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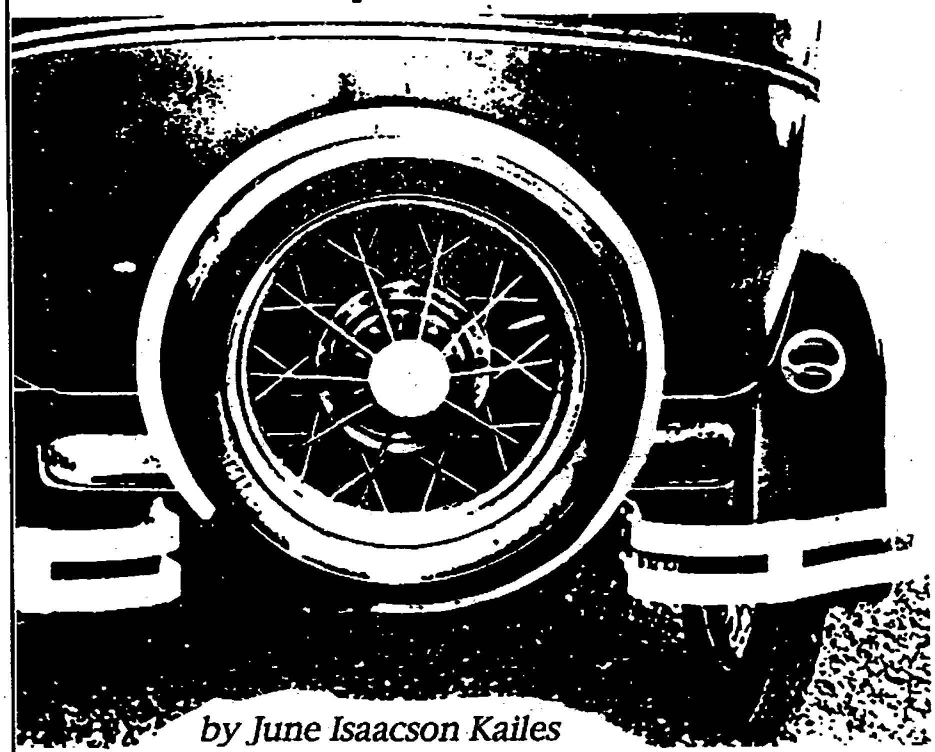
# Mid-life Cripdom:

## Getting Fewer Miles per Gallon?



by June Isaacson Kailes

Does sitting around talking with peers sometimes transform into a conversation about aches, pains and decreasing energy similar to discussions you've heard, or hear, your grandparents or people who are 65 and older engaging in with each other? Some have affectionately referred to this kind of conversation as "the organ report."

When survivors of polio began talking about new vague ailments that focused around fatigue, pain and loss of function, we in the disability community thought, "What a bummer!" Years later we discovered, contrary to common belief among people with disabilities and others, that this was not just a polio issue! The question is: Why are people experiencing changes, sometimes dramatic, in function as we age? Are we wearing out faster than our nondisabled peers?

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# Mid-life Cripdom: Getting fewer miles per gallon?

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Barry Corbet wrote in 1987 in *The Options Group: Perspectives on Aging with Spinal Cord Injury*, "I have a T12/L1 injury, so it's not surprising that chronic pain has been a factor ever since my accident. But now comes the fatigue and it's fatigue that seems way out of proportion to what I see in my non-disabled peers. It's a little overwhelming. When that new fatigue combines with the old pain, my pain threshold drops, so it seems like more pain. That means more fatigue. The combination limits my sitting time, which limits what I do. It's a vicious cycle.

"What it means to me is that my disability is taking more of my time. It means time, for me, has become the same thing as energy. It means this: I have very little discretionary time and very little discretionary energy. It means that I have to prioritize my life." (p. 3)

As a friend, Kathleen Lankasky, puts it, "If my body feels like this at 41, what is it going to feel like when 50, 60 or 70? What preventive measures can I be taking now so that I don't lose any more physical abilities? These questions need answers before it's too late — or is it already?

