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Health Promotion for People with Chronic Neuromuscular Disabilities

Sunny Roller

As an educator, support group leader, manager of the Post-Polio Research and Training Program at the University of Michigan Medical Center, and one of the many persons with postpolio symptoms, I have personally experienced and observed among my peers the interplay of aging and long-term disability. We are moving into our middle and late years and have begun to experience the effects of normal aging. Our uniqueness as people with disabilities, however, stems from the fact that our expected aging challenges have been combined and complicated with the newly recognized late effects of polio. These could become even more seriously complicated by the effects of disuse and new disease.

The polio population serves disability researchers. We are the first who have been identified as having the late effects of neuromuscular impairment. People with spinal cord injury (SCI), spina bifida, and cerebral palsy (CP) are also now reporting similar late effects. Since the mid-1980s, increasing numbers of polio survivors with progressive new weakness, severe disabling fatigue, and a variety of pain management problems have sought medical attention.

In our 1991 study of 120 polio survivors (56% of whom were women) at the University of Michigan, we found that 82% had a treatable musculoskeletal problem of some kind (Maynard, 1991). Modern rehabilitation methods can bring people back to satisfactory levels of functioning. New braces, for example, could support legs that are weakening. Strengthening exercises could alleviate some pain problems. A shoe lift could relieve hip pain and enhance walking endurance. But 35% of the polio survivors in this study were obese; 36% had an elevated cholesterol level; and 35% had a comorbidity such as diabetes, gastrointestinal disease, and heart trouble

(see Table 1). Sixty-two percent had an exercise capacity below the expected and achievable levels. Based on these findings, prevention efforts that focus on improved diet and individually designed exercise plans were medically recommended.

To avoid depression and reduce stress, people with the late effects of polio must be continually encouraged to use creative approaches to reduce their physical problems, many of which may be preventable. Because of their special vulnerabilities to new health problems such as pain, weakness, and fatigue, polio survivors need intensive instruction, coaching, and support to learn how to apply general health promotion practices to their unique conditions and circumstances. But often, because of very limited wellness opportunities, they have been at a disadvantage because they cannot work out on the local health club machines that are meant for members without neuromuscular disabilities. Many weight loss centers do not even have a scale that is wheelchair accessible. Swimming classes are not often given in pools that are warm enough or accessible enough, and adapted coaching by the instructor is not generally provided.

Polio survivors and our counterparts who have similar disabilities justly desire and deserve to maintain lifestyles that are as fully functional, diverse, and independent as possible. As we begin to cope with the late effects of our disease, new questions arise. "What can I do to feel good?

Table 1. Secondary pathologies found in postpolio sample

Condition	Percent of subjects with condition
Anemia	7%
Elevated cholesterol ratio	36
Hypertension	8
Obesity	35
Other significant medical comorbidity (one or more from list below)	35
Diabetes	2.5
Respiratory diseases (COPD/asthma)	7.5
Heart trouble	8
Circulation trouble in limbs	5
Gastrointestinal disease (e.g., gall bladder problems or stomach ulcers)	8
Urinary tract disorder (e.g., infections, stones, or prostate problems)	4
Rheumatoid arthritis	3
Non-polio nerve/muscle disorders causing weakness or paralysis	9

From Maynard, F., et al. (1991). *The late effects of polio: A model for identification and assessment of preventable secondary disabilities*. Alexandria, VA: National Technical Information Services, U.S. Department of Commerce.

*Judged to be serious enough to potentially affect functional capacity.

Could I ever feel as well as an athlete looks? Must I be condemned to struggle from one medical crisis to the next in future years, or is there something I can do along the way to prevent new problems? Can I possess a sense of harmony and pleasant satisfaction with who I am and the life I am living? Is it possible to have a disability, feel less pain, be more rested, and have more energy for the activities I want to participate in?" We want to stay strong and pain free, prevent injury, stay out of the hospitals, and contribute on the job until we choose to retire, and we need insurance coverage that will support our commitment to staying healthy and productive.

