

# POST-POLIO HEALTH

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## Overuse and Disuse Weakness

Frans Nollet, MD, PhD, Amsterdam, Netherlands

### Summary

Overuse can be defined as the chronic overloading of muscles in daily life activities resulting in physical complaints such as muscle fatigue and pain. Overuse can develop in case of a reduced capacity of muscle to endure loads due to paresis (slight or partial paralysis), but also when normal muscle is chronically overloaded, for instance when a muscle has to compensate for other paretic muscles. This paper focuses on the overload of muscles but other structures such as tendons, ligaments and joint capsules may also suffer from overuse symptoms.

The treatment of overuse is individual and starts with a careful analysis of capacities and demands in daily life activities, which is followed by an individually tailored treatment plan containing a mixture of lifestyle alterations, bodily aids, environmental adaptations and exercise.

### Overuse and cardiorespiratory conditioning

The symptoms of post-polio syndrome (PPS) such as muscle pain, increased fatigue after physical activity and delayed recovery following physical activity may signify that muscles are overused in conducting ordinary daily life activities.<sup>1,2</sup> Support for such a chronic overuse of muscles in people with prior polio has been found in studies showing elevated levels of serum creatine kinase that were related to the distance walked during the previous day,<sup>3</sup> and in studies showing a type I fibre predominance in lower leg muscles supposedly due to fibre type transformation from chronic overload.<sup>4,5</sup>

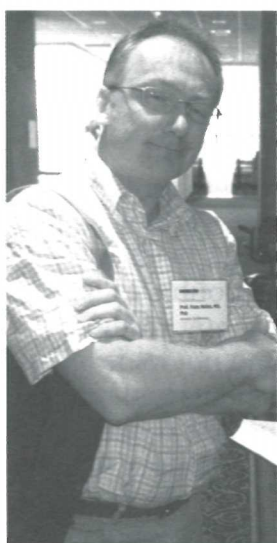
Also, PPS subjects recover slower from fatiguing exercise than stable polio subjects.<sup>6,7</sup> Another factor that is said to contribute to the symptoms is a poor cardiorespiratory condition.<sup>8-10</sup> However, the cardiorespiratory condition of polio subjects was not worse than that of healthy, comparably active subjects.<sup>11</sup> In this study it appeared that the reduced submaximal performance capacity of the polio subjects was strongly correlated with the limited available muscle capacity and the effectiveness of movement was diminished compared with the control subjects.

Lower concentrations of some oxidative enzymes in muscles of polio subjects have also been reported while other oxidative enzymes were within normal ranges.<sup>12,5,13</sup> The clinical significance of these findings has been debated.<sup>14</sup>

It is important to distinguish between complaints of overuse in muscles with polio residua and in nonaffected muscles. The latter may result from increased compensatory muscle activity. This has been shown for upper extremity complaints<sup>15</sup> and may also be found in back muscles and leg muscles in case of postural deviations and altered gait patterns.

### Abilities and disabilities

A decline in the ability to perform activities was mainly found for walking, climbing stairs and for transferring.<sup>16-22</sup> In a recent study, physical functioning declined



Dr. Nollet at PHI's Ninth International Conference on Post-Polio Health and Ventilator-Assisted Living, June 2005.

little over a 6-year period.<sup>23</sup> In agreement with the concept of overuse was the finding that the extent of paresis was the only prognostic factor for a decline in functioning. A significant increase in "handicap severity" for mobility, occupation and social integration was found in PPS subjects over a period of 4-5 years, while in non-PPS subjects the "handicap severity" remained unchanged.<sup>24</sup>

In a recent study it was shown that energy cost of walking increased linearly with increasing severity of paresis of the legs.[unpublished data] Thus a reduced

physical capacity was associated with an increased energy demand for a functional task, i.e., walking.

### Management including treatment

No curative treatment is available for PPS. Management of PPS is preferably multidisciplinary in order to restore the balance between decreasing capacities and the demands for daily living.

### Pharmacological treatment

At present no medication for PPS symptoms is available. Pyridostigmine is the only drug that has been investigated in randomised double-blinded trials.<sup>25,26</sup> In a multicenter study, pyridostigmine was found not to be effective.<sup>25</sup> In selected patients with proven neuromuscular transmission defects pyridostigmine did not reduce fatigue, although a limited beneficial effect on physical performance was found.<sup>26</sup>

### Multidisciplinary management

To reduce overuse and rebalance capacities and demands, conservative management consists of three essential components: exercise, assistive devices and lifestyle changes. Therefore, PPS patients are best treated within a multidisciplinary, specialized rehabilitation setting. Since individuals show considerable differences in polio residua, treatment is individually adjusted and should be preceded by a thorough customised medical and functional evaluation.

