



Colorado Post-Polio **Connections**

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Communicating With Care Givers

As polio survivors, many of us are dealing with the issues related to post-polio syndrome, aging, and other medical and mobility problems. We have learned to adapt our lives and our lifestyles so that we can not only live but live quality lives. We all have our unique ways of doing things that more able bodied persons have not yet had to confront. We know that we have a burning need to maintain our independence and our abilities as long as we can.

In our lives, as we age, as our abilities diminish, we have to become more dependent on others for help with activities that we could do independently when we were younger. One of the areas of dependence that we face can be in accessing the medical community for anything from an annual physical to planned surgery to emergency care to having home health care. How we feel about the quality of the care we get in any of these situations depends on several factors, factors over which we have some control.

Whether we have caregivers at home, in our community or in the medical community we need to communicate in such a way that our needs are met. Communication, in this instance, is made up of several parts, namely, anticipation and planning, communication, participation, and evaluation.

Laura L. Casey, in How to get the Health Care You Want (Austin, Texas: 1 Life Press, 2007), talks about the communication cycle in getting health care. This cycle can be applied to all areas of care giving:

Communication—Tell the truth about what your issues are, what you believe is important to you and what will contribute to your wellness. *(Continued on page 3)*

In My Opinion . . .

We all are caregivers and we all have caregivers. Generally, our primary caregivers have been those who love us, our spouses, our children, and our parents, many with increased responsibilities as we age. Some of us have professional caregivers to help meet our needs. Other members of our community are also caregivers, from the carry out person at the grocery store to the friendly person who sees us struggle with opening a door and who opens it for us. Polio survivor or not, we all need others in our life. And, we are thankful for those who care for and about us.

As we age and as we become less functionally independent, we may need to depend more and more on others to continue to live independently. Often, when that happens, our age-old fight to be independent kicks in, and often, losing that independence that we struggled so hard to get can lead to some personal grief, and sometimes, depression.

We need to have some control in our lives, no matter how dependent we become. Whether through decreased functioning or an unplanned accident, the issue then becomes how to have that control and, at the same time, best assure that our special needs are met and our safety and well being are assured with the help of our care givers.

I am a planner. I try to anticipate what could happen in most situations. I think that comes, in part, from the fact that I have to watch every step I take so that I don't accidentally fall. Therefore, when I have to be hospitalized, I think about what I need in order to function in that environment, including how to let the caregivers know that I cannot get up and walk to the bathroom without my brace, my crutches or a wheel chair. I also know that I will have to tell every person who comes into my room that I need special help. Just knowing my abilities and needs helps me plan for the eventuality.

Also, I am learning to ask for help when I need it—a departure from my youth when my motto was “I can do it myself, thank you!” As a result of specifying my particular needs at the grocery store where I have been a customer for many years, the clerks and carry-out persons know that I will push my own cart to my car but I need help in unloading the groceries. Yet I need to remind them on occasion. I have a clear idea of what I need and I communicate it in specific terms to my helpers.

The article “The Relationship between Care Giver and Care Receiver,” speaks about how to work with professional caregivers, but I think that it can be generalized to all care giving relationships and it addresses the issues of emotional needs.

Ileta Smith reviews Dr. Lauro S. Halstead's second edition of Managing Post Polio, an update of his 1990's book and Jeanine Ellison-Fisher features Boettcher School for Crippled Children and some of the alumni of that old Denver institution. Enjoy the work of our writers.

Margaret C. Hinman, Editor

Communicating with Care Givers

(Continued from page 1)

“As adult patients navigating a health care delivery system, our role is to communicate as clearly, completely, and honestly as possible.” (Casey, p. 13) Talk about your health concerns and your apprehensions. She recommends keeping a health journal, recording not only your actions but the actions of care givers. The stress of illness can make us forgetful and easily confused, and a journal can help us to remember what we want to say to our care givers.

The U.S. Agency for Healthcare Research and Quality (AHRQ) suggests five steps to help prevent medical errors, and these can apply to all communication with the care givers:

1. Speak up if you have questions or concerns.
2. Keep a list of all the medications you take and bring it with you to every hospital or doctor’s visit.
3. Make sure you get the results of any test or procedure that is done.
4. Talk with your doctor and health care team about your choices if you need hospital care.
5. Make sure you understand what will happen if you need surgery.

