



Colorado Post-Polio **Connections**

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We're Still Here!

By Margaret Hinman

A conservative estimate of the number of polio survivors in the United States who have some long term, lasting effects of the disease is more the 550,000 persons. Even with these numbers, polio is considered an “orphan disease,” a disease that does not receive the press coverage or the money for research that other diseases do. This is, in part, due to the success of the polio vaccines that have resulted in the almost complete elimination of the onset of new cases in this country. In addition, most of us are “mature” citizens and those polio survivors that are younger than the mid-forty’s are usually people who contracted the disease in another country, so the research, in the eyes of some, will go away as we “go away.”

However, we’re still here! We have grown up and matured, many of us going from braces and crutches to throwing them away to having to return to assistive devices as we have aged. We have held jobs, participated in career paths that have taken us places where many people would not think we could go with a disability, have raised families with compassionate children often because of our disability, and have performed activities that defy the expectations of the world around us.

Post-Polio Health International is spearheading an awareness campaign to help draw public attention to our presence in society. In an attempt to support this effort, the Connections and the Colorado Post-Polio Advisory Council are asking all of our polio community to help make our greater communities aware that “We’re Still Here!”

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In My Opinion . . .

We're Still Here! —I am not a public crusader, so I don't usually get on the bandwagon for causes, choosing instead to do whatever I do in my own quiet way. However, I was inspired by my experience at the Post-Polio Health International Conference to speak out about their campaign to let the world know that, although we are aging, polio survivors are still a viable segment of the greater population.

As I've matured, I have become more open about why I wear a brace and use crutches. I have learned to ask for help and to accept gracefully offers to hold open doors and carry packages. I have found that people are happy to be helpful and when I tell them that I am a polio survivor. I get one of a handful of responses: "What is polio?" (From the younger generation and teens), "Oh, I'm sorry!" (For what I don't know. It is a part of my life and everyone has a weak leg somewhere. Mine happens to show!), "Boy! You really are doing well!" Or the response that always amazes me, "I know someone or I have a relative who had polio."

So, although polio is considered an orphan disease (not prevalent enough to put a lot of money into for research), we are still here! Therefore, PHI's campaign is an opportunity for each of us to do something, something that doesn't take a lot of effort but gives us a chance to let the world know that We're Still Here!

Mary Christenson's story about her experiences in Ethiopia reminds us that, although polio has been all but eradicated in the world, it will be many years until someone no longer has to say, "We're Still Here!"

Fatigue—As fatigue is one of the consequences of my aging with polio, I try to plan my days carefully so that I can do what I enjoy doing rather than catching up on my rest. So, the position paper from the PHI conference has helped me in that it gives a good broad overview of fatigue as it relates to polio, and supports my choice to use my time wisely.

The book, Yoga In Bed, reviewed by Jeanine Ellison-Fisher, follows that theme nicely, talking about the benefits of yoga for physical well being and offers a way for those of us with physical disabilities to participate in yoga as an activity that is meant to relax, not cause fatigue.

Margaret Hinman, editor

Polio in the Global Community

Polio is a disease that has had an effect on many individuals around the world. In the 1980's, 1,000 or more children were paralyzed by polio each day.¹ As part of the global community, individuals can watch advances in disease eradication by accessing reliable resources on the Internet. In the United States, polio vaccines were developed and successfully administered during the 1950s and virtually eliminated the onset of new polio cases from individuals born in the United States. Care related to individuals with a history of polio in the United States now focuses on post-polio syndrome, which can

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affect persons primarily 50 years of age or older. However, until recently, many other areas of the global community experienced new cases of polio. The Polio Eradication Initiative developed as a result of the World Health Assembly's 1988 resolution to eradicate polio by the year 2000.² This organization currently reports an estimated 919 cases of new non-vaccine-derived polio world-wide with the highest numbers of cases currently seen in India, Nigeria, Sudan, and Pakistan.³ Ethiopia is one of the countries that have seen tremendous success with the Polio Eradication Initiative.

Ethiopia is a country in East Africa with an estimated population of over 85 million people.⁴ This compares to the United States population of over 307 million individuals. Ethiopia is almost twice the size of Texas. The life expectancy is estimated at 52 years for men and 54 years for women.⁵ The economy is based on agriculture with coffee being a major export contributing to the economy.