### Exercise

Exercise can optimise cardiorespiratory fitness and may add to the patient's sense of well-being.<sup>27-29</sup> Exercise should be nonfatiguing and performed at sub-

**Frans Nollet, MD, PhD**, a physiatrist, is head of the department of rehabilitation medicine of the Academic Medical Center, University of Amsterdam, Netherlands. He was appointed a faculty professor at the University of Amsterdam in 2003. He started his research in the field of post-polio syndrome in 1994. In 2002, he received his PhD for his thesis, *Perceived health and physical performance in post-poliomyelitis syndrome*.

Nollet has co-authored 17 publications related to post-polio problems. To request a listing of his publications and for a bibliography of the 34 references used in preparing his conference presentation, email [info@post-polio.org](mailto:info@post-polio.org) or [f.nollet@amc.uva.nl](mailto:f.nollet@amc.uva.nl).

The Academic Medical Center serves as the national referral site for the late effects of polio in the Netherlands. In the past, Nollet and his colleagues have studied the relation between functioning, abilities and impairments, and changes over time in polio survivors. They also conducted a randomized controlled study on pyridostigmine (Mestinon®). Currently, they are running a prospective study of changes in health status focusing on the influence of aging and comorbidities, and a study on carbon leg braces and the effect on energy cost of walking and functioning.

There are about 13-15,000 polio survivors in the Netherlands with a population of 16 million. For more information about the nation's polio survivors, contact the Post-Polio Support Group of the Dutch Association for Neuromuscular Diseases (VSN) at [www.vsn.nl](http://www.vsn.nl) or by emailing Anita Driessen ([anita.driessen@vsnl.nl](mailto:anita.driessen@vsnl.nl)).



maximal levels to avoid overloading of the limited muscle capacity. Exercise can improve muscle strength, especially in case of disuse and muscle groups which are only moderately affected.<sup>30</sup> Intensive strengthening exercises are not generally recommended, although they may occasionally be indicated. Functional training may also be useful to improve the efficiency of ambulation.

### **Orthoses and assistive devices**

Braces may be helpful to support weak muscles and to stabilize joints. The condition of existing, often old, braces should be carefully examined and judged whether they are still adequate based on biomechanical evaluation of walking abnormalities.<sup>31,32</sup> Assistive devices include crutches, wheelchairs, motorized scooters and home adaptations such as elevators or seating devices in the kitchen or shower. All of these devices should be individually indicated.

### **Lifestyle changes**

Pacing of activities and taking rests are of major importance to relieve symptoms. It has been shown that upper extremity complaints often result from overuse of shoulder and arm muscles.<sup>33</sup> Usually PPS patients have successfully learned to deny their symptoms from childhood and to achieve a "normal" life.<sup>34</sup> Therefore, they may have great difficulty with adapting their lifestyles to their decreasing abilities and psychological support may be indicated. ●

**Patient work-up:** In our hospital, the diagnostic workup of an individual suspected of overuse contains some specific elements according to standard protocol.

*Computerized tomography (CT or CAT scan) of muscle tissue:* At reference level, transversal scans of the body are made to reveal signs of subclinically affected muscles resulting in atrophy and/or fatty infiltration of muscles. This is extremely informative for the large muscle groups of the trunk and the lower extremities because these muscles may appear normal from strength testing while in fact they are not.

*Analysis of gait:* This may provide detailed information on gait abnormalities and (compensatory) functional (over) loading of muscles.

**Patient treatment:** Patients are evaluated by a multidisciplinary team specialized in neuromuscular disorders. The key players are the physical therapist, the occupational therapist and the social worker. If necessary the psychologist, the orthotist and the orthopaedic shoemaker can be added. After the evaluation by each team member a treatment plan is formulated and executed.

Specific elements in the treatment plan include:

- ❖ a starting point of the problems as prioritized by the individual;
- ❖ an evaluation of daily life activities with a diary inventory;
- ❖ involvement of the family members in altering daily life behaviour;
- ❖ if possible, an individualized aerobic exercise program, and
- ❖ specific products, such as orthoses and assistive devices.