(AARP. [Work in Partnership With Your Health Professional to Prevent Medical Errors.](http://www.healthwise.net) www.healthwise.net)

The second part of the communication cycle Ms. Casey recommends is to participate—Make sure you understand what is happening or will happen. If you don’t understand, ask for an explanation again and

again until you understand. If you disagree with the care giver, speak your opinion. (Casey, p. 14)

She also recommends that you evaluate—evaluate your caregivers. If you don’t like someone, or don’t appreciate the way they treat you or communicate with you, then communicate and remove them from your experience.

As polio survivors, another part of the communication cycle is anticipation and planning. We do it in our daily lives, setting up our households such that we can minimize stress on our bodies, planning our routes so that we can safely navigate our environment, planning ahead to avoid dangerous situations, such as icy sidewalks. If we feel at all vulnerable, we become cautious and we control for the factors that could give us trouble.

Using anticipation and planning before communicating with care givers, especially in the medical community, can make our experiences there less stressful and more effective. Anticipation and planning give us the tools to communicate our needs in those, we hope, less frequently used environments. For example, people who have difficulty getting up on a high examining table in a doctor’s office can ask for alternatives, including going to a doctor that has a low examining table. Those of us who cannot get out of a hospital bed without assistance, will need alternatives to getting up to go to the bathroom or to take a shower. Inability to use your hands to use the call button may make it necessary to have the call button by your feet or may require a voice activated one. Persons using crutches and having planned *(Continued on page 4)*

Communicating with Care Givers

(Continued from page 3)

surgery on the hands or arms need to anticipate, communicate and plan not only how to be mobile in the hospital but upon returning home. Thinking of these and other situations before they happen and having a plan that will work for each individual need will reduce the anxiety that goes with any of the above situations. Communicating those needs should then help the medical profession to work in partnership with you.

Each of us is unique in our needs. The more we know what we can do and what we need and how we function, the better we can communicate those abilities and needs to our care givers.

Another factor in communication with care givers is how we communicate. Keeping the health journal and making copies of it available to our care givers can be a benefit, as can having copies of all of our medical records in a notebook or folder. Writing down our needs in large print and posting them in a prominent place on or by a hospital bed can alert any personnel of your special needs. Having an advocate that knows you and your needs and is with you to see that your needs are met is another way of caring for yourself, is also a helpful means of communication when we are in a stressful medical situation.

Margaret C. Hinman

The Relationship between Caregiver and Care Receiver

Each care receiver's style of receiving care and each caregiver's style of giving care is

as varied and individual as the persons themselves. Cooperation between caregiver and receiver is necessary to help the situation work out to both parties' satisfaction.

However, this collaboration doesn't always come easy. The key to cooperation between the care receiver and the caregiver is open communication and mutual respect. Respect is necessary not only for the other person, but for oneself as well. Without self-respect it is difficult to express concern for the other person or to ask questions that help clarify expectations. As a caregiver knowing what the expectations of the care receiver are is a must in providing quality care.

Open communication is crucial in establishing an effective working relationship between caregiver and care receiver. Being open, honest, and as straightforward as possible about what is expected from each other is imperative due to the personal nature of the relationship. Confusion and poor communication are destructive and can wreak havoc on an otherwise good working relationship.

While it is true that misunderstandings and mistakes often occur during communication and perceptions may differ, these differences should not be allowed to become barriers to effective communication. Very often, the failure to discuss problems and misunderstandings leads to aggravation of the situation. It is beneficial to the relationship to discuss differences and to talk about how things are perceived by one another. However, in some situations the differences between caregiver and receiver are too large to

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The Relationship between Care-giver and Care Receiver *(Con't.)*

overcome, and severing the working relationship may be the only solution

When the initial relationship between caregiver and care receiver is established, ongoing maintenance is necessary as it is in all extended employment situations. This particular association is especially delicate due to several unique characteristics. These include the one-on-one interactions and physical dependency the employer has on the employee. Of course the level of dependency varies with each care giving situation, but the ongoing need for constant communication is crucial for the working relationship to remain positive and healthy for both the caregiver and care receiver. Flexibility and a give and take attitude from both parties are essential.

