



Colorado Post-Polio **Connections**

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In This Issue

You Got That Darn Cane,
Crutch(es), Walker and
Now What? . . . p.1

Informed Consumer
Information—Bracing . . .
p. 2

In My Opinion . . . p. 3

Post-Polio DME
Assistance Fund . . . p. 7

And by the Way . . . p. 8

Book Review: Polio and
Its Aftermath, by Marc
Shell . . . p. 9

Some Miscellaneous
Thoughts . . . p.10

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You got That Darn Cane, Crutch(es), Walker and Now What?

By Marny Eulberg, M.D.

These days frequently, especially if your insurance is an HMO, after the doctor has written a prescription for the cane, the crutch or crutches, or the walker, the prescription is sent to a Durable Medical Equipment vendor who then gives it to a truck driver to deliver to your home. The truck driver has no training or skills in fitting these devices or teaching you how to use it; he/she is hired for their delivery and driving skills! Or, you may decide to get that cane out of the closet that a relative used, dust it off, and use it yourself!

(Continued on page 3)

Informed Consumer Information—Bracing

*By Margaret Hinman and John Callan, C.O., L.O,
orthotist, Colorado Springs, Colorado. Thank you, John.*

Acquiring bracing, whether for the first time or as a replacement for a current brace, involves not only a major financial decision but also has significant physical and emotional implications. For polio survivors who have not used brace(s) in many years and who celebrated the time when they got rid of that old leather and metal monstrosity, the return to bracing because of returning weakness and the effects of aging can result in grief for the loss of former mobility. It can also recall the memories of the times when they originally wore braces. For those persons, dealing with those issues will help the wearer be more amenable to wearing the brace(s), which will ultimately improve mobility, provide for increased safety and improve the quality of life.

(Continued on page 4)

In My Opinion . . .

Part of the facts of life for many polio survivors is the reality that as we age we become more dependent on others or on help from assistive devices. This often happens earlier in our lives than we expect or want, although the need for dependency on people and things is also a reality for others as they age. Our renewed dependence is complicated with an added emotional cost of having to deal with the loss or reduction of independence and mobility that we have worked so hard throughout our lives to achieve. Yet, we need to salvage our mobility and our quality of life by embracing, often reluctantly, the help that we need.

As we have matured, technology has also matured so that the devices that we needed and discarded in our younger years have also improved. So, when and if it is time to get some assistance, we have choices and we need to be informed as to what is available and how to make the best use of the equipment that is available. Therefore, the two main articles in this issue are meant to help with the decision making process when getting new durable medical devices.

Also, take notice of the announcement about grants that are available for those of us in Colorado who need new durable medical equipment or repairs for equipment in use and are having difficulty paying for them. The Colorado Post-Polio organization has set aside part of the donations they receive to fund these grants.

There is a short article about the 10th annual Post-Polio Health International conference in Warm Springs, Georgia. The agenda for the three-day conference in April looks to be interesting and informative, and there will be members of our Colorado Post-Polio community in attendance.

The book review by Woody Trosper in this issue is about a history of polio and its aftermath. This may be of interest to those of you who want to keep up with information about polio and like to read.

You may notice that we do not have a personal story in this issue of the Connections. When I volunteered to become editor of this newsletter, I was clear with the advisory board of the Colorado post-polio organization that I would not do the newsletter by myself. Over the past two and one half years I have had the help and support of a great team of volunteers who have taken the risk of interviewing, reading and writing articles so you can have a newsletter that is both informative and a means of sharing our lives.

All of us on the Connections staff are volunteers and amateurs in the newsletter business. None of us have ever worked for any news organization but all of us have been willing to give of our time. I appreciate and acknowledge the efforts of every one of my staff. However, as with any volunteer effort, people get tired of doing the work, have other priorities that take precedence over the organization, move away, and generally wish that others would come forward to help with the effort so the weight of the task is spread around. *(Continued on page 11)*

So You Got That Darn . . .

