



# The Polio Post

Ohio Polio Network Newsletter

Editor: Alice Sporar

Fall 2012 Issue

## POST-POLIO CONFERENCE NEW PHILADELPHIA, OH

by Alice Sporar



Be sure to register for the September 29 Post Polio Conference in New Philadelphia. The deadline for registration is September 15, 2012. For more information, call Brenda Ferguson 330-633-8221, Ruth McCort 330-724-8302, or Patrick Kelly 740-374-0538.

The Conference includes presentations on New Bracing Options with Roger Marzano, LPO, LPed and Managing Post-Polio Pain with Ernest Johnson, MD. Also, there will be an Ohio Polio Network meeting and presentation of the Bernice Krumhansl Award.

Please join us for an informative conference and a chance to meet new people and visit with friends.

Everyone on the mailing list should have received *The Polio Post* Conference Special issue. If you didn't, please contact one of the people listed in the first paragraph of this article.

### Inside this Issue

A Message to Dr. Death From a Psychiatrist	2
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Aging (or Stuck) in Place	3
------------------------------	---

Whatever Happened to Polio ? Timeline	4
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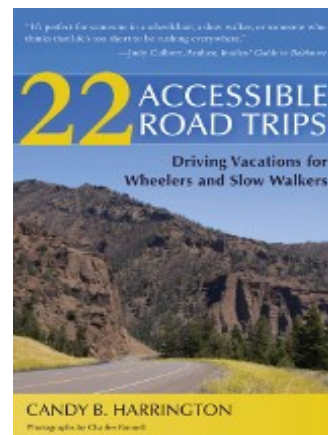
Don't dis—me with that language	5
The disability language A - Z Guide	

Post-Polio Contact Information	9
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### TRAVEL

Special Living Magazine is offering a book, 22 Accessible Road Trips by Candy S. Harrington. The September issue will feature more information on accessible travel.

To subscribe, go to [specialiving.com](http://specialiving.com) or contact them by mail at Specialiving Magazine, PO Box 1000, Bloomington, IL 61702 or visit the website [www.specialiving.com](http://www.specialiving.com).



# A Message to Dr. Death From a Psychiatrist

by *Ernest W. Johnson M.D.*

Dr. Jack Kevorkian has made a point—BUT unfortunately he lacks the insight (and compassion) of a clinician. His training was in pathology.

As I read of his "victims" (? willing) I contemplated the role of all physicians and especially psychiatrists—"To improve the Quality of Life."

Definitely—not to snuff it out. Since life itself can be characterized as a chronic and ultimately fatal disease, (how and why) can Dr. Death justify hastening this inevitable destination?

He says he is aborting pain—It is no longer a reasonable justification, since our technology now has advanced to remarkably complete pain control for the cancer patient.

Why accelerate the disease of a patient with ALS (a favorite target of Dr. Death)? This seems to be a drastic treatment for the reactive depression almost always accompanying a physically disabling condition. But isn't that what rehabilitative techniques are designed for? To improve the quality of life by providing useful adaptations accommodating to weakness and loss of function.

All physicians must improve the quality of life—and certainly not by prematurely ending it!

That is abandonment of the Hippocratic Oath and additionally our (especially psychiatrists') "raison d'etre." I don't have details on all his cases, but Dr. Death has shown his profound clinical ineptness by shepherding to the great beyond—a patient with 'chronic pain syndrome,' a person with multiple sclerosis. Among others, these are clearly usual, classic and expected rehabilitation successes.

Yes, Dr. Death, you have made a point about the need (rarely) for acceding to patients' wishes—near death—to be granted their desire.

I'm prompted to acknowledge the possible rationality of one of your more recent clients—a psychiatrist apparently with bone cancer. Again his desire to die is a consequence of his medical knowledge and background and, I hope, not encouraged by you, Dr. Death.

Rather, Dr. Death has moved medicine backward many centuries to when the feeble and disabled were eliminated from society (and more recently in Nazi Germany).

Recall that the caretakers are generally the most discomfited around the severely disabled, and Sir William Osler (our forbear) noted that the family members were generally in more pain than the dying patient.

Physicians also project their feelings (? of impotence) about death. Other cautions include:

- 1) Depression must be acknowledged and treated before the suicide is assisted.
- 2) Pain control by experts with newest technology must be made available.
- 3) Latest rehabilitation technology to improve quality of life—e.g. by environmental control! is prescribed, taught and used!
- 4) Education of family members and all primary care physicians of 1), 2), and 3).

Dr. Death—you probably have missed the point!

Our job as physicians is to IMPROVE the QUALITY of LIFE, NOT destroy it.

