M.E. Sufferers

RESEARCH LITERATURE

Illness Course


The majority of adolescents with CFS experienced an improvement over time in functional impairment, self-reported fatigue and additional symptoms, and a concurrent improvement of autonomic cardiovascular control.


Of a group of 25 participants diagnosed with CFS 25 years ago, 5 self-reported that they maintained a diagnosis of CFS, while 20 reported no longer having a diagnosis. However, those who remitted from CFS showed significantly more impairment on 21 out of 23 outcomes compared with controls.


The prognosis of CFS is better in adolescents than in adults. Activity level, exercise tolerance, and orthostatic testing could not distinguish patients with CFS from adolescents who have recovered from infectious mononucleosis (controls), while certain cytokine network analyses, life stress factors, and autonomic symptoms could.

* Racciatti D, Gorgoretti V, Sepede G, Gambi F, Pizzigallo E. An Italian study on health-related quality of life and fatigue in patients with chronic fatigue syndrome and patients

CFS patients had a higher level of fatigue and a more greatly reduced health-related quality of life than chronic hepatitis C patients.


Over a 10 year period, rate of CFS remained approximately the same, although a high level of mortality was found (18% of those with medical or psychiatric exclusions group, 12.5% for the CFS group). Physical measures of disability and fatigue, along with measures of specific somatic symptoms, better differentiate individuals who later are diagnosed with CFS than more psychosocial measures such as stress and coping.


People who have CFS and fibromyalgia were found to be less likely to improve over time than people who have CFS alone.


Patients who have CFS plus Fibromyalgia or Multiple Chemical Sensitivity were more disabled than patients with just CFS.

CFS-like cases at baseline were three times more likely to be unable to work at follow up than fatigued employees who did not meet CFS criteria at baseline (ORs 3.3).


Persons with chronic fatigue syndrome are as impaired as persons whose fatigue could be explained by other medical or psychiatric conditions, and they have less energy than non-fatigued controls.


A population of CFS patients in Wichita, Kansas, was followed for three years. Only 20%-33% of the subjects were classified as having CFS at follow-up, 56.9% ever experienced partial or total remission, 10% sustained total remission, and 23.1% received alternative diagnoses, of which 20% were sleep disorders. Higher fatigue severity scores and total number of symptoms were negatively associated with ever remitting. Duration of illness < or = 2 years was positively associated with sustained remission. Unrefreshing sleep persisted in at least 79% of the subjects across all periods but, as with most of the CFS symptoms, tended to be less frequent over time.


Researchers interviewed CFS patients in Wichita, Kansas, about their histories. Symptoms fluctuated over the course of illness. However, only stomach pain (non-CFS symptom) was more likely to be reported as duration of illness increased (p < 0.05). There was no association between onset type and the likelihood of reporting a symptom during an interview, except that chills and severe headaches were more likely to be reported by sudden cases.

In a population of nurses, impairments in physical, role, and social functioning increased as fatigue severity increased. Bodily pain increased as fatigue severity increased, and ratings of overall health increased as severity of fatigue decreased. Nurses with fatigue not meeting CFS criteria reported better quality of life than those with CFS or medical exclusions.


A sample of 3400 nurses who belong to a statewide or a national nurses organization were questioned about possible CFS issues.


CFS patients with initial infection as a precipitating factor more often report acute onset of fatigue, more frequent accompanying symptoms, and more frequent improvement on referral than do patients without initial infection.


In a CFS patient population, (68.8%) had stopped work, and on average this had occurred 3 years after symptom onset. Patients had markedly lower functional scores than population average values, more so when they had 2 or 3 of these diagnoses. Having fibromyalgia, younger age at onset, and lower socioeconomic status were most consistently associated with poor function.

Compared to patients with a minor medical condition, CFS patients in Belgium were substantially more fatigued and more socially withdrawn. CFS patients and physicians proved to differ in their opinion on the patient's motivation.


After two years, only 20% of subjects meeting the criteria for CFS scored in the healthy adult range for fatigue impact and physical function.


CFS has a pervasive negative impact on quality of life, particularly physical and psychological functioning.

**Illness Context**


Samples of Dutch vs. Portuguese CFS patients were compared.

Homebound patients form a distinct subgroup of CFS patients who might profit from a treatment approach that is tailored to their specific needs.