The treatment plan also includes group therapy. We have developed a 12-week program together with the Rehabilitation Center in Amsterdam aimed at providing practical tools to change behaviour in daily life. Each week deals with another topic, e.g., work, family, sitting and standing, and so on. The program consists of theory and practice exercises, with group interaction as an essential component.

# Acute Postoperative Pain

Selma Harrison Calmes, MD, Olive View/UCLA Medical Center, Sylmar, California

**Why try to prevent and treat postoperative pain?** After all, you had an operation – it's supposed to hurt! This old attitude is changing today as the result of numerous influences. The new attitude evolving is that we are not supposed to have any pain at all. In reality, it is very difficult to achieve this new goal of no pain at all, which may not even be realistic – or good for you. But postoperative pain (abbreviated as “postop” from now on) can usually be made much better with some relatively easy techniques.

**What about the role of post-polio in postop pain?** It does seem that post-polio people often report more pain than other patients. Many of us have experienced, for example, very severe pain with a simple stub of a toe. Pain signals travel up (and down) the spinal cord, and I postulate that pain signals are modified (probably enhanced, or “wound-up”) because of inflammatory changes in the spinal cord from the original polio infection of the cord. There is no experimental evidence (as far as I am aware) to support this concept; it is a theoretical idea only. But, we do know in other patients that pain signals are often modified in the spinal cord.

**What is available for acute, postop pain management?** Planning for a particular surgical event should be done at the initial pre-anesthesia visit. Multiple interventions should be planned, as a mix of approaches generally leads to greater efficacy and fewer side effects.

1. **IV OPIATES** are what most postop patients receive, because they are effective. These are drugs like morphine, and they work directly on the pain receptors in the brain and spinal cord. They have side effects such as nausea, urinary retention and depressed respiration.

Typically, they are given only when a patient requests pain relief. The RN has to get a key to the narcotic box, sign out and prepare the medicine, and then administer it. This process often takes a long time, and it also results in an “up and down” blood level of the drug, not a constant therapeutic level. High blood levels of the opiate reached soon after the medicine is given can cause side effects such as airway obstruction, and low blood levels as the medicine is wearing off can give inadequate pain relief.

Patient Controlled Analgesia (PCA) systems, which were developed by anesthesiologists in the late 1960s, can deliver a constant blood level of drug, and boluses are possible when patients determine they need more pain relief. These machines solve the “up and down” problem and the RN time problem. PCA can be started in the recovery room soon after surgery is completed.

Morphine and Demerol® are typical drugs used for PCA. Demerol® is used less and less because it has more side effects. Other long-acting narcotics can be delivered in this system. Many hospitals today have PCA available with RNs well trained in its use. PCA, in general, is very safe and effective.



Intramuscular (IM) opioids should not be used because the onset of pain relief is too long, and they are often ineffective. An anti-inflammatory drug Toradol® (ketorolac) is popular for its additive effects to opioids for pain relief but has many contraindications. It is an anti-inflammatory drug (an NSAID, like Vioxx) and is given IM or IV. It acts on the initiation of the pain signals at the site of the painful stimulus, in this case, a surgical incision.

## 2. TECHNIQUES THAT ARE PART OF THE ANESTHESIA PLAN:

■ *Injection of local anesthesia at the surgical site(s).* This is done by the surgeon, usually before the surgery begins, so it helps decrease the pain stimulus from the incision site during surgery and thus decreases the amount of other anesthesia needed. If a long-acting local anesthetic (usually bupivacaine or marcaine) is used, pain relief can be as long as 48 hours. This forms the background, or basal pain relief technique. It is not always possible to inject local anesthesia at a surgical site, usually because of infection. Because giving the injection takes time, it is often difficult to convince surgeons to take this simple but important step.

■ *IV injection of a long-acting narcotic toward the end of surgery.* This is done to cover the initial pain as a patient wakes up from general anesthesia. The usual drug is morphine; some use longer-acting drugs. A possible problem is that this could delay awakening, but cautious dosing, with additional small doses as it becomes clear where the patient is in the awakening process, can solve this problem.

