

POLIO NETWORK NEWS

"Many of the popular claims made for the power of the mind to alter the health of the body are based on speculation, but a growing body of science-based research is now establishing the role that the brain plays in health and disease. The findings of this new field of study have the potential to revolutionize our understanding of the brain and the body as an interconnected whole."

Brain-Body Science: A Progress Report, The Charles A. Dana Foundation, Brain-Body Institute, December 1999

Stress

Stress begins in the brain and is expressed in the body as well as in the state of our minds. When we find ourselves in a situation that challenges us emotionally or physically, we react with the classic "fight or flight" stress response. The brain sends out chemical messengers in the form of stress hormones to almost every system and organ of the body, setting off a cascade of physiological changes.

Heart rate, blood pressure, and muscle tension rise sharply, the stomach and intestines become less active, and the blood level of glucose (blood sugar) rises for quick energy. The brain arms the body

for battle or escape. Stress hormones activate immune cells that rush to the battlefield to protect the body from whatever is threatening its stability. When the stressful event is over, the body returns to normal functioning.

Understanding both the social conditions that trigger this response, as well as the psychological states that may buffer or protect us from stress, is critical.

The Toll of Chronic Stress

Chronic stress creates a different scenario. For example, if you are under constant pressure at work, or having difficulties with a spouse or loved one, the body reacts with the stress response. But if the stressful situation continues over days, weeks,

or months, the stress response may not turn off. If it doesn't, protective hormones shut down the regular repair and maintenance functions of our bodies. The result can be a suppressed immune system, prone to infection.

The cumulative toll of stress can affect the body in a number of ways. Scientists have observed bone loss, muscular weakening, hardening of the arteries, and increased insulin levels that cause greater levels of fat deposition in the body, especially around the abdomen. Some people end up with the "apple" body shape that researchers have shown predisposes some individuals to heart disease.

Stress and Natural Killer Cells

Many researchers have focused on the activity of natural killer (NK) cells – specialized immune cells that protect the body from health threats by seeking out and destroying abnormal or virus-infected cells

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An Antidote to Post-Polio Stress: Pleasure Seeking

Mary Westbrook, PhD, Sydney, Australia

When talking about stress, we must distinguish between stressful events (stressors) and a person's reactions, both physiological and psychological, to such events (stress responses). There are some events that almost everyone would experience as very stressful: consider the late effects of polio. Lightning has struck us twice; the physical gains we achieved melt away and the lives we built are threatened on every side by ongoing losses such as forced early retirement or the inability to continue favourite social and leisure activities. How will it all end?

Post-polio is a chronic stressor in response to which our stress levels fluctuate. Such changes may be caused by happenings (a fall, a new symptom, lack of access, being dropped from a friend's social calendar) and/or by our state of mind and body (tiredness, pain level, other worries). When we feel stressed our post-polio symptoms get worse¹. So life often becomes a vicious circle. We receive much advice on techniques to reduce both stress levels and symptoms of fatigue, pain, and increasing weakness. So we learn to pace ourselves, slow down, delegate, have

rests during which we do absolutely nothing, give ourselves permission to say 'No' (to all the nice things we want to do), meditate, do relaxation and stretching exercises, purchase aids and special equipment, and try

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massage and body therapies. Yes, many of these strategies do provide some relief, but they are also frequently sources of irritation, boredom, frustration, and regrets that we are not otherwise engaged. Post-polio seems to have taken over our lives. While some of us manage to achieve Buddha-like serenity, many of us, I suspect, do these things in the hope that we will feel well enough to do a little bit of busy living again.

Polio survivors' reactions to our ongoing stressors are often accompanied by the shame that Kitty Stein², who has MS, describes. This shame response tells us, "I'm bad; it's me; I'm not dealing with it well," whereas the healthy response is, "Yes, I am having a hard time. How can I get help or help myself?" Stein goes on to advocate that people with chronic health conditions acquire a "nurturant" voice, and enter into a mutual, loving relationship with themselves. Unfortunately, self-nurturance is foreign to most polio survivors who are characterised by their self-criticism and their compassion for others but not themselves.³

In his research investigating factors related to Americans' feelings of well-being or happiness, Bradburn⁴ found that neither the number of positive nor negative events that people were experiencing in their present lives predicted their ratings of their overall happiness. However, the discrepancy between these two types of events was an excellent predictor. The greater the excess of positive over negative experiences, the higher a person's rating of happiness.

When I taught psychology to health professionals involved in rehabilitation, I suggested this equation had important implications both for them and their clients. When a person becomes disabled, there are usually deficits and losses that can never be cured or replaced. However, if we consider the person's overall life situation, there are often changes and additions that can be made that will increase the person's positive experiences and their overall well-being. Sad to say, rehabilitation programs concentrate more on providing vocational skills than the social and recreational skills that would serve disabled people well in their changed lives. Bradburn's model is a useful one for health practitioners in that it focuses their attention on what they can achieve for their clients and lessens feelings of helplessness or inadequacy that may develop if they concentrate only on the problems that cannot be solved.

Several psychologists have provided tips for the seeker of pleasure. In her recent book, polio survivor Rhoda Olkin writes of the importance of having something to look forward to and suggests this is especially important for people with disabilities because the effects of pain, fatigue, and weakness can occupy a large portion of time and erode our ability to find pleasure⁵. Olkin says that we need "four levels of positive future events: 1) small pleasures that occur at least once a day, e.g., reading in bed and eating two stale marshmallows; 2) slightly larger events that occur at least once a week, e.g., listening to the *Prairie Home Companion*; 3) monthly events, e.g., visiting with a good

friend and going out for a nice dinner; and 4) larger events that occur maybe once a year, e.g., family vacation and a favourite holiday."