The experience of decreasing functional abilities and the development of new or more significant secondary conditions is a cross-disability issue and much can be learned from some of the discussion that has taken place and research that has been completed on living long-term with polio and spinal cord injury.

## What is the issue?

For people with disability the issue is just starting to creep out of the closet. There are many people who live with disability long-term — and long-term can be five to 30 or more years post onset — that are experiencing changes in function as they age. Some of these changes may be part of the typical aging process (whatever that is), but these changes may occur at earlier ages for people with disabilities than for people without disabilities. People who have lived with disability long-term are experiencing signs of aging that combine elements of aging with conditions unique to living with disability.

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Many people with disabilities considered their disabilities to be static. A new or increased level of disability or a new or more significant secondary condition was not anticipated, and many have found it a violation of their expectations.

The process of aging not only relates to chronological age but also to duration of time spent living with disability. Depending on one's lifestyle, genetic heritage and type of disability, living long-term with a disability produces wear and tear on muscles, skeletal and other body systems.

## Good news!

There is good news! In the past getting older was a non-issue. In the past we didn't age, we just died! We are the first generation to live this long, so the question is not will we live, but how *well* will we live. So now we are asking questions about the quality of our living and the quality of our aging.

When I began to articulate my concerns to health providers, my complaints sounded vague and slightly bizarre: "I'm not walking as fast as I used to," "my balance is not as good as it used to be," and "I have more spasticity, aches and pain." Health providers gave me more than a few blank looks and a lot of "you're just getting older" and "it's the natural course of events" lectures. In other words, my concerns were often minimized!

I knew something was different but I chose not to accept my unique dual self-diagnosis of increasing brain damage resulting from: (1) spending too much time on airplanes breathing smoke-filled air and, after the smoking ban, just breathing dirty recirculated air; and (2) poor sleeping positions resulting in blood draining from my brain. Both factors escalating the pace of brain cell loss!

I decided to confirm just how strange I was by conducting my own, very scientific, I'm sure, statistically signifi-

# Terms / Terms / Terms

**Aging** — (The New York State Developmental Disabilities Planning Council offers a definition in their 1994 *Aging with Cerebral Palsy: The Clinical Concerns,* p. 5) is a conception-to-death progression of developmental changes that ultimately lessen a person's ability to cope successfully with the demands of the environment. During the early stages of aging (infancy, childhood, adolescence) skills and capabilities continue to increase; in the middle stages of aging (i.e., adulthood), maintenance of function is the focus. In the later stages of life, function declines significantly as a result of aging. Disease, trauma and other challenges can cause a decline in function at any stage

**Provider** — is a term used frequently in the following articles to reflect a broad base of people who provide health-related services to people with disabilities. Providers include but are not limited to physicians, because issues really are relevant to all health providers, including: architects, dentists, ergonomists, gerontologists, gynecologists, neurologists, nutritionists, occupational therapists, orthopedists, orthotists, pediatricians, pediatrists, physiatrists, physical therapists, recreation professionals, rehabilitation technologists, speech therapists, x-ray technicians and many more.

**Health promotion, or health self-care** — focuses on behaviors that affect health status and are under the direct control of an individual, such as wearing seat belts, exercise, diet, weight, substance abuse, getting vaccinated against infectious diseases and obtaining periodic screening for heart disease, cancer and diabetes. There is recognition that, due to factors beyond their control, some people do not always have direct control of some of these matters. Health promotion involves educating people about the risks related to health abuses and attempting to increase each person's commitment to a healthy lifestyle that can help prevent premature death and new or increasing disability.

**Primary disabling condition** —is caused by a disease or disability, and is often manifested by a functional limitation(s).

