

Patient talk: Mental health & the emotional toll of missed & mis-diagnosis

Dr. John Reiman



Bridging the Gap

Medicine is an imperfect science, an enterprise of constantly changing knowledge, uncertain information, fallible individuals, and at the same time lives on the line.

Atul Gawande



We are having *normal* reactions . . .
to very *abnormal* circumstances

Mental & Emotional Experiences in Leakland

Who am I?

**I don't recognize & am
unfamiliar with this me.**



Categories of Emotional Response

MAD

Angry
Annoyed
Displeased
Enraged
Exasperated
Offended, etc.

SAD

Depressed
Melancholic
Pessimistic
Disconsolate
Despairing
Dejected, etc.

SCARED

Afraid
Alarmed
Frightened
Shaken
Fearful
Unnerved
Panicky, etc.

ASHAMED

Apologetic
Embarrassed
Distressed
Contrite
Sorry
Humiliated
Abashed, etc.



Personal Emotional Journey

MAD:

- Frustration with body's failure to reveal leak
- Cathartic yet painful expressions of anger during symptoms

SAD:

- Persistent low-level dysphoria & disappointment
- Struggles with choicelessness & suspended animation feelings

SCARED:

- Navigating fear of the unknown & functional losses
- Relating experiences to loss & grief, learning to live with uncertainty



Shame & Personal Agency

PERSONAL AGENCY/FAULT:

- Internal struggle with self-blame & perceived fault
- Blaming self as a misguided attempt to regain a sense of control

POWERLESSNESS & LOSS OF CONTROL:

- Recognize how the human psyche struggles with powerlessness
- Understand the impact of cognitive challenges on clear thinking



Glad

HOPE & DIAGNOSIS RELIEF:

- . Peaks of hope from speculative diagnosis
- . Relief from accurate diagnosis bringing moments or durations of gladness



Communicating Emotions

REACTIVE COMMUNICATION:

- Respond to "How are you doing?" with "What would you like to know?"
- Assess how much others want to know or can handle
- Choose between giving a conventional response or sharing deeper feelings

PROACTIVE COMMUNICATION:

- Select someone who wants to know & can handle your experience
- Share with a capably listening other to bridge from isolation & reconnect

SHARE JOYS, BRIGHT SPOTS & WONDERMENTS



Listening & Discovery

The greatest gift one being can give another is to listen them into discovery.

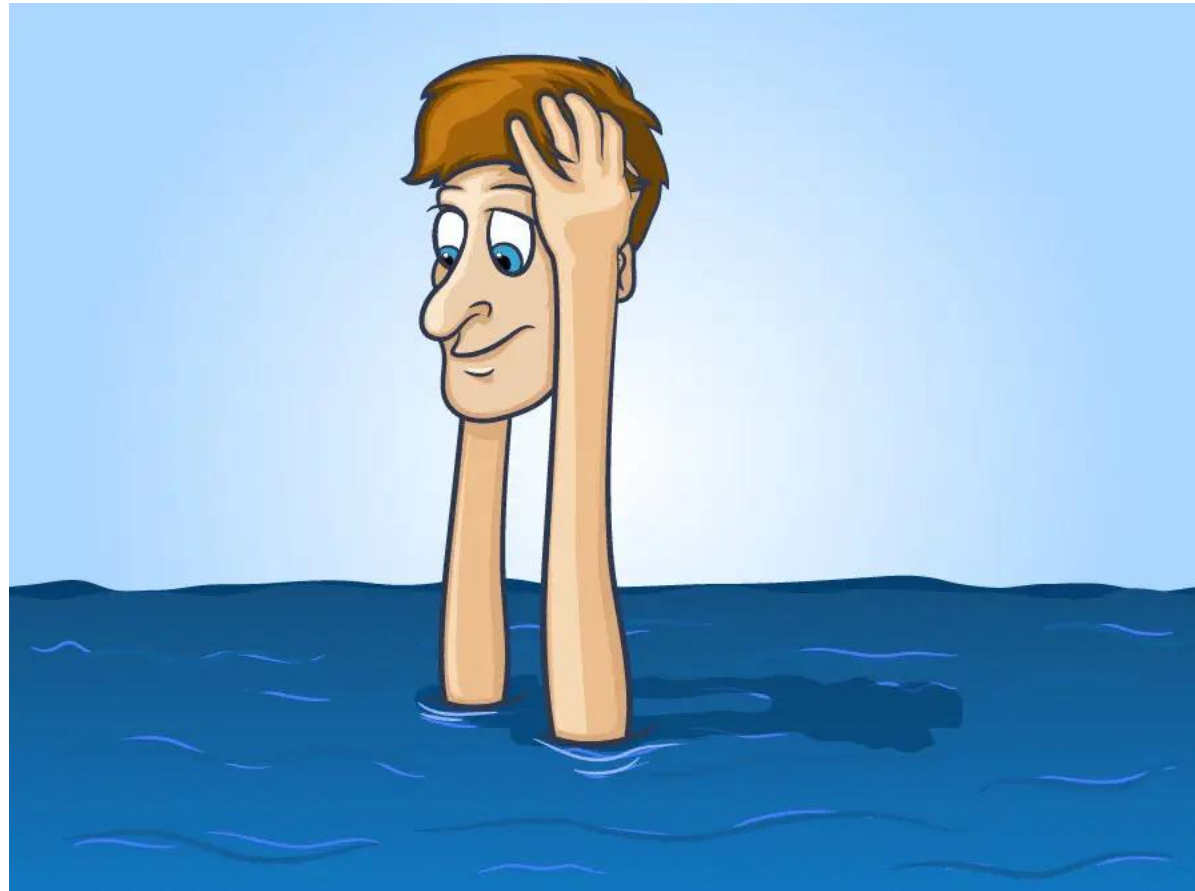
Quaker Quote

VALUE OF BEING HEARD:

- Helps illuminate personal resources, wisdom & growth opportunities



Resources & Self-Compassion



Keep Your Head Above Water!

HELPFUL RESOURCES:

- Spinal CSF Leak Foundation: Information, podcasts & hints
- Online Forums: Inspire for community support
- Supportive Professionals: Counselors experienced in medical/diagnostic issues

SELF-COMPASSION:

- Ask yourself, "Today, where & how can I offer myself even the tiniest bit of ease, mercy, compassion, or kindness within or around my experience, just as it is?"



Thank you