

Dr. Chris Hughes, Professor Of Physical Therapy

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The long road to recover which nearly every Chiari patient faces is one of the least researched, and talked about, aspects of the Chiari experience. Yet, it is probably also one of the most important. Faced with a traumatic surgery, years of symptoms, and potentially permanent deficits, patients often face a difficult uphill battle to reclaim their lives. Yet often, if they are willing to work hard and persevere, the results are well worth it as activities that were once lost are reclaimed.

Unfortunately, there is no real standard, or protocol, for recovering from Chiari surgery. Some surgeons suggest a few neck exercises at home, while others refer their patients to psychiatrists and physical therapists. The reality however - at least based on the feedback this publication receives - is that many patients end up finding their own way. They discover which medical professionals will listen and help them. They try things and stick with them if they work; discard them if they don't. Most of all, it appears that people who come back from a long way down just keep plugging along and never give up.

To help fill the void of information regarding recovery issues, we asked Dr. Chris Hughes, Professor of Physical Therapy at Slippery Rock University and a recent addition to the Conquer Chiari Scientific Advisory Board, to address some of the issues faced by recovering Chiari patients. We put Dr. Hughes In The Spotlight...

There's no real protocol for rehabbing from Chiari surgery. If you saw a Chiari patient tomorrow, who was a few weeks post-op, how would you go about evaluating them and devising a rehab plan?

CJH: A patient who has had Chiari surgery is unique in that both neurological and orthopedic interventions need to be addressed. Past symptoms associated with Chiari such as dizziness, weakness, sensory deficits, and balance and visual disturbances etc following surgery should still be re-evaluated as to their impact on the success of a potential rehabilitation program. Furthermore a thorough specific evaluation of cervical range of motion and strength about the cervical spine and shoulder girdle should be done to aid in developing a specific exercise program. Overall, a careful history and musculoskeletal assessment to determine overall posture, upper extremity and cervical and trunk function can allow for prioritizing a good program of physical therapy.

Is it important, or even possible, to separate the acute recovery from the actual trauma of the surgery - meaning cutting the neck muscles - from the recovery from chronic symptoms, such as leg weakness?

CJH: In relation to its impact on a physical therapy assessment it may not be. We would normally determine current state of ability with our exam process and also integrate the prognosis from the referring physician into our plan of care. This would help prioritize goals and potential for recovery. It is very important to work with the referring physician/surgeon on this aspect so that everyone is on the same page.

How do you tell if there is a problem due to nerve damage, and what, if anything can be done about it?

CJH: In many cases a long standing neurological compromise would have been previously identified through physician ordered tests or other neurologic consults. However with physical therapy we commonly assess nerve injury as part of our exam by detailing the patient's history of signs and symptoms and also by evaluating sensation along dermatomal (common nerve innervation pathways in skin) and myotomal patterns (muscles innervated by same peripheral nerve distribution and also through reflex responses (diminished, brisk etc).

One of your specialties is the shoulder, which with syringomyelia patients tends to be a problem. If there is damage from a syrinx which affects nerves in the shoulder, what can happen to the joint?

CJH: Depending on what nerve root or structure was compromised we could see abnormal shoulder function due to weakness and also diminished sense of shoulder position and also even shoulder instability due to combination of these factors. Not to mention changes in posture that lead to chronic neck pain, and also other symptoms related to shoulder impingement.

Many Chiari patients are left to their own to rehab. If a patient wants to get help, how should they go about finding a therapist to work with?

CJH: When it comes to physical therapy your physician may be a good initial source since they refer patients to physical therapists on a regular basis and more than likely are familiar with who they have had success with in the past. In addition the American Physical Therapy Association (www.apta.org) lists therapists by state and additional credentials such as board certifications on their website. Advanced board certifications include being board certified in Neurological Physical Therapy and Board certified in Orthopaedic Physical Therapy. Support groups within the community may also be a good source of information. As is the case with many of our patients you can always phone or visit a PT practice and talk to the therapist to see how they would manage a patient with Chiari. The PT may also be able to refer you to some colleagues who have experience treating this patient population as well.