Vaccination programs in Ethiopia have been largely successful in reducing the new cases of polio. Although an outbreak of polio was noted in the southwest portion of Ethiopia near the Sudan border, a widespread initiative was launched in 2008 with the support of the World Health Organization (WHO) and UNICEF to vaccinate children under the age of five. There have been no new reported cases of polio since this planned program in Ethiopia in October and November of 2008.³

In the spring of 2009, I had the opportunity to travel to Ethiopia. As an Assistant Professor in the Doctor of Physical Therapy (DPT) program in the School of Physical Therapy at Regis University in Denver, Colorado, I traveled with one other PT faculty member and seven DPT students to spend one month collaborating with the physical therapists in Ethiopia at different facilities that provide rehabilitation services to individuals with a variety of diagnoses as well as participating in service learning activities. Prior to our departure, I received multiple vaccinations and was surprised that they included a polio "booster." Individuals from the nursing, health services administration, and service learning programs at Regis University joined the PT group for the final two weeks of the trip.

One of the facilities that collaborated with our PT faculty and students is part of the Cheshire Services Ethiopia (CSE) that provides rehabilitation services to children and adolescents with disabilities from many areas in Ethiopia. The Cheshire Services Ethiopia is one of several institutions comprising the Cheshire Homes and Service organizations located around the world. There are three components of CSE including the rehabilitation center located approximately 12 ½ miles from the capital of Ethiopia, Addis Ababa. This center provides access to surgical options, post-op rehabilitation, and education to children and young people who typically reside at the center for 4-6 months. Following rehabilitation, they rejoin their families with newly learned skills and reduced disability. In addition, there is a workshop run by individuals skilled in the manufacturing of orthoses and walking devices to assist the children in maximizing their potential. The mission of CSE is to "bring about attitudinal change in society and people with disabilities by taking affirmative actions for inclusive opportunity in Ethiopia through provision of rehabilitation services and economic empowerment." Physical therapy plays a key role in optimizing the child's potential before they return to their home. →

Polio in the Global Community (*From page 3*)

The majority of children we worked with at the CSE had a diagnosis of polio. They were primarily between the ages of 5 and 16 and often had surgery shortly after arrival at the Cheshire residence to reduce muscle tightness in order to improve their function. Many of these young individuals came from rural areas of Ethiopia and had severe limitations in abilities to walk or function in their home environment. Following surgery, the children participated in rehabilitation to improve their motion, build strength and endurance, and incorporate their new mobility skills. In addition to rehabilitation, they attended school, participated in sports, and demonstrated their creativity through talent shows and music. It was not uncommon to see a game of soccer with children using crutches as needed to support their posture or propel the ball. Hippotherapy, or the use of horses to help strengthen muscles and balance, was also available.

Although we were there only a short period of time, the interaction between the students, physical therapists, and children/adolescents was inspirational. There was a sharing of language, laughter, and rehabilitation. The therapists from Ethiopia and other healthcare providers facilitated communication through their abilities to translate words and teach the faculty and students basic communication skills to enhance the rehabilitation. Their welcoming affect provided a wonderful learning environment and allowed a free exchange of ideas that strengthened the provision of care to the residents at Cheshire. The staff at CSE demonstrated their dedication to the mission of the Cheshire Home and Services. The CSE's vision to "see a world in which disability is prevented and people can participate equally and as fully as possible in the life of their society" was evident in their demonstration of commitment to the children and programs at CSE.

The experience of working with healthcare professionals and children/young adults with disabilities related to polio was life changing for the students and faculty from Regis University. The ability to develop pathways of communication that resulted in mutual learning and sharing of expertise opened the door for a continued relationship to improve the abilities of individuals who have experienced the disability that can come as a result of polio. The reduction in cases of polio as well as the commitment to serve those affected by this disease appears to be a goal shared by therapists and individuals in the global community.

Mary Christenson, PT, PhD, Regis University, School of Physical Therapy

¹ Polio Eradication Initiative. United Nations Foundation. <http://www.unfoundation.org/our-solutions/campaigns/polio-eradication-initiative/>. Accessed September 10, 2009.

² The History. Global Polio Eradication Initiative. <http://www.polioeradication.org/history.asp>. Accessed August 10, 2009.