Ineluctably,  
Ernest W. Johnson, MD  
Editor  
*Spring 1994*

## Aging (or Stuck) in Place

by *William Stothers*,

*San Diego, California* [wstothers@cox.net](mailto:wstothers@cox.net)

With an aging population and a lousy economy, the notion of “aging in place” is a hot topic. How can we live out our so-called golden years independently, without being forced to leave comfortable surroundings for what seems to be a warehouse of sad, worn out “old people”?

Aging in place promises that we can stay in our own homes, self-reliant and in control. For polio survivors in North America, who pride themselves on their independence and self-reliance that was drummed into them from their early rehab days, maintaining control and independence is a *Big Deal*.

Personally, I am one of those aging in place. For 30 years, my wife and I have lived in the same house in a great neighborhood. We have a wonderful local market around the corner, accessible public transit a block away. We are happy here.

As I have written before (February 2012 *PHI Association Member Communique*), we manage to get done those things around the house that we cannot physically do through an informal “time-banking” arrangement whereby neighbors help us with tasks we can’t do, and we help them with things they find difficult.

But as I look ahead, I can foresee a day when this informal situation begins to fray and unravel as our functional abilities decline, increasing our need for household assistance and decreasing our ability to help others in equal exchange.

We don’t want to be stuck in place.

What then? An assisted living facility? A retirement/nursing home? These are not attractive choices, at least for us.

Other options exist. Eleanor Smith, polio survivor, founder of [Concrete Change](#), and visionary behind the concept of “visitability,” lives one option: Co-housing.

This is an idea first explored in Denmark, and is growing in interest and popularity in the United States. The [Cohousing.org website](#) explains it this way: “Cohousing is a type of collaborative housing in which residents actively participate in the design and operation of their own neighborhoods. Cohousing residents are consciously committed to living as a community. The physical design encourages both social contact and individual space. Private homes contain all the features of conventional homes, but residents also have access to extensive common facilities such as open space, courtyards, a playground and a common house.... The need for community members to take care of common property builds a sense of working together, trust and support. Because neighbors hold a commitment to a relationship with one another, almost all cohousing communities use consensus as the basis for group decision-making.”

(Continued on page 4)

**Aging (or Stuck) in Place (Continued from page 3)**

Eleanor Smith, who uses a wheelchair full time, had long wanted to belong to an intentional community, and in the late 1990s, she got involved with a small group of like-minded people in the Atlanta area. They acquired 20 acres of land and worked with a developer to create East Lake Commons. This co-housing project is one of the largest in the country with 67 houses. Most projects are in the 20 to 40 house range.

Of course, from the start, Eleanor pushed visitability. And the finished project embraces it. In an [essay](#) on the Cohousing website, Eleanor describes how she can visit her neighbors, hang out on the porch and interact generally. As a result of her tireless work, visitability is gaining a strong foothold in new cohousing projects, and even is being worked into remodels and renovations of old ones.

Eleanor Smith's community is age and gender diverse, with adults, families and children. East Lake Commons is quieter than downtown urban Atlanta, but it resonates with the sounds of nature and the activity of children.

Senior cohousing is an emerging area, both in additional initiatives and in the fact. Given low turnover in cohousing communities, normal aging and new disability is turning some of those communities into senior communities, with new challenging circumstances.

As we polio survivors wake up daily to new adventures in living, we face questions about how we can best manage our circumstances and thrive. Cohousing moves the idea of aging in place into a richer, more invigorating concept of aging in community. It may not be for everyone, but it seems to offer an integrated way of living, participating and sharing in community life and activities.

Ø For more information on cohousing go to: <http://www.cohousing.org/>

Ø For Eleanor Smith's essay on her experience go to: <http://www.cohousing.org/cm/article/visitability>

Ø For more on "visitability" go to: <http://concretechange.org/>

*Bill Stothers is a long time editor and consultant on media and disability policy. He edited Mainstream, a national advocacy and lifestyle magazine for people with disabilities and major newspapers in Toronto and San Diego. He is a member of the Board of Directors of Post-Polio Health International and currently serves as its Chair.*

Source: Post-Polio Health International ([www.post-polio.org](http://www.post-polio.org))

## Whatever Happened to Polio? Timeline

Smithsonian National Museum of American History

### **Through 1799**

Evidence of sporadic epidemics of polio predate recorded history.

**1789**, British physician Michael Underwood provides first clinical description of the disease.

(Continued on page 7)

# Don't dis me with that language — The disability language A – Z guide

## Putting people first

Society today has made clear that most disapprove of derogatory terms about people with a disability. However there are still some insidious terms being used in everyday conversations, and most of us are unaware of the harm they can do to people's self esteem.

Many of us may not even be aware of the language people with a disability consider to be appropriate. For example, "people with a disability", or "person with a disability" are considered much more preferable than "the disabled" – which ignores the vital reality that we are all people first!