Five adolescents who were considered to have recovered from CFS participated in semistructured interviews regarding their experience.


Guidelines for the care of women with CFS during pregnancy, labor and birth, lactation, and the postpartum period are presented.


The authors designed a protocol to assess work ability in people suffering “ill-defined painful and disabling disorders, the outstanding prototype of which is fibromyalgia/chronic fatigue syndrome.”


Parents were significantly less accurate regarding the adolescent's thoughts and feelings about CFS than about other life events.

Psychologic distress in the mother corresponds with an adjusted odds ratio of 5.6 for the presence of CFS in the child.

**Coping**


Researchers did in-depth interviews to determine how CFS sufferers coped with their illness over time.


CFS/ME online forums had more than ten times the relative activity of any other disorder or condition related forum.


CFS patients having greater perceived stress management skills show less emotional distress and fatigue, and the influence of stress management skills on distress and fatigue appear greatest among patients who have elevated IL-6 levels.

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Coping styles of CFS patients are explored.


Patients with chronic fatigue syndrome appear to be less physically active compared with asymptomatic controls. There is no difference in variation of physical activity levels between patients with chronic fatigue syndrome and healthy control subjects, but the validity and reliability of some methods of measuring physical activity is questionable or unknown.


An accommodative coping style (e.g. acceptance) is related to a better mental health-related quality of life in patients with CFS.


CFS patients who had been sick for a long time reported higher use of active coping, positive reframing, planning, and acceptance, and lower use of behavioral disengagement.


Studies of CFS patients showed the following: 1) The need to make sense of symptoms and gain diagnosis, 2) for respect and empathy from service providers, 3) for positive attitudes and support from family and friends, 4) for information on CFS/ME, 5) to adjust views and priorities, 6) to develop strategies to manage impairments and activity limitations, and 7) to develop strategies to maintain/regain social participation.


Interviews probed how families cope with CFS in one of the parents.


More than 90% of persons with CFS used at least one drug or supplement within the preceding two weeks. Among users, people with CFS used an average of 5.8 drugs or supplements, compared to 4.1 by generally unwell subjects and 3.7 by well controls. Persons with CFS were significantly more likely to use antidepressants, sedatives, muscle relaxants, and anti-acids. In addition, persons with CFS were significantly more likely to use pain-relievers, anti-histamines and cold/sinus medications than were Well controls.


Although anxiety symptoms are high in CFS, particularly in teenage girls, it does not appear to be associated with school attendance or other measures of disability.

CFS patients tend to lead a healthier lifestyle compared to the general Dutch population.


Women were interviewed about how they learned to live with CFS.


CFS patients frequently used complementary and alternative medicine treatments, including body-based therapy (e.g. chiropractic and massage) and mind-body therapy (e.g. prayer).

* Nater UM, Wagner D, Solomon L, Jones JF, Unger ER, Papanicolaou DA, Reeves WC, Heim C. Coping styles in people with chronic fatigue syndrome identified from the general population of Wichita, KS. J Psychosom Res. 2006 Jun;60(6):567-73. PMID: 16731231

Subjects with CFS and chronic fatigue reported significantly more escape-avoiding behavior than normal controls.


In a study in Wichita, Kansas, CFS subjects were more likely to use any drug category than controls (p = 0.0009). Pain relievers and vitamins/supplements were the two most common agents listed by both groups. In addition CFS persons were more likely to use
pain relievers, hormones, antidepressants, benzodiazepines, gastro-intestinal, and central nervous system medications.
M.E. SUFFERERS

Media Coverage

“Voices from the Shadows”
http://voicesfromtheshadowsfilm.co.uk/

Review by Scott Jordan Harris for RogerEbert.com (February 10, 2012):

Comment by Stanford’s Jose Montoya, M.D., about the film:
http://www.mediafire.com/download/3k74cq9pd2k67pw/Jose_Montoya.pdf

“I Remember M.E.”
http://www.youtube.com/watch?v=401--WCB5dc

Review by Roger Ebert for the Chicago Sun-Times (December 7, 2001):
http://www.rogerebert.com/reviews/i-remember-me-2001

“The Wedding Gift”

A 1993 BBC TV movie about a woman with CFS and the effect that the disease has on her marriage, based on the true story of Deric and Diana Longden.

http://www.amazon.com/The-Wedding-Gift-Walters/dp/B004XVMCTE/

Review by Roger Ebert for the Chicago Sun-Times (July 22, 1994):