**Selma Harrison Calmes, MD**, an anesthesiologist from Olive View/UCLA Medical Center, Sylmar, California, presented this paper at PHI's Ninth International Conference on Post-Polio Health and Ventilator-Assisted Living, June 2-4, 2005. Calmes, a polio survivor herself, has counseled many polio survivors and health professionals on anesthesia issues.



For short operations, the long-acting narcotic can be given even before anesthesia starts, as a pre-medication, planning on a postop effect also.

■ *Regional anesthesia, with additional drugs/techniques to prolong its pain relief.* Regional anesthesia includes spinal, epidural and various blocks of the arms, hands, legs, feet and peripheral nerves. Not all operations can be done with regional anesthesia; but if this is possible, it can serve as a background technique for postop pain relief. First, a long-acting local anesthetic could be used, to give pain relief for 24-48 hours. A good example of this would be an axillary block or supraclavicular block of the arm done with the long-acting local anesthetic marcaine or bupivacaine, as mentioned.

Another possibility is to add narcotics to the local anesthetics injected into the spinal canal or epidural space. These narcotic drugs migrate into the spinal cord and actually enter it to "sit" on narcotic receptors in the spinal cord, giving long-acting pain relief from small doses. If many days of pain are expected, a small plastic catheter can be placed in the epidural space and a continuous infusion, or bolus injections, of local anesthetics, narcotics or a mixture of both, can be given. Catheters give excellent pain relief. (This is how "labor epidurals" are given for obstetric patients.) They are a manpower intensive technique, however, and many hospitals don't have adequate staff to manage them.

*continued on page 6*

Staff can't just walk away and think the technique will work perfectly.

No matter which pain relief technique is used for a postop patient, certain "system" pieces must be in place: The RNs should ask frequently how much pain a person is having and what the pain is like. The timing of questioning varies from the recovery room to the floor. If significant pain is reported, it should be expected that the RN administer additional pain medicine, and then reassess the pain to see how effective that medicine in that dose was. These two requirements must be met by every hospital that is accredited. The RN is also to record your pain level, the intervention used and the response to the intervention. Unfortunately, there are many difficulties getting these requirements established consistently, especially the reassessment part.

Unusual circumstances may interfere with efforts to get good postop pain relief. For example, low blood pressure (hypotension) or breathing (ventilation) problems may occur postoperatively for various reasons and interfere with the ability to "push" narcotics to the needed level. Finally, surgical misadventures can lead to new pain postop. The most common example I see is unrecognized postop bleeding in a laparotomy patient, with blood accumulating inside the abdomen. This is typically painful. If the usual pain relief techniques don't seem to be working well, the patient needs to be re-evaluated to determine all possible causes of pain. Return to the operating room might be needed instead of additional morphine.

### 3. POLIO AND POSTOP PAIN

**MANAGEMENT:** Postop pain management depends on narcotics such as morphine. Many post-polio patients have obstructive sleep apnea. Narcotics may increase the apnea episodes and increase the risk of death. (Deaths have occurred in "normal" postop patients with sleep apnea.) The solution is, first to try to rely on other pain relief techniques such as generous local anesthesia or Toradol®, etc., and, second, to put the patient where they can be observed (an ICU) for 24-48 hours postop.

Breathing is often marginal in post-polio patients also, and the respiratory depression from narcotics can cause further problems. The solutions are to, first, identify ahead of time patients with limited respiratory reserve; next, make an appropriate plan (use local or regional anesthesia and avoid narcotics, if possible), admit the patient to an ICU postop and be ready to support ventilation. Artificial ventilation (sometimes using the patient's home ventilatory system) might be done for several days, and pain management could then be adequate since the risk of respiratory depression is taken away. During weaning from ventilation, if that were desired or possible, pain medication would have to be cut back, of course.

Finally, technical issues can be prominent for post-polio patients. For example, I might want to place an epidural catheter for several days of postop pain relief after a major operation, but a patient's severe scoliosis would make this very difficult or even impossible. New technology such as ultrasound identification of the epidural space may help with this problem. ●



**Polio Survivors and Associates (PSA)**, a Rotary Fellowship, was formed to encourage participation in the Rotary PolioPlus program and to help connect all people and organizations interested in polio-related issues. The group is looking for Rotarians who had polio, but anyone can join the group. Contact Chairman Dave Heagerty (dheagerty@coakley-heagerty.com) or Founder Ray Taylor (raytaylor@mindspring.com).