³ Wild Polio Virus Weekly Update. Global Polio Eradication Initiative. <http://www.polioeradication.org/casecount.asp>. Accessed August 17, 2009.

⁴ The World Factbook. Central Intelligence Agency. <https://www.cia.gov/library/publications/the-world-factbook/geos/et.html>. Accessed August 3, 2009.

⁵ Country Profile: Ethiopia. BBC News. http://news.bbc.co.uk/2/hi/africa/country_profiles/1072164.stm. Accessed September 4, 2009.

We're Still Here *(From page 1)*

Post-Polio Health International has designated October 11-17 as “We’re Still Here!” week. The focus of this year’s effort is to let the world know that we’re still here by drawing attention to accessibility issues, particularly during that week. PHI is not asking that polio survivors necessarily launch a big, large group campaign to right some oversight or wrong unless a group of us want to organize to do that. Instead, it is asking that each of us be aware of some accessible location that is particularly “friendly” or “unfriendly” and say something about it, either complementing the management of an establishment or calling attention to an unmet need in some establishment. This can be done by starting out the conversation with “I am a polio survivor and I appreciate that . . .” or “I am a polio survivor and I would like to point out to you, or ask you to consider . . .”

So, to help you get your creative thinking caps on and come up with something that you can do, several survivors had come up with some ideas to let people know that “We’re Still Here!”

- Let an establishment know when you appreciate that the bathrooms are especially accessible because the toilets are the right height, the grab bars are placed so they are easy to use and/or, that there is enough room so that a person in a wheel chair can get to the facilities easily.
- Contact the management of an apartment/housing complex, shopping center, and/or business establishment to ask them to not place piles of snow in the handicapped parking spaces this year.

- Ask businesses, or public building management to adjust the automatic door openers/closers so that they allow more time for people to enter, or place the opener buttons where they are reachable from a wheel chair.
- When people who are parking in handicapped parking spaces without a handicapped sticker or license plate, contact the manager to ask them to ask the offender to move.
- Ask management of a business to place handicapped parking closer to the door the next time they re-stripe their parking lot, pointing out that the current handicapped parking is not really accessible when it is “miles away” from the door, particularly in bad weather.
- Point out to businesses or other entities that having handicapped parking without a ramp to the sidewalk is not accessible to those with walkers or wheel chairs.
- Contact the city, county, or state street and highway departments when a walk-light button is available at a corner but cannot be accessed by a person in a wheel chair because the button is too high, or the light post is not accessible because it is set behind a trash container, in a lawn and not on concrete or is surrounded by a curb rather than a ramp.
- Attend a city council meeting or a building planning commission meeting to ask them to be especially aware that following the letter of the ADA *(Continued on page 6)*

We're Still Here! *(From page 5)*

requirements may not translate into “true accessibility” and offer some suggestions as to how to make the new construction work in reality.

- Finally, on a personal note, when people hold a door, or carry a package for you, give them a big smile, let them know you are a polio survivor and say a heartfelt “Thank you!”

These are just some ideas that do not take a lot of time or special effort out of our lives and can make a difference to the world. They may not result in immediate changes, or any change at all, but the persons that you contact will remember you, and will become aware that as polio survivors, We're Still Here! And, if change comes because of our concerns, then we can be proud of the fact that we still can make a difference in the world, just like we have throughout our lives!

Book Review: Yoga In Bed by Edward Vilga

Reviewed by Jeanine Ellison-Fisher

Quoting from a paper presented at the recent PHI Warm Springs Conference, author Barbara Duryea, MSN, CPHQ writes, “The John P. Murtha Neuroscience and Pain Institute, in Johnstown, Pennsylvania, has completed a preliminary outcome study evaluating the benefits of Hatha Yoga and meditation in patients with post-polio syndrome (PPS) . . . The results showed significant improvements in a patient population where a lack of deterioration is often viewed as success. These patients improved and at the end of 12 weeks they were actively involved in self-care.”

Yoga is a mind-body practice in alternative medicine . . . it is a philosophy, not a religion. One can use it to increase or maintain physical fitness and to relax. Yoga is different than working out; it encourages self-acceptance, non-competition, gentleness in stretches, and calmness in mind. And it is about breathing, well and deeply.