Laura Hillenbrand:

December 21, 2011
The Daily Beast
Laura Hillenbrand’s Acclaimed Bestsellers Haven’t Changed Her
By Sandra McElwaine


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February 4, 2011
The New York Times
An Author Escapes from Chronic Fatigue Syndrome
By Tara Parker-Pope


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November 28, 2010
The Washington Post
Laura Hillenbrand Releases New Book While Fighting Chronic Fatigue Syndrome
By Monica Hesse


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November 10, 2010
USA Today
“Seabiscuit” Author Hillenbrand Back with True Tale “Unbroken”
By Deidre Donahue


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August 11, 2003
People
Against The Odds
By Allison Adato

http://www.people.com/people/archive/article/0,,20140762,00.html
Elisabeth Tova Bailey:

February 10, 2011
The New York Review of Books
Tigers, Humans, and Snails (Review)
By Tim Flannery


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January 22, 2011
The Yale Journal for Humanities in Medicine
The Sound of a Wild Snail Eating (Review)
By Howard Spiro, M.D.

http://yjhm.yale.edu/reviews/rev-hspiro20110122.htm

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September 13, 2010
CarolineLeavittVille
Elizabeth Tova Bailey Talks about the Sound of a Wild Snail Eating


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September 10, 2010
Huffington Post
The Beautiful Sound of A Wild Snail Eating (Review)
By Nina Sankovitch


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August 28, 2010
NPR
‘The Sound of a Snail’: A Patient’s Greatest Comfort
Paradigm Change

Roger King:

June 11, 2012
Gwarlingo
What Makes a Healthy Life? Writer Roger King Explores Love & Fatigue in America
By Michelle Aldredge

May 9, 2012
A Conversation with Roger King and Wilhemina Jenkins
http://www.youtube.com/watch?v=xXtfWwZ7aTs&list=UUzrFQHNiCc_6AMpw_GpWZOA&index=1&feature=plcp

April 30, 2012
The New Yorker
“Love and Fatigue in America”
http://www.newyorker.com/arts/reviews/brieflynoted/2012/04/30/120430crbn_brieflynote
d4

April 25, 2012
State Journal-Register
Book Notes: “Love and Fatigue in America”
By Rae Francoeur
http://www.sj-r.com/mysource/entertainment/x787571970/Book-Notes-Love-and-
Fatigue-in-America

March 30, 2012
The Times Literary Supplement (UK)
Roger King, “Love and Fatigue in America”
By Eric J. Iannelli


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March 12, 2012
Publisher’s Weekly
Love and Fatigue in America

http://www.publishersweekly.com/978-0-299-28720-7
**Peter Hobbs:**

April 27, 2012
Maclean’s
Out of Illness, a Vital Creative Life
By Noah Richler

http://www2.macleans.ca/2012/04/27/out-of-illness-a-vital-creative-life/

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April 27, 2012
The Globe and Mail (Canada)
Tried By Horrible Disease, Peter Hobbs Turns To Writing
By John Barber


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April 27, 2012
Montreal Gazette
Peter Hobbs Arrived At One Of The Year’s Best Books The Hard Way
By Ian McGillis

Host: How did it feel then when you found that you had Chronic Fatigue Syndrome?

Michael Crawford: Obviously it hit me hard. I was doing a musical called Woman in White, an Andrew Lloyd Weber musical about five years ago. I created for this character what I thought was the most wonderful costume, this great big fat suit. I played this Italian count, Count Fosco. I thought it was just the bees’ knees, being so clever. I used to lose about a pint of water a night in this suit. Slowly I became more and more unwell - - I damaged my immune system. I lost nutrients and things from my body. I got this virus and thought it was flu, and everyone else thought it was flu. Two or three weeks later, I still had the same condition. There was aching, tiredness, fatigue, and I just couldn’t get better. So I started lots and lots of tests. And to this day, with doctors, there’s not too much understanding of the condition. And thousands and thousands of people have it, thousands of young children have it. It’s quite -- it’s so debilitating for a child not to have the strength to go and play with other children or to have a normal life. They’ll offer some medication that will maybe buck you up or something. That didn’t seem like a very good solution to me, because they really didn’t know what they were giving me. So I decided just to go. I went out of London and to New Zealand. I bought a house there, being fortunate enough to be able to do so. I got a small boat and I changed my lifestyle completely. I took every bit of pressure that I could out of my life. And I sailed, I grew vegetables, I smelled the roses for a couple of years. And by golly, I got better. My life started to change and I got more strength back. I felt well enough 18 months ago to go back and do The Wizard of Oz in London, at the London Palladium. I’ve just finished, and hopefully I’m going to retain this feeling.