Having to retire early from my university position led to a drastic reduction in my daily social contacts and particularly the interchange of stimulating ideas. A daily treat that substituted for this was joining mailing lists on the Internet. I belong to a number of post-polio lists and have joined many others related to my interests such as disability studies, L M Montgomery, mysticism, and women's issues. Most mornings I receive about a hundred e-mails, some fascinating and maybe demanding a reply, and others quickly deleted. I read them with a cup of coffee much as I had a cup of coffee in the staff room at work. The Internet provides treats that are readily available when I feel low. At such times nothing beats a visit to Amazon.com or Barnesandnoble.com, a wander through their aisles, and maybe the purchase of a book online. Art galleries on the net are a means to pursue another interest.

Many polio survivors recognise that gaining pleasure from having interests is a survival strategy. In a survey of Australian polio survivors⁶ I asked, "What advice would you give to someone who developed post-polio symptoms?" The fifth most common recommendation was "Develop new interests" and "Maintain those interests that you can." The most frequent advice was, "Talk with other post-polio survivors" or "Join a support group." When I attended GINI's Sixth International Post-Polio and Independent Living Conference in 1994, I remember initially feeling confused because I felt so comfortable and relaxed. Then I realised that it was because everyone had had polio, so the "disability factor" that must be dealt with in other social encounters did not exist.

Mary Westbrook, PhD is a psychologist who conducted the first Australian research into post-polio. She spoke at the GINI conference in 1994 and contributed to the recently revised *Handbook on the Late Effects of Poliomyelitis for Physicians and Survivors*. In 1998 she was made a Member of the Order of Australia for her service to people with disabilities through research into post-polio, physical disability, and education in the health professions.

One of my new pleasures, my commonplace books, began about seven years ago, almost by accident. One day I was given an art diary that seemed too beautiful to be used for scribbles about my daily appointments. Then I realised it was just the place for the quotations that I like to keep. My books contain extracts from articles, poetry, letters from polio mailing lists, photographs of special happenings (my recently built wheelchair-accessible courtyard garden that substitutes for the large garden I can no longer tend, my baby granddaughter, Marilla), cards from friends that were particularly moving, advertisements for a film

INTERNATIONAL POLIO NETWORK

Polio Network News (ISSN 1066-5331)
Spring 2000 ■ Vol. 16, No. 2

Polio Network News is an international newsletter for polio survivors, health professionals, and resource centers to exchange information, encourage research, and promote networking among the post-polio community.
ISSUED QUARTERLY

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COORDINATED AND PUBLISHED BY:
Gazette International Networking
Institute (GINI)

EDITOR: Joan L. Headley, Executive
Director

GRAPHICS/ASSISTANT TO THE EDITOR:
Sheryl R. Prater

SPECIAL THANKS TO: Ellen Peak

Annual subscription (US dollars only)
USA: \$20
Canada, Mexico, & Overseas surface: \$25
Overseas air: \$30

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Networking Institute (GINI)

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or art exhibition that I enjoyed, and a few cartoons. The contents consist of writings that "speak to my condition."

Pleasures can slip by without our extracting much of their joy. An exercise entitled, "First the good news; then stop!," is surprisingly effective in counterbalancing a focus on the negatives in our lives. At the end of each day, I review the day's happenings and single out those personal activities that were enjoyable. Recalling a phone call from a friend and the enjoyment of reading a thriller reminds me that life can still be good.

How does pleasure affect our bodies? According to neuroscientist Candace Pert, "Our new understanding of neuropeptides and receptors has enabled us to see more of what is going on in conditions of stress. When stress prevents the molecules of emotion from flowing freely where needed, the largely autonomic processes that are regulated by peptide flow, such as breathing, blood flow, immunity, digestion, and elimination collapse down to a few simple feedback loops and upset the normal healing response."

Experiencing pleasure or "having fun is the cheapest, easiest, and most effective way I know to instantly reduce stress and rejuvenate mind, body, and spirit – it gets our emotions flowing, and our emotions are what connect us, give us a sense of unity, a feeling that we are part of something greater than our small and separate egos," says Pert⁷.

I open my commonplace book and Nancy Mairs⁸ tells me of her visit to Knole, an English stately home with 365 rooms. "Only the oak-paneled Great Hall can be reached by wheelchair. I can huddle in it grieving over the rare and fabulous silver furniture the others will see upstairs in the King's room without me. Or I can contemplate the ancestral portraits all around me, the elaborately ornamental oak screen at one end, and, when I've

What Psychotherapists Should Know About Disability (ISBN 1-57230-227-5) by Rhoda Olkin, PhD, professor in the clinical psychology program at the California School of Professional Psychology in Alameda, California; \$35, hardback; 368 pages, August 1999; Guilford Publications Inc., 72 Spring Street, New York, NY (New York) 10012 (800-365-7006, 212-966-6708, info@guilford.com; www.guilford.com).

looked deeply enough, wheel out in the rare bit of English sun, dreaming that Vita Sackville-West and Virginia Woolf once walked by this very spot, heads together, arms entwined, their laughter fluttering through the gate and into the deer park beyond. Only one of the options will give me joy. I choose joy."

My pleasures may not please you, but I encourage you to explore the treats and small adventures lurking around corners in every day. ■

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