Self esteem and changing habits

For many of us, learning to accept help from others may be easier said than done. Like most human beings, individuals with disabilities often enter the world of care receiving without the requisite knowledge and skills to ease the transition from independence to dependence. Examples include: lack of knowledge of the skills necessary to effectively manage the role and responsibilities associated with being an employer, knowing how to direct the care needed, and an awareness of the necessity to maintain personal characteristics such as self-esteem in the face of adversity.

Making a decision to take on all of the aspects of an employment relationship can take a great deal of time and effort and may

feel a bit overwhelming. Acquiring knowledge and building skills that are needed to hire someone and develop a healthy caregiver/care receiver relationship takes both time and practice. Responsibilities associated with being an employer may include hiring, training, maintaining a working relationship and replacing caregivers as necessary.

However, anything worthwhile typically demands hard work and gaining experience through trial and error. Building an effective employer/employee relationship between the caregiver and care receiver is no exception.

Division of responsibilities is part of the formal process that must occur in the employer/employee relationship. Attention to detail is critical in both the development and maintenance of the working relationship. One of the key issues centers around the area of control. For the care receiver, asserting some level of control over aspects of daily living is critical but not always easy. Maintaining independence while being dependent on another individual requires both patience and practice. A feeling of independence hinges on the need to possess certain abilities and being able to utilize them.

Sometimes it is necessary for a person with a disability to look at areas other than the physical self to assert their independence. As for most of us, maintaining self esteem in a difficult situation can be challenging, and individuals with disabilities are no exception. Relying on others for assistance with Activities of Daily Living (ADLs) such as eating, bathing, mobility, *(Continued on page 6)*

The Relationship between Care-giver and Care Receiver *(Con't)*

grooming, reading and writing, is no easy task and can lead to frustration and depression if not properly tended.

Developing a perspective that enhances self-reliance and independence when receiving the help of others usually requires time and patience and the acceptance that change is necessary in order to maintain a certain quality of life.

State of Oregon, www.oregon.gov

And By the Way . . .

Here are some hints about how to help our care givers better meet our needs:

- Communicate—tell them about your special needs. Write them down.
- Explain your condition to your spouse and children, especially if it has deteriorated and they are unaware of changes that have occurred over time.
- Tell them, “You can help me by. . . “
- Help the caregiver to understand what you cannot do if the caregiver’s expectations are too high.
- Make sure they hear you. Have them repeat back what your expectations are.
- Insist on them doing it the way you need it to be done.
- In finding a professional caregiver, take the time to find one that will do what you want and need. If not get another one. Don’t accept someone who cannot meet your needs.

- Plan ahead. Think about how you do it, how you want it done, what you cannot do and be ready to communicate those needs both verbally and in writing.
- Have the courage to ask for help.
- Participate in training others to help.
- Help others to feel comfortable helping.
- Accept offers from generous others.
- Genuinely appreciate—Find ways to say “thanks” and smile.
- Use posters spelling out the task to be done.
- Make checklists for the in-home care givers to follow.
- Keep your medical history in a notebook that goes with you whenever you need to see a medical professional or need hospitalization.
- Post pertinent information where care givers can see it easily. Include mobility limitations, muscle weaknesses and resulting limitations, medications you are on, etc.
- Make use of already available systems and aids such as Medical Alert, Life Line or Vial of Life.
- Ask people around you to help, if you need something.
- Get over the attitude related to our need for independence and to let the world know that what we can do needs to be tempered with our need to make our lives easier.
- Anticipate what your needs might be in unusual situations, such as hospitalization or traveling, and have them written down and posted in a prominent place.