Host: New Zealand’s good for you. It’s a beautiful place.

Michael Crawford: Yes, it is. Good fresh air.

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Paradigm Change

My Idyllic New Life, By Michael Crawford: Moving to New Zealand Restored Star’s Health
By Richard Shears


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March 11, 2012
The Sunday Telegraph (Australia)
The Secret Life of Phantom Star
By Jonathon Moran


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March 4, 2011
Daily Mail (UK)
I Was So Ill I Thought My Career Was Over: Michael Crawford Reveals the Very Personal Reason Why He’s Back on Stage
By David Wigg

http://www.dailymail.co.uk/femail/article-1362592/Michael-Crawford-reveals-personal-reason-s-stage.html
Sophie Neville:

May 3, 2012
Stroud News & Journal (UK)
“`I Was Forced To Take Stock of My Life” -- Bestselling Author Speaks to the SNJ
By Chris Wayne

http://www.stroudnewsandjournal.co.uk/news/9685926._I_was_forced_to_take_stock_o
f_my_life_____bestselling_author_speaks_to_the_SNJ/
Politicians & Celebrities:

February 2, 2012
Honolulu Star Advertiser
Okamura Stepping Down From House, Cites Health Reasons
By Derrick DePledge


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January 26, 2012
Sun-Star (Philippines)
Seares: When Miriam Santiago Rumbles....
By Pacico A. Seares


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November 11, 2011
Counterpunch
Flying Solo with Keith Jarrett
By Jeffrey St. Clair


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November 1, 2010
Ecologist
Campaign Hero: Countess of Mar
By Tom Levitt

http://www.theecologist.org/how_to_make_a_difference/cleaner_air_water_land/658600/campaign_hero_countess_of_mar.html
Athletes:

May 4, 2012
ABC radio (Melbourne)
Linley Frame: Olympian and Chronic Fatigue Sufferer
By Lindy Burns

http://www.abc.net.au/local/audio/2012/05/04/3495770.htm
http://www.mediafire.com/download/75q3cjb9eeeer17/Linley_Frame_Interview.pdf

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March 1, 2012
This Is Hampshire (UK)
Olympian’s Bid to Inspire
By Simon Moss

http://www.thisishampshire.net/news/9563383.Olympian_s_bid_to_inspire/

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December 25, 2011
Youngstown News
Former YSU Recruit Kaitlin Rohrs Battles Rare Disease Head On
By Joe Scalzo

Life with CFS:

June 23, 2013
Telegraph (UK)
Emily Didn’t “Only” Have ME
By Naomi Whittingham

http://www.telegraph.co.uk/health/10137694/Emily-didnt-only-have-ME.html

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March 27, 2012
Persephone Magazine
Parenting With Chronic Fatigue Syndrome (No Oxymoron Jokes, Please)
By Sara Habein


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March 25, 2012
Scholars & Rogues
Art Sunday: “Trapped In Our Bodies” - Coping With Chronic Fatigue Syndrome through Photography
By Sarah Allegra


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March 1, 2012
Daily Mail (UK)
Happy To Be Virgins: Successful and Popular...Meet The New Breed Of Women In Their Prime Who Have Never Had Sex
By Antonia Hoyle

http://www.dailymail.co.uk/femail/article-2108377/Meet-new-breed-women-prime-happy-virgins.html#ixzz1ntds5JTW

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December 12, 2011
The Daily Gazette
Teen Chosen For Olympic Torch Relay

http://www.gazette-news.co.uk/news/local/9411885.Teen_chosen_for_Olympic_torch_relay/

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May 13, 2011
The Shields Gazette (England)
Is ME Becoming A Forgotten Disease?
By Angela Reed

http://www.shieldsgazette.com/news/health/is_me_becoming_a_forgotten_disease_1_3379101