Would you expect most Physical Therapists to be familiar with Chiari/syringomyelia, or not?

CJH: I think most therapists should have a "theoretical" understanding of the problem but experience in this area based on treatment of past patients or similar problems can be very valuable, especially when setting patient goals. Since therapists deal on a regular basis with restoring some of the impairments related to Chiari I think most would be able to provide good care and help the patient overcome any physical limitations that stem from Chiari/syringomyelia.

Do you think patients should go to a specific type of facility, such as hospital based, or do you think a general PT practice is ok?

CJH: Depends on the severity of symptoms. If neurological symptoms are a predominate issue then a specific facility that treats [these types of] patients may be needed. If chronic pain is present then a visit to a chronic pain center may be your best bet. However if symptoms are more related to orthopedic issues (ie decreased strength in upper extremity, lower extremity, etc.) then a good outpatient physical therapy facility may be the best place to go.

If someone has neck weakness and stiffness from the surgery, and general weakness in the shoulders and arms, what could they expect physical therapy to be like? What type of activities would they do?

CJH: Following a physical therapy evaluation the physical therapist will set goals with the patient to work on the functional limitations and deficits apparent from the exam. This would entail anything from balance and coordination exercises to also specific strengthening exercises for neck and shoulder girdle muscles as well as postural exercises. Self stretches as well as therapist assisted stretches may also be warranted along with appropriate modalities (such as moist heat, electrical stimulation and cryotherapy) as long as sensory deficits of the area to be treated are not compromised to control for any pain the patient is having. The patient should also be given a specific home exercise program that they can perform independent of treatment performed with the therapist.

How much of a person's recovery is dependent on exercises they do at home, versus in the PT facility?

CJH: Each aspect of the therapy program is very important and the home program and clinical treatments should be designed to complement one another. The therapist works on not only performing things the patient can't do on their own (ie specific stretches, use of modalities etc) but also provides the guidance and patient education to increase compliance on the home exercise program and reduce the risk of injury by prescribing the safest and most productive forms of exercise. Since the patient can exercise far more frequently than the number of PT visits usually provided by insurance coverage I personally place great emphasis on making sure the patient understands how important it is to do the home program on a regular and progressive basis.

How is progress monitored?

CJH: Progress can be seen on specific exercises (increase in repetitions, endurance, strength) or may be an improvement in overall function during daily activities. If the program is well designed then the two outcomes (exercise progression and an improvement in daily activities) should go hand in hand.

I realize there's no research on this, but it can take up to a year for the body to adjust from the surgery, meaning the syrinx collapses, and the tissue recovers from compression. Do you think a patient should try physical therapy during this time, or should they wait?

CJH: In my opinion starting physical therapy can be done once the physician gives the ok following surgery. In non-surgical cases some of the symptoms (ie pain, weakness etc) can be reduced with a timely referral.

Many Chiari/syringomyelia patients, even after surgery, continue to suffer from myofascial type pain. What are your thoughts on these types of treatments:

Warm water exercise:

CJH: Can be beneficial to relax the muscles and also promote movement and reduce pain

Massage:

CJH: Of the right intensity can increase blood flow to areas that may have trigger points and be causing muscle ache and local fatigue in neck and shoulder girdle muscles.

Acupuncture:

CJH: Would not necessarily be my first choice but falls into the category of other forms of alternative treatments. More research needs to be done in this area.

Low-level laser:

CJH: Still very new to determine effectiveness but current trials are showing some possibilities. Again, more rigorous randomly controlled trials need to be performed.

There is virtually no published research on Chiari and rehab issues. Ignoring money for the moment, how would you go about designing research in this area? What are the first couple of things you would want to look at?

CJH: A strong randomized controlled trial (RCT) would look at establishing a valid (large sample) subject pool and compare various treatment regimes for similar problems. In addition the trial would have to be a long term longitudinal study. One of the major challenges would be in establishing a suitable cluster of outcome measures to determine effectiveness of interventions.

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