Because more and more women with chronic neuromuscular disabilities are living longer, our society needs to address the long-term needs of this growing population. Health promotion programs that help people stay well could fill a gap in our health care system and eliminate unnecessary spending connected with the devastating effects of poor health and functional decline among people with disabilities.

With these factors in mind, I advocate two health promotion models. The first is the residential model developed in Europe, which I have studied in Germany. The second is a commuter model described in the book *Stay Well* (Roller & Maynard, 1991). Both models of health care provision are unique because they prescribe a holistic set of treatments in one accessible location. A one-stop shopping mode of program delivery would meet our serious need for convenient therapies. Some therapies would lead to maintaining sound health. Other therapies could lead to the prevention of new problems. Depending on their quantity, duration, and intensity, the same therapies could be used for either maintenance or prevention. The importance of a holistic wellness program is that it considers the whole person as a unit with interlaced parts, each of which has a dramatic effect on the others. This approach is appealing because as women, we have unique needs in a variety of areas—as described in detail throughout this book—mental, physical and spiritual needs. Also, for those of us with very limited physical function, if we could not succeed at exercise, there would be other wellness interventions to learn and participate in that include the areas of nutrition or general lifestyle enhancement. Thus, such a comprehensive menu would provide us with more choices and opportunities to improve our health.

RESIDENTIAL MODEL

In 1992, the World Institute on Disability awarded me a grant to do a descriptive study of the health spa system in Germany. In November of that year, my collaborator, Eva Wortz, and I flew to Bavaria to visit three spas. Our purpose was to investigate unique techniques and methods of

support for helping people with long-held neuromuscular disabilities stay well and prevent new disabilities as they grow older. In the United States, our mental picture of a spa is a building that houses equipment and pools. Very healthy people go to these spas to get more healthy. A spa might also mean a tanning salon. Or a spa may simply be another word for a hot tub. In Germany, spas are like small towns. They are made up of hotels, restaurants, churches, and shops. There are clinics and various treatment centers that house swimming pools and specially equipped treatment rooms. Spas have parks, tennis courts, lakes, and concert halls. Many doctors and therapists have offices on the spa grounds. People take part in their own customized holistic wellness programs. This residential concept entices the participant to live at the facility for a length of time to focus full time on maximizing health. Individuals go to the spa to rejuvenate their health and to prevent further deterioration. These visits require a doctor's prescription in order to be covered by insurance.

The required elements of the spa's unique holistic approach include a residential time away from home; a relaxed and aesthetically delightful environment; a group of individualized exercise, nutritional, and recreational treatments; an individualized health education program; and a time to set goals for long-term follow-up of health-enhancing behaviors. Some of these elements are described in the following paragraphs.

Residential time away provides participants with disabilities a unique opportunity to fully focus on health rejuvenation. As one woman polio survivor, a German spa participant, remarks:

I would rather choose such an inpatient treatment plan than outpatient treatment. The community of patients is psychologically supportive and helps one forget one's own pains. In such a treatment plan, one is there only for one's body—one is taken care of in every respect. In an outpatient treatment plan, one must also go home and take care of the family afterwards. This is less successful.

Upon entering a German spa, one cannot help but become engulfed in the health-promoting surroundings. The relaxed and aesthetically delightful environment was obvious and alluring to us. The scenic beauty, the peaceful pools and lakes, the glittering elegance in the small shop windows, and the contented humming chit-chat of strolling spa guests all coalesced to lift spirits and create positive attitudes that lead to good health. All of the spa directors and physicians that we met emphasized that a spa should never look or feel like a hospital. "It must be fun," one of the therapists stressed, with serious enthusiasm. Hospitals are designed for sick people. Spas are built to intensify health promotion and invite the well-being of the visitors.

The accessible spa clinics we visited looked like hotels and offered a long list of treatments. We learned that these clinics would be ideal places

for people with severe disabilities to participate in a holistic wellness program because all treatments could be completed in this one barrier-free and accessible building. People who are able to walk longer distances over more difficult terrain could stay at a regular spa hotel and walk from building to building to receive treatments.