My Yoga teacher says that just about any exercise can be Yoga, if you add breathing. It is about staying loose, going with the flow . . . it's calming . . . centering . . . de-stressing . . . naturally . . . and it is extremely personal. In spirit, no one knows exactly how another feels inside our bodies. It is about learning where we each need to go and find the best poses to achieve that. And, it never hurts. If it does not feel right, go easy or try something else.

Have you ever thought Yoga looked pretty close to impossible? So often the common stretches that are publicized look incredibly difficult for those of us with balance problems or significant weaknesses in one or more of our limbs. Actually, many of us can do Yoga . . . in a chair, or in a bed. There are several books/videos on the subject. Yoga in Bed is in both book and video format. There is also a video called Yoga In a Chair, another labeled Yoga for the Rest of Us, and a book entitled Get Fit in Bed. Also, for those of us who want to participate in yoga classes there are instructors who know how to modify the poses for those with special needs, but they are hard to find.

After the usual disclaimers about being careful, especially for those who need to be careful with their spine, and advising a check with your doctor *(Continued on page 7)*

Yoga (From page 6)

if you have any questions, Yoga in Bed, by Edward Vilga, provides a good easy read. The book starts with how it happened to come about . . . for “convenience” and “accessibility,” as well as “organic.” It’s a natural method for calming ourselves at the beginning and/or the end of the day. “If you can, look at the way animals practice their brand of yoga. Just watch your dog or cat awaken from a nap (or settle down to rest). Without fail, they enjoy a few luxurious stretches before embarking on any activity.”

Yoga In Bed offers 18 Morning Poses to “Invigorate Your A.M.!” Each pose (physical posture) is explained, along with nice big pictures of each; variations are offered and the benefits of each pose are listed. The 16 Evening Poses are provided, to “ease into Dreamland,” to “Relax and Restore,” to “Clear Your Mind.” They are easy to see and read.

The author offers a chapter on **napping** too. This book speaks to that--the goal of napping is the “true calming of the storms of the mind” so anything that helps

with that is good to know. Apparently, many researchers are saying 30-60 minute naps are ideal. There are 5 Napping tips offered, and quotes from the famous folks who have modeled how important napping can be . . . to our physical, emotional and spiritual well-being. Churchill used napping to enable his handling the stress of running the war. Several American presidents have used naps to keep their stress down. Salvador Dali sat up for his nap in order to limit the time to about 30 minutes! He did this by putting a metal bowl in his lap and a spoon in his hand, so that when he started into deep sleep, the spoon dropped, making a loud noise that woke him up! These days we might use an alarm clock, but whatever works!

And at the end of the book, Vilga, the author of Yoga in Bed, speaks of the Yoga of Sleep, the importance of good sleep and how to encourage it, including some advice and resources for those who have difficulty with getting a good sleep. “Getting Good in bed,” he says, “yields a healthier you.” Here’s to that!

And By the Way . . .

Polio survivors who attended the 10th Post-Polio Health International Conference in April at Warm Springs, Georgia learned:

- That appropriate exercise is good for polio survivors.
- It is not the anesthesia that can be a problem for polio survivors, but the whole process. Therefore polio survivors need to insist on a total cardio-pulmonary exam and to talk to the anesthesiologist before having surgery.
- Be your own advocate. You have a right to answers when talking with your care providers.
- That we really have no answers for our condition.
- That we are blessed, looking at others who are a lot worse off.
- That many people met new friends and re-connected with old friends.
- That however bad the circumstances of the polio survivors were who attended the conference, they had a great attitude about their lot in life.

Finding Causes of and Managing Fatigue

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Summary

Fatigue is the most frequently mentioned complaint of people with post-polio syndrome (PPS). And fatigue is often severe. However fatigue is not very specific and is a prominent complaint in many neuromuscular disorders, in many chronic diseases such as multiple sclerosis, in oncology and even on itself in chronic fatigue syndrome. How to understand fatigue in PPS and how to deal with it is the aim of these sessions.

. . .