**Secondary condition** — is a disease, injury, functional limitation, disability or handicap that occurs at any point during a person's life and is the result of the existence of the primary disabling condition. The primary disabling condition can be a risk factor for any given secondary condition. In addition, the presence of the primary condition often alters the standard intervention for the prevention or treatment of the secondary condition. And the process of aging or the years lived with a disability may also be a risk factor for some secondary conditions. Conditions might include pain, fatigue, changes in skills or physical condition, fractures and pressure sores.

cant survey of friends with disabilities. My results established that I was not alone!

Given the uniqueness and unorthodoxy of my self-diagnosis and my research, I pursued some other opinions and found more informed, plausible explanations and some advice. But I was only able to do this because I traveled a lot and could seek out the few select providers "in the know" located in various distant parts of the country.

These issues and new realities for people with disabilities are significant and further influenced by newly revised life expectancy statistics, which show that the older you get, the longer you're going to live. The National Center on Health Statistics in 1990 reported that during the past three decades life expectancy increased 16.4 years on the average for people 65 and older. A male born today has a life expectancy of 72-73 and a female, about 78 years. But, if you reach age 65, your life expectancy goes up an added 18 years for females and 12 years for males.

According to the Rehabilitation Research and Training Center on Aging with Spinal Cord Injury, less than 50 years ago the average life expectancy for a person with a spinal cord injury in the United States was approximately three years post-injury; today the life expectancy approaches that of the general population.

So what does this mean for mid-life crips? Most of us will live longer than we think, and we have much to think about regarding what we can influence or change in terms of the quality of our aging years. Don Lollar stated in *Preventing Secondary Conditions Associated with Spina Bifida or Cerebral Palsy: Proceedings and Recommendations of a Symposium*, 1994, that the Public Health Service found that 53% of the effect of attaining and maintaining good health is related to lifestyle, and only 13% is related to biological inheritance. John Fries explains in *Aging Well, A Guide for Successful Seniors*, that it will pay dividends to keep ourselves in the best health possible!

But the question remains: how do people with disabilities do this? Aging translates into a natural acuity loss for all people. But aging has a greater effect on people who already live with significant functional limitations. Some people with disabilities compare this aging with disability experience to the following analogy: A person without a disability has $1,000; a person with a disability has $100. If you take away $10 from the person without a disability, they still have $990. The person with a disability, however, is left with only $90. The point is that people with disabilities need to be thinking about practicing supporting, preserving and sometimes conserving their resources. This will necessitate new coping behaviors. The question, again, remains how?

## Bad news

There is also bad news. Sondra Barrett, in "Complementary Self-Care Strategies for Healthy Aging," *Self-Care and Older Adults Magazine*, Fall 1993, writes that all of us baby boomers, with and without disability, are growing older and becoming more vocal in expressing our concerns about aging. At the same time providers are becoming more aware than ever of what they don't know related to what constitutes the "typical course of aging."

> **There is little empirically-based information about how people with disabilities maintain or lose function as they get older and to what degree they experience atypical aging.**

Even less is known about the aging process and its interaction with age-related conditions and pre-existing functional limitations associated with disability. As Jenny Overeyander and others summarize in *Aging and Cerebral Palsy — Pathways to Successful Aging: A National Action Plan*, published in 1994 by the New York State Developmental Disabilities Planning Council, there is little, if any, substantive or empirically-based information about how people with disabilities maintain or lose function as they get older and to what degree they experience atypical aging. What is known, is known by only a select few at the cutting edge of the issue.

People with disabilities are reporting unexpected changes in their energy and activity levels as they age. Roberta Trieschmann in her 1987 book, *Aging With Disability*, states that most people with major physical disabilities of at least 30 years duration note some tenderness and soreness in joints, muscles and tendons which have been carrying the extra load of impaired physical function from other parts of the body. Heavy use or overuse of certain body parts to compensate for lost motor ability in other body parts can lead to problems over time. As people with disabilities age, the physical penalty increases.