Boettcher School for Handicapped Children and the Friendships Started There

by Jeanine Ellison-Fisher

“If it hadn’t been for the Boettcher School, many of us would not have been able to attend school at all in those days.” These are the words of Roberta (Bobby) Croce, one of the Post Polio Survivors who attended the Denver school for many years. Originally named the School for Crippled Children, it was quickly renamed after Mr. Charles Boettcher, a noted Denver area businessman and philanthropist. This school for handicapped children opened in 1940 and was in operation until...we aren’t sure, but some of the friendships which started there have lasted longer than the building! The school has been closed and was demolished probably sometime after the Handicapped Children’s Act came into being in the 80’s. That Act created a process of mainstreaming/integrating handicapped children in their neighborhood school classrooms, making a centralized school for handicapped children unnecessary.

Some of these long lasting friendships between students with polio began when they started school at Boettcher in the late 40’s and early 50’s, over 60 years ago! In addition to Roberta Croce, two of these people are Marlene Harmon and Gloria Aemmer. Marlene and Gloria are well known in the Denver area polio network. They met when they were in their early years of elementary school in the late 40’s, and they were there when the Post Polio organization first began in the early ‘80s. They have both been mainstays in the

Post Polio organization for over 25 years. Marlene is now the current chairman and Gloria the treasurer of the Colorado Post-Polio Connections support group organization.

Both Marlene and Gloria have so many memories of Boettcher . . . of the lovely court yards between the classrooms at Boettcher School, of the “nap area” up the elevator on the second floor, of the chocolates and envelopes with five dollar bills at Christmas and baskets at Easter and a gold watch at graduation, all given by Mr. Boettcher.

They have many stories of Mrs. Catherine Hayes, the long enduring principal, “she would say everybody has a disability, some show and some don’t,” quotes Marlene; and Mrs. Cassario, their “wonderful & favorite” music teacher, who was a inspiration to many. Mrs. Cassario is now 88 years old and Marlene continues to be in contact with her. She was also a home room teacher and a great supporter of the students. There were talent shows, Christmas, Halloween and Valentines parties. They did The Wizard of Oz once. Mothers brought in cookies or cupcakes for birthdays. Math, music and art programs were outstanding according to these students, and scholarships were available for some.

There never were very big classes, maybe 10-12 kids per grade, and two grades were often put together, so maybe 20 kids were in a classroom. There were fully equipped home economics classrooms, sewing in the 8th grade, and how to bake and cook with 3 kitchens. They put on luncheons for the staff. There was a
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Boettcher School . . . *(Continued from page 7)*

separate cafeteria, gymnasium and auditorium; they had a choir and a band.

Gloria started Kindergarten there in 1947 for a full day. Among her favorite activities were the music programs. Around 1950, when she was about 4 or 5, her picture was taken with a little boy; they were sitting at a table pretending to pour tea, with her brace showing. They were in the newspapers and a trailer movie which showed in the movie theatres, and afterwards a box for donations to the March of Dimes was passed around. Gloria sang, "Buttons and Bows" with another little girl who had cerebral palsy, both wearing long puffy dresses. She says, "We probably were chosen because we were so cute and we could sing!" The music teacher would make sure everyone in every grade was in a program. The piano was in the junior/senior high area so "we didn't sing with a piano until later." Special scenery & props were made by the art classes. After performing, the lower grades would go upstairs to the cot room to rest.

Marlene's grandmother from Denver came to her home in Rochester, NY, and told her parents about the public school for handicapped children in Denver. Because of this information, she started Boettcher at age 8 or 9 when her family moved to Denver.

Roberta (Bobby) remembers going to school while still in Children's Hospital, on a stretcher, through the tunnel underneath Downing Street to Boettcher School. She traveled in a group of children through that tunnel lit by bare light bulbs, probably before Jeanine Ellison-Fisher and Mary Kay

Harris Kriegsman, also on stretchers, arrived in the spring of 1951. Jeanine attended Boettcher for only about 6 months and Mary Kay only 2 weeks before she moved away from the city, but their friendship has lasted to this day as well.

Marlene and Roberta graduated from Boettcher High School while Gloria's father fought a "successful battle" to get her to attend East High School. In those days, the public schools were reluctant to take handicapped students, but some principals agreed to do so. Roberta says about Boettcher, "...it was the only school we could attend, a wonderful place and I hoped that the bus would come every day and get me there on time." She also has a lot of stories about getting in trouble for playing cards there.