Everyone who goes to the spa must first be evaluated by a physician. At the spas we visited, participants staying at the spa clinics must receive a battery of tests to assess strengths and deficits. Physicians then collaborate with therapists and the participant to set up an individualized program. The customized treatments must take into consideration the late effects of the neuromuscular disability—like polio or SCI. The daily schedule must include all the appropriate rest breaks, for example. That is a key to success demonstrated at Bad Griesbach, one German spa we visited.

The treatments include physical and occupational therapy; speech therapy; psychotherapy; group treatments, including stress reduction techniques, cognitive treatments, independent living training, and diet counseling and participation; and complementary medical treatments, such as massage, mud baths, and aroma and herbal therapy. An important part of the spa experience is the educational programming that accompanies the actual therapies. Participants who make a serious commitment to learning new attitudes to end self-defeating health behaviors attend lectures and workshops on various health topics—from how to quit smoking to how to cook nutritious meals. Commitment is expressed through attendance at all therapies and scheduled lectures, which are mandatory. Avoiding any of these activities may mean that the participant is discharged from the spa and is charged with all costs of treatment, rather than receiving insurance reimbursement.

It was explained that a long-term follow-through therapy plan is laid out and discussed with spa participants as part of their educational program. Therapists meet with participants to let them know what treatments they need to do when they return home and how often they must be done. Most of the people we interviewed agreed that, for people with disabilities, the full benefit of the 4- to 5-month good feeling that comes after the stay at the spa would likely require a return visit, perhaps annually.

Most spas are not aggressive in attracting people with disabilities, but all three spa directors we interviewed revealed that with proper preplanning they could accommodate special needs. Anyone who goes to a spa for treatments will have various amounts of reimbursement provided if they first receive a prescription from their physician. Typically, an eligible person would wait for 3–5 weeks and receive a certain amount per day for food, lodging, and all treatments. The average spa visitor goes once every 3 years for 3–4 weeks.

Because the spa treatments—or “Kur,” as the Germans describe it—will help keep a person healthy in general and fit and able to work, preventing premature medical retirement, the person’s visit is reimbursed by one of the state insurance programs or private health insurance. There is a German Spa Association that coordinates research on spa treatment and effectiveness. They have been quoted as saying that for every mark spent on a stay at the spa, 3 marks go back to the German society (R. Hasselberger, personal communication, November 29, 1992).

If a person with a disability lives close enough to a spa and is in need of treatment, he or she can qualify to have three or four “Kurs” per week. This becomes a German version of a community-based health promotion program that people travel to regularly, rather than the live-in arrangement, which is more common at the German spas.

We believe that the German health spa model could be adapted and used in the United States. This model supports the concept of prevention as well as the independent living philosophy of personal empowerment because it promotes self-care after the stay and is dedicated to the prevention of new disabilities that could ultimately inhibit a person’s ability to function freely. It appears that Franklin D. Roosevelt participated in his own version of a spa-like health promotion program here in the United States when he vacationed at Warm Springs, Georgia, during his later years to swim, eat right, and feel rejuvenated. Based on that small American tradition and on the success of the German health spa concept, U.S. health care professionals and consumers could assess their local/regional facilities, professional resource pool, and community interest and need for potential wellness programming opportunities that are accessible to people with disabilities. Adapted variations on the spa programs and practices could be established based on their findings.

COMMUTER WELLNESS PROGRAM

A second model, called the commuter wellness program, lays out a plan for a comprehensive and integrated program that would offer a range of treatments all in one location that is within driving distance of the person’s home.

