

Is the prospect of falling over at home or on the street something you would enjoy, just to make your ego happy? Does being ambulant give you and those that you love and care for, more or less independence?

The answers to these questions need to be carefully thought through. If the answer is "less independence," you should consider a life that includes some time in a wheelchair.

Some of the things to consider are:

- Can you rise from a chair easily without assistance?
- Can you use a street crossing without fear of falling over?
- Can you get more than halfway across a set of traffic lights before the DON'T WALK sign stops flashing?
- Can you climb a small flight of steps which has no handrail?
- Can you climb a larger flight of steps without feeling exhausted?
- Can you easily catch a bus or train? Can you easily get in and out of a car? Do you feel safe in the shower or bath?

This is not a definitive list, but a starting point.

To conclude, this question of when to stop walking shows that "swimming against the tide" of society in the long run only hurts "the swimmer," and society loses the opportunity of receiving our valuable input.

We need to be part of society, not apart from it just because we cannot walk. ■

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The Changing Dynamics of Aging with Polio

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"Aging with polio" refers to two interrelated phenomena. On a macro level, it refers to dramatic improvements in life expectancy, which are part of the "longevity revolution" that is simultaneously altering the landscape of aging and disability (Jones et al., 1997; Seelman & Sweeney, 1995). Thanks to recent advances in medical rehabilitation, emergency medicine, and consumer education, for the first time in history persons with significant disabilities, like their nondisabled counterparts before them, are surviving long enough to experience both the rewards and challenges of mid- to later-life (Ansello & Eustis, 1992). No where are the changing demographics of disability more evident than for persons aging with the long-term effects of polio. Estimates from the most recent National Health Interview Survey indicate that there are between 430,000 and 1,000,000 polio survivors alive today in the USA, and more than half of these individuals are 55 years of age or older (NHIS, 1994-95).

The changing dynamics of polio have not come without their "costs," however. In exchange for the personal benefits of increased longevity, many polio survivors, as they age into mid-life and beyond, experience the onset of new, and frequently unexpected, health problems and functional changes that threaten to erode independence and reduce quality of life (Maynard, Frchheimer, & Roller, 1991; Campbell, Kemp, & Brummel-Smith, 1994). Clinicians treating polio survivors were some of the first to call attention to the health problems associated with long-term disability (Maynard, 1981; Halstead, 1985). Since the

early 1980s, their primary focus has been on the cluster of new polio-related symptoms (e.g., fatigue, muscle or joint pain, cold sensitivity, etc.), impairments (muscle weakness), and functional losses known as "post-polio syndrome" or PPS (Halstead & Grimby, 1995). But the health risks of aging with polio are not limited to changes in symptoms and/or declines in function. Living with the long-term effects of polio also places survivors at potentially increased risk for age-related chronic diseases and health conditions, such as diabetes, high blood pressure, heart disease, emphysema or COPD, osteoporosis, and obesity, to name just a few (Maynard et al., 1991). While these conditions affect the rest of the aging population, they may occur more frequently, and at younger ages, for persons with physical disabilities because of their "narrower" margin of health and the barriers they face in maintaining their health (DeJong, 1995; Marge, 1988; Pope & Tarlov, 1991).

The significance of both post-polio syndrome and early onset age-related chronic diseases lie in their potential to "accelerate" the aging process and produce "excess" or secondary disabilities (Lollar, 1994). Because of the costs of these consequences for individuals as well as society, preventing the new health risks of aging with polio, and other long-term disabilities, has become a major public health objective of the 21st century (Healthy People 2010: Draft for Public Comment, 1998; Brandt & Pope, 1998; Guralnik et al., 1996; Marge, 1988).

Recent findings from the Aging with Disability (AwD) Survey

Study* illustrate the types of chronic health conditions persons with polio are at risk for as they age, and document the health disparities that exist between persons aging with polio and their non-disabled counterparts. To test for evidence of "accelerated aging," the frequency of selected chronic conditions reported by polio participants in the AwD Study was compared to national estimates of these same conditions for age-matched cohorts from the 1994-1995 National Health Interview Survey. The polio sub-sample of the larger AwD Study consisted of 218 individuals, who ranged in age from 42 to 89, and had been living with the effects of polio for an average of 50 years.

Out of the 14 chronic conditions examined in both studies, polio survivors reported significantly higher rates for almost all mortality and morbidity diagnoses compared to national estimates for age-matched cohorts. This pattern is most pronounced for the youngest group of 45- to 64-year-olds, where frequencies of chronic conditions are two to ten times greater for those aging with polio than for their same-age counterparts in the population at large. Key findings from this analysis are summarized below.

