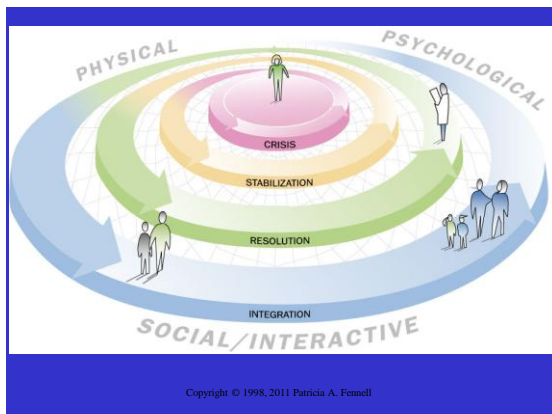
- Nicole
- Family
- Friends
- Treatment/Management professionals
- Workplace, School, Community
- Pharma, The Academy, Government Org

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“Everyone’s Story” (Part II)

- Gender
- Race/Ethnicity
- Family
 - Traditional/non-traditional
 - Partner/spouse
 - Parent/child
- Religion
- Community
 - Workplace
 - School
 - Neighborhood
 - BUSINESS

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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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Quality of Life Factors and CI

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Impact of Research on Quality of Life Factors and CI

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*
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Understanding the TWIN Rollercoasters

The Chronic Illness Rollercoaster

- Moving through the Phases
- Developmental changes (sex, kids, age)
- Media
- It Takes a Village...

The Research & Media Rollercoaster

- Conflicting research findings
- Dueling experts
- Media, press releases
- Your doctor

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Participate in the Research

- Online participation
- Clinical experts
- Patients

Go to:

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The Chronic Illness Workbook



STRATEGIES and SOLUTIONS
for TAKING BACK YOUR LIFE
Patricia A. Fennell, MSW, LCSW-R

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.

Available for \$20.00 from Albany Health Management Publishing © 2007

For more information or to order, visit: www.AlbanyHealthManagement.com or contact: communications@AlbanyHealthManagement.com

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For More Information:

For further information on the following please contact AHMA at---

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www.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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