Causes of fatigue

Fatigue is mentioned by up to 80% of people with post-polio syndrome and the scores on fatigue questionnaires are often high, indicating severe fatigue. But, what is fatigue? Fatigue can be defined as ‘a persistent, subjective sense of tiredness that interferes with usual functioning.’ This refers to the general feeling of fatigue, however local muscle fatigue is also often present and is among the symptoms to define post-polio syndrome: ‘new muscle weakness or abnormal muscle fatigability.’

In post-polio syndrome fatigue is most frequently related to physical factors.

Local muscle fatigue

Local muscle fatigue is the decline in the ability of the muscles to generate force. Several factors have been identified that may play a role in this:

- I. Failure to drive muscles from the central nervous system due to alterations in the central nervous system to activate the nerve cells due to polio—the precise mechanism is not understood;
- II. Transmission failure from the nerves to the muscle fibers due to the fact that nerve connections with muscle fibers that were formed in the recover phase after the acute polio are of less quality and therefore less able to sustain the transfer of the signal from the nerve to the muscle;
- III. Decreasing capacity of the muscles due to post-polio syndrome to meet the physical requirements needed to execute daily life activities. The muscles that slowly decline in

strength have to work at an increased level of their maximal capacity, and this will be inversely related to the duration physical activities can be maintained;

- IV. A decrease in endurance properties of muscles. Muscles that are chronically used at a certain load, especially leg muscles, change their properties towards endurance, however not fully. Shortages of relevant enzymes have been reported;
- V. Especially less and not affected muscles may be chronically under loaded in daily life and suffer from disuse. As a consequence they are less loadable.

General fatigue

General fatigue, the feeling of being tired, may have several causes.

- I. People with post-polio syndrome may feel fatigued due to the fact that they are constantly acting above or in the upper range of their physical capacities. This may result in a chronic state of exhaustion. It is important to realize that movement efficiency is often reduced. This implies that walking may cost twice (or even more) the energy of normal walking in case of two affected legs.
- II. Brain alterations due to polio virus damage have been suggested as a possible cause of general fatigue.
- III. Recent studies have demonstrated signs of chronic inflammation in the cerebrospinal fluid in PPS. This may also play a role in fatigue.
- IV. Deconditioning of the cardio respiratory system. Persons with post-polio syndrome have been found to be deconditioned, or to have a condition comparable to a sedentary life style.
- V. Psychological factors, such as ‘giving up the fight,’ social factors related to the persons life situation, and sleep problems may all contribute to fatigue. However, these are not the main causes of fatigue in post-polio syndrome.

Other causes of fatigue

It is very important to rule out other causes of fatigue. Of course the list of potential causes is very long, but a few common causes such as anemia, hypothyroidism, and depression need to be mentioned.

Factors associated with fatigue in PPS

In a recent study, so far unpublished data, several of the above mentioned factors were found to be associated with fatigue. Lower physical functioning, more pain, sleep problems, lower well-being and an active coping style were found to be associated with fatigue. Of course, in this study not all potential factors were included.

Pharmacological treatment

No pharmaceuticals have been proven effective in reducing fatigue. Randomized controlled trials (RCT's) in which drugs are tested against a placebo and both investigators and patients are blinded for the intervention are the gold standard to prove effectiveness of interventions. Results from such studies have so far been disappointing in that not drug was found to be effective.

Modafinil, a drug used in narcolepsy, was recently demonstrated as not effective in reducing fatigue in a study by Vasconcelos OM, Neurology 2008 confirming the negative results reported earlier by Chan KM in Muscle and Nerve in 2006.

Intravenous Immunoglobulins (IvIg) have been studied in two trials by Borg K, in Lancet Neurology in 2006 and by Farbu E, European Journal of Neurology in 2007. The study by Borg found effect for muscle strength and for 'vitality.' The study by Far found an effect for pain. Both studies however found no effect for fatigue.

Pyridostigmine, a drug that improves neuromuscular transmission was demonstrated not effective in two studies, one by Trojan DA in Neurology in 1999 and one study by Horemans HL in Neurology Neurosurgery and Psychiatry in 2003.

Other drugs were investigated in only one study involving limited numbers of patients. Negative results were found by Dinsomre S for high-dose *prednisone*, and by Stein DP, for *amantadine*, an anti-inflammatory drug, both published in Annals of New York Academy of Sciences in 1995. A study in 2005 by On AY, demonstrated a significant effect of *lamotrigine*, an antiepileptic drug, supposed to have neuroprotective properties, on fatigue. So far confirmative studies have not been published. Finally, a recent pilot study by Skough K, in 2008, found no effects for coenzyme Q10.