Gloria went on to Colorado Women's College, majoring in business and accounting while Marlene got a full scholarship to the Colorado Art Institute but she didn't go because it was located in an old building, upstairs on the second floor, and she would have to pull herself up on the railings.

Marlene went to architectural school for an associate's degree and when the Denver Federal Center called Boettcher for recommendations she was hired on the spot. They were redoing the opportunity school, the machine shop & barbershop and beauty shop, so Marlene designed them as well as a couple of houses off Monaco and Hampden. She describes how she could sit for a long time, and loved designing things. Later she was with the US Geological Survey, illustrating geological books until she was in a car accident, which put her on disability.

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Boettcher School . . . (Continued)

Still later she went back to school and studied accounting, graduating from Metropolitan State College in Denver in 1980.

Metro had a center for the physically disabled in the west building and Marlene worked for the student counseling program. They would send kids with various handicaps, some blind, to her with questions, so she started a weekly support group. That must be where she got her start in support groups which she continues to participate in and lead in the metro Denver area, even to this date.

Dr. Eulberg to Keep Post Polio Clinic after Retirement

Dr. Marny Eulberg will continue to see polio survivors in the Denver Post Polio Clinic after she retires from her position with the St. Anthony Hospital Residency Training Program at the beginning of November, 2007. The Post Polio Clinic will still be held at the St. Anthony Family Medicine Center West in St. Anthony Central Hospital. There, Dr. Eulberg and Mary Christenson, physical therapist, will do evaluations, education and recommendations for polio survivors several days a month, once every month or two rather than every Tuesday afternoon.

St. Anthony Family Medicine Center West will be the location of the clinic, at least until a new medical office building is built next to St. Anthony North Hospital. Dr. Eulberg can be contacted via her voice mail at 303-899-5369.

Dr. Eulberg is retiring from her family medicine practice and the residency program so that she can devote more of her time to meeting the needs of polio survivors. In addition to her work at the Post Polio Clinic, she will conduct and write research that compares the outcomes of persons using conventional bracing with those persons using new bracing technologies.

Another focus in her retirement will be to work with Marmaduke Loke, Certified Prosthetist Orthotist, at Dynamic Bracing Solutions. Her work there will include assisting with the training of persons to use the dynamic brace and helping evaluate potential clients as to their ability to use the dynamic brace.

Book Review: **Managing Post-Polio – A Guide to Living and Aging Well with Post-Polio Syndrome**, 2nd Edition, edited by Lauro S. Halstead.

Reviewed by Ileta Smith

The theme of aging with a disability is woven throughout the book. The contributors to the book were very informative and forthright in offering advice on a variety of subjects. Although the book is written primarily for polio survivors and their families, health care providers should also find it helpful.

Six criteria are used to diagnose Post-Polio Syndrome (PPS): a confirmed prior episode of paralytic polio; standard EMG evaluation that demonstrates changes consistent with prior Anterior Horn Cell Disease; a period of neurological recovery followed by an extended period of neurological and functional stability;

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Book Review: Managing Post Polio

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gradual or abrupt onset of new weakness in polio-affected muscles; the new weakness should be present for at least a year; exclusion of other health conditions that may cause new weakness, fatigue, muscle atrophy, joint and muscle pain, decreased endurance, and diminished function.

A person with PPS weakness often experiences a pattern of diminished strength, endurance, and function despite no obvious change in their usual level and intensity of activities. When a new weakness occurs, every effort should be made to provide more rest and support for those muscles. Once the new weakness is stabilized and a period of functioning without excessive effort or discomfort has been completed, then it is reasonable to explore the possibility of an exercise program.

There is considerable evidence that almost everyone can benefit from some form of exercise. Exercise programs should be supervised initially by a healthcare provider experienced in neuromuscular diseases, customized to the person's needs, residual strengths, and symptom patterns. Having two or more exercises that can be alternated, exercising specific muscles every other day provides a period of rest for each muscle group. Exercise intervals can be as short as two to five minutes alternating with equal intervals of rest.