Polio Survivors & Associates (PSA) members on float in Rotary International's Centennial Parade in Chicago, Illinois, June 18, 2005, with a theme of Celebrating Rotary-Serving Survivors. Left to right: Evelyn and Dave Heagerty, Linda Bieniek, Shirley Pozzuoli, Joan Headley, Jack Campbell, and Betty and Ray Taylor.

Photo by Jill Campbell

**The Polio Oral History Project** is still collecting stories of polio survivors, health professionals, families and friends. Contact Anna Rubin, Project Manager and Principal Interviewer, International Rehabilitation Center for Polio, Framingham, Massachusetts, 508-872-2200 ext. 241, agrubin@partners.org, www.polioclinic.org (click on "History").

**The National Museum of American History** at the Smithsonian Institution, the site of the *Whatever Happened to Polio?* exhibit is looking for polio survivors to volunteer to be guest docents on Saturdays from 1-3 pm to answer questions from the public. For more information, call Elisabeth Kilday at 202-633-3694 or email her at kildaye@si.edu.

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### *Glimpses from ...*

## **PHI's Ninth International Conference on Post-Polio Health and Ventilator-Assisted Living: STRATEGIES FOR LIVING WELL**

June 2-4, 2005, Saint Louis, Missouri



THE PHI BOARD presented Legacy Awards, remembering Gini Laurie (1913-1989) who was the founder of PHI, during an evening organized by Board members Linda Bieniek, Beth Kowall and Sunny Roller.

(L to R) Ray Klingensmith (MO), Trustee of the Rotary Foundation of Rotary International (RI), accepted an award on behalf of RI for its exemplary leadership in funding and contributing to global health. Christopher P. Howson, PhD (NY), Vice President for Global Programs, accepted a Legacy Award for the March of Dimes, recognized for its exemplary leadership in fundraising and sponsoring medical care, research and health education. Allen I. Goldberg, MD, FCCP (IL), Honorary Board member, and Sunny Roller hosted the program. Doris Jones (MO) was acknowledged for her 34 years of service to the organization as its accountant. Lauro S. Halstead, MD (DC), was given a Legacy Award for his long-time exemplary contributions to health education and leadership in public awareness about the late effects of polio. The final award was given to the Edouard Foundation for its exemplary funding of research into polio's late effects and neuromuscular respiratory disorders. Morton Freilicher (NY), the representative of the Foundation, was unable to attend.

PHOTOS by Sheryl Rudy



Sally and Allan Aitken, Quebec



Joanne and Richard  
Flickinger, WA



Sunny Roller, MI, Dan Matakas,  
MI, and Nickie Lancaster, TN



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Post-Polio Health International signed the **Statement of Solidarity On 15th Anniversary of American with Disabilities Act** initiated by the American Association of People with Disabilities (AAPD). The statement concludes:



“With the aim of making America work better for everyone, the undersigned organizations pledge to build on the progress of the last 15 years and join together to promote the full participation and self-determination of

the more than 50 million US children and adults with disabilities. We believe that disability is a natural part of the human experience that in no way should limit the right of all people to make choices, pursue meaningful careers, live independently, and participate fully in all aspects of society.”

The full text of the statement is on AAPD’s website ([www.aapd-dc](http://www.aapd-dc)). AAPD is the largest national nonprofit cross-disability member organization in the United States. Membership is affordable and only \$15.00 annually per person.

Join the more than 100,000 members supporting the goal of unifying the potential of 50 million people with disabilities. AAPD membership also offers some specific benefits such as a credit union, life insurance, prescription card, car rentals, etc. ●

*Letter to the Editor*

“I read the article ‘In Search of the Perfect Mini-Van.’ I have a difficult time climbing up in an SUV or van. So, I bought the Chrysler PT Cruiser. The back seats are split, so one seat is still available for a third passenger. They fold up inside and don’t have to be removed. The PT Cruiser sits like a car, so getting in and out is no problem. My new SuperLight scooter made by Wheelcare, Inc. ([www.wheelcare-inc.com](http://www.wheelcare-inc.com)) fits perfectly. If one purchases a new vehicle, most US auto manufacturers will reimburse the cost of installing the lift. I even had flame decals put on the sides of my red Cruiser.”

—Martha Garner-Holman, Batavia, Ohio

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### **Application for Help with Medicare Prescription Drug Plan Costs (SSA-1020)**

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