(Continued from page 1)

So, you have this piece of equipment sitting in your front room. What do you do with it? First of all, recall what its purpose is—to help you walk better and/or prevent falls. The ideal situation would be that, in addition to the prescription, for the equipment, your health care provider also wrote a prescription for one or more physical therapy appointments so that a physical therapist can adjust the device to fit you and help you learn to use it the most effectively. This is especially useful if you are using this type of assistive equipment for the first time.

What height should the handgrip on the device be? Most of us have observed a person using a cane or walker that seems too low as they are bent far forward leaning on the device or they are walking with their elbows bent nearly to a 90-degree angle and thus are only able to put a small amount of pressure on the handgrip.

Here are a few guidelines for correct height of the handgrips of canes, crutches, and walkers: 1) when using the hand-held device the elbow should be bent at about 15 degrees (so slightly bent), 2) the hand grip should be at a level that is opposite the bony prominence of your thigh bone {medical term = greater trochanter of the femur}; depending on your height, this is usually about 6 _ inches below your waist, and 3) with your arms hanging loosely at your sides, the hand grip should be even with the crease in your wrist or the place where you'd wear a wristwatch. (This guideline may not work if you have had surgery to stop the growth of one of your legs and hence your leg lengths are not proportional

to your arm length and upper body proportions.)

Generally it is recommended that you use a cane or a single crutch in the hand **OPPOSITE** the weaker or painful leg. Intuitively, this seems to be the **wrong** side but it allows the most natural walking pattern! Don't model your cane use after actors on TV – Fraser Crane's father and Dr. House both use the cane on the wrong side on the TV screen!! When you watch people walk, they swing their right arm forward as the left leg moves forward and the left arm goes forward with the right leg. So, if you use a cane or single crutch usually it is best to hold it in the opposite hand (left hand for weak right leg and right hand for weak left leg) and swing the cane forward as you move the weaker leg forward. Using it in this manner also decreases the lean of the trunk/body to the side of weakness. But, of course, if you have a weak hand/arm or painful shoulder/wrist/elbow on the "correct" hand then you may need to use the cane or crutch on the same side as the weak leg.

There are attachments that can be purchased for cane and crutch tips to allow better traction in snow and ice, but they must be "retracted" when going indoors to avoid punching holes in tile and linoleum and to allow the better traction provided by the rubber tip when on smooth surfaces. Some attachments for canes go around the wrist so that a person can reach for an object without having to put the cane down, helping prevent losing the cane. There are also devices that allow one to balance a cane on the edge of a table or counter and keep it nearby and out of the way of others.

So, walk well and safely!

Informed Consumer . . .Bracing

(Continued from page 1)

Those of us who currently have braces are aware of some of the advances that have been made since the 1950's and 60's. We know that there are new materials that make the braces lighter and, in many cases, more functional and versatile. Plastics and graphite composites, aluminum, stainless steel and titanium metals as well as various styles of joints are some of the materials choices that are available. And, all have their positive and negative aspects.

The days when a person was fitted for a brace and then got what was given to him/her no longer exist, that is, if one will take the time and effort to become informed about options. Brace wearers now have choices and have a right to some say in the decisions that go into the making of a new brace. At the same time, it is the responsibility of the orthotist to make sure that the brace one is getting will safely accomplish its purpose.

After the doctor writes that prescription and the issues of insurance allowances and payments for braces, and which orthotists (brace makers) the insurance company will pay, it is time to do some research in order to insure that you get the very best brace for you. To help with that research, here are some issues to consider:

1. Goals and limitations--Before going to the orthotist, ask yourself what your goals and limitations are in acquiring the brace. Knowing your physical conditions that bracing is supposed to address and having some idea what you want the brace to do

and how you want it to feel allows you to communicate those priorities to the orthotist. It also allows you to assess if those needs can be met by that orthotist, another orthotist, or by any orthotist. If you are having difficulty sorting those issues, you can also ask the orthotist to help you define those goals.

2. Know who is doing the work with and for you. There are many people involved in the brace-making industry and in the brace-making process, including orthotists, orthotic technicians, and fabricators, to mention a few. The American Board of Certification for Orthotists, Prosthetists and Pedorthotists web site at www.abcop.org has a list of certified and licensed orthotists in your area.