Central fatigue is often described as overwhelming exhaustion with occasional flu-like aching and a marked change in the level of energy, endurance, and mental alertness; it usually occurs every day and

tends to progress during the day, and feels to some like "hitting a wall." When this fatigue occurs, it is helpful to stop, rest, and if possible, take a short nap. Sometimes a little rest is all it takes to reverse the fatigue and restore sufficient energy to continue throughout the remainder of the day without undue discomfort. Management of fatigue should follow many of the same principles for weakness and pain.

Pain in the muscles and joints is the first or second most common symptom of individuals with PPS. The three type-specific pains are:

Type I: Post-Polio Muscle Pain: felt only in muscles affected by polio and can occur as a superficial burning discomfort, or as a deep muscle ache. This pain typically occurs when the individual tries to relax at night, or at the end of the day. Treatment includes periodic rest, stretching, heat, use of assistive devices, lifestyle modifications, and use of medications.

Type II: Overuse Pain: includes injuries to the soft tissues, muscles, tendons, and bursa (tissues surrounding a joint). Treatment incorporates many of the same techniques as used for Type I pain.

Type III: Biomedical Pain: a degenerative joint disease, low back pain, and pain from pinched nerves. Treatment is directed at improving posture and back care, together with decreased weight bearing, and stress on unstable joints.

In addition to weakness, fatigue, and pain, those experiencing PPS may find they are experiencing diminishing functions described as follows: *(Continued on page 11)*

Book Review: Managing Post Polio

(Continued from page 10)

New respiratory complications are most likely to be experienced by individuals who were paralyzed at the initial onset of polio, and those who have developed severe scoliosis after their initial paralyzes. A Pulmonologist should evaluate and manage respiratory complications.

Dysphagia occurs when the poliovirus damages nerves that supply muscles of chewing and swallowing. Dysphagia should be managed under the care of a professional who diagnoses and treats this disorder on a regular basis.

Cold intolerance is experienced by many polio survivors. Management of cold intolerance is largely to alleviate the symptoms: wear multiple layers of clothing, get massages, and apply local heat for 20 minutes or less.

If you are anticipating surgery, anesthesia should be considered. If the effects of polio are minimal and surgery is performed under local or regional anesthesia, then no precautions other than those observed with any minor surgery are necessary. If there is significant polio involvement, and general anesthesia is to be used, it is imperative to consult a Pulmonologist and an Anesthesiologist before surgery.

If you have been diagnosed with more than one illness or medical condition unrelated to PPS, you and your doctor need to consider how much each condition might contribute to your symptoms. Secondary disabilities are a second injury or illness to a person with an existing disability.

The polio epidemic left many survivors to deal with physical, emotional, and psychological issues. Polio was the prototype disease for rehabilitation medicine. Many major rehab facilities were developed as polio disappeared and their expertise was applied to other chronic and disabling conditions. After being discharged, many polio survivors found their rehabilitation programs ended. Few received any follow-up. The victory of a cure for polio benefited those who would never get it, not those who had contracted polio. Today polio is thought of more as an immunization than as a paralyzing disease.

Six individuals wrote their own polio stories. They each told about contracting polio, recovery, living with polio, and facing diminishing functions. They were very candid in describing their feelings through each progressive life stage.

I found the contributing authors to be very forthright in their articles. Although their honesty can cause previously buried or forgotten feelings to surface and new feelings of uncertainty and fear to arise, it is refreshing to have the polio façade, *I can do anything and be happy and cheerful doing so*, dropped to reveal the authentic self we have felt the need to keep hidden. Yes, we face challenges with a *can do* attitude, but we also experience anger, fear, doubt, and grief for our dwindling abilities. By acknowledging our vulnerabilities, we gain the strength and courage to face them.

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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 e-mail 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 e-mail her at www.nhanson@eastersealscolorado.org.

Our next issue will focus on keeping control of our lives—setting up our own medical records file and end of life decisions. We need suggestions from you on what kinds of information you consider important to keep in your medical records file for our “And By the Way. . .” column.

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**