Here are a few language dos and don'ts and communication tips to think about next time you are talking to, or about, a person with a disability.

### A - Ability

It's important to remember, when communicating with or about people with a disability, that they may have one disability – but they have many abilities. Try to highlight their abilities.

### A haemophiliac, an epileptic, a paraplegic

This use of 'a' before the noun implies that once you know the condition, you can categorise the person solely based on their disability. Instead use *person with haemophilia; woman with epilepsy; a man who has paraplegia*.

### Abnormal / sub-normal

Not acceptable. Use *people/person with a disability*.

### B - Blind

Use only to describe a person who really is blind. Otherwise *person with a vision impairment* is preferred.

### C - Carer

Should be reserved for the 'family' of a person with a disability who provide unpaid support. Paid workers should be referred to as assistants, attendants or care workers.

### Challenged

Euphemisms, such as *intellectually challenged*, are seen as 'overly' politically correct. Don't use them.

### Confined to a wheelchair

A wheelchair is not confining, it provides mobility to those who can't walk. A person *uses* a wheelchair.

### Cripple

Should only be used as part of a direct quote, as part of an organisation's name – or by Steady Eddie!

### D - Deaf

Many people who are unable to hear identify themselves as belonging to a group with its own language and culture. In such cases a capital 'D' is used when referring to this group, eg. *A Deaf spokesperson said...* Use if a person really is Deaf. In other cases *person with a hearing impairment* is preferred.

### Defect

Not acceptable. Use *congenital disability, blind from birth* etc.

### Despite

People with a disability are active in their community because of their abilities, not despite their disability.

### Disabled

Emphasises the disability not the person. Use *people/person with a disability*.

(Continued on page 6)

The disability language guide A - Z (Continued from page 5)

### **Disabled toilet/disabled parking place**

We all know what is meant, but the toilet or car park is not disabled – it is an inaccurate description, use *accessible toilet/accessible parking space*.

### **Disadvantaged**

Don't use to describe a person just because they have a disability – a disability in itself needn't be a disadvantage (although often society's response to a person's disability can be a disadvantage).

### **E - Euphemisms**

'Nice' terms such as *intellectually challenged, differently abled, physically challenged* are a denial of reality.

### **F - Fits**

The preferred term is seizures.

### **H - Handicap**

Don't use to describe a disability, however this term can be used to describe the obstacles that restrict an individual's participation, eg. *Handicapped by lack of accessible transport*.

### **I - Intellectual disability**

Terms such as *Mongol, retard* or *mentally retarded* are frowned upon. Use *people with an intellectual disability*.

### **Invalid**

An outdated term with negative connotations. Use *person with a disability*.

### **M - Mental illness**

Preferred over mentally disabled. Alternatively use the appropriate clinical name, eg. Person with schizophrenia. Do not use *insane, lunatic, mad, crazy*.

### **Mongolism**

Use *person with Down Syndrome*.

### **N - Normal**

This is a statistical term. In order to distinguish from people with a disability it is acceptable to use double negatives such as *non-disabled* or *person without a disability* or descriptive terms such as *sighted, hearing, ambulant*.

### **P - Paranoid schizophrenia**

This is a specific condition and these terms should not be used to make a person sound more colourful or dramatic.

### **Patient**

Should only be used when a person is actually receiving medical care or treatment, or in hospital. At other times use the same adjective as you would for a person without a disability, eg *client, consumer, customer, commuter, visitor, patron*.

### **Patronising language**

Don't describe people as *brave, special* or *suffering* just because they have a disability.

### **People with a disability**

While this is the preferred phrase it can be cumbersome and linguistically limiting. Variations can be used such as *Victorian with a disability, driver with a disability* or *mother with a disability*.

### **People with disabilities**

Can imply only people with more than one disability. Use *people with a disability*.

(Continued on page 7)

**The disability language guide A - Z (Continued from page 6)****Politically correct**

If in doubt make sure you are politically correct by using *people with a disability*. Don't use euphemisms like *physically challenged* or *differently abled*.

**Psychiatric disability**

An acceptable term to describe a mental illness. Alternatively use the appropriate clinical name eg. *Person with schizophrenia*. Do not use *insane*, *lunatic*, *mad*, *crazy*.

**R - Retarded**

Derogatory, outdated and unacceptable – instead use *people with an intellectual disability*.

**S - Spastic**

Derogatory, outdated and unacceptable, unless as part of an organisation's name. In most cases *person with cerebral palsy* is the acceptable alternative.

**Sufferer**

Avoid using to indiscriminately describe a person with a disability – individuals don't suffer just because they have a disability. Alternatives include *survivor* or *person with a disability*.