The letters after the service provider gives you a clue as to what their certification includes: Certified Orthotist (C.O.), Certified Prosthetist (C.P.) or Certified Prosthetist-Orthotists (C.P.O.). Orthotists work with bracing and prosthetists work with artificial limbs. Some practitioners do both orthotics and prosthetics.

Orthotist often specialize, although they may be able to do general orthotics. Specialties may include the lower extremities, the upper extremities, spinal orthotics, pediatrics, and geriatrics.

(Continued on page 5)

Informed Consumer . . . Bracing

Continued from page 4)

They can also focus on orthopedic problems or neuromuscular problems, can do custom fabrications or provide off-the-shelf orthotics.

3. Bracing options—Find out what kinds of braces this orthotist can/is willing to provide. There are many different orthotic products available and an exploration of the options will help you make the decision about what will work best for you. Find out what materials are available, what kinds of joints are available and what the different designs will do and not do. Also, involved in this part of the decision is whether the brace will come off the shelf, will be custom built in house or come from another vendor.

New bracing technology and changes in functionality can mean that one may not need the same kind of brace that has been traditionally worn. For example, persons who have traditionally worn a short leg brace (AFO or ankle-foot orthotic) may need to now use a long leg brace (KAFO or knee-ankle-foot orthotic). And, technology is also available that allows some traditional KAFO wearers to only need an AFO.

4. Casting—Learn how the orthotist is going to do the casting. To be fitted for a custom brace, a cast will be made to provide a mold for the fabrication of the brace. How the cast is applied will affect how the brace fits. Orthotists can cast with the client

lying down, sitting up or standing. A standing casting will more closely approximate how the client will use the brace while standing and walking. For those of us who cannot stand independently, the orthotist should have parallel bars so that the client will have something stable to grasp while being casted.

Also, learn if the orthotist will cast you as you are or will include corrections in the brace. For example, corrections can include such things as realigning foot and leg deformities and correcting leg length differences.

5. Building the brace—Find out who does the design work, who modifies the cast, who makes (fabricates) the brace. Usually, the orthotist who has done the casting can best modify the cast because (s)he has done the casting and knows the intricacies of your particular case. However, some orthotists specialize only in doing the casting, leaving the modification process to a technician and then sending the cast to a fabricator who builds the brace based on the modified mold.

There may not be an issue with this process but knowing that this is how the process is done by this orthotist can help pinpoint potential problems in the future, if they arise.

6. Follow-up and repairs—The next issue to discuss is what the orthotist will do after you take possession of the brace. Does getting the brace from this orthotist include follow up, and how much, and modifications, or are you stuck *(Continued on page 6)*

Informed Consumer . . . Bracing

(Continued from page 5)

with the brace you take home? Is the orthotist willing to work with the client until the brace fits right and comfortably? Some orthotists will not do this, so it is wise to have this information up front. Does the orthotist guarantee satisfaction for the brace, and what does that guarantee mean? What happens if the brace does not work to your satisfaction? And, is there additional cost for this service?

Repairs and turn-around time when something goes wrong or breaks are part of the reality of wearing a brace, especially if worn for a long time. When a person has only the brace (s)he wears and the brace needs to be modified or repaired, the wearer can be immobilized without it. Some orthotists are sensitive to this and some are not, so it is helpful to know up front what the policy is and what to expect, particularly in an emergency.

The wearer's expectations also factor in. Many brace wearers get a new brace after wearing the old comfortable one for years and years and want the replacement to be exactly like it. Duplicating a brace exactly may not be possible even if the materials and the design are the same, because over time a brace structure changes gradually and often subtly, leaving the wearer of the new brace with feelings that the duplicate is not like the old one.

7. Physical therapy—It is beneficial to have some training in wearing the new brace. Because learning to wear a new brace takes time and practice, a physical therapist can provide invaluable help in adjusting to it, helping with gait and balance issues and in helping identify whether modifications might make the brace work better, fit better or be more comfortable. This is especially helpful if the client is requiring a duplicate of an old brace. Learn whether the orthotist works with a physical therapist. If not, find a physical therapist who will help you. Also, find out if you can bring that physical therapist with you to the casting and the fitting. Such a team approach will help you function better and provide more comfort and satisfaction in wearing the brace.
8. Insurance—It pays to check with the orthotist to make sure that the insurance company will pay their share of the cost of the brace. Also, before being casted, find out if the orthotist needs to check with the insurance company. This can save the surprise of getting that bill when you expected the insurance company to pay for it.