“Stay Well!” is an example of a commuter program that introduces polio survivors to new tactics that can be customized to their needs. Generated from consumer-reported requests for self-education and based on a pilot program codesigned and conducted by polio survivors and health care professionals in Michigan, “Stay Well!” is an expanded and untested community health promotion program. Its design is worthy of serious consideration. The program strives to help participants

1. Alleviate, manage, and prevent a variety of secondary conditions that are associated with long-term muscle impairments
2. Promote good health and wellness
3. Introduce new health promotion tactics customized to individual needs
4. Facilitate long-term adoption of health-enhancing behaviors

This is a modular program designed to be established at an accessible and convenient community location and led by a committed group of community members, including consumers with disabilities, health care professionals, and others. As stated in the handbook, *Stay Well! The Polio Network’s Manual for a Health Promotion Program* (Roller & Maynard, 1991), the program contains three major content or curriculum areas. These include sound nutritional practices, individualized physical exercises, and general lifestyle enhancement techniques. Each curriculum section should be adapted to meet the priorities of potential program participants.

The nutrition section teaches participants to identify and adopt a diet that can optimize total well-being. Often people with the late effects of polio are faced with having to conserve energy to maintain optimal health. This necessary change in lifestyle can create new weight problems. Because many people with polio have limited physical activity, we often should not exceed a 1200-calories-per-day diet.

As part of “Stay Well!”, participants are encouraged to 1) discover the “New American Diet” and its potential benefits, 2) decrease fat intake, 3) achieve and maintain optimal weight, 4) achieve a gradual and moderate increase of dietary fiber, 5) reduce overall sodium intake, and 6) recognize the importance of adequate intake of calcium-rich foods to prevent osteoporosis.

The exercise section teaches that, by individualizing and practicing the principles of fitness, exercise, relaxation, pacing, and utilization of local community resources for exercise equipment, it is possible to stay optimally healthy with a postpolio disability. Participants are taught that this can be accomplished by defining and practicing the principles of 1) a stretching program for flexibility, 2) a strengthening program, 3) a cardiovascular fitness training program, and 4) aquatic exercise. The principles of proper posture and back care, body mechanics, and joint protection are also taught, and participants are introduced to guidelines for using community resources.

The overall goal of the lifestyle enhancement section is to give participants an opportunity to enhance their repertoire of strategies for conducting daily activities. It teaches that this can be accomplished by learning how to 1) increase personal levels of self-acceptance and self-confidence; 2) identify and cope more effectively with stress; 3) apply the principles

of assertive behavior, including coping with anger; 4) connect with available community service resources such as postpolio groups, government agencies, and other health care services; 5) develop satisfying leisure-time activities; and 6) tap available personal resources, which include our internal coping skills and values as well as external resources such as friends, a nurturing home environment, and financial resources.

"Stay Well!" is a model health promotion program that could provide convenient opportunities for polio survivors and people with similar disabilities to learn how to apply general health promotion practices to their unique conditions and circumstances. It is dedicated to preventing the unnecessary progression of disability and encouraging its participants to get well and stay well for years to come.

CONCLUSIONS

As we consider both residential and commuter health promotion program models for people with disabilities, some unanswered questions remain. Will health care insurance cover the costs of such preventive health care activities in the United States? Could an interdisciplinary conference among American health promotion specialists and professionals from abroad be held to discuss and design wellness programming for people with disabilities? Could grant funding be provided to groups of health care professionals and consumers to conduct research on the outcomes of wellness program protocols and the most successful modes of program delivery? What can we learn and apply through wellness programs that will address the specific needs of women who have physical disabilities?

Further research is needed on the effectiveness of complementary therapies, such as some of those practiced at the German spas, in preventing secondary disabilities; the feasibility of establishing regional spas for people with chronic disabilities at national facilities such as Warm Springs, Georgia; the conceptual, philosophical, or physical barriers to creating health promotion programs for people with disabilities existing in our local communities that need to be recognized and addressed; the resources that are already in place in our communities that could be utilized to build a health promotion program; the possibility of sharing resources that already exist among agencies and organizations; and funding sources that could be accessed to support a health promotion program for people with chronic neuromuscular disabilities.

We know that accessible, holistic, live-in wellness programs are being provided for people with disabilities in Germany. A holistic commuter program like "Stay Well!" offers us another model that might be even more quickly adaptable in U.S. community structures. These models can

give us a new vision for lifelong wellness for women with disabilities in the United States.

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