- "Low vision/blindness" was reported by 21.0% of younger polio survivors compared to estimates of only 4.5% for 45 to 64-year-olds in the population at large.
- 14% of polio survivors in each age group reported a diagnosis of emphysema/COPD compared to national estimates of only 1% and 4.6% for corresponding age groups.
- For mortality risk factors, 14.0% of polio survivors in the 45 to 64 age group reported a diagnosis of diabetes compared to only 6.3% for this same cohort in

the population at large. The disparity in rates of high blood pressure (HTN) is even greater. 41.0% of younger polio survivors report a diagnosis of HTN compared to 22.2% for this cohort in the population at large; and, among those 65 and older, the frequency of HTN is 54.0% among polio survivors compared to only 36.4% for the population at large.

Together, these findings document the health disparities of persons aging with polio and highlight their changing needs for health care. To reduce the risks of "accelerated aging," these findings suggest that persons aging with polio and their families need access to: more preventive services and at younger ages; more informed medical and allied health providers who are knowledgeable about the new health risks associated with aging with disability; and, more targeted health promotion programs that incorporate training in self-care and self-advocacy, as well as education on risk factors and the prevention of chronic disabling disease.

*The AwD Study was conducted between 1993 and 1998, under the auspices of the Rehabilitation Research and Training Center on Aging with Disability, located at Rancho Los Amigos Medical Center, Downey, California. The full study involved a cross-sectional, group comparison study of persons aging with cerebral palsy, polio, rheumatoid arthritis, and stroke. The total achieved sample was 555.

References

- Ansello, E.F., & Eustis, N.N. (1992). A common stake? Investigating the emerging 'intersection' of aging and disability. *Generations*, 16(1), 5-8.
- Brandt, E.N., & Pope, A.M. (1997). *Enabling America: Assessing the role of rehabilitation science and engineering* (pp. 40-61). Institute of Medicine, Washington, DC: National Academy Press.
- Campbell, M.L., Kemp, B.J., & Brummel-Smith, K. (1994). Later life effects of early life disability: Comparisons of age-matched controls on indicators of physical, psychological and social status. *Final report to the National Institute of Disability and Rehabilitation Research*. Rehabilitation Research and Training Center on Aging with Disability, Rancho Los Amigos Medical Center, Downey, CA.
- DeJong, G. (1995). *Preventing and managing secondary conditions in an era of managed care*. Presentation to the conference on "Secondary Conditions and Aging with a Disability," Department of Physical Medicine and Rehabilitation, SUNY Health Science Center at Syracuse, Syracuse, NY.
- Guralnik, J.M., Fried, L.P., & Salive, M.E. (1996). Disability as a public health outcome in the aging population. *Annual Review of Public Health*, 17, 25-46.
- Halstead, L.S., & Grimby, G. (Eds.) (1995). *Post-polio syndrome*. Philadelphia, PA: Hanley and Belfus, Inc.
- Halstead, L.S., & Rossi, C.D. (1985). New problems in old polio patients: Results of a survey of 529 polio survivors. *Orthopedics*, 8(7), 845-850.
- Healthy people 2010: Draft for public comment* (Sept. 15, 1998). Office of Disease Prevention and Health Promotion, Department of Health and Human Services (HHS), Washington, DC.
- Jones, M., Sanford, J., Arch, M., & Bell, R.B. (1997). Disability demographics: How are they changing. *Team Rehabilitation Report*, 8(10), 36-44.
- Lollar, D.J. (1994). *Preventing secondary conditions associated with spina bifida or cerebral palsy: Proceedings and recommendations of a symposium*. Washington, DC: Spina Bifida Association of America.
- Marge, M. (1988). Health promotion for persons with disabilities: Moving beyond rehabilitation. *American Journal of Health Promotion*, 2(4), 29-35.
- Maynard, F.M. (Ed.). (1981). *Defining the issue: Post polio aging problems*. Rehabilitation Institute of Chicago/March of Dimes.
- Maynard, F.M., Frchheimer, M., Roller, S., et al. (1991). Secondary conditions associated with declining functional abilities among polio survivors. *Archives of Physical Medicine & Rehabilitation*, 72, 795.
- Pope, A.M., & Tarlov, A.R. (Eds.) (1991). *Disability in America: Toward a national agenda for prevention*. Washington, DC: National Academy Press.
- Seelman, K., & Sweeney, S. (1995). The changing universe of disability. *American Rehabilitation*, Autumn-Winter, 2-13.

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