These are some of the issues that should be considered when getting a new brace. This will facilitate achieving the ultimate goals of bracing, to increase and improve functionality, to provide safety and to improve the quality of life of the wearer. Being informed about the brace you will be wearing before you get it will go a long way towards achieving those goals.

Post-Polio DME Assistance Fund

The Colorado Post-Polio Advisory Council has established an assistance fund to help those polio survivors who are in financial need to assist with the purchase or rental of durable medical equipment needed for a polio-related condition. Persons are eligible to apply for funds after January 1, 2009. Eligible persons must be residents of Colorado who are polio survivors and who need assistance with co-payment for such items as crutches, canes, braces, wheel chairs, and other equipment needed to maintain or improve their quality of life.

This assistance will be based on financial need as determined by a DME Fund Committee and based on information from an application form that can be obtained from Nancy Hanson at Easter Seals Colorado, phone--303-233-1666, ext. 237., nhanson@eastersealscolorado.org.

Grants for up to \$500 will be awarded on a first come, first serve basis and will be issued on a sliding scale until the fund is exhausted. Renewal for future years will depend on the amount of funds in the Colorado Post-Polio budget.

Persons can also donate to the fund either directly or as a memorial. To do this make checks payable to Colorado Easter Seals and then designate that the funds are to go to the Post-Polio DME Assistance Fund. If donations are made to Easter Seals Colorado without designating that they go to this fund, they are put into the regular Post-Polio restricted fund and the DME Assistance Fund will not receive the benefit of your generosity.

And by the Way . . .

Here are some expectations that polio survivors have when they get durable medical equipment:

- That the device works from the start, the first time they get it.
- That the device fit properly.
- That the vendor or orthotist listen to them.
- That the service provider has sensitivity and empathy.
- That the service provider has experience, as much as possible, with the specific needs of polio survivors.
- That the service provider respects the patient's needs as identified by the patient and has patience, understanding and the skills to discuss those needs if they cannot be met.
- When the patient has a choice both about who the service provider is and what options are available, that the patient can make those choices freely.
- That the service personnel be sensitive to the fact that being without the device further disables the user/wearer and is willing to provide an alternative for the time the user/wearer is without the equipment.
- That the service provider knows of options that are available so that a patient can have a say in choosing what option works best for them.

(Continued on page 8)

And by the Way . . .

(Continued from page 7)

- That the device will make things better, and make more things possible.
- That the user know up front what the charges will be for repairs or replacement, if there are any.
- If there is a warranty and what it includes. If there is a mobile service that will take the equipment in for repairs.
- If a spare is provided when repairs are needed.
- What the turn-around time is for repairs.
- That if the device is not right, that the patient has the right not to accept the device.

The Colorado Post-Polio Connections would like to thank the following volunteers who help with the writing, proofreading and mailing and have made this newsletter possible:

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POLIO AND ITS AFTERMATH, The Paralysis of Culture

By Marc Shell, 2005

Reviewed by Woody Trosper

On its cover flap, we are told that “this powerful book reminds us of the personal cost, the cultural implications, and the historical significance of one of modern humanity’s deadliest biological enemies.” Despite the “historical” part of that statement, we are further told that the book mainly “conveys the wide-spread panic that struck as the disease swept the world in the mid-1950s.” In fact, large parts of the book deal exclusively with the happenings of the 1950s. This is a disappointment to those of us who had polio in the preceding years.

Historical and cultural discussions are included which apply to the present, however. The author feels that in the years after the polio vaccines became available, the world quickly accepted the successful vaccines as “triumph” over polio. In fact, he compares this deliberate forgetfulness to a sort of Post-Traumatic Stress Syndrome in the public. “The history of polio is the history of forgetting polio.” The general belief became that “polio vaccine portended the end of all epidemics,” overlooking AIDS, new types of flu, etc. In the euphoric abandonment of public worry about polio, needed studies were left undone: medical aspects of the disease (how the virus spreads and does damage within the body, possible interventions and/or cures, etc.) and better ways to organize public efforts during such outbreaks. He notes that the disease portions of post-polio studies in America should be done soon, or the subjects will be dead.

