



Myalgic Encephalomyelitis (ME) Call for Just Care

ME pain and exhaustion crashes patients to unconsciousness,
 abnormal sudden irresistible pull to dark void.
 A kind of deep faint, unwakeable,
 days missing at a time.
 Return awareness slow, hard, heart breaking,
 memory loss, confusion, dizziness, pain all over.

Science thinks genes, virus or trauma affect our
 cells' power stations,
 too few facts at this stage to truly know.
 Prevention, treatment and cure remain a future
 hope,
 for now, to survive another hour, another day, is
 the play.
 A rhyme to parlay living its horror is my way,
 my pray, for more research and better care, for a
 life worth living.

As ME patients we are millions invisible uncounted
 uncared,
 too ill for health appointments to communicate our
 needs.
 The painful hopelessness we live overrides outsider
 compassion,
 funders, researchers, providers would rather not
 know.
 In moments of fleeting clarity, I raise my voice to
 a shout,
 as past researcher and doctor and patient, for
 radical change.

What can be done for ME patients right now
 include:

education, research, funding, awareness, best
 practice standards.

Provide what is just for us, as with ME we are more
 ill than:

advanced cancer, stroke, end stage kidney disease,
 congestive heart failure, schizophrenia or major
 depression patients.

Only 5% with ME recover, 95% progressively
 become severe,
 25% of such severe become permanently house
 and bed bound.

6 times higher suicide rate than the normal
 population.

Learn our symptoms to help fight our case:

Pain burning, all over, no treatment, takes away
 mobility and joy.

Trigger of post exertional malaise prevents
 attempting normal living or exercise.

Cognitive fog steals relationships, work ability and
 financial stability.

Bladder and bowel irritability adds embarrassment
 and mess.

Photophobia with chronic headache leads to living
 in darkness,

severe sound and emotion sensitivity adds isolation
 and loneliness.

Temporary paralysis and ticks, unknown chemical
 sensitivities, random in occurrence, contribute
 poor quality of life.

Cardiac palpitations and gravity intolerance
 stopping normal standing,

sitting, or walking, no tolerated extended comfort.

Stomach paralysis, nutritional emergencies, tube
 feeding,

malnutrition, organ failure, when severe, cause of
 death.