Assessment of and managing fatigue in individuals with PPS

Assessment

I. Medical evaluation

It is very important to start with a thorough medical evaluation to exclude other pathologies as mentioned earlier.

II. What is meant by fatigue?

The next thing is to go into a full consideration of the complaint of fatigue. Is it local or general, related to activity and which activities, does it increase over the day, does it respond to rest?

III. Are other contributing factors present?

Consideration has to be given to sleep quality, mood disorders and coping styles.

IV. What is the activity pattern?

The activities of daily life have to be inventoried. What is the activity level of a person, what kind of work does someone do, what are social and home activities, how is mobility outdoors. Are there any aids being used for walking, mobility in and outdoors and so on?

V. What is the social system?

How is the person's social environment, does he or she have sufficient support and understanding at home and work?

VI. What are the person's own perceptions?

How does someone value his or her complaints of fatigue (and other complaints, post-polio syndrome, polio residuals and so on)?

VII. What are the physical capacities?

What is somebody able to do give the polio residuals and co-morbidities? What is the physical burden of activities such as standing, walking, transfers, stair climbing, and the individual's various activities?

VIII. Conclusion

Finally a conclusion can be made on which factors cause or sustain fatigue. These are to be targeted in interventions.

Assessment tools

Tools that may be of value in the assessment of fatigue are validated questionnaires to assess fatigue severity, pain, coping styles, mood, and physical functioning.

Diaries to inventory daily life activity are extremely useful to gain insight in what someone's life looks like, in what a person actually does over the days. A common finding is that people with PPS appear to be much more active than they spontaneously report.

Clinical tests may be included to determine the extent of the polio residuals, and capacity tests to assess physical abilities.

Management

The first important thing is that the person obtains insight into the factors contributing to fatigue. The next and crucial thing is readiness to change. Many factors contributing to fatigue are related to behavior and to cogitations. For instance, if someone is constantly overusing oneself, but considers that as normal, it will be impossible to obtain any change in behavior. It is well known that many polio survivors are so-called 'over achievers' who are not easily prepared to reduce their activities. Occasionally, the reverse is also seen that some polio individuals may avoid physical activity, for instance, if they think that this may damage muscles, and they may very well be mainly having fatigue due to the vicious circle of fatigue, inactivity, physical deconditioning and so on.

To diminish fatigue, energy conservation skills are often to be learned. This may be done individually or in group therapy programs. On the other hand regular physical activity is advised to maintain physical functioning. This implies an individual non-fatiguing exercising program that can be easily done at home, or in an (adapted and accessible) fitness setting. Environmental adaptations at home or work, transportation aids, braces and assistive devices may all be needed tailored to the individual's needs. Rehabilitation therapy is therefore usually multidisciplinary organized and may involve physical and occupational therapists, social workers, psychologists, orthotists, shoe technicians and adaptation technicians.

Preferably, the effect of multidisciplinary interventions to reduce fatigue should evaluate the achievements obtained after the program and during follow-up.

**Presenter's notes from Post-Polio Health International's 10th International Conference, "Living with Polio in the 21st Century," Warm Springs, Georgia. April 24, 2009.*

This Is Your Newsletter-----

Colorado Post-Polio Connections is a newsletter by and for polio survivors, their friends and others who are interested in being part of our network. The editors and staff invite your contributions to the newsletter. If you have comments, articles, or suggestions for topics for future issues, please email us at post-poliocolo@comcast.net or write to us:

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Please include your name, address, phone number and email address in any correspondence. To change mailing information, contact Nancy Hanson at 303-233-1666, ext. 237 or email her at nhanson@eastersealscolorado.org.

Our next issue will, at least in part, focus on some of the highlight of Post-Polio 10th International Conference, “Living with Polio in the 21st Century.”

Disclaimer

The opinions expressed in this newsletter are those of the individual writers and do not necessarily constitute an endorsement or approval by Easter Seals Colorado or the Post-Polio Advisory Council. If you have personal medical problems, consult your own physician.

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BLIND OR HANDICAPPED**