(Continued on page 9)

Polio and its Aftermath . . .

(Continued from page 8)

The author's discussions of Post-Polio Syndrome are not long. Interestingly, he points out that this problem had been diagnosed as early as 1875. He does, however, point out that it will become harder and harder to forget polio in the near future, as more victims of the last US epidemics age and develop problems. He also points out that the number of diagnosed cases is probably dwarfed by the number of undiagnosed or misdiagnosed cases, all of which could also develop Post-Polio Syndrome. Add to the US problem that of other countries where polio still occurs, and the cover suggests that "we have much more to fear from polio now than we know." Thus, this medical problem may become "the time bomb for the twenty-first century."

The exception to discussion of Post-Polio Syndrome is the lengthy coverage of Franklin Delano Roosevelt, and of his use of Warm Springs throughout his life. FDR is included in the discussion of "handicapitalism," or the development of big charities for the handicapped. This includes discussion of the precedent setting efforts in the U.S. that combined public and private philanthropy efforts, thus establishing a pattern for future efforts against other diseases.

Another topic was the personal reactions of polio patients, especially those who felt that "I was [X] years old when my childhood ended." Effects on young children are discussed at some length, with separation from parents emphasized; also significant was the denial by many parents that what had happened was polio. Added in were the patient's personal feelings of guilt

("I didn't try hard enough," or "I'm being punished for some sin," or "I'm causing my parents too much trouble and/or shame."). Other feelings were "what if..." and "why me?" The author notes that very few of the studies of polio actually present the young child's points of view; most start out with a mention of this and go on to discuss effects on parents and caretakers instead. He notes that such studies seem to have ignored historical letters written by children with polio. The book has an entire section on "The Handicapped Family." Sibling jealousy, personal lack of self-confidence, and the effects of "tough love" are discussed. The latter could sometimes lead to cruelty. There is little mention of slightly older children, such as teens.

Interestingly, "horse therapy" is covered in an entire section. Hydrotherapy (hot tub exercise) is discussed in depth, especially in the sections on FDR. The efforts of Sister Kenny are covered, but not much is said about those who disagreed with her.

It is possible to learn many new facts in the reading of this book. For example, the famous painting by Andrew Wyeth, called "Christina's World," shows a woman sitting in a field, with her back turned. The featured Christina had had polio, as had Wyeth's sister. In another part of the book there are sections which refer to probable historical polios (Moses, Claudius, Sir Walter Scott) as well as more recent survivors (Jack Nicklaus, Neil Young, Joni Mitchell). Elsewhere, the author refers to cases in which polio seemed to have caused stuttering or double vision. Another reference is to a one-minute movie called "Cripple Creek Bar-Room," filmed in 1899; this is believed

(Continued on page 10)

Polio and its Aftermath . . .

(Continued from page 9)

to have been the first western. The ordinary man who became Captain America had had polio. These were all new facts for this reader, who noticed that racism was not discussed.

The author points out that American thinking mostly ignores the effects of polio epidemics in other parts of the world. For example, the worst of all polio epidemics happened in Tasmania in 1937-1938. The resistance to and difficulties in distribution of polio vaccinations that has led to never-ending cases in poorer nations is not covered. The author does not discuss the effects of Americans ignoring or refusing vaccinations, which could lead to increasing numbers of cases here.

One reviewer calls this book “something of a hybrid. It is part memoir, part literary, film and cultural criticism, part cultural history, and part meditation on the meaning of disease, especially the cultural meaning of polio.” In trying to cover all these aspects, the main theme is sometimes hard to follow. In other cases, the points seem strained. This is especially true in the prolonged discussion of the movie “Rear Window,” in which the author believes that the Jimmy Stewart character was probably recovering from polio rather than an accident.