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May 24, 2010
Los Angeles Times
A Chronic Fatigue Syndrome Sufferer Reconnects with the World
By Diane Shipley

http://www.latimes.com/news/health/la-he-my-turn-20100524,0,3805527.story

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Psychology Today
The Stigma of Chronic Fatigue Syndrome
By Toni Bernhard

http://www.psychologytoday.com/blog/turning-straw-gold/201104/the-stigma-chronic-fatigue-syndrome

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The Wall Street Journal
Unlocking Chronic Fatigue Syndrome
Paradigm Change

Molly’s Story

http://issuu.com/wsij.com/docs/mollycsfsstory.pdf/1?mode=a_p

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March 14, 2011
The Guardian (UK)
What I’m Really Thinking: The Woman with ME

http://m.guardian.co.uk/lifeandstyle/2011/mar/12/what-really-thinking-woman-with-me?cat=lifandstyle&type=article

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Reno Gazette Journal
Life Slows to a Halt for Those With Debilitating Weakness
By Geralda Miller

http://www.rgj.com/article/20090310/LIV/903100302/Life-slows-halt-those-debilitating-weakness?odyssey=nav%7Chead

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December 10, 2008
The Telegraph (UK)
‘I Had Three Years of Nothingness, Of Hell’
By Elizabeth Grice

http://www.telegraph.co.uk/health/3692639/I-had-three-years-of-nothingness-of-hell.html
Deaths:

May 17, 2012
This Is Lincolnshire
Lincoln Man Stood On Railway Track In Front Of On-Coming Train


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April 27, 2012
This Is Gloucestershire (UK)
Investigations Continue Into Death of Newent Woman Who Drilled Hole In Head


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April 2012
Daily Mail (UK)
ME Drove My Daughter To Suicide
By Andrea Perry

http://www.dailymail.co.uk/health/article-32448/ME-drove-daughter-suicide.html#ixzz1sq0iLi9L

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March 31, 2012
Burton Mail (UK)
Complications From ME Led To Death of Teenager
By Katie Bowler


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March 30, 2012
The Guardian
ME Is Often Dismissed - But Sufferers Like Emily Collingridge Are Dying
By Scott Jordan Harris

http://www.guardian.co.uk/commentisfree/2012/mar/30/me-emily-collingridge-chronic-fatigue-syndrome

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February 27, 2012
This Is Derbyshire (UK)
Tragic Tale Of Woman With Chronic Fatigue Syndrome “Too Tired To Eat”


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December 21, 2011
The Daily Gazette (UK)
Wivenhoe Parents’ Check-Up Warning After Cancer Kills Son At 24
By James Cox

http://www.gazette-news.co.uk/news/local/9429928.Wivenhoe_parents_____check_up_warning_after_cancer_kills_son_at_24/
UK Sufferers:

June 11, 2013
The Lingerie Addict
Diversity is More Than a Bra Size: What It’s Like to be a Woman with a Disability in the Lingerie Industry
By Catherine Clavering


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June 7, 2012
Gazette Live (UK)
Middlesbrough Woman Overcomes Illness to Land Job in Fashion
By Lindsey Sampson


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May 15, 2012
Limerick Leader (UK)
ME Sufferers in Limerick Highlight Their “Invisible” Pain
By Anne Sheridan

http://www.limerickleader.ie/community/community-news/me-sufferers-in-limerick-highlight-their-invisible-pain-1-3841459

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May 15, 2012
This Is Sussex
Kelly Oldershaw Bounced Back After 7 Years In Bed With ME

http://www.thisissussex.co.uk/Kelly-Oldershaw-bounced-7-years-bed/story-16031507-detail/story.html

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May 12, 2012
Stornoway Gazette (UK)
Toxic Tiredness Examined On TV
http://www.stornowaygazette.co.uk/lifestyle/lifestyle-leisure/toxic_tiredness_examined_on_tv_1_2068942
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May 12, 2012
Diss Express (UK)
Canine Capers Help Africa Trip
http://www.dissexpress.co.uk/community/community-news/canine-capers-help-africa-trip-1-3834117
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May 11, 2012
Redditch Standard (UK)
Sufferer Aiming To Raise Awareness
By Carl Jackson
http://www.redditchstandard.co.uk/2012/05/11/news-Sufferer-aiming-to-raise-awareness-39498.html
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May 10, 2012
Mercury (UK)
Anne-Marie’s ME Message
By Bethan Evans
http://www.thewestonmercury.co.uk/news/anne_marie_s_me_message_1_1373495
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May 10, 2012
The Shields Gazette (UK)
Shining a Spotlight On Mystery of ME