**T - The blind, the deaf**

Avoid using 'the' in this manner as it unconsciously eliminates the person and creates a generalisation based purely on disability.

**U - Uses a wheelchair**

Do not say confined to a wheelchair – a wheelchair provides mobility and is liberating, not confining. Say *uses a wheelchair*.

**V - Vegetables**

Vegetables are what you cook and eat – not to be confused with *people who are comatose*, *unconscious* or *in a coma*.

**Victim**

Some people are victims of war, crime, or exploitative wages. It is inappropriate to describe people as victims of a particular disability.

**Visual Impairment**

Implies a person who is unattractive to look at! Use *vision impairment* or *sight impairment*.

The NSW Department of Ageing, Disability and Home Care would like to thank **Link Disability Magazine** ([www.linkonline.com.au](http://www.linkonline.com.au)) for developing and allowing us to adapt their list.

**Whatever Happened to Polio Timeline (Continued from page 4)****1800 to 1899**

**1840**, Jacob Heine describes the clinical features of the disease as well as its involvement of the spinal cord.

**1894**, first outbreak of polio in epidemic form in the U.S. occurs in Vermont, with 132 cases.

**1900 to 1950**

**1908**, Karl Landsteiner and Erwin Popper identify a virus as the cause of polio by transmitting the disease to a monkey.

**1916**, large epidemic of polio within the United States.

**1921**, Franklin Delano Roosevelt (FDR) contracts polio at age 39. His example has a major impact on public perceptions of individuals with disabilities. Although FDR is open about having had polio, he conceals the extent of his disability.

(Continued on page 8)

**Whatever Happened to Polio Timeline (Continued from page 7)**

**1927**, FDR forms Warm Springs Foundation in Georgia for polio rehabilitation.

**1929**, Philip Drinker and Louis Shaw develop the “**iron lung**” to aid respiration.

**1930s**, two strains of the **poliovirus** are discovered (later it was determined that there were three).

**1931**, scientists create the first **filter able to trap viruses**.

**1933**, FDR inaugurated president of the United States.

**1934**, the first of the **Birthday Balls** to raise funds for the Warm Springs Foundation is held on FDR's birthday January 30.

**1935**, Maurice Brodie and John Kolmer test polio vaccines, with disastrous results.

**1938**, FDR founds the National Foundation for Infantile Paralysis, known today as the **March of Dimes**.

**1940s**, **Sister Kenny**, an Australian nurse, comes to the U.S. to promote her new treatment for polio, using warm compresses to relax painful, contracting muscles and massage for rehabilitation.

**1945**, FDR dies on April 12.

**1947 - 50**, **Dr. Jonas Salk** is recruited by the University of Pittsburgh to develop a virus research program and receives grant to begin a polio typing project. He uses tissue culture method of growing the virus, developed in 1949 by John Enders, Frederick Robbins, and Thomas Weller at Harvard University.

**1951 to 2000**

**1953**, Salk and his associates develop a potentially safe, inactivated (killed), injected **polio vaccine**.

**1954**, nearly two million children participate in the field trials.

**1955**, news of the success of the trials is announced by Dr. Thomas Francis in a formal press conference at Ann Arbor, Michigan, on April 12, the tenth anniversary of FDR's death. The news was broadcast both on television and radio, and church bells rang in cities around the United States.

**1955 - 57**, incidence of polio in the U.S. falls by 85 - 90%.

**1957 - 59**, mass clinical trials of **Albert Sabin's live, attenuated vaccine** in Russia.

**1962**, the Salk vaccine replaced by the Sabin vaccine for most purposes because it is easier to administer and less expensive.

**1968**, passage of the Architectural Barriers Act, requiring that all federally financed buildings be accessible to people with **disabilities**.

**1979**, last case of polio caused by “wild” virus in U.S.; **last case of smallpox in the world**.

**1980s**, **post-polio syndrome** identified by physicians and people who had polio.

**1980**, the first **National Immunization Day** for polio held in Brazil.

**1981**, **poliovirus genome** sequence published.

**1985**, Rotary International launches PolioPlus program.

**1988**, Rotary International, PanAmerican Health Organization, World Health Organization, Centers for Disease Control, UNICEF begin **international campaign** to stop transmission of polio everywhere in the world.

**1990**, Passage of the **Americans with Disabilities Act (ADA)**, providing broad legal protections for people with disabilities.

**1999**, inactivated polio vaccine replaces oral polio vaccine as recommended method of polio immunization in the United States.

**2001 to present**

**2005**, 50th anniversary of the announcement of the Salk vaccine on April 12.



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The Polio Post  
c/o Alice Sporar  
7251 Olde Farm Lane  
Mentor, OH 44060-3995



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