In his one-page summary at the end of the book, the author stresses “how and why we forgot the aftermath of polio.” 84 pages of indexes, text credits, and notes follow this summary. The latter are important, because they often contain discussions not included in the text and which are often enlightening.

Flipping from the main text to these notes is very distracting, however. Missing from all these entries in the back is a detailed list of the movies (dozens) and books (hundreds) and articles (thousands) to which the author refers. The section on “text credits” is only 4 pages long. Tracing an individual book or article that the reader is interested in is difficult. When reading this book, be prepared to write down your own notes of books, movies, etc., to seek out. The author points out, in addition, that he has accumulated many works that are not even published and thus cannot be traced.

In summary, this reader found this book full of information, in fact, too full of information. It was confusing at times and certainly was not a quick read. If it was sometimes desired to refer back to something, the index was not a big help. The presentation seemed more like a dissertation than a work for the general public.

Some Miscellaneous Thoughts

- Braces, crutches, canes and walkers can show signs of wear so examine them frequently. This insures that you can make adjustments and repairs before an accident happens.
- Replace crutch and cane tips frequently as the tread wears off.
- Crutches and canes are not of much use in snow, ice and slick floors. Proceed with caution.
- Shoes are part of any bracing system. To achieve the best stability and balance, use shoes that are flat on the bottom, with little or no side-to-side or front to back cant. Skate board shoes or deck shoes usually are the flattest. Wearing flat-bottomed shoes for general wear allows more shoe-

ground interaction. This doesn't mean that you cannot have other shoes for those special occasions.

- Many crutches and canes have ergonomic handgrips that help distribute the pressure on the wrists better, thus not aggravating or increasing the chance of carpal tunnel syndrome.
- Some crutch and cane tips have a spring factor in them that may help cushion the weight on them. They cost more but last longer.
- Crutches, canes and walkers now come in a variety of colors, some with decorations, so that wearers can walk with style!
- Braces made of designer materials like graphite can also come in colors other than medical white and pink.

In My Opinion . . .

(Continued from page 2)

I have tried to tailor the contents of the newsletter with several factors in mind: 1) the need to have current relevant health information for polio survivors, particularly those who are in areas that do not have a "polio doctor" or others survivors near by, 2) book reviews for those of us who do not get out as much as we once did but still want to keep up with current information, but can do so within our own homes, 3) stories about others so that again, those of us who are somewhat isolated can see what others have done and hopefully allow us a connection with our peers and finally, 4) practical suggestions by other survivors as to how they have dealt with issues that face them.

The newsletter staff meets once a quarter to discuss the business of the next

newsletter, but this has become an opportunity to develop friendships and to share our joys and our concerns. However, some of the staff live some distance from the meeting, and we do our work over the phone and via the internet.

With this in mind I am asking readers anywhere within our Connections network to think seriously about volunteering to be part of our staff. The benefits include an opportunity to be a volunteer from your own home, to get to know some great people, and to contribute to an endeavor that I believe is of some value to all of us polio survivors.

The expectations for the newsletter staff are a willingness to give some time and effort to the endeavor, the ability and/or desire to write, the willingness to get feedback from the editor and to know that the role of the editor is to edit, cut and change submissions. It has been the policy of the editor to be in communication with the writers and to share changes that occur related to the submitted document.

Newsletter staff can do their work from home. Through use of the phone, the Internet and mail, almost all communication can be accomplished. This means that staff doesn't need to be living in the metro Denver area to participate in this endeavor.

So, I am asking that you consider volunteering to help with the newsletter. Fewer or no volunteers will mean a smaller newsletter or no newsletter at all. If you would like to talk further about your possible role or just to get more information, call me at 303-460-1454 or email me at post-poliocolo@comcast.net. I would love to hear from you.

Margaret Hinman, editor

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:

Colorado Post-Polio Connections
Easter Seals Colorado
5755 West Alameda Avenue
Lakewood, Colorado 80226

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 again focus on durable medical equipment, exploring the issues of wheeled equipment, such as scooters, chairs and vans. We need comments from you about wheel chairs, scooters and handicapped vans for the “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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**FREE MATTER FOR THE
BLIND OR HANDICAPPED**