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May 9, 2012
Bromsgrove Standard (UK)
Bromsgrove Woman To Raise Awareness of ME
By Carl Jackson

http://www.bromsgrovestandard.co.uk/2012/05/09/news-Bromsgrove-woman-to-raise-awareness-of-ME-39018.html

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May 8, 2012
Herald (UK)
“I Was So Weak I Could Not Even Lift My Arm to Turn the Alarm Off”
By Anna Coogan

http://www.herald.ie/lifestyle/i-was-so-weak-i-could-not-even-lift-my-arm-to-turn-the-alarm-off-3102398.html

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May 6, 2012
This Is the West Country (UK)
Brent Knoll Mum, 44, Sets Up New Group To Help Others

http://www.thisisthewestcountry.co.uk/news/somerset_news/9686271.Brent_Knoll_mum__44__sets_up_new_group_to_help_others/

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April 26, 2012
This is Scunthorpe (UK)
I Don’t Think There’s Enough Awareness of ME Out There

http://www.thisisscunthorpe.co.uk/don-t-think-s-awareness/story-15921622-detail/story.html

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April 25, 2012
This Is Sussex (UK)
Unlikely Pair Show They Are The “Real Deal”
By Dave Comeau


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April 19, 2012
Sunderland Echo (UK)
Photography Exhibition On ME Sufferer’s Illness

http://www.sunderlandecho.com/lifestyle/photography-exhibition-on-me-sufferer-s-illness-1-4460570

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April 17, 2012
Comet (UK)
Letchworth 20-Year-Old’s Sudden Death Caused By Dysfunctional Immune System
By Nick Gill

http://www.thecomet.net/news/letchworth_20_year_old_s_sudden_death_caused_by_dysfunctionalImmune_system_1_1351436

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April 11, 2012
Wiltshire Gazette & Herald (UK)
Teen To Aid Charity


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March 30, 2012
The Sun (UK)
Sophie Was A Lively Little Girl...Now She’s So Weak She Can’t Even Text
Robbed Of Life: Heartbreaking Victims of ME and Fibromyalgia
By Lynsey Haywood


*January 27, 2012
Daily Record (UK)
Mother-of-Two Tells How M.E. Left Her Bedridden and In Agony
By Maria Croce


*December 21, 2011
Gazette (UK)
Retired Church Minister From Yate “Used To Sleep For 22 Hours A Day”
By Alexandra Womack

http://www.gazetteseries.co.uk/news/9430143.Retired_church_minister__used_to_slee_p_for_22_hours_a_day/

*August 23, 2011
BBC
A Day in the Life of Scott Jordan-Harris

http://www.bbc.co.uk/blogs/ouch/2011/08/a_day_in_the_life_of_scott_jor.html

*May 3, 2011
This is Staffordshire
‘Don’t Call My M.E. Yuppie Flu or Laziness,’ Says Rachel

**US Sufferers:**

May 12, 2012
Herald-Mail
Halfway Woman Won’t Let Illness Keep Her From Being Mom
By Marie Gilbert

http://articles.herald-mail.com/2012-05-12/lifestyle/31683349_1_chronic-fatigue-syndrome-illness-active-mom

**Other Countries:**

April 29, 2012
The Sunday Times (Malta)
“I Feel I’m Living In A Cage That Is Closing In On Me”
By Ariadne Massa

http://www.timesofmalta.com/articles/view/20120429/local/-I-feel-I-m-living-in-a-cage-that-is-closing-in-on-me-.417447

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April 25, 2012
Auckland Now (NZ)
Call Goes Out For Research On ME
By Simon Smith

http://www.stuff.co.nz/auckland/local-news/eastern-courier/6790823/Call-goes-out-for-research-on-ME

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May 16, 2012
The Newcastle Herald (Australia)
Stockton Beach Most Polluted
By Richard Baines

March 6, 2012
Northern Star (Australia)
Rachel On The Walk Of Her Life
By Paul Appelkamp


April 4, 2011
The Charlottetown Guardian
A Healthy Passion
By Mary MacKay

http://www.theguardian.pe.ca/Arts/2011-04-04/article-2398503/A-healthy-passion/1

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