People who have lived with disability long-term are developing secondary conditions or are experiencing their existing disability becoming more significant. Secondary conditions are those that occur because of the pressures of the primary disability and may include, for example, pain, fatigue, changes in skills, mobility, strength or balance, or fractures, pressure sores, etc. What's coming into sharp focus for many of us is that the changes brought about by regular aging (yet to be clearly defined) can play havoc with a person's ability to function. Don Lollar's written proceedings of a symposium on secondary conditions gives this example (p. 59) : There are some people who have cerebral palsy who, after years of practice, have perfected balance and walking. But this carefully perfected balance in the body can be easily lost when, as a natural part of the aging process, for example, spinal curves flatten, tendons and ligaments lose flexibility, muscles lose strength, and the righting and protective reflexes slow. These changes may be just enough to cause. falls that result in injuries such as fractures and other conditions that totally affect this precariously achieved balance.

## Current state of knowledge

The clearest statements that I have seen on the current state of knowledge come from Aging with a *Lifelong Physical Disability: A Self-Help Guide,* published in 1992 by Ontario Federation for Cerebral Palsy. This publication explains that physical and physiological changes occur in all people as they age, many of them resulting in a reduction of functional ability. When these changes occur in people who already have disabilities, they may interact with an existing disability to produce additional or a more significant decrease in function. (p. 1)

These functional losses may occur at an earlier age than in people without disabilities because the "condition that caused the disability may cause weakness and other conditions that interact with changes due to the aging process. In addition, stresses caused in attempting to compensate for the effects of the disability may tend to produce more functional losses." (p. 1)

Judith Durance explains in the same publication that people have very large reserves for most of their body systems. They tap these reserves as young people without even knowing it. As people get older they may not even realize that the reserves have decreased until they stress themselves. It's not, for example, until someone runs to catch a bus or does some significant gardening that they suddenly realize the reserve is missing. Calcium is an example of the body's large reserves. More than 50% of bone loss has to occur before it can be noticed in regular X-rays. (p. 3)

Durance states that having a disability can use up the reserve capacity earlier, so that when aging occurs individuals with existing disabilities lose more function and thus increase their level of disability. In other words, there is a cumulative effect. For example, an individual, with cerebral palsy who develops painful large toe joints as a result of osteoarthritis may be unable to continue to walk, whereas someone else would be able to manage with a different type of shoes. (p. 7)

*Aging with Cerebral Palsy: The Clinical Concerns,* to be published in 1995 by the New York State Developmental Disabilities Planning Council, reports that the presence of disability may adversely interact with the aging process and can result in atypical aging. At some point, the interaction of aging and disability may change the reserves that an individual with a disability has with which to respond to the physiological stressors associated with aging. The stressors that occur, especially in the later stages of life, may accelerate declines in functional abilities. There are several processes that interact: the aging process, the primary disability and secondary conditions that develop because of the primary disability. The interaction of these factors — aging, long-term disability and associated conditions, and age-related conditions — can lead to a decrease in over-all function. It is hard to project which of these factors has the greatest impact and what can be done to slow or stop these changes. What is known is that environmental supports, such as assistive technologies, play an increasing critical role in maintaining the balance among functional limitations associated with aging, long-term disability, and independence for people with disabilities.

As Durance states "although we cannot replace the cells we lose as we age," research is showing us that we can improve the efficiency of the remaining cells by staying as flexible as possible and by challenging our heart, lungs, and muscles to maximize in strength and endurance through exercise. (p. 9)

The following articles take a closer look at aging with disability concerns, resources and advocacy issues. □

***About the author of this and the following related stories:***

June Isaacson Kailes, a disability policy consultant based in Los Angeles, consults nationally in the areas of disability-related advocacy, leadership development, public policy, independent living center management and Americans with Disabilities Act compliance. She also serves as the Consumer Dissemination Specialist for the Research and Training Center on Aging with a Disability at Rancho Los Amigos Medical Center in Los Angeles.