

# Living on the Edge of Uncertainty

## The Chronic Illness Experience: A Patient's Perspective

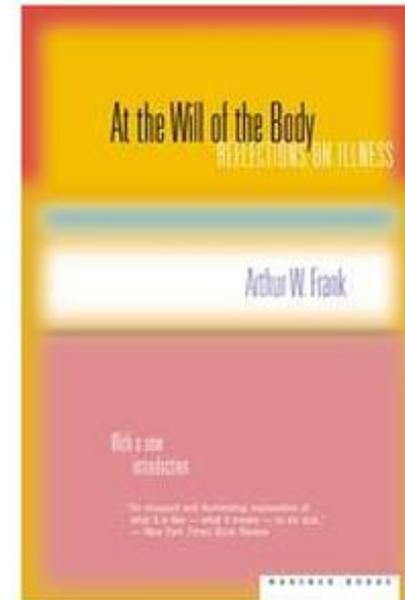
Marina Symcox, PhD

GIST Support International



Arthur Frank, PhD

**“At the Will of the Body:  
Reflections on Illness”**



*“Because we can choose how we experience illness,  
we can be more than victims.”*

## My Story: rescue at death's door.

*“When you learn that your life is threatened, you can turn toward this knowledge or away from it.” (Anatole Broyard)*

- Dx with terminal GIST at age 38 yrs. (1997)
- Internet support group as a life line.
- Hospice. (Jan. - Sept. 2000)
- Recovery by imatinib. (Oct. 2000)

# Observations about Serious Illness

*“Being ill is a perpetual balance of faith and will.” (Arthur Frank)*

## Coping versus Personal Transition

- Adjustment is not an end point personality change.
- Continuous personal adaptations over time are required for ever changing circumstances.

## “Disease” of the body versus “Illness Experience” of living with broken body

- Disease can not be separated from a person’s identity.
- “Disease treatment” is **NOT** “Care of Illness.”

# Adaptation to Illness: Stoicism versus Dialogue

- **Stoicism:** an internal choice to detach from an external crisis.
- **Dialogue:** interactive social context to make sense of an external crisis.

*“Storytelling seems to be a natural reaction to illness. People bleed stories, and I’ve become a blood bank of them. (Anatole Broyard)”*

# Dialogue and Illness Narratives:

## “The Wounded Story Teller” (Arthur Frank)

*“The opportunity to tell one’s own illness story as one wants to tell it—in one’s “own” voice—is a kind of grace.” (Arthur Frank)*

- **Restitution Stories:** medicine is hero, patient passive, health restored.
- **Chaos Stories:** trapped in unsurpassable adversity.
- **Quest Stories:** patient is hero, meaning, perseverance.

**Challenge for Support Groups:** Can you grant equal authority to all types of illness stories?

# Mourning What is Lost

*“You eke out your illness...only you will love it”*

*“All of my old trivial selves fell away, and I was reduced to essence.” (Anatole Broyard)*

- Mourning is an affirmation of the life that has been led.
- Avoid those who seek to minimize what you have lost.
- **Loss of:** freedom to plan, continuity with your past and your body, some relationships, connection to cultural mainstream, innocence about your mortality.
- “Sinking all the way through, and discovering a life on the other side.” (Arthur Frank)

# Experiences in the Health Care System

*“I would like a doctor who is not only a talented physician, but a bit of a metaphysician too. Someone who can treat body and soul...I just wish he would brood on my situation for perhaps five minutes” (Anatole Broyard)*

*“Life threatening illness gave doctors a new dimension of importance for me. I had never expected so much from them or been so sensitive to their shortcomings.” (Arthur Frank)*

# Experiences in the Health Care System

- Non-recognition of the Illness Experience: Medicine is disease management oriented. Patient Angst, demoralization.
- Asymmetry of medical intimacy: patient feels vulnerable, passive.
- Falling through the cracks of bureaucracy, many handlers = anonymity, lack of continuity.
- “Medicalization” of the Illness Experience: Is tragedy a disease requiring an anti-depressant medication?

# Cancer in (American) Popular Culture

*“Healthy people comfortably accept the social myth that illness behavior is inside the person.*

*We want to enclose the ill person in a psychological language that turns his reality inward, closing it off to external influence.*

*Then we hand the whole thing over to medicine.” (Arthur Frank)*

# Cancer in (American) Popular Culture

- The Cancer Personality. (repackaged as “stress and your immune system”)
- The Tyranny of Positive Thinking. (Jimmie Holland)  
Comforters who are Accusers. (AF)
- Myth: Cancer brings enlightenment, or closer relationships.
- Myth: Metaphors that Stigmatize. War Analogies.
- Myth: Glossy media images of cancer patients.
- The Cost of Appearances (AF). Denial benefits whom?

# Living with Terminal Disease

*“Some prevail by continuing to live; some prevail by dying. Those who are ill and those who witness illness can only have faith in the wholeness of either outcome.” (Arthur Frank)*

- Search for meaning and spiritualism.
- Faith to accept whatever happens and at the same time a will to bring about change.
- Redefinition of personal scale (time and space).  
Changing family dynamics.

# The Remission Society & Valuing Illness

*“Wellness and sickness perpetually alternate as foreground and background...”*

*In health there can only be fear of illness, and in illness there is only discontent at not being healthy.*

*In recovery I see not health but a word that has no opposite...Gravy.” (Arthur Frank)*

# The Remission Society & Valuing Illness

## Finding Gravy:

- “The sick person’s best medicine is desire—  
desire to do things, to get back to his life.” (AB)
- Celebration of recovery, wonder, and losing it if  
recovery goes too far.
- Redefinitions. “If freedom requires good health,  
then it is precarious indeed.” (AF)

# The Remission Society & Valuing Illness

## Finding Gravy:

- Illness as a dangerous opportunity for personal growth. (hazards of becoming an illness narcissist)
- Forfeiting my disease as my drama, and watching it flourish as “Somebody else’s Intellectual Property of Research.”
- Relishing half opportunities, finding generosity of spirit.

## **Marina's Favorite Books (in English):**

- **Arthur Frank, PhD At the Will of the Body: Reflections on Illness.**
- **Anatole Broyard Intoxicated by my Illness and Other Writings on Life and Death.**
- **Jimmie Holland, MD The Human Side of Cancer: Living with Hope, Coping with Uncertainty.**

# Books

- Gilda Radner **It's Always Something.**
- Zoe Koplowitz **The Winning Spirit: Life Lessons Learned in Last Place.**
- Sherwin B. Nuland, MD **How We Die: Reflections on Life's Final Chapter.**
- Viktor E. Frankl, MD **